

Educational Issues Following Treatment for Childhood Cancer

Treatment for cancer during childhood or adolescence may affect educational progress due to prolonged absences or reduced energy levels that frequently occur during treatment. In addition, some types of cancer may require therapy to control or prevent spread of the disease to the brain and/or spinal cord (central nervous system). This therapy can sometimes affect memory and learning abilities. Parents and teachers should be aware of potential educational problems that may be related to cancer treatment so that children and teens at risk can be watched closely and given extra help if the need arises.

What increases the risk of educational problems?

Factors that may place children and teens at increased risk for difficulties in school include:

- Diagnosis of cancer at a very young age
- Numerous or prolonged school absences
- A history of learning problems before being diagnosed with cancer
- Cancer treatment that results in reduced energy levels
- Cancer treatment that affects hearing or vision
- Cancer treatment that results in physical disabilities
- Cancer therapy that includes treatment to the central nervous system (see below).

Are children and teens with certain types of cancer at higher risk of developing educational difficulties?

Yes, children and teens with the types of cancer listed below are more likely to have received treatments that may affect learning and memory. Since treatments for these types of cancer vary widely, not everyone who was treated for these cancers is at increased risk.

- Brain tumors
- Tumors involving the eye or ear
- Acute lymphoblastic leukemia (ALL)
- Non-Hodgkin's lymphoma (NHL)

What types of treatment place children and teens at higher risk for learning and memory problems?

- Methotrexate – if given in high doses intravenously (IV) or injected into the spinal fluid (intrathecal – IT or intraommay - IO)

- Cytarabine – if given in high doses intravenously (IV)
- Surgery involving the brain
- Radiation to any of the following areas:
 - Brain (cranial)
 - Ear/infratemporal region (midfacial area behind the cheekbones)
 - Total body (TBI)
- Cisplatin or carboplatin (may affect hearing)

What testing is recommended?

Any young person who has had any of the above cancer treatments, or who is having difficulties in school, should undergo a specialized evaluation by a pediatric psychologist (neuropsychological testing) at the time of entry into long-term follow-up. This type of testing will measure IQ and school based skills, along with more detailed information about how the child processes and organizes information.

Even if the initial neuropsychological evaluation is normal, it is important for parents and teachers to remain watchful. Further neuropsychological evaluations may be necessary if the child or teen begins having trouble in school or develops any of the problems listed below. In addition, repeat testing is often recommended at times when academic challenges are more likely to occur, such as at entry into elementary school, middle school, high school, and during pre-college planning.

What learning problems may occur?

The brain is a very complex structure that continues to grow and develop throughout childhood and adolescence. Some problems may not become apparent until years after therapy is completed. Common problems areas include:

- Handwriting
- Spelling
- Reading
- Vocabulary
- Math
- Concentration
- Attention span
- Ability to complete tasks on time
- Memory
- Processing (ability to complete assignments that require multiple steps)
- Planning

- Organization
- Problem-solving
- Social skills

What can be done to help with learning problems?

If a problem is identified, special accommodations or services can be requested to help maximize the student's learning potential. The first step is usually to schedule a meeting with the school in order to develop a specialized educational plan. Examples of strategies that are often helpful for children and teens with educational problems related to cancer treatment include:

- Seating near the front of the classroom
- Minimizing the amount of written work required
- Use of tape-recorded textbooks and lectures
- Use of a computer keyboard instead of handwriting
- Use of a calculator for math
- Modification of test requirements (extra time, oral instead of written exams)
- Assignment of a classroom aide
- Extra help with math, spelling, reading, and organizational skills
- Access to an elevator
- Extra time for transition between classes
- Duplicate set of textbooks to keep at home

What laws protect the rights of students who have undergone treatment for cancer?

In the United States, there are three public laws that protect the rights of students with educational problems related to cancer treatment. These laws are:

The Rehabilitation Act of 1973 – Section 504

This legislation provides accommodations for students with a "physical or mental impairment which substantially limits one or more major life activities," or students who have "a record of such impairment", or who are "perceived as having such an impairment" (The Rehabilitation Act, 1973). Qualifying conditions include chronic illnesses such as cancer, as well as many other disabilities, including hearing problems, vision problems, learning disabilities, speech disorders, and orthopedic handicaps. All childhood cancer survivors in the United States are eligible for accommodations under this law, and all educational institutions receiving federal funding (including colleges and universities) are required to comply. Accommodations may include modifications in the

curriculum (such as allowing the use of a calculator and extra time for assignments or test-taking) and the environment (such as seating near the front of the classroom or allowing extra time between classes).

The Individuals with Disabilities Education Act (IDEA)

The IDEA legislation (PL 105-17) requires that public schools provide "free and appropriate education in the least restrictive environment" for disabled students between the ages of 3 and 21 years of age. In order to qualify for special education services under IDEA, the student must meet qualifications under at least one disability outlined in the law - those that most commonly apply to students treated for cancer include "specific learning disability," "traumatic brain injury," or "other health impairment." In order to access services under the IDEA legislation, parents must initiate the process by requesting that the student be evaluated for an "Individualized Education Plan" or IEP. The student will then undergo an assessment process to determine what assistance is required. A conference is then held to discuss the results of the evaluation and, if the student qualifies, to determine an individualized plan to meet the identified specialized educational needs. Services available under the IDEA legislation include tutoring, specialized classroom placements (such as a resource room), psychological services, adaptive physical education, physical, occupational and speech/language therapy, and transportation services. All services and accommodations required by the student should be specified in the IEP (the written document describing the special education program). The IEP should be reviewed and updated on an annual basis to assure that it continues to meet the student's educational needs.

The Americans with Disabilities Act (ADA)

The ADA law (PL 101-336) protects against discrimination in employment, transportation, communication, government and public accommodations for people with disabilities. It guarantees equal access to public spaces, event, and opportunities and may be particularly helpful for students seeking higher education or employment.

Where can I get more information?

Additional information is available from the National Information Center for Children and Youth with Disabilities (phone: 1-800-695-0285; website: www.nichcy.org).

Candlelighters Childhood Cancer Foundation, for the free publication: *Educating the Child with Cancer, a Guide for Parents and Teachers* (phone: 1-800-366-2223; website: www.candlelighters.org.)

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Additional health information for childhood cancer survivors is available at
www.survivorshipguidelines.org

Note: Throughout this *Health Links* series, the term "childhood cancer" is used to designate pediatric cancers that may occur during childhood, adolescence, or young adulthood. *Health Links* are designed to provide health information for survivors of pediatric cancer, regardless of whether the cancer occurred during childhood, adolescence, or young adulthood.

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