LEUKEMIA & LYMPHOMA SOCIETY*

Side-Effect Management: <u>Effects of Childhood Cancer Treatm</u>ent on Learning

Some treatments for childhood cancer can increase the risk of changes in cognitive (thinking) function. These changes may affect concentration and memory. For some childhood cancer survivors, cognitive effects can lead to learning problems at school.

Childhood leukemia and lymphoma patients may receive therapy that affects the central nervous system (CNS). The CNS includes the brain and spinal cord. Therapies that affect the CNS increase the risk for cognitive (thinking) effects including educational issues. Examples of these therapies include

- Methotrexate or cytarabine—if given in high doses intravenously (IV) or injected into the spinal fluid (intrathecal [IT])
- Total body irradiation (TBI), prior to a stem cell transplantation

Significant cognitive effects are more often associated with treatment plans that include radiation to the brain or brain surgery, which are not routinely used to treat childhood leukemia or lymphoma.

For some childhood cancer survivors, cognitive effects can lead to learning problems that can affect performance in school.

SIGNS OF LEARNING PROBLEMS

Concentration and memory problems may begin during treatment or become noticeable months or years after treatment. These can be short-term or long-term problems.

The signs of learning problems include

- Problems with memory
- Difficulty staying focused
- Difficulty processing information or learning as quickly as peers
- Difficulty completing multi-step tasks
- Not doing well in school, compared to past performance
- Problems with organization, planning, studying and/or time management
- Difficulties with hand-eye coordination

Children with learning problems caused by cancer treatment can still learn and develop new skills, but it may take them longer than their peers and they may need special accommodations or additional instruction. Learning issues that a child had prior to cancer treatment may become more apparent after treatment. Other factors can also contribute to cognitive issues and can be treated separately. These problems include poor nutrition, dehydration, anxiety, depression, fatigue and insomnia. Treating these separately may help improve cognitive (thinking) function.

MANAGING LEARNING PROBLEMS AT SCHOOL

Going to school is a big part of feeling normal for children and adolescents, but going back to school after cancer treatment can also bring new challenges for your family. It is important to identify the areas of learning where your child may struggle. Then you can work together with the healthcare team, teachers and school staff to provide support and resources to help your child be successful in school.

Neuropsychological Testing. Children who are at risk for cognitive effects or who are having difficulty in school should have neuropsychological testing done by a licensed pediatric neuropsychologist (an expert in the way the brain works) to check for possible learning challenges. Discuss the need for neuropsychological testing with your child's healthcare team, who can refer you to a pediatric neuropsychologist.

School Psychological Assessment. Neuropsychological testing is often not covered by insurance and can be expensive. A school-based assessment may also be an option (or may be a requirement of the school) to help determine your child's educational needs. These assessments are usually performed to determine if your child is eligible for special education programs. Generally, school-based assessments are less effective than neuropsychological testing at linking cancer treatment with learning or behavior problems. Ask your child's school administrators for more information.

Meeting Your Child's Educational Needs. With the help of the healthcare team, inform teachers and school staff about your child's educational needs before he or she returns to school. Work together with the healthcare team, teachers and school staff to develop a program tailored to your child's specific needs. The program may include

 Special accommodations—accommodations can be made to meet a child's educational needs, such as allowing for additional time to complete class work or take exams. Children may qualify for special help under federal laws.

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- Long-term planning—plans can be developed to help a child through school transitions from middle school to high school and into adult life.
- Cognitive behavioral therapy—certain cognitive therapies can help children develop strategies to address learning problems. For example, one strategy may be breaking down complex problems into smaller tasks.

All childhood cancer survivors may be at risk for behavioral, emotional or social problems regardless of cognitive effects. If you notice changes in your child's behavior, speak to your child's healthcare team and ask for a referral to a mental health professional.

LAWS THAT HELP PROTECT CHILDREN WHO HAVE EDUCATIONAL NEEDS

The following three federal laws help protect the rights of students with disabilities including those with educational needs resulting from cancer treatment:

- The Individuals With Disabilities Education Act (IDEA)
 - Under IDEA, public school children with disabilities may receive an Individualized Education Plan (IEP) that outlines a formal plan to accommodate a child's individual needs.
- The Rehabilitation Act of 1973 Section 504 Plan
- The Americans With Disabilities Act (ADA)

For more information about the transition back to school and laws that help protect children, visit www.LLS.org/booklets to view *Learning & Living with Cancer: Advocating for Your Child's Education Needs*.

MANAGING LEARNING PROBLEMS AT HOME

The following are some things you can do at home to help your child manage cognitive side effects:

- Get organized by making sure everything has a place in your home and get rid of clutter.
- Stick to a schedule. Children need structure to feel a sense of control.
- Be patient with your child and allow extra time to accomplish tasks.
- Minimize distractions when your child is working on homework. For example, put away phones and electronics.
- Encourage your child to exercise his or her brain by reading, playing educational or memory games, or by doing something creative such as drawing or playing music.
- Encourage your child to be physically active. Ask the healthcare team for an exercise program.

- Provide foods that promote healthy brain functioning such as fish, dark leafy greens, fresh fruits and vegetables and whole grains.
- Maintain a regular sleep schedule so your child can get the recommended amount of sleep for his or her age.
- Teach your child to avoid alcohol, smoking or "vaping," and other drugs, which can alter his or her mental state.

Questions To Ask Your Child's Healthcare Team

- What are the possible cognitive effects of my child's treatment(s)?
- When are cognitive effects likely to happen?
- Are there any changes, signs or symptoms I should tell my child's pediatrician about right away?
- What can I do to ease the symptoms of my child's cognitive effects?
- Will my child have difficulties in school because of the cognitive effects?
- Can my child be referred for neuropsychological testing?
- Will insurance cover the cost of testing by a neuropsycologist? If so, under what conditions?
- When would it be appropriate for my child to be re-tested for cognitive effects?
- What accommodations at school do you recommend for my child?

GET ONE-ON-ONE SUPPORT.

The Leukemia & Lymphoma Society team consists of master's level oncology social workers, nurses and health educators who are available by phone Monday–Friday, 9 a.m. to 9 p.m. (ET).

INFORMATION SPECIALISTS

- Call 800.955.4572
- Visit www.LLS.org/InformationSpecialists

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- Call 800.955.4572
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