



The Other Side Of The Mountain

A parent's guide to surviving childhood cancer



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National
Children's
Cancer
Society

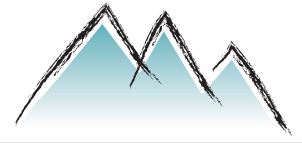
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EMBRACING THE CLIMB



Your child is a survivor. Childhood cancer survivorship begins the day of diagnosis, and it lasts a lifetime. As the parent of a child with cancer, you are a survivor, too. The journey and the uphill battles you will face together will undoubtedly alter your life forever, and it's often hard to foresee the experiences that lie ahead of you.

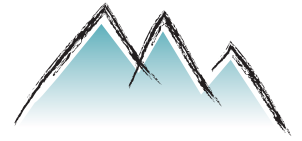
There will be changes, side effects, and emotional challenges. And yes, times when the climb before you seems insurmountable. With the help and support of family and friends, knowledgeable doctors, and organizations like The National Children's Cancer Society (NCCS), you will find strength, courage and surprising beauty along the way.

This guide is designed to help you with some of the hurdles you will face throughout your journey. Use it as a reference to address the questions and issues that may arise at any point. Whether your child just recently received a cancer diagnosis, is mid treatment, or already completed therapy, you and your family are standing at the summit of a mountain that over 500,000 other childhood cancer survivors have faced. You are not alone.

Please allow us to offer you additional information or emotional support at any time. You can reach our Beyond the Cure Survivorship Program at 800-5-FAMILY (532-6459) or online at theNCCS.org. It's our hope that as you integrate this incomparable experience into your life, you will find the strength to handle the challenges before you, along with the beauty and grace that accompanies life's most difficult climbs.



EMBRACING THE CLIMB



How to Use this Guide

“The Other Side of the Mountain” was written to help you and your family throughout your survivorship journey. You’ll find information related to each phase of your child’s treatment, along with other important aspects of your life—from emotional struggles and spiritual growth, to health insurance, school and family.

In each section, you’ll find coping tips from others who have shared this very personal climb. Just as every child with cancer is unique, every family handles this journey differently. Learning how other parents have dealt with the struggle to maintain family structure can offer you great practical information that isn’t always available in medical books or websites.

The experiences of other survivors will help and inspire you throughout every stage of your child’s treatment. To learn more, visit us online at theNCCS.org.





Finding care for those you care about most.

Every parent wants the best possible care for their child. When it comes to cancer, that means seeking out the best pediatric doctors and hospitals available. Hospitals associated with the Children's Oncology Group follow designated treatment protocols, which ensure the quality of your child's care. But always keep in mind, you are your child's best advocate. For this reason, it's important to educate yourself and learn as much as you can about your child's diagnosis, the course of treatment and any potential complications you may face.

Where do I start?

At such an overwhelming time, it's hard to know where to begin and what sources to trust. As other parent survivors will tell you, it helps to stay informed. Use informative and reliable sources like your public library, hospital resource rooms, your doctors and members of your medical team. Nurses, as well as other parents of survivors, also offer excellent and practical day-to-day information about cancer and the effects of treatment.

Look for websites that are professionally sponsored to ensure accuracy and reliability. Share them with your child and his or her siblings. It's also wise to monitor children's web use to ensure the information they are getting is accurate and age appropriate.

At diagnosis: Seeking answers and finding your way.

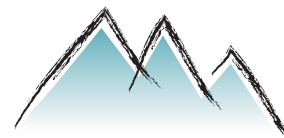
Parents and professionals alike stress the importance of learning the answers to the following questions about your child's diagnosis and treatment:

- What is the specific diagnosis, including stage and location?
- What is on the initial pathology report?
- What course of treatment does the doctor recommend?
- Will chemotherapy be administered and how?
- Are there other treatment options?
- What are the benefits and risks of treatment?
- How long will treatment last?
- Is there a clinical trial available, and if so, what is it?
- When should you call the oncologist? The pediatrician?
- Should a baseline neurocognitive test be done?
- What is the treatment roadmap, including types of treatment and timeline?
- How will the diagnosis and/or treatment affect fertility?

Building your support team.

Many doctors play an active role in your child's care, and they can be an important source of information regarding your child's diagnosis, treatment and possible late effects. Typically, one physician will be assigned as your child's primary oncologist. If this isn't done for you, choose one you feel comfortable talking with and make him/her your primary source of medical information. Ask the best way to contact your doctor. Explain how you would like to communicate and how much information you want about your child's diagnosis, treatment, prognosis and statistics related to the diagnosis.

Some hospitals offer "care conferences." These meetings are arranged by a social worker or nurse and include all the medical personnel involved in your child's care, along with any family members you wish to invite. Having a cohesive meeting can give you a greater sense of order and understanding. To schedule a care conference, talk to a member of your child's medical team.



First priority: Second opinions.

Part of being educated, is getting more information and other opinions about your child's diagnosis and treatment options than what may be offered. Questioning a doctor may be awkward, but most physicians understand the desire for a second opinion, and it's well within your rights. Consider asking your doctor: *Where would you take your child for treatment? Where should I take my child for a second opinion?*

Chances are your second opinion will likely be similar to your first opinion. Because most hospitals are associated with the Children's Oncology Group (COG), they follow the same treatment protocols. To see if your child's hospital is a certified COG member, check the online directory at childrensoncologygroup.org.

Some insurance companies will cover getting a second opinion as long as you obtain proper approvals and documentation. Even when insurance doesn't cover the appointment, parents often say a second opinion was worth the additional expense and awkwardness because it brings them added peace of mind.

Just Between Us | Survival Tips from other Survivors

"Information can be overwhelming. You could have given me everything in the world and it would not have made sense to me. The only thing I understood was that my son had cancer."

- Rachel, mother to Roman (Rhabdomyosarcoma)

"I kept a journal. As time goes by, I have taken my many pages of recorded information and created an outline to provide to other doctors treating the side effects. I also attached surgical notes that may be helpful. It took practice, but I can now meet a new doctor and be prepared as if going on a job interview."

- Linda, mother of Sam (Neuroblastoma)

"Ask your doctor what over-the-counter meds are safe (i.e. aspirin, Advil, etc.)"

- Casey (Survivor of Ewings Sarcoma)

Plan ahead for each appointment.

It's not uncommon for your doctors' visits to be an emotional experience. The information you receive may feel overwhelming, but it's important to retain as many details as you can from each visit. These tips have proved helpful for other parents.

- 1) **Keep a notebook.** Write down any questions in advance and document your doctors' answers to your questions. Keep your notebook handy for future reference.
- 2) **Decide if your child will attend.** Before your appointment, discuss whether you want your child in the room while you are discussing medical information.
- 3) **Bring someone you trust with you.** Another set of ears can remind you of questions to ask, help you listen and decipher what the doctor says.
- 4) **Ask if you can record the conversation.** Refer back to the recording if you have trouble remembering your doctor's answers.
- 5) **Keep thorough, detailed contact information in your phone.** It may also be helpful to keep a paper copy.
- 6) **Ask questions.** Never feel guilty about asking your doctors to repeat information or explain things further.
- 7) **Discuss any changes in your child.** Inform your doctor of any differences in your child's condition or behavior.
- 8) **Ask for copies of all lab reports.** Keep them in your child's medical journal for future reference.



Keep an up-to-date medical journal.

Recording everything in a medical journal can be critical to your child's current and future medical needs. Your journal should contain a variety of information about your child's diagnosis, treatment and health. You can also record changes in weight, body functions, sleep patterns and bowel habits, as well as aches and pains related to medications, blood transfusions and procedures. This will allow you to recognize any patterns and help your physicians make recommendations. Always have your doctor or nurse spell any unfamiliar words.

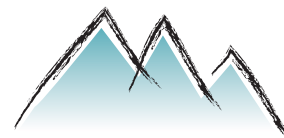
Include in your medical journal:

- Your child's diagnosis, including stage and location of cancer; date of diagnosis and your child's age at time of diagnosis
- Names and contact information of doctors, hospitals and medical team members (include who treated your child for what)
- Chemotherapy drug names, dosages, frequency and modality
- Surgery date and type
- Radiation dosage and areas affected
- Date and type of transplant; treatments in preparation for any transplants
- Any complications and follow-up recommendations
- Current medications
- Late effects and recommended testing
- Blood transfusions or blood products, including any reactions or problems
- Number of relapses and the dates they occurred

During Treatment: Trying to predict in unpredictable times.

As your child's treatment begins, your need to stay informed continues. Your medical team can offer you answers to these important questions.

- How often will we come to the hospital?
(This will be a rough estimate as each child reacts to treatment differently.)
- How often will my child be inpatient? Outpatient?
- How do I reach the doctor during the day? At night? On weekends?
- When should I take my child to the emergency room?
- What care needs to be done at home? Are there medical supplies we'll need?
- What possible side effects should I anticipate? How long will they last? What are the symptoms?
- Have other patients experienced these side effects?
- What can we expect on a daily basis?
- What late effects are known about the treatment?
- What resources are available for my family?
- What should I look for in my child's complete blood count (CBC)?
- How will treatment affect school attendance and participation in other recreational or social activities?
- Are there any physical limitations?
- Will my child need physical or occupational therapy? If so, is this available at home or the hospital?
- Will a homecare agency be involved?
- Are there changes I should make in my child's diet?
- When can my child be said to be in remission? Cured?



After each visit, ask the doctor for a summary of your child's appointments and keep this with your other records. This should include any medications, blood counts, recommendations and test results.

Prepare for the unexpected.

Every child responds differently to treatment, so planning ahead as much as possible, allows you to feel better prepared for unexpected challenges. It helps to keep a suitcase packed for emergencies and routine hospitalizations. Pack light, but don't forget a favorite stuffed animal or blanket to comfort your child. Keep your medical journal up-to-date with all the medications your child has received and any side effects. This will avoid confusion in case of an emergency.

Because appointments and hospital stays are often long and boring, engage your child and other visiting siblings in fun activities such as crafts, hand-held video games or art projects. The hospital child life specialist and recreational staff often have good suggestions. Many hospitals also offer on-site teachers or computer access to help patients with school work.

It can also help to talk to other families whose child has had a similar diagnosis. Ask the doctor or other members of the medical team if they can connect you with a family. Or always feel free to contact the NCCS for further support.

After Treatment: Cancer free doesn't mean appointment free.

Your child's final days of treatment will be a celebrated time for your family, but don't overlook the importance of getting all the information you need regarding follow-up care and possible late effects. Your child will need a primary care physician, and you will need to find out where to go to assess and manage any late effects your child may experience.

Attending follow-up medical appointments is mandatory to maintaining your child's health. Good follow-up care may reduce or even prevent some of the possible long-term issues related to cancer treatments. You and your child may feel anxious and fearful about going to the doctor, but careful monitoring is vital to your child's wellness. Ask your doctor for answers to these medical questions:

- How often will my child need check-ups?
- When do we go to the oncologist, and when do we go to the pediatrician or primary care physician?
- Does my child need to be seen by any specialists?
- What tests, if any, should be done at follow-up visits? Should my child's heart be tested?
- Should my child have a bone density test or take any special vitamins/medications to strengthen bones?
- Does my child need neurocognitive or neuropsychological testing?
- Can you refer my child to a long-term survivor clinic?
- What are the warning signs of relapse or secondary cancers?
- Are there known late effects related to the treatment my child received?
- Are there any warning signs of related side effects?
- Should my child be on a particular diet?
- What late term dental effects may occur?
- What emotional changes should I expect?
- Will infertility be an issue for my child?
- At what point should I transfer my child from pediatric to adult care?



Follow-up and follow through.

While your child's regular treatments are becoming less frequent, you will still have the need for regular oncology follow-up care, as well as a complete physical every year. Dental examinations are recommended every six months. Your doctor may also recommend your child see a specific sub-specialist on a regular basis.

Long-term follow-up clinics provide the most comprehensive treatment for cancer survivors, but they aren't designed to meet your child's everyday healthcare needs. Few primary care physicians have training in the late effects of childhood cancer, so you should look for a pediatrician who is thorough, well trained and a strong communicator. Family, friends or your child's oncologist can help you locate a reliable doctor.

Each new doctor will need a comprehensive transcript of your child's medical history. Before your appointment, ask the hospital or one of your doctors to send summaries of your child's health and treatment history. If your child's doctor created a risk profile for potential late effects, ask for a copy. This will make the transition between physicians easier for everyone.

You can also create your own risk profile by using our Late Effects After Treatment Tool at leatt.thenccs.org. This free interactive tool is designed to prepare survivors for the potential medical issues they may face after treatment has ended, along with offering strategies for maintaining overall good health.

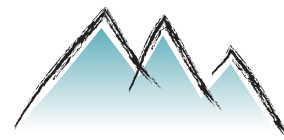
From childhood survivor to adulthood.

Just as every child takes on more responsibility as they get older, childhood cancer survivors must learn to take control of their own health. It can be difficult, but there are ways for you as a parent to ease the transition. For starters, ask your child what he/she knows about his or her diagnosis and previous treatments. Help fill in any blanks as needed.

Teach your child to keep current medical records and to be responsible for listing medications and dosages. Teens can now begin to schedule and track their own appointments, get medications and supplies, and search for an adult care provider. Guiding them throughout these added responsibilities will give them a feeling of independence and the ability to care for him or herself when you are not around.

As your teen reaches adulthood, discuss insurance coverage and healthcare financing. When old enough, give them an insurance card to carry. Encourage them to discuss any questions or issues with the doctor. More than anything, be there to talk about your child's feelings openly so any fears do not become obstacles to attending future appointments. Emphasize that the purpose of long-term follow-up care is not to dwell on the negatives, but to provide information and recommendations on how to live a healthy life moving forward. Your child may be growing up, but he or she will always need your support.





Issues related to your child's coverage.

As if the experience of childhood cancer wasn't tense enough, the cost of treatment is often an added stress. Naturally, parents want what's best for their child, but in some cases, that translates to higher healthcare costs. Because of this, it's very important that you thoroughly understand your health insurance coverage. Your child may be covered by a private insurance plan, a public assistance program such as Medicaid, or both. Maintaining continuous healthcare coverage is vital at this time. Any lapse in coverage may result in refusal of a new policy to cover a pre-existing condition.

A customer service representative from your health insurance plan can help you better understand what your plan covers with regard to your child's cancer treatment. Your hospital social worker or a member of the hospital's finance department can further assist you. Remember, a well-informed parent is a child's best advocate.

How can I become better informed?

Becoming a better advocate for your child requires you to educate yourself on every aspect of your child's treatment and coverage. Here are some good tips to speed along your learning.

- 1) **Ask questions.** Take notes on the answers you receive and keep accurate records you can refer back to in the future.
- 2) **Request a case manager.** Contact your insurance company and ask for a person to serve as your consistent point of contact and source of information.
- 3) **Be prepared to spend time on the phone.** Being informed often means being put on hold.
- 4) **Learn the company's referral policy.** Know if and when referrals are needed before scheduling appointments.
- 5) **Ask about co-payments and deductibles.** Inquire about organizations that can assist with these and other treatment-related expenses not covered by insurance.
- 6) **Know what medications are covered by your insurance plan.** Know the insurance company's formulary or tiered pricing system and whether it only covers generic medication.
- 7) **Ask about non-medical expenses.** Find out if your plan covers things such as lodging, meals and transportation. If not, ask about organizations such as the NCCS that can help with these expenses.
- 8) **Know the cap on your insurance coverage.** Caps on how much the insurance company is willing to pay can be placed on occurrence, person, procedure and time period.
- 9) **Ask about home healthcare and medical supplies.** Not all insurance covers these.
- 10) **Look closely at bills.** You may discover costly billing or reimbursement mistakes on hospital bills and insurance company explanations of benefits.
- 11) **Understand the appeal process.** Learn how and when to appeal to insurance companies if necessary.

How do legislation changes affect insurance?

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. Healthcare has experienced many changes in the way a person can obtain coverage. For the most current information on legislation that may impact health insurance, visit usa.gov.

HEALTH INSURANCE AND BEYOND



Understanding your health insurance options.

MANAGED CARE

Most employer-provided health insurance is a form of managed care. This model provides healthcare 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 you are covered under.

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 which option is best for you. For more information and/or to review your options, visit www.healthcare.gov.

STATE AND FEDERAL PROGRAMS

Medicaid and **State Children's Health Insurance Programs (S-CHIP)** are two government-sponsored programs you may qualify for.

DRUG COVERAGE PROGRAMS

The NCCS offers a discount prescription drug card to assist with the ever-increasing cost of prescription drugs. The NCCS card is for those individuals with little or no prescription drug coverage and is accepted at pharmacies nationwide.

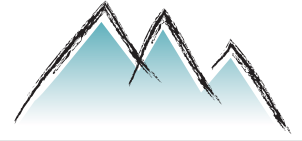


In addition to providing you significant savings on generic and name brand drugs, every time the card is used to fill a prescription \$1.00 is donated to the NCCS.

Get your card at thenccs.org/agility or find the app on Google Play and the Apple app store.

Battling with your insurance company.

If your insurance company refuses to pay for a given treatment or medication, don't take no for an answer. Fighting any insurance company can be time consuming and tedious, but it is important and can save you money. Many companies decline a claim simply because treatment for childhood cancer is unfamiliar ground. By questioning their call, you may make them reevaluate their policies. This can benefit your child, as well as other childhood cancer patients down the road. Should you start having problems with your health insurance, contact the nonprofit Patient Advocate Foundation at 800-532-5274. Your senator or congressperson may also have caseworkers who deal specifically with state insurance questions. To locate your state representative, visit house.gov, or get your state senator's contact information at senate.gov. If you don't have Internet access, ask your hospital social worker to assist you.



Your rights during time away from your job.

To care for a child with cancer, many parents must work reduced hours or take a leave from their job. There are laws to protect parents in this situation. You'll find these acts discussed in detail below. Should you need help paying for your health insurance premiums while you're away from your job, ask your child's hospital social worker to provide you with resources.

Family Medical Leave Act (FMLA)

The Family and Medical Leave Act of 1993 stipulates that a covered employer must grant an eligible employee up to 12 work weeks of unpaid leave during any 12-month period to care for an immediate family member (spouse, child or parent) with a serious health condition.

A covered employer is required to maintain group health insurance coverage for an employee on FMLA leave whenever such insurance was provided before the leave was taken and on the same terms as if the employee had continued to work. FMLA applies to all public agencies, local education agencies (schools) and private sector employers who employed 50 or more employees in 20 or more work weeks during the current or preceding calendar year. To learn more about the FMLA, go to dol.gov.

Americans with Disabilities Act (ADA)

The ADA was enacted in July of 1990 to protect people with disabilities from discrimination, and to ensure equal access to employment and public facilities. This act may benefit parents of children with cancer. While the ADA defines the term disability, it doesn't include a list of conditions that are always considered disabilities. Each case is examined on an individual basis. According to the Equal Employment Opportunities Commission (EEOC), cancer isn't always considered a disability. Cancer is a disability under the ADA when it or its side effects substantially limit one or more of a person's major life activities. To learn more, call the Department of Justice at 800-514-0301 or visit ada.gov.

COBRA

In 1985, The Consolidated Omnibus Budget Reconciliation Act (COBRA) was enacted to supply continued coverage of health insurance to workers who lost eligibility for health insurance because they were relocated or changed jobs, or because their work hours had been reduced. This coverage is temporary, and the employee is responsible for the cost. Ask your employer's human resources manager if you are eligible for continued coverage through COBRA. Or learn more through the Department of Labor at dol.gov/cobra. Or call the Employee Benefits Security Administration's toll-free Employee and Employer Hotline at 866-444-EBSA.

HIPAA

The Health Insurance Portability and Accountability Act of 1996 was designed to protect access to health insurance in a variety of situations. HIPAA may help you:

- Get health coverage for yourself and your dependents if you start a new job
- Lower the risk of losing existing healthcare coverage, whether you have that coverage through a job or through individual health insurance



- Maintain continuous healthcare coverage for yourself and your dependents when you change jobs
- Buy health insurance on your own, should you be dropped from an employer's group plan and have no other healthcare coverage available

Your state's commissioner of insurance can provide you with more information. Or visit the Centers for Medicare and Medicaid Services website at [cms.hhs.gov](https://www.cms.hhs.gov).

Just Between Us | Survival Tips from other Survivors

"Always make sure you are educated about your personal insurance coverage. Spend lots of time on the phone and ask lots of questions. Pay close attention to itemized bills."

- Shannon, mother of Olivia (Retinoblastoma)

"It's so important to just ask if changes are possible! We asked our insurance company to do an end of year audit for us to make sure we paid the bills in the correct order of date to meet our deductible."

- Linda, mother of Sam (Neuroblastoma)

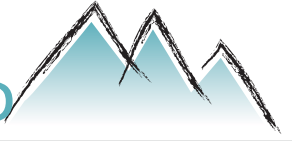
Keep your child continuously insured.

Having a child who is a cancer survivor means monitoring your health insurance coverage very carefully— even into adulthood. Whether your child is still in treatment or finished years ago, your child should always have health insurance. Without it, you and your child's health and financial future will be at risk.

This is especially important when your child becomes an adult. Young adults are one of the fastest growing groups without insurance. Be sure your young adult understands the importance of maintaining continuous coverage. Research options for keeping your young adult insured. Can your child remain on your insurance policy or be enrolled in a federally subsidized plan? If your child is looking for a job, encourage them to seek employers who offer health insurance and suggest that they explore individual health insurance plans also. A lapse in coverage is a lapse in good judgement.

Visit [USA.gov](https://www.usa.gov) for current legislation that may impact health insurance coverage.





Being open to an open dialogue

We spend years teaching our children the importance of honesty, and never will this policy be more important than when your child has cancer. Parents of survivors and healthcare professionals alike encourage parents to be truthful with their child at every stage of the survivor journey.

Diagnosis: The truth beats the unknown.

Parents often think they are protecting their child by withholding scary information, but children are usually less frightened when they know the truth about their health. Kids often pick up on their parents' fears and sense when something is wrong. They may piece clues together about not feeling well with frequent doctor visits, and because they don't know the facts, they will worry or possibly imagine things that are not true. An uninformed child may even believe their illness is a punishment for something they did wrong.

It's also important that your child learn about their illness from you. Family, friends or members of your medical team may inadvertently say things that let your son or daughter know about their cancer. Your child may feel hurt or betrayed that you weren't honest with them.

Children who know the truth are less likely to feel stress or guilt, which means they are more likely to cooperate with treatment. Talking about your child's cancer can help your family feel closer and more unified. Childhood cancer affects the whole family, and open communication can make dealing with the changes easier for everyone.

What do I say?

Telling your child they have cancer is a personal matter, so naturally, family, cultural and religious beliefs will come into play. Talk openly to your son or daughter in a way that is age appropriate, and be honest with other siblings about the diagnosis and treatment. Encourage everyone in your family to ask questions and express their feelings.

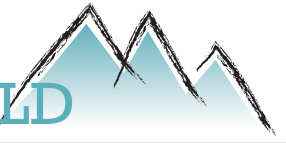
You will likely question the best way to talk to your child. For starters, who should be present? Some parents prefer to explain their child's diagnosis and treatment with the help of someone from the medical team. Others invite a clergy member from their own church or synagogue to pray with them.

Children are very perceptive though, so it's best to talk about things soon after the diagnosis. Choose a quiet place to talk and use dialogue they will understand. Some parents recommend rehearsing what to say and keeping it less emotional, more matter of fact.

During treatment, knowledge is power.

Your need to communicate openly with your son or daughter will continue throughout treatment. During this time, your child will endure many uncomfortable, even painful situations. Knowing what is going to happen next and why will help him or her feel less out of control and more cooperative. If your child is old enough, let him or her be involved in making medical decisions. As kids gain independence in their teens, they are more likely to cooperate when given the chance to express their opinions.

COMMUNICATING WITH YOUR CHILD



Encourage your child to become familiar with all areas of the hospital. A trip to the pharmacy allows them to see how medications are made. Touring the surgery rooms removes an element of the unknown. By empowering a child with knowledge, you'll increase their understanding while reducing their fears.

Keep in mind, no child is going to have a positive attitude all the time. There will be bad days. It doesn't mean that your child is losing strength. It merely means the experience is difficult and they will need your support.

Just Between Us | Survival Tips from other Survivors

"I told my husband to wait to tell Markesha because I wanted my pastor there, and other members of my church to support her, and tell her in a way that a child would understand."

- Annette, Mother of Markesha (Liver cancer)

"Our best advice was from the radiation oncologist. Spencer was 7. The doctor said to tell him then that he was sterile. We were open in discussing that - this is what we are doing and this is what it is going to cause. He grew up with that knowledge... We hit the teen years and had an initial adjustment period, but he's accepted it. I think we got good advice."

- Carrie, mother of Spencer (Leukemia)

"We tried to explain things in ways he would understand, like the stem cells are your own personal super hero cells, which will make you strong and grow. We also did our best to be prepared with options that would give him some control if possible... like a specific bandage or way of doing something."

- Linda, mother of Sam (Neuroblastoma)

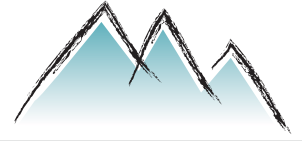
Treatment ends, communication continues.

As life moves beyond cancer, you'll need to keep talking honestly with your child. The battle with cancer is difficult for the entire family, and everyone will likely want to put the experience behind them. Try to remember, survivorship is a journey that lasts a lifetime. Your child's illness and treatment may lead to future physical problems, emotional challenges and social concerns. Knowledge about late effects will help your child lead a full, healthy and productive life. Keep the communication open so they can come to you when concerns arise.

Every child will understand their diagnosis in different ways, at different ages. Kids diagnosed as toddlers or preschoolers need new explanations as they mature. It's easy to "move forward" and forget that your child may need new information to process what happened when they were younger.

While the cancer process is often painful and wrought with feelings of helplessness, undoubtedly the experience will have some positive aspects. You may recognize the support from family and friends, the knowledge of your medical team and pride in the strength and courage of your child. With this journey comes the reminder of how truly precious life is.





A single diagnosis will affect your entire family.

Having a child diagnosed with cancer can make you feel like your world is falling apart. Children aren't supposed to get cancer, right? But they do, and childhood cancer doesn't just affect one child, it affects the whole family forever.

The emotional challenges can be enormous for a parent who must now care and comfort a sick child, maintain the household, take care of other children, and make very difficult medical decisions. Parents often have to miss work or even leave jobs while finding some way to ensure the family's financial stability. The pressure can mount, and it's felt by everyone in the family.

They aren't sick, but they still need you.

Children are particularly sensitive to the drastic changes that occur within a family after a sibling has been diagnosed. Brothers and sisters frequently miss their parents and the sibling who are gone during hospitalizations. They are forced to stay with other relatives or friends and often need to take on greater responsibilities at home. More than anything, they begin to worry.

Confusion, fear, anger and jealousy are often expressed through behavioral changes. It's important to recognize that these changes may be symptoms of unexpressed emotional issues. These suggestions can help you cope with the difficulties your other children may be facing.

- 1) **Talk openly about cancer.** Use words they can understand that are age appropriate. Encourage them to ask questions. If you aren't sure how to discuss things, talk to a member of your oncology team.
- 2) **Reassure your children.** Tell them they didn't do or say anything that caused their sibling's cancer. Assure them that childhood cancer isn't contagious and it is very rare.
- 3) **Encourage them to spend time with their sibling.** Find activities to do at home or let them visit the hospital. Don't worry that the hospital visit will be too traumatic. Imagining what happens there is usually scarier than seeing a sick brother or sister.
- 4) **Spend time with each child individually.** Find things that they like to do that make them feel special.
- 5) **Encourage them to express their feelings.** Let them keep a journal to work through their emotions. Allow them to be angry, sad or scared and reassure them that all these feelings are normal. If necessary, consider counseling to help your kids deal with their concerns or frustrations.
- 6) **Watch their body language.** When you discuss cancer, look for clues to their true feelings. Try to get them to open up about it.
- 7) **Ask the hospital child life specialist for help.** Find out if the hospital offers special activities for siblings. Or take advantage of programs and camps offered to siblings of childhood cancer survivors.
- 8) **Talk about your family situation with teachers.** They can be a tremendous support to children during the day.

Above all, remember that although they aren't sick, siblings still need their parents. Remind them that you love them, and shower them with affection. Hugs and kisses can't cure cancer, but they can help all your children remember they are part of a family and surrounded by love.



Coming together as a couple when everything is coming apart.

Every individual copes with the stress of childhood cancer differently. You and your spouse or partner are facing the strain of a life-threatening illness, spending time apart, struggling to pay bills and attempting to create some sense of normalcy within your family. It can be overwhelming for a couple and can wreak havoc on your relationship.

It's not unusual during treatment to find that you and your spouse take on different responsibilities. One of you may become the primary caregiver to your sick child, while the other continues to work, care for your other children and maintain your home. Some families create a system for dealing with the caregiving equally. Still, it's not unusual for couples to have difficulty communicating thoughts, feelings, concerns and needs.

It's important to embrace your differences, as well as your strengths. Try to recognize your own personal weaknesses and find ways to work together through this difficult time. Your family needs you, and you both need each other. According to author Deborah Raies-Dana, "One of the most loving things you can do for your spouse, and your marriage, is to give each other the freedom to work through the pain and deal with the situation as needed, without judging the behavior." (Dust to Diamonds, 2004)

An excerpt from *Amanda's Gift* | written by her father, Scott MacLellan

"There is no time for intimacy and no peace with which to want it. Our identities soon became intertwined with activities aimed at survival, not growth. I am no longer a husband, I am provider of health insurance and weekend caregiver. I am no longer friend and lover, I am father to "the healthy child" who still lives at home. We all become something other than what we imagined...

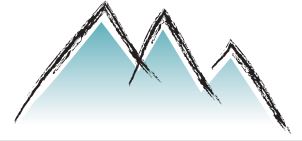
Amanda's illness became our life. All our activities already centered around her care, but we also allowed it to define who we were as people. It became our only common bond. It became the thing for which we stood. We became "the couple with the sick little girl." People would marvel at our ability to stay together in spite of the illness. In fact, the illness was the only thing keeping us together at all!

Our toughest time came when Amanda entered a relatively healthy phase and things returned to a somewhat normal life. It was then our common bond broke and we had to face each other as individuals and as a couple. It was then we had the time to consider our own personal egos. It was then we felt the deepest void between us... For Deborah and me, the key was to integrate Amanda's illness into the rest of our lives... We started looking at Amanda's illness as a part of our lives, not our life itself."

Going it alone.

Childhood cancer is difficult on every parent. But the weight of making difficult medical decisions solo can be very overwhelming for a single parent. Until recently, few studies had been done to evaluate the effects of a catastrophic illness on a single parent family, much less come up with a definition of a lone-parent family. New study findings have suggested that the impact of caregiving on single parents is similar to that of two-parent families. The demand and health-related quality of life varied little between the two family units. (Klassen AF et al., 2011).

Single parents of childhood cancer survivors face the same challenges as two-parent families, which make it critical to plan ahead and use whatever resources are most available to you. More effort may be required on your part to talk to your peers and community members.



Identify family support early in treatment. Other children may need to step up and help out. Carefully discuss your child's treatment plan and any of the treatment's possible adverse effects. You can't anticipate everything, but knowing what some of the expectations and interventions are, will help plan for the appropriate support, and identify which resources are needed to help you through these difficult times.

Being single doesn't mean being alone. You can seek the support of friends, your extended family or a member of the medical team when you need support. Consider joining a support group, or look to other parents going through a similar experience to help you cope. Try to stay on top of information and plan ahead as much as possible. Don't be afraid to communicate your worries and concerns, and always reach out when you need answers, help or just a friendly ear.

Take back control.

Once your child's treatment ends, follow up care begins and everyone is anxious to get back to "normal." Your old sense of normality will likely have shifted. Childhood cancer changes people, but it doesn't have to define you. It helps to recognize how the experience has changed you, how you and your spouse have grown, and begin to integrate these changes into your lives as individuals, as a couple and as the parents of a childhood cancer survivor.

As you and your spouse begin to take back control of your lives, make extra time for yourselves as a couple. Go out to dinner together, play a game or watch a movie. Go out with friends and spend time enjoying your family. If you are religious, it can help to pray together. Now is the time to learn again to laugh with each other, hold hands, share your thoughts and, if need be, forgive each other for the distance between you. Taking back control will remind you of all the things that brought you together as a couple.

Redefining your community.

Parents often find it difficult to talk to their peers and other community members about their child's cancer diagnosis. Most adults have limited experience with cancer, especially those that affect children.

Despite all your efforts, some of your friends may not stay connected with you during this difficult time. Some friends may drift away because a cancer diagnosis reminds them of their own vulnerability. Your schedule will naturally become more hectic and you may find some friends react badly if you can't return phone calls or stay in regular contact. Thankfully though, most people are willing to embrace your limited time constraints and offer friendship when you are available.

A cancer experience can alter your life forever. You may find that you want or need to make new friends. There is no wrong way, only a "new normal." As you transition back to a more regular life, it's important to develop and maintain a network of friends who will support you and the changes your family has experienced.





Holding on as the ride gets bumpy.

A cancer diagnosis brings with it a roller coaster of emotions for everyone in your family. As treatment continues, emotions quite often stabilize, but life is never quite the same. Welcome to the “new normal.”

During this difficult time, the way you handle stress will affect your ability to manage your constant emotional changes. Good coping skills can help you integrate the cancer experience into your life, instead of being ruled by it. Here are some ways to help you cope with the stress.

- 1) **Give yourself permission to feel.** Whether positive or negative emotions, all feelings are normal.
- 2) **Become your child's advocate.** No one knows them better than you, so be an active part of the treatment team.
- 3) **Educate yourself.** Learn as much as you can comfortably handle about your child's diagnosis and treatment.
- 4) **Be realistic.** Recognize which areas of your child's life can be controlled and which cannot. Understand that some questions do not have answers.
- 5) **Take care of yourself.** Get enough sleep, eat properly and exercise. Make time for yourself with hobbies or other things you enjoy.
- 6) **Accept help.** Learn to take support when people offer it.
- 7) **Get emotional support.** Join a support group, talk to friends, a counselor or clergy. Or connect with other parents who have a child with cancer at the NCCS' private Facebook support group at: www.facebook.com/groups/childhoodcancersupportnccs/.
- 8) **Keep a journal.** Record special moments, both happy and sad.

Just Between Us | Survival Tips from other Survivors

“I learned that each day, each hour would change. So, in order to be able to deal with the stress, I had to take each minute as it came.”

- Tina, mother of Kenton (Liver Cancer)

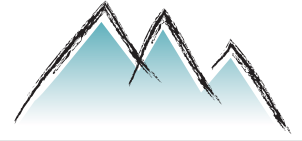
“I realized that I shouldn't squander our time together on needless concerns - like a clean house. I promised myself for those summers together, I would only clean my house on rainy days. The other days were for spending time together.”

- Carrie, mother of Spencer (Leukemia)

“Parents should know that after 5 years, the emotional roller coaster still exists. These 5 years have been the most dark and traumatic, but at the same time the most beautiful and joyous time of my life. It's very bittersweet.”

- Shannon, mother of Olivia (Retinoblastoma)

EMOTIONAL CONCERNS



When the bad feelings don't get better.

Sometimes, managing the emotional toll of a child's diagnosis and treatment can become too great for a parent. If you find yourself having trouble coping, speak to a healthcare professional at your child's hospital. A counselor can help you sort through your feelings and offer you ways to manage the stress you're under. The following organizations can help you locate a professional near you:

The American Counseling Association: [counseling.org](https://www.counseling.org) or 800-347-6647

How do you know if you're depressed? Sometimes it's hard to tell. Symptoms of depression include:

- Depressed mood every day or most of the day
- Difficulty sleeping
- Ongoing lack of interest in anything-including things you enjoy
- Constant lack of energy
- Excessive irritability or constant worrying
- Persistent feelings of helplessness, worthlessness or guilt
- Change in appetite or a noticeable weight loss or gain
- Change in alcohol or drug habits
- Neglecting your own health needs
- Difficulty concentrating

Should you need additional emotional support, call us at 800-532-6459.





Learning to embrace their new educational needs

When a child gets cancer, parents have to adjust their thinking about school attendance and their child's needs for learning. Treatments can cause many absences, so be sure to discuss attendance plans with your school and your child's teachers as quickly as possible. Some hospitals have school liaisons that will assist with all areas of education. These people work with your child throughout treatment to maintain some educational consistency. That also means they should be included in any meetings regarding your child's learning.

If you have other kids in school, be sure to inform all of your children's teachers about your family's situation and ask them to alert you if problems arise. You will need to re-inform teachers and administrators at the beginning of every new school year in order to keep everyone up-to-date on your children's educational needs.

Enroll in the school of flexibility.

Parents may feel an instinct to shelter their child while they are sick, but kids should attend school whenever possible. Research shows that long-term survivors who attended school during treatment had better social skills, more self-confidence and were also less likely to have academic problems than kids who were in tutoring programs at home.

The reality is tough; many children with cancer have to miss school frequently due to treatment, complications, or a compromised immunity. For this reason, many schools offer Homebound Tutoring or private tutoring to students who must be absent from school over an extended period. If your child does a homebound program, they would remain enrolled in school and be expected to return as soon as they are able.

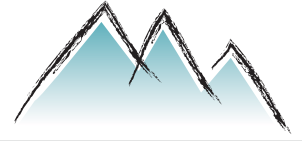
Programs are administered in different ways so it's important to find out what your school can provide. Most students benefit from intermittent home tutoring, meaning they attend school when they are able, and are tutored at home when they are not. This process can be discussed and arranged through a school counselor. Intermittent instruction, however, may not be right for every child or available in every district.

Sometimes, your child may need to be hospitalized. While he is inpatient, the hospital's educational coordinator can help with academics. Many coordinators will also help when your child is outpatient.

Missing school without missing out.

Unfortunately, by missing school, kids also miss the important socialization lessons that school provides. There are ways to help your child stay involved while they are at home.

- 1) **Attend special days and parties.** Work with the school to allow your child to be there for activities like Halloween, Valentine's Day or classroom functions.
- 2) **Interact with classmates.** Encourage friends to send cards, letters and pictures. You can even set up a collection box at school to make it easy for people to stay in touch with your child. Email is another great way to keep in touch.



- 3) **Help your child keep in touch through social media or other free websites.** Create an account for your child on the “Messenger Kids” app, which provides a safer, more controlled environment for parents to monitor activity and for your child to stay in touch. Also, a personal website can be established on caringbridge.org to update family and friends.
- 4) **Use video conferencing to interact.** Skype, FaceTime, Facebook Live all provide opportunities to connect in real time.
- 5) **Invite friends to visit and play.** It's important your child continue being a kid.

When school isn't an option.

There are some children who need to avoid school altogether during treatment. If that is the case with your child, consider homeschooling. When a child is home schooled, there is no official connection to public or private schools. It's legal in all 50 states and Canada, but each state has its own laws regarding the process. To find out the laws in your state, visit homeschool.com.

Back to school (and worrying).

During treatment, children get accustomed to spending most of their time with their parents. Worried parents can be very protective during this time, often focusing on germ prevention and avoiding the stresses of the outside world. When your child eventually returns to school, it's natural to feel a lot of anxiety. Remind yourself that for a child, going to school is an important part of reclaiming a normal life.

For your child, returning to school can be exciting, but it may also be frightening. Academic and social concerns are normal. Cancer and treatment often have visible side effects that can make a child feel self-conscious. School absences and effects from treatment can also impact a child's learning path. Talk with your child about their concerns and remind them of the courage they've shown in their cancer journey. Encourage them to use their strengths in every aspect of their life.

Just Between Us | Survival Tips from other Survivors

“The other children became very protective of her because they knew about her cancer and treatment”
- Annette, mother of Markesha (Liver Cancer)

“Returning to school is heartbreaking, but very exciting. After all, this is progress.”
- Rachel, mother of Roman (Rhabdomyosarcoma)

“I wish the schools were better educated about childhood cancer but I'm slowly finding out that it's my job as a parent to provide the school with proper and adequate information, specific to my child.”
- Shannon, mother of Olivia (Retinoblastoma)

“Parents and educators need to communicate often. Teachers need to realize that the last thing a child wants to do when in pain, is study. Facilitation of learning is key.”
- Casey (Survivor of Ewings Sarcoma)



Take it easy, and adjust accordingly.

Going back to school can trigger a variety of emotional responses. Stay in contact with your child's teachers and communicate regularly about changes in academic and social behaviors. It's helpful to have a teacher, counselor or school nurse to oversee your child's adjustment back into school.

The transition back to school will be easier if you and your family make the following decisions about your child's condition.

- 1) **What do you want to share?** Consider how much information about your child's diagnosis and treatment you are willing to let the school community know.
- 2) **How will you provide this information?** Will your child give a presentation to the class? Will you talk to school administrators? Or will you ask someone from the hospital to lead the discussion?
- 3) **When should the discussion take place?** Discussions should occur prior to your child's return to school after diagnosis/treatment and following any new developments that could impact their performance.
- 4) **Who should the teachers and your child's peer's contact with questions?** Ask your child who they would like to handle questions. Consider how you will handle rumors should they start.

Sometimes, the school needs educating.

Before your child goes back to school, meet with school administrators and teachers to discuss your child's needs and health issues. Your child's medical team will be able to offer the school information on your child's condition. Don't be afraid to ask your social worker or a member of the nursing staff to attend your meeting to help convey accurate information and dispel any rumors or myths surrounding diagnosis and treatment.

What most children survivors want is to be treated normally. To make this happen, you'll need to educate your school community. Your child's treatment may last more than one school year, so you may need to present this information at the start of each grade.

Before returning to school, discuss these things with teachers and your principal.

- 1) **Your child's health in detail.** Talk about your child's diagnosis, treatment plan, as well as low blood counts and your child's risk of infection.
- 2) **Central line issues.** Tell them if your child has a Port-a-cath or Broviac.
- 3) **When to contact you.** Stress the importance of calling you if your child has a fever and of informing you if anyone in school has contracted an infectious disease such as chicken pox.
- 4) **Any immunization restrictions.** Discuss with the school nurse what is expected if there is an outbreak of a disease for which your child has not been adequately immunized.
- 5) **Future absences.** Talk about who will pick up and return schoolwork when your child is absent from school.
- 6) **Accommodations for your special needs.** Consider whether your child will need permission or a special pass to go to the nurse or restroom when necessary.
- 7) **Who will administer your child's medication at school, if needed.**
- 8) **If there are issues preventing your child from completing assignments on time.** Mention if there are side effects of treatment or if your child has chronic fatigue.



- 9) **If there are areas in which your child is falling behind.** Set up tutors if necessary.
- 10) **Arrangements for your child's condition.** Discuss if there are activities your child cannot participate in or if extra time will be needed to move between classrooms.
- 11) **Class room seating.** Talk to teachers about your child's placement in the classroom if they need to accommodate for hearing and visual problems.
- 12) **Side effects caused by treatment.** Find out if the school is equipped for a wheelchair or walker and if handicapped parking spots are available. Discuss whether special permission is required to wear a hat or a scarf to school.

Kids will be kids.

No matter how much you try to give everyone the facts about your child's condition, sometimes lack of knowledge translates into a lack of kindness. Warn your child that they might be teased. Encourage the school and your teachers to set a tone that doesn't tolerate teasing. If you have questions or problems, talk to the school counselor about ways to make the social transition easier for your child. It is vital to educate your child's school and classmates to best avoid unkind behavior from peers.

Know the signs of learning problems.

Sometimes, childhood cancer survivors develop difficulties in school as a result of treatment. Academic problems can appear immediately or not show up for several years. A 504 Plan is part of the Rehabilitation Act of 1973 and requires schools to meet the needs of students with disabilities. When your child is first diagnosed, consider requesting a 504 Plan and maintain it through high school. Resources are easier to access when the plan is already in place. Keep in mind; studies on childhood cancer are continually revealing new facts about educational late effects. Childhood cancer is rare and many educators are not familiar with the late effects on learning. Children who are struggling to learn may display difficulties with:

- Handwriting or spelling
- Reading comprehension
- Remembering math facts (such as multiplication tables) or using math calculations correctly when solving problems
- Processing, copying or writing information after seeing it
- Short-term memory
- Planning and organizing
- Completing tasks on time, both in class and at home

Watch for other indicators such as falling math and spelling grades or frequent teacher complaints about your child's attention span. Your child may become frustrated with assignments, complain about school or battle you more about homework. It's not uncommon for children to experience difficulty remembering information that has been seen (compared with information that is heard) or trouble remembering things that are novel or non-meaningful. Your child may also appear to "space out" (without other symptoms of hyperactivity or impulsivity).

Talk to the teachers if your child begins having trouble, and alert them that the problems could be related to treatment. Difficulties can sometimes be alleviated by changing the learning environment, relocating your child's seat or allowing more time on tests. In some cases, the child's learning ability may never fully be restored. A neuropsychological evaluation may be helpful in identifying the root of the problem. No matter what the issue, work with your educational team to reduce your child's stress and find ways to boost your child's confidence.



IDEA and Special Education

There are federal guidelines in place to ensure that every child's special educational needs are met. The Individuals with Disabilities Education Act (IDEA) states that "children with disabilities" are entitled to a "free appropriate public education which includes special education and related services to meet the unique needs of all disabled individuals between the age of 3 – 21."

Related services covered under IDEA include physical, occupational and speech therapies, counseling, sign language interpretation, providing classroom aides, and transition planning for success after high school. IDEA lists several categories of disabilities and impairments, but most children with cancer are eligible under the "other health impairment category." IDEA guidelines only apply to state-funded schools. Private schools are not mandated to meet the guidelines and may not have the budgets to provide your child with special services. However, children may be able to receive some services at your local public school, even if they attend a private school. Discuss your options with administrators at your public school.

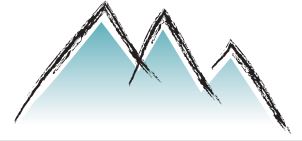
Getting your child the tools to succeed.

If you feel your child meets one of the IDEA criteria, ask your principal or the school's director of special education for the necessary paperwork. Your child's doctor will have to provide documentation and your child will undergo a series of evaluations to determine eligibility. Sometimes, these evaluations do not show a deficiency until several years after treatment is completed, so reassessments should be made every three years, at a minimum. Studies indicate that children treated for cancer may need to be tested more frequently.

If the school is unwilling to test your child, ask your doctor for a referral to the hospital psychologist for appropriate testing and recommendations, and then share the results with the school. Strongly encourage your school to do as much of the testing as possible. Often, it is not covered by health insurance. For further assistance with the process, talk to the education consultant at your hospital. Special education is defined as "specially designed instruction, at no cost to the parents, to meet the needs of a child with a disability (34 CFR, Sec. 300.17)." Local and state governments interpret and implement the federal guidelines differently. Special education includes everything from classroom-setting instruction to special accommodations and related services. Education must be provided in the least restrictive setting. That means that your child won't necessarily be placed in a special education classroom. For a copy of your school's special education policies, write or call your local school district.

IDEA empowers you to advocate for your child and work as an equal partner with the school to develop an Individualized Education Program, or IEP. This will be the framework of your child's education. In developing the IEP, you will attend each meeting and share your concerns, questions, special factors, and ideas about your child's education.

All students who qualify for special education and related services are also protected under Section 504 of the Rehabilitation Act of 1973, which prohibits discrimination by any federally supported organization against qualified students with disabilities. Section 504 upholds students' equal access to educational services even if they are not eligible under IDEA. In order to qualify for Section 504, your child must have a physical or mental impairment (a cancer diagnosis is considered "other health impaired") that substantially limits a major life activity, such as school.



Under Section 504, a child with a disability may receive the benefits of any educational preschool, elementary, or secondary program that receives federal funds. This allows your child to receive nonacademic services such as special transportation, after-school care, or other specified activities. It will also exempt your child from an attendance policy if there is one. It's important that you do not discontinue your child's 504 Plan just because treatment has ended. Remember, some late effects do not surface for years.

Your academic records must make the grade.

No matter what your child's learning needs, it's important to keep all academic records and update them yearly. Your files should be comprehensive and include the following information:

- 1) **Pertinent School Contact Records.** Include school contact information, teachers' names, any correspondence from the school, all test results and report cards.
- 2) **General Health Information.** Include all immunizations, medications and correspondence with the school about your child's treatment.
- 3) **Valid Attendance Records.**
- 4) **Special Requests.** Put all requests you have for the school in writing and save a copy.

Be sure to share the file with your child. These files can be helpful down the road with further education and special need services. These records will be useful to your child up to the age of 21.

After treatment, time will tell.

The late effects of childhood cancer are detected over time, so it's important you, as a parent, watch for new learning problems as your child ages. This doesn't mean your child's learning is getting worse. Following treatment, your child's brain is simply not developing and growing at the same pace as the brains of other children.

New abilities show up at different ages for children. Learning abilities that normally occur at a certain age for a healthy child may occur later for a child who has undergone cancer treatment. For this reason, the late effects of childhood cancer that interfere with learning are often referred to as an "acquired developmental delay." As a child gets older, one can expect to see problems that may not have been noticeable before. We recommend repeated neuropsychological evaluations to identify and address problems as early as possible.

A study guide for testing in the classroom.

Talk to administrators at your school about getting the right kind of neuropsychological testing. Examinations that focus on IQ and academic achievement will probably not be helpful to your child. Be sure your child is tested for:

- Processing speed
- Attention
- Visual-motor integration
- Planning and organization
- Visual, verbal and working memory
- Applied abilities
- Reading decoding and comprehension.

Some children experiencing difficulty with attention may benefit from medication. Work with a neurologist, developmental-behavioral pediatrician or child psychiatrist to determine if medication is right for your child.



Help your child adapt to different ways of learning.

Childhood survivors who are experiencing learning late effects have difficulty demonstrating their knowledge in a “read-write” world. These children often do well when a “listen-speak” approach is taken with their education. Many things can be done to accommodate these learning needs.

- 1) **Acquire reading material on tape.** Listening, instead of reading will allow the material to sink in better. This can be done for textbooks in all subjects and books the child picks out for enjoyment.
- 2) **For standardized testing, allow the child to record answers on the test form itself and ask for extra time.** Children treated for cancer often have difficulty transferring answers to a separate fill-in “bubble page” or other types of scanning documents.
- 3) **Allow the child to take oral exams.** Have the test read to your child and allow him or her to give answers orally.

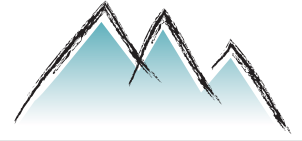
Encourage your child to take advantage of the benefits of technology. A child can learn to apply math with a calculator without having to memorize multiplication tables. Voice recognition software for the computer also allows a teenager to dictate work directly into it. Finding ways to adapt to your child’s individual needs will encourage learning and promote healthier self-esteem.

Smart planning for college.

Many childhood cancer survivors will eventually head off to college. Rest assured that the same courage and determination that got your child through cancer treatment will serve them well in college. There are many things to consider when choosing a school. If your child requires regular follow-up care, be sure the school is located near a reliable hospital with respected doctors to continue overseeing their care. If your child requires special accommodations, find out if the school will provide them. Inquire if the school has an office that serves students with disabilities.

Here are some helpful questions to ask:

- Does the school have an office that serves students with disabilities, including a full-time staff (Student Disability Services-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 your child finishes college?
- Do they have an ADA/504 coordinator?
- Who should parents contact if they have questions during the school year?
- Who counsels students during registration, orientation, and course selection?
- Is tutoring available, and are the tutors professors or students?
- Is tutoring automatic or does it need to be requested?
- 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 are classroom accommodations requested?



Of course, the cost of a college education can be staggering. Financial aid may be available for your child, and your child's guidance counselor can help you with the process. As a cancer survivor, your child may also be able to apply for special scholarships for childhood cancer survivors. The NCCS' Beyond the Cure Scholarship Program makes college scholarships available to survivors of childhood cancer who have been diagnosed before the age of 18. To learn more about our program and other scholarships available to survivors, visit theNCCS.org.

Applications made easier.

Keeping comprehensive files that include academic records, special education services and any additional support your child has received will be helpful during the admission process. Here are some additional questions to ask:

- Does the college offer early enrollment?
- Is additional time provided for students to meet with professors and learn the location of classes?
- Can students take longer to graduate?

Leaving home without anxiety following.

Your child may have done well in the high school setting, but sometimes, the transition to college life can be a bigger adjustment. If your child has experienced any limitations, make college decisions that contribute to your child's educational growth and success.

- 1) **Be realistic about the college completion timeframe.** Think carefully about course requirements, course sizes, course waiver provisions and course curriculums. Encourage your child to take 5-6 years to graduate if necessary.
- 2) **Choose instructors with teaching styles that complement your child's learning style.** If your child learns best in class discussions, ask advisors to help choose professors who encourage class participation.
- 3) **Consider health insurance coverage.** Will your child continue your healthcare coverage or be covered through the university?
- 4) **Encourage your child to get acquainted with other students with disabilities.** It can be helpful to learn from others the type of problems your student may face, and to hear suggestions for overcoming the challenges they may encounter.

An education in life.

You and your family are childhood cancer survivors. As you consider these important aspects of your child's educational growth, remind yourself of the journey you have shared together. The things you have learned throughout your climb will enrich all aspects of your life, not just your child's education. Your cancer experience has provided you with lessons of strength and emotional growth that can't be learned in books. Celebrate your child's amazing achievements!

*After treatment information provided by Dr. Daniel Armstrong, Director,
Mailman Center for Child Development*





Improving diet, exercise habits and your well-being.

There are no known causes for childhood cancer. The best diet and the healthiest habits do not prevent it. But it's still important for parents to help their children establish a lifestyle that promotes good health now and in the future.

There are many lifestyle factors that have been linked to health problems and cancer in the general population. These include diet, obesity, sun exposure and the use of alcohol and tobacco. Cancer survivors, who have undergone multiple treatment modalities such as chemotherapy, radiation, surgery or a bone marrow transplant, are at an increased risk for health problems, as well as a second cancer.

There is increased awareness of the long-term health problems that may occur the longer a childhood cancer survivor lives. With this greater likelihood of health concerns, it becomes even more important for survivors to maintain a healthy lifestyle to reduce or prevent some of the long-term effects from treatment.

Eating right and staying active can improve your health and overall sense of well-being. Research continually suggests that a healthy diet can reduce the chance of certain diseases, including cancer. As a parent, it's important to remember that healthy choices begin at home. Set a good example and encourage healthy habits for all your children.

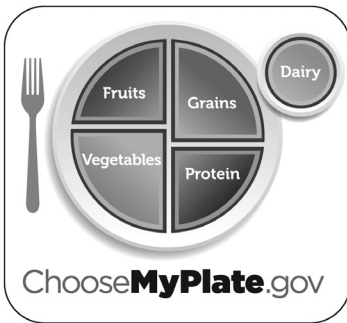
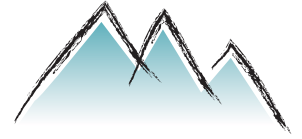
Healthy eating during treatment.

Many studies show that having your child follow a healthy diet while undergoing cancer treatment can help minimize the unpleasant side effects. Cancer therapies often affect a child's appetite and weight so getting your child to eat healthier foods isn't always easy. Treatments can cause mouth sores, constipation or diarrhea which often interferes with appetite.

Should your child lose their appetite, giving small, frequent servings of food that are high in calories will help them maintain weight. On the other hand, children who have been prescribed steroids often have a voracious appetite and gain weight. It's important that you don't restrict your child's food intake to get the weight off. This weight gain will be temporary, so your focus should be maintaining your child's well-balanced diet. If you become concerned about your child's weight loss or gain, discuss his or her specific nutritional needs with your doctor. Often, nutritional supplements like Pediasure can help a child get the necessary nutrients.

You may see other changes in your child's eating habits, as well. Treatment often causes changes in tastes, making some children pickier eaters. If getting your child to eat healthy foods becomes too much of a battle, switch your strategy. The important thing is that a child eats and always gets plenty of fluids.

Hospital food can be less appetizing than the foods kids are used to eating at home. Many parents find bringing in the child's favorite meals can get them to eat more. Most kids just want to eat what their friends are eating, so you won't be the first parent to fight this battle. Diets limited by cancer treatment can be very challenging to manage. Try to be creative and think ahead.



The shape of healthy eating.

Because what your child eats has such a direct impact on their health, it's important for them to consume a well-rounded and healthy diet filled with a variety of fruits, vegetables, nuts and beans. That means limiting the intake of red meat and processed foods which are high in fat and sugar, and low in fiber. You should restrict the amount of salty and sodium-heavy processed foods which your child eats, too.

Pay particular attention to portion sizes, what the portions consist of and how they correlate to standard serving sizes. Be sure that 2/3 of your child's diet consists of plant based foods, and 1/3 or less is from animal foods such as meat and cheese. Cured meats, such as bacon and cold cuts, should only be eaten on rare occasions. Using the new USDA MyPlate icon will help you make wise and healthy choices for you and your family.

Ready, set, move!

The importance of physical activity can't be overlooked in promoting a healthy lifestyle. Exercise increases energy, improves mood and boosts self-esteem. It also stimulates the immune system while reducing the symptoms of pain, diarrhea and constipation. Experts recommend people of all ages get regular physical activity, including children, who need at least 60 minutes of moderate physical activity every day. Of course, you should always consult your child's doctor before beginning any strenuous exercises. Certain types of chemotherapy may lead to heart disease, which can be aggravated by vigorous activity.

Most of us believe our kids get more than enough exercise, but actually, one in five children in the United States are overweight or obese. Many kids spend too much time in front of the television, computer or playing video games instead of being active. Research has indicated there is an increased risk of obesity associated with certain treatments for childhood cancer, which makes it even more important to get your child accustomed to being active. Exercise can be something you share. Whether it's walking, hiking, biking, swimming or playing sports, it's a great way to spend time together, improve your health and reduce your own personal stress.

Where there's smoke, there are health problems.

Tobacco is the largest cause of preventable cancer in adults. Unfortunately, smokers aren't the only victims. Second-hand smoke from a lit cigarette and from a smoker's exhalation can cause lung cancer and heart disease. For children, second-hand smoke is even more dangerous because their lungs are still developing. In homes where a parent smokes, there's a higher incidence of asthma, along with inner-ear fluid buildup and middle-ear infections.

If you're a smoker, you're not only risking your child's health, you're setting an example that they may choose to follow. Recent studies show that seven out of ten high school students have tried smoking cigarettes. Making healthier lifestyle changes and communicating with your child about the risks of smoking can bring this number down.

Electronic cigarettes or vaping may seem like a safe alternative, but research shows e-cigarettes contain highly addictive nicotine and potentially toxic chemicals not yet understood.

During your child's treatment, second hand smoke may increase the risk for lung problems. Don't let others smoke in your home. If you're a smoker, quit. Your health and the health of your family depend on it.



A toast to being alcohol free.

There is evidence that drinking large amounts of alcohol can elevate the risks of several types of adult cancers and chronic conditions. Excessive drinking can have many emotional side effects too, such as depression, impaired judgment, and the shedding of inhibitions. Those who have undergone treatment are at an increased health risk, so drinking is not recommended as part of a healthy lifestyle for cancer survivors. If you choose to drink in front of your child, do so in moderation.

The legal drinking age is 21, yet a staggering 70% of American high school seniors have consumed some form of alcoholic beverage within the last month. Many studies show that the earlier a person starts drinking, the more likely they are to have alcohol-related problems in adulthood. Talk to your teen about the risks of alcohol consumption, especially as it relates to their long term health and survivorship. Be sure the behavior you demonstrate serves as a positive role model.

Just Between Us | Survival Tips from other Survivors

"We called places ahead of time and made special arrangements. For example we went to dinosaur bone dig a half hour before the scheduled time without the crowd. It's amazing how people will do their best to accommodate a sick child. We also put a list of things to do and places to be approved by the nurse educator and made sure they were okay."

- Linda, mother of Sam (Neuroblastoma)

"At the same time you push healthy eating, sometimes you have to understand that occasionally, you may just need to let them eat whatever. When my daughter lost a lot of weight, her doctor said to let her eat whatever - just to keep/put weight on and get her eating again."

- Shana, mother of Mackenzie (Rhabdomyosarcoma)

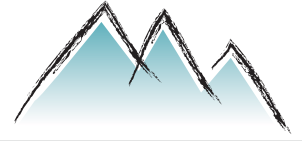
Here comes the sun.

Everyone enjoys spending time in the warm sunshine, but too much sun exposure can cause serious health problems. Studies have found that excessive ultraviolet (UV) radiation can cause skin cancer in adulthood. Children undergoing chemotherapy or radiation may also be more sensitive to sun exposure. Be sure your child's skin is protected from the sun at all times. Use these tips to ensure your child is well protected.

- 1) **Use a minimum of SPF 30.** Apply 15-20 minutes before sun exposure. SPF 30 will block out 97% of UVB rays, which are the more dangerous burning rays.
- 2) **Apply sunscreen every two hours.** Apply a thick layer and reapply after swimming. Keep track of the freshness date on the package.
- 3) **Limit your time in the sun.** Avoid peak hours of damaging rays between late morning and early afternoon.
- 4) **Have your child wear a hat.** If the hat doesn't protect the ears, be sure to apply sunscreen to the ears and back of the neck.
- 5) **Have your child wear UV-protective sunglasses.**
- 6) **Dress your child in UV-protective clothing.** Long-sleeve shirts and long pants, when appropriate, will protect your child's skin from the sun's damaging rays.
- 7) **Avoid indoor tanning beds.** They contain the same dangerous UV rays as natural sun exposure.
- 8) **Set a good example.** The sun habits you practice will protect your family now and down the road.

These and other healthy lifestyle habits will help your child be stronger through their cancer treatments and healthier for many years to follow.





Spiritual 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.

Spiritual Responses 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 or friend, spiritual advisor or professional.

Your Faith Community

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.

Who Will Provide Spiritual 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, they should:

- 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



Here are some additional tips on taking care of your spiritual well-being:

- 1) **Be open to the breadth and depth of yourself.** You have reserves within and surrounding you that can help you through many difficulties.
- 2) **Engage the strength of your spirit.** That is what has maintained you thus far. Trust that it remains and will be supported and strengthened if you remember that you are not alone.
- 3) **Speak for yourself.**

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

Content contributed by Reverend Jay Kanerva, M.Div.

Just Between Us | Survival Tips from other Survivors

"Prayer does give a comforting, powerful feeling."

- Rachel, mother of Roman (Rhabdomyosarcoma)

"Every family has different ways of dealing with cancer. I for one; lean on God. I have changed since my son was diagnosed. I am more patient and my faith is stronger. We wouldn't have gotten through this without God and all the wonderful people He sends to us."

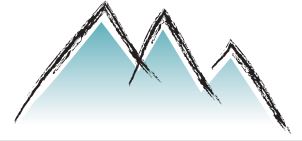
- Tina, mother of Kenton (Liver Cancer)

"The power of prayer is not only to God, but also the positive energy you create. Asking others to pray for Sam gives us strength knowing it is sending this positive energy to him. Also, it helps to know we have the support of our community." - Linda, mother of Sam (Neuroblastoma)

"I was raised Christian in a very spiritual home. But I definitely had my boxing match with God over my daughter having cancer. I stopped praying, going to church, even reading my Bible. Eventually, I dropped the gloves and fell to my knees. I went back to my roots of knowing that He has a master plan for my daughter. The negativity of the anger only keeps you in the dark place longer."

- Shannon, mother of Olivia (Retinoblastoma)





Finding hope and strength in what you've lost.

A cancer diagnosis seems to change life almost overnight. Normal, everyday routines are often replaced with an overwhelming sea of changes and uncertainties. Survivors and their families experience significant losses, and with those losses, grief often follows. These feelings are often overlooked in the face of illness. But like the emotional concerns that come with your child's diagnosis, it's important to find ways to cope with the grief these losses have caused.

It's normal to mourn your old life. Parents often grieve for their "healthy child," knowing their child's medical history will now always include cancer. Others feel a loss of control, security or confidence in their futures. And for many, it's difficult to give up the feeling that they can shelter their children from hardship. Innocence has been replaced with fear and sadness.

Many families have not yet been exposed to significant hardships, and seeing a child face the threat of death changes one's perspective on the world. All these losses and feelings are real and valid. But in spite of these life changes, it should comfort you to know that there is life beyond childhood cancer. Over 500,000 survivors today are living proof.

Grief can't always be anticipated.

Some losses that accompany cancer are unexpected. Just as every child's treatment is different, every person will experience unique losses and reasons to grieve. There is no standard, but it helps to remember you are not alone.

Many survivors and their families are faced with these personal losses:

Hair- Though an obvious external loss, it can mean different things for different people.

For some parents, it's a constant reminder of the cancer and the loss of their healthy child.

Fertility- The loss or possible loss of fertility is a side effect of some treatments.

Amputations- To save a child's life, an eye may have to be removed or an arm or leg must be amputated.

Learning ability- Some cancers and treatments affect the brain in ways that make it more difficult to learn, even after treatment is completed.

Energy and strength- A child may not be able to participate in favorite activities due to weaker body strength and physical energy.

Childhood- Many parents feel that the cancer experience turns their child into an "old soul."

Personality- The stress of the cancer experience and side effects of some medications can cause significant changes in a child's personality.

Normal activities- Things that were previously considered normal-school, sports, social events, church, vacation, even visiting friends and family- may be lost or greatly reduced during treatment.

Attention to other children- Often, the demands of the sick child gives parents less time to spend with their other kids.

Freedom- Parents and children frequently have to adjust to a lifestyle that allows less freedom and spontaneity.

Income- It is common for a parent to reduce work hours or leave a job to care for the child with cancer.

Time for adult relationships- Many parents find they must sacrifice some attention from their marriage or other friendships to care for their sick child.

Community connections- Some friendships stay strong throughout treatment, but some parents report a falling away of support and a feeling of isolation.

Deaths of other children with cancer- Meaningful friendships are forged with other children and families facing cancer. Some of these kids will not survive their disease or treatment.

DEALING WITH LOSS



Everyone copes differently.

Though the cancer experience is overwhelming for everyone, each person must ultimately find their own way to cope. Grief experts and authors Martin & Doka discuss people's different styles of grieving. "Intuitive Grievors" experience feelings very intensely, often finding it helpful to express their feelings by sharing their experiences and crying. Intuitive Grievors can also have times of confusion, difficulty concentrating, disorganization, exhaustion and anxiety. For people who grieve this way, it's especially important to recognize what has been lost and find ways to express your feelings.

For those who are "Instrumental Grievors," grief may seem less intense. Their grief impacts how they think, and there is often a reluctance to talk about their feelings. Parents who grieve this way tend to focus on problem-solving and taking as much control of the situation as possible. Sometimes, their energy levels can be even higher than normal as they gear up for problem solving.

People can have one style of grieving or a mixture of both, but every individual must find ways to lessen their grief. Parents in the same family may have different ways of coping with their grief. One may prefer to deal with situations and losses as they occur while their spouse may need to anticipate possible problems and come up with ways to deal with them ahead of time. Sometimes, parents need outside support to find ways to be supportive to each other.

The losses you experience do matter. As a parent, you can't ignore these real feelings and experiences or they eventually will zap you of the energy you need to care for your sick child, your family and yourself.

Just Between Us | Survival Tips from other Survivors

"As a parent, the hardest thing for me to deal with was the feeling of guilt I carried. You have to let go of that."
- Shana, mother of Mackenzie (Rhabdomyosarcoma)

"As we watched, I saw all that life has to offer unfold before me. I saw joy, excitement, fantasy and dreams. I also saw a touch of loss of innocence and the recognition that not everything is as wonderful as it's cracked up to be. But even with that, I saw how the heart of a child can still find love and faith."
- Scott, father of Amanda (Lymphoma)

Let go. And hold on.

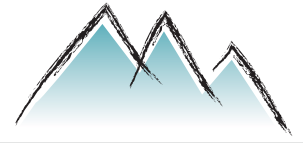
Parents who have learned to cope well with childhood cancer have usually learned two things: to let go and to hold on. When parents learn to let go, they begin to recognize that there are things simply out of their control. Ultimately, the success or failure of cancer treatment is outside anyone's control. Accepting this and other matters you have little power over leaves you with more energy to focus on the things you can control.

Those who "hold on," have learned to not let cancer and its treatment take any more from life than it has to. Don't give up anything that you can keep unless you decide it's no longer worth your while. Priorities can shift and some things may no longer feel like they are worth your time. But never allow the disease to make you feel like it's all you have, or all you are.

Holding on means working to not let cancer have the last word in your life or the lives of your children. In the midst of this difficult time, life offers gifts and growth. Some parents find themselves getting smaller, trapped in fear, grief and bitterness. Those who grow have found ways to let go, while also seeing the beauty of holding on. You have the freedom to choose how cancer will affect you and your family. Open yourself up to wherever the journey takes you.

Content contributed by Greg Adams, LCSW, ACSW, CT- Director for Good Mourning, Arkansas Children's Hospital

RESOURCES



Help for the climb

For additional resources, visit thenccs.org or talk to a member of your child's medical team.

Medical

National Cancer Institute

800-4-CANCER cancer.gov
Provides state-of-the-art information about the treatment of individual types of cancer, clinical trials and late effects.

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.

Chemo Care

844-268-3901 chemocare.com
Provides information about chemotherapy and side effects.

Insurance/Legal

HealthCare.gov

800-318-2596 healthcare.gov
A government sponsored web site on healthcare information.

Patient Advocate Foundation

800-532-5274 patientadvocate.org
Solve insurance and healthcare access problems.

Social Security Administration

800-772-1213 ssa.gov
Provides answers to questions regarding social security benefits.

Support, Advocacy and Financial Assistance

The National Children's Cancer Society

800-5-FAMILY (6459) theNCCS.org
Emotional support, advocacy, education, and financial assistance to parents of children with cancer and an online community for parents and survivors.

American Cancer Society

800-ACS-2345 cancer.org
Information on parental issues such as coping with diagnosis, understanding the health care system, financial and insurance information, and transitioning your child back into school.

Cancercare

800-813-HOPE cancercare.org
Individual and group counseling both on-line and via their toll-free counseling line.

Alex's Lemonade Stand/Supersibs

866-333-1213 alexslimonade.org
Support for brothers and sisters of children with cancer.

First Hand Foundation

816-201-1569 firsthandfoundation.org
Financial assistance for treatment, equipment, displacement and vehicle modifications for children with health problems.

United Healthcare Children's Foundation

855-698-4223 uhccf.org
Financial help for medical services such as speech, physical or occupational therapy, prescriptions, and medical equipment such as wheelchairs, orthotics and hearing aids.

Healthy Living

American Institute of Cancer Research

800-843-8114 aicr.org
Offers specific nutrition information for the cancer survivor.

SmokeFree

877-448-7848 smokefree.gov
Help for those who want to quit smoking

Sun Safety for Kids

818-845-8538 sunsafetyforkids.org
Provides information on sun safety.

Learning Disabilities

National Center for Learning Disabilities

888-575-7373 ncl.org
Solutions and opportunities for individuals with learning disabilities.

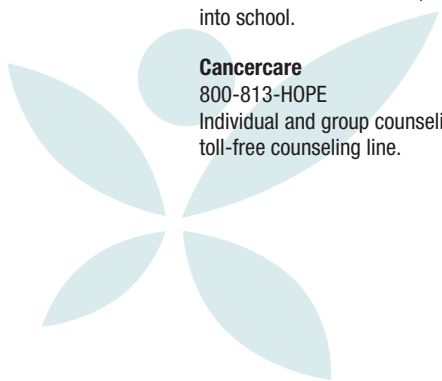
Survivorship

Beyond the Cure Ambassador Survivorship Program

Sponsored by The National Children's Cancer Society
800-5-FAMILY theNCCS.org
Information on all aspects of cancer survivorship, a late effects assessment tool and college scholarships.

Livestrong

855-220-7777 livestrong.org
Awareness, advocacy and support for the cancer community.



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