

SPECIAL EDUCATION NEEDS DURING AND AFTER CANCER TREATMENT

Cancer. No Family Should Have to Fight Alone.

Case Illustrations

- Sarah is nine years old and in grade four. She lives at home with her dad, mom, older brother and younger sister. Diagnosis: Standard Risk Acute Lymphoblastic Leukemia (ALL).
- Aiden is six years old and in grade one. He lives in a single parent home with his mother, two older brothers, and younger sister. Diagnosis: Relapsed High Risk Acute Lymphoblastic Leukemia (ALL).



Impact on Family



Parents live in crisis mode

- Lack of sleep
- Varying emotions
- Highs and lows
- Increased risk of mental health disorders (depression, anxiety, PTSD)

Most parents struggle consistently with “normal” parental roles. Consequently, the responsibilities increase upon diagnosis in the following areas:

- They become the medical expert in their child’s disease, treatment, side effects and medications
- They are more involved in their child’s education due to long absences from school
- They become the communication expert between the hospital, school, friends, relatives and community

Siblings in the family are affected

- Separated from their brother or sister
- Separated by one parent for weeks or months
- They worry about getting sick themselves and infecting their terminally ill sibling
- They worry about their sibling (i.e. death)
- Fear, jealousy, and abandonment issues all depending upon the ages/understanding of child
- They may have behavioural issues at school and suffer from depression or loneliness

The financial impact on these families is tremendous

- A Provincial survey was done in the 1990’s that indicated the out-of-pocket expenses for the families by the time a child finished treatment on average was \$30,000; this did not account for lost wages, relapse, or palliative care situations. Twenty years later, this figure is probably higher

Statistics

- Each year, about 1,500 children/youth are diagnosed with cancer
- ***Childhood cancers have a close to a 75% cure rate, with leukemia leading the overall cure rate at 90%***
- Most common types of cancers include leukemias, tumours of the brain and nervous system, the lymphatic system, kidneys, bones and muscles
- Cancer affects all ethnic, gender, and socioeconomic groups
- ***3 out of 5 survivors will develop long-term and late effects of treatment***
- 30% of children diagnosed will relapse (this leads to further treatment, such as radiation, high doses of chemotherapy, and transplant).



The Two Significant Statistics that Impact the Special Educations Needs of Children Diagnosed with Cancer

- ***Childhood cancers have a close to a 75% cure rate, with leukemia leading the overall cure rate at 90%***
- ***3 out of 5 survivors will develop long-term and late effects of treatment***

How Does Cancer Treatment Affect a Child's Learning?

- Treatment for children is lengthy (based upon a standard protocol for leukemia without a relapse)
 - Girls' treatment lasts 2.5 years
 - Boys' treatment lasts 3.5 years
 - Relapses result in longer treatments and more hospital admittance
- Frequent hospitalizations affect school attendance
- Students may feel sick for 24 hours or more after chemotherapy
- Child may seem listless and lethargic when they first return to school
- Appear pale and complain of dizziness, headaches, shortness of breath
- Tire easily
- Children attend school with a Port-a-Cath or Hickman line (catheters), which causes increased risk to the child
- Suffer lapses in concentration
- Drowsiness (especially 5-8 weeks post-radiation, and can last for 1-2 weeks)
- Physical side effects, such as weak ankles, aches, physical pains
- Difficulty walking or climbing stairs
- Lack of coordination and concentration, which can cause problems with handwriting
- Change in physical appearance (weight loss or gain depending on phase of treatment)
- Concerns of child being bullied as a result of physical appearance
- Bleeding
- Seizures
- Emotional effects
- Sun sensitivity as a result of some chemotherapies
- Learning disabilities
- Psychological Impact on children as a result of medical trauma

Implications of Long-term Side Effects or Late Effects of Treatment

- 3 out of 5 survivors develop late effects/long-term side effects once cancer treatment has ended, whether months or years later
- Direct effect on growth hormone production, bone, and developing tissues, which all affect the final height and development of the child. This lack of growth can cause mental health concerns for children, which will impact their social development at school and impede upon their learning.
- Those who survive may have permanent side effects, which may include but are not limited to deafness, blindness, heart, kidney, and fertility issues
- Secondary cancers
- Chemotherapy and radiation can also affect the brain and central nervous system and these effects may gradually emerge as learning difficulties. The impact of chemotherapy on information retention and processing is referred to as “chemo-brain.” Although students may achieve within the usual intelligence range, they may be less successful with tasks that require memory and fast mental processing skills, attention, concentration, visual motor processing, and working under time constraints. Consideration of these factors should be taken when assessing the student's progress, and subsequently in programming for their learning.
- Children who have undergone cranial radiation often struggle with short-term memory function
- Children will continue to miss school as a result of follow-up medical appointments that begin weekly, monthly, three months, and six months to a year
- Educational challenges can actually increase rather than decrease over time due to the effects of cranial radiation and certain treatment protocols, e.g. the full effects of radiation may not occur until 5 years after treatment. This may include disabilities in math, problems with information processing, short term memory recall.
- It is important to remember that all children respond differently to treatment

Special Education Needs

Home Instruction: Needs to be set-up for the length of time the student is on treatment, regardless of whether they come back to school even for short periods. This is necessary for normalization and social interaction, and is encouraged by the child's medical team at their oncology hospital. The reasons why home instruction needs to be in place while the child is on treatment are:

- Protocols are unpredictable and often don't go as planned (e.g. fevers cause treatment to stop until the infection is treated, allergic reactions to chemotherapy, child is not responsive to chemo, etc.)
- Child may be admitted to the hospital as a result of an infection for days to weeks as their immune system is vulnerable
- Child can suffer from severe side effects from chemotherapy and radiation
- Fatigue, low blood counts, and suppressed immune system can make attendance at school irregular
- Temporary neurological side effects can cause difficulty with fine motor skills, leg pain or drop foot, lack of concentration and attention span
- Don't know from day-to-day whether they will be able to come to school, thus the importance of home instruction in conjunction with the option of coming to school when they are well enough
- Flexibility of hours rather than hours being removed if child attends school when he/she is well enough

Case Conferences: A case conference should be done at the beginning of each year or in the case of high school each semester. A summary of medical treatment and educational concerns needs to be shared. An Individual Education Plan (IEP) for a medically fragile student needs to be put in place and if appropriate an Identification, Placement, and Review Committee (IPRC). These case conferences need to be continued after the student is off treatment, for there are often issues with continued medical follow-up, tests, therapy (physical therapy, occupational therapy, speech) and long term effects from cancer treatment.

It is recommended that a child be placed on an IEP after his/her return to school if they have received radiation as a part of his/her treatment protocol. In addition, specific forms of cancers may be considered an immediate consideration for an IEP, such as relapsed leukemias and brain cancers.

Conclusion

Quotes from Children:

- “I thought I was dying, until they sent the teacher to help me work on nouns and adverbs. I thought to myself, they wouldn’t make a dying boy work on nouns and adverbs, so I decided I could get well.” (Johnson et al., 1992)
- “Through the relapse and difficult times, death was on my mind, but having people being happy and positive around me, not sad or depressed, allowed me to feel that I was going to be OK and that I was going to make it and not die.”

