Educational/Vocational Issues of Childhood Cancer

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What do your students want you to know?
Physical Challenges
Most Common Physical Challenges

- Fatigue
- Muscle weakness/low stamina
- Unsteady gait
- Neuropathy (hands and feet)
- Nausea and vomiting
- Chronic pain

- Mood swings
- Altered physical appearance (scarring, weight loss/weight gain, jaundice, hair thinning/loss, amputation, braces)
- Gross and fine motor deficits
- Hearing and visual loss
Cognitive Challenges
Most Common Cognitive Challenges

- Slower processing speed
- Difficulty with word retrieval
- Short-term memory loss
- Inability to focus/concentrate for long periods
- Poor organization
- Difficulty multi-tasking
- Visual/spatial deficits
Psycho-Social/Emotional Challenges
Most Common Psycho-Social/Emotional Challenges

- Lack of exposure to play groups, sports, and other extra-curricular activities
- Loss of contact with friends and peers
- Variation in maturity levels
- Desire for independence
- Need for acceptance
- Finding a social group in which to belong
- Quest for normalcy
- Feelings of being different
- Turmoil of emotions including sadness, fear, guilt, anger, worry, anxiety, loss, and grief
Spiritual Challenges
Most Common Spiritual Challenges

• Why me?
• What did I do so wrong to deserve this?
• Where is this all-loving God?
• Why do bad things happen to good people?
• Who is watching over me?
Bernie Siegel, MD, writes, “Spirituality means the ability to find peace and happiness in an imperfect world, and to feel that one’s own personality is imperfect but acceptable. From this peaceful state of mind come both creativity and the ability to love unselfishly, which go hand in hand. Acceptance, faith, forgiveness, peace, and love are the traits that define spirituality for me.”

Academic/Vocational Challenges
Most Common Academic/Vocational Challenges

- Curriculum and scheduling
- Standards of Learning
- District and State Assessments/Testing
- Type of Diploma – Standard v. Advanced
- SAT and ACT testing
- Career Goals
- Transition issues
- College and/or Vocational Planning
Who has these challenges?

- 2 out of 3 survivors have at least 1 late effect
- 1 out of 3 survivors has 2 or more late effects
- 1 out of 3 survivors has a late effect that affects quality of life and/or mortality
What helps?

1. Strong support systems and partnerships
2. School health plan
3. Educational plans, such as a 504 or an IEP
4. Accommodations
5. In-service trainings for school staff and classmates
Strong support systems and partnerships

- School team
- Medical team
- Parent
- Child
Components of the school health plan

• Describes the chronic illness
• Lists medications given at school
• Outlines medical procedures
• Lists accommodations that are needed for the medical condition
Educational Plan

- 504 plan
- IDEA
What is Section 504?

It is a civil rights statute that prohibits discrimination based upon disability.
What constitutes a disability?

- A mental or physical impairment which substantially limits one or more major life activities
- A record of such an impairment, or
- Is regarded as having such an “impairment.”
What is defined as an “impairment”? 

Any disability, long-term illness, or disorder that “substantially” reduces or lessens a student’s ability to access learning in the educational setting because of a learning problem, behavioral issue, or health-related condition.
What are major life activities?

- Self-care
- Manual tasks
- Walking
- Seeing
- Hearing
- Speaking
- Sitting

- Thinking
- Learning
- Breathing
- Concentrating
- Interacting
- Working
What is IDEA?

Individuals with Disabilities Act is a federal law that provides funding for special education and provides a “free and appropriate education” to all students who fall within the special education category.
Purpose of IDEA 2004

To ensure that all children with disabilities have a free public education that emphasizes special education and related services designed to meet their unique needs and to prepare them for further education, employment, and independent living... and to ensure that the rights of children with disabilities and parents of such children are protected.
Who qualifies for special education services under IDEA?

• Any child 2-21 years of age, inclusive, who has a “disabling condition” which limits his or her progress in the regular classroom
• Any child who needs special education or related services to make progress or appropriate strides in education
What constitutes a “disabling condition”?

- Autism
- Deafness
- Deaf-Blindness
- Developmental Delay
- Emotional Disability
- Hearing Impairment/Deaf
- Intellectual Disability

- Multiple Disabilities
- Orthopedic Impairment
- Other Health Impairment
- Specific Learning Disability
- Speech/Language Impairment
- Traumatic Brain Injury
- Visual Impairment
Helpful Accommodations

• Two sets of books or instructional materials; one set for home and one set for school
• Permission to carry a water bottle throughout the school day
• Mid-morning and afternoon snack breaks
• Bathroom privileges when needed
• Rest period when needed

For more accommodations, please see the handout in your binder.
In-Service for School Staff and Classmates

- Answers questions
- Makes one less curious
- Makes one less afraid
- Makes one feel more comfortable
- Offers helpful hints and suggestions on how to help
In Their Own Words:
“Being diagnosed with cancer really had a big impact on my life. At the beginning, I did not know how I was going to make it through. Keeping my faith in the Lord is what kept me strong and that is what kept me here today. Going through this diagnosis was hard enough by itself. I also had to miss school for treatments. Finding out that all of my classmates were slowly learning about my illness scared me a lot. In the process, I lost a close friend because she could not cope with my illness. With her being my only real friend, eventually I had no friends. It was hard for me to go through all of the treatments and that was the time when I really needed her to be there with me. It seemed like everybody looked at me as a different person now that I had cancer... Through the diagnosis, I learned that God was my only friend... Another thing that was hard, and I know it’s probably the same for all cancer patients, was losing your own hair. I felt like I was changed into a person I did not know, like I was no longer _____.

College Essay from Hodgkin’s Lymphoma Teen
College Essay from Leukemia Survivor

“When the doctors told me that I had Leukemia, it changed my life. Although I was only six years old, I have vague memories. I do remember that I struggled a lot. I was bald and everyone stared at me all the time. I couldn’t play sports or do anything physical because of my porta-cath. Inside it hurt, but it made me more determined to overcome cancer. In school, my cancer had a different impact on me. I was, and still am, an awful test taker. It took me much longer to understand concepts. I’d have to have things repeated to me a couple of times where other students understood right away. I also got side tracked easily, and it’s still hard for me to stay focused.”
“As anyone might imagine, the diagnosis of “cancer”, particularly to a teenager, who has so many hopes, dreams, activities, interests, and social life, the realization of having a physical problem that could seriously limit or eliminate many, if not all of these, was frightening. In addition to the physical limitations came the emotional ones, and combined, they were very difficult. My ability to focus on those dreams and goals for the future was really limited at first. The physical effects of the chemo on my ability to concentrate and retain information I was getting at school were pretty bad. In the midst of all this treatment I was trying to take SATs for college and that was pretty difficult as well. My physical stamina was reduced, and I had to work doubly hard in trying to stay in some sort of reasonable shape. Then there was the feeling that you were different from everyone else because you had cancer. As chemo took effect and my hair came out, it was pretty tough too, especially for a teenage girl. So, there were a lot of physical and emotional stressors that affected me as a student....