



The  
National  
Children's  
Cancer  
Society

25 years of serving kids and their families

# MEDICAL ADVICE WHEN DEALING WITH CHILDHOOD CANCER

## MEDICAL ADVICE WHEN DEALING WITH

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### 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?

#### 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.

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### 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, they follow the same treatment protocols. To see if your child's hospital is a certified COG member, check the online directory at [curesearch.org](http://curesearch.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.** Collect business cards from all medical team members, and write down each doctors' name, address and phone numbers on a single sheet of paper. Keep a copy at home and in your appointment book.
- 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.

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### 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?

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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. Your child (and you!) 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 family practice doctor?
- 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?

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### 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. Or contact the American Medical Association at 800-621-8355.

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 Assessment Tool at [beyondthecure.org](http://beyondthecure.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 fertility 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. Your child may be growing up, but he or she will always need your support.

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# RESOURCES

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## Help for the climb

For additional resources, visit [beyondthecure.org](http://beyondthecure.org) or talk to a member of your child's medical team.

### Medical

#### National Cancer Institute

800-4-CANCER [cancer.gov](http://cancer.gov)  
Provides state-of-the-art information about the treatment of individual types of cancer, clinical trials and late effects.

#### CureSearch

800-458-6223 [curesearch.org](http://curesearch.org)  
Funds research and provides information to those affected by childhood cancer.

#### Chemo Care

[chemocare.com](http://chemocare.com)  
Provides information about chemotherapy and side effects.

### Insurance/Legal

#### HealthCare.gov

[healthcare.gov](http://healthcare.gov)  
A government sponsored web site on healthcare information.

#### Patient Advocate Foundation

800-532-5274 [patientadvocate.org](http://patientadvocate.org)  
Solve insurance and healthcare access problems.

#### Social Security Administration

800-772-1213 [ssa.gov](http://ssa.gov)  
Provides answers to questions regarding social security benefits.

### Support, Advocacy and Financial Assistance

#### The National Children's Cancer Society

800-5-FAMILY [theNCCS.org](http://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](http://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.

#### Association of Cancer Online Resources (ACOR)

[acor.org](http://acor.org)  
Electronic support groups to patients, caregivers, and survivors.

**Cancercare** 800-813-HOPE [cancercare.org](http://cancercare.org) Individual and group counseling both on-line and via their toll-free counseling line.

#### Supersibs

888-417-4704 [supersibs.org](http://supersibs.org)  
Support for brothers and sisters of children with cancer.

#### First Hand Foundation

816-201-1569 [applications.cerner.com/firsthand](http://applications.cerner.com/firsthand)  
Financial assistance for treatment, equipment, displacement and vehicle modifications for children with health problems.

#### United Healthcare Children's Foundation

952-992-4459 [uhccf.org](http://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](http://aicr.org)  
Offers specific nutrition information for the cancer survivor.

#### SmokeFree

877-448-7848 [smokefree.gov](http://smokefree.gov)  
Help for those who want to quit smoking

#### Sun Safety Alliance

703-481-1414 [sunsafetyalliance.org](http://sunsafetyalliance.org)  
Provides information on sun safety.

### Learning Disabilities

#### National Center for Learning Disabilities

888-575-7373 [nclld.org](http://nclld.org)  
Solutions and opportunities for individuals with learning disabilities.

### Survivorship

#### Beyond the Cure Survivorship Program

Sponsored by The National Children's Cancer Society  
800-5-FAMILY [beyondthecure.org](http://beyondthecure.org)  
Information on all aspects of cancer survivorship, a late effects assessment tool and college scholarships.

#### Livestrong

866-673-7205 [livestrong.org](http://livestrong.org)  
Awareness, advocacy and support for the cancer community.