

YOUR CHILD'S EDUCATIONAL NEEDS DURING CANCER

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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.** You can set up a Facebook account and regularly post updates on their progress. Please note: Facebook does not allow young children to have their own account so you will need to closely manage and

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monitor any activity. A personal website can be established on caringbridge.org to stay connected with family and friends.

- 4) **Use video conferencing to interact.** Skype is a free video conferencing service that's easy to use. Web cameras are becoming a standard component of many computers. Web cams can also be purchased separately and are an inexpensive and simple way to add video conferencing to your existing system.
- 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)

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.

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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.

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.

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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.

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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 and providing classroom aides. 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.

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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 kids who are treated for cancer are prescribed medications used to treat ADHD. Talk with your oncologist to see if your child may benefit from this therapy. Work with a neurologist, developmental-behavioral pediatrician or child psychiatrist to determine which medication and what dose would be appropriate. Keep in mind, you may have to try different medications at different doses to find the right one for your child.

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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 can also allow a teenager to dictate work directly into the computer word processor. 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?

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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 beyondthecure.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*

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RESOURCES

Help for the climb

For additional resources, visit beyondthecure.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.

CureSearch

800-458-6223 curesearch.org
Funds research and provides information to those affected by childhood cancer.

Chemo Care

chemocare.com
Provides information about chemotherapy and side effects.

Insurance/Legal

HealthCare.gov

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 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.

Association of Cancer Online Resources (ACOR)

acor.org
Electronic support groups to patients, caregivers, and survivors.

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

Supersibs

888-417-4704 supersibs.org
Support for brothers and sisters of children with cancer.

First Hand Foundation

816-201-1569 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
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 Alliance

703-481-1414 sunsafetyalliance.org
Provides information on sun safety.

Learning Disabilities

National Center for Learning Disabilities

888-575-7373 ncld.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
Information on all aspects of cancer survivorship, a late effects assessment tool and college scholarships.

Livestrong

866-673-7205 livestrong.org
Awareness, advocacy and support for the cancer community.