

ABSTRACT OF CAPSTONE

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The Graduate School

Morehead State University

March 24, 2021

CHILDHOOD CANCER SURVIVORS' SUCCESS – PREPARING EDUCATORS

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Abstract of Capstone

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A capstone submitted in partial fulfillment of the  
Requirements for the degree of Doctor of Education in the  
Ernst and Sara Lane Volgenau College of Education  
At Morehead State University

By

Darlen Michelle Harless

Louisa, Kentucky

Committee Chair: Dr. Michael W. Kessinger, Associate Professor

Morehead, Kentucky

March 24, 2021

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## ABSTRACT OF CAPSTONE

## CHILDHOOD CANCER SURVIVORS' SUCCESS – PREPARING EDUCATORS

Childhood cancer changes the lives of all that it touches. The treatment is often as harmful as the disease itself and can impact the cognitive, physical, social, and emotional development of the child. Long term effects can manifest years after treatment. This capstone was based on a vision of providing these young cancer survivors an opportunity to experience and enjoy getting an education from teachers who have an understanding of what the survivors have gone through.

To meet this vision, the author went on a mission to develop professional learning modules for educators whose students have had cancer. The modules address specific issues unique to the childhood cancer survivor and can help the educator to provide necessary interventions to meet the academic needs of the individual. The modules are delivered online in a mixed media format that allows educators easy access and the ability to complete them at any time.

The five modules developed for this capstone provides the participant with information to better serve the cancer survivor. Module One includes an introduction to childhood cancer and treatments. Cognitive, physical, social, and emotional late effects along with interventions and accommodations are presented in Modules Two, Three, and Four. The fifth module gives implementation strategies for the student once they return to school. The module also has a wide variety of possible accommodations that educators can use to help the student.

KEYWORDS: Childhood Cancer, School Reentry, Cognitive Late Effects, Physical Late Effects, Social/Emotional Late Effects

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Date



## CHILDHOOD CANCER SURVIVORS' SUCCESS – PREPARING EDUCATORS

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## DEDICATION

I would like to first thank my Lord and Savior who allowed me the opportunities to be pursue my doctorate. It is by his Grace that I am who I am today.

I would also like to thank my husband David, for supporting me in this endeavor. You encouraged me when I was overwhelmed with due dates, assignments, and life. I especially thank you and love you for accompanying me on the journey through childhood cancer and all the resulting side-effects. You have been my rock when I fell apart.

I want to thank my parents for instilling a love a learning and teaching me that nothing was out of my reach. Lessons, I have carried throughout my life and have served me well. I love you for all you do for me and my kids.

And finally, to my kids, Dovie and Wesley, you are the best of me. You both are God's blessings to me, and I cherish every moment we have. I could not imagine my life without either of you. I love you both with my whole heart.

Dovie, you have taught me to look outside of the box. You challenge me to be the best person I can be.

Wesley, you are the reason for this capstone. You are my hero. No one is stronger than you. You are the best of all of us.

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I would like to first thank Dr. Michael Kessinger for all the help he has given me on this journey through getting into the EdD program, classwork, and finally being the chair on my committee. Your help has been indispensable, and I will be forever thankful. Your ability to make me drill down to the details and focus has been crucial to my success.

Martha Williams, my friend and mentor. Your work ethic is second to none and you inspire me every day to work harder and to be a better person. Your dedication to God is a light in my life as I endeavor to be more like you.

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## **Executive Summary**

### **What is the core of the capstone?**

No parent ever wants to hear the words, “Your child has cancer.” Yet up to two children in 10,000 children each year are diagnosed with some form of the disease (Butler & Haser, 2006). In 1960 the survival rate for Acute Lymphoblastic Leukemia (ALL) was 57.2%. In 2014 the 5-year ALL survival rate increased to 90% (Noone et al., 2018). This has led to a growing population of survivors left to cope with the late effects of cancer treatments. “Many survivors experience at least one long-term adverse effect of cancer and its treatment” (Roberts, et al., 2014, p. 153). Each childhood cancer survivors’ story is different, but they share many of the common late effects, which include attention problems, concentration difficulties, working memory deficits, and processing speed. ALL survivors often find themselves with declines in neurocognitive functioning several years following treatment (Moore, Hockenberry, & Krull, 2013).

Returning to school for these students does not need to be another burden for the family or the children affected by this terrible disease. This capstone developed a professional learning series to aid school personnel in facilitating a successful school reentry plan for the childhood cancer survivor. The capstone project was made available through OER Commons, an open educational resource site. The professional learning series included five modules that were intended to be 30 minutes of training per module on topics that will educate the educator on types of cancer, treatment, and the long-term effects of the disease and treatment.

Module 1 provided an introduction to childhood cancers and their treatments. Module 2 examined the cognitive effects that survivors may experience. Module 3 looked at the social and emotional effects that childhood cancer survivors and even their peers may face. Module 4 focused on the physical effects of childhood cancer. Module 5 concludes with a discussion on how school personnel can facilitate a successful return to school.

### **Problem Statement**

School reentry for childhood cancer students is challenging for numerous reasons. First, these students are chronically absent. Childhood cancer students have numerous doctors' appointments, regularly at clinics far away from home. Students also fear school reentry due to physical changes in their bodies.

Students may have endured amputation, hair loss, weight loss or gain, and find that their physical endurance is not the same as their peers. Students may also have "chemo-brain" while on treatment. "Chemo-brain" can be short-term side effects such as memory problems and processing speed problems (Prevatt et al., 2000). "Cognitive dysfunction affects one-third or more of the estimated 350,000 survivors of childhood cancer" (Northman et al., 2018, p.276). These problems sometimes persist and become long-term cognitive side effects for the students.

Yi et al. (2016) report that cancer survivors could have lower grade point averages, repeat a grade, and have more chronic absences than peers. They also found that these students with childhood cancer have trouble completing school assignments during treatment because they were too physically ill.

Childhood cancer students may also have many social and emotional issues during school reentry (Prevatt et al., 2000). Survivors of childhood cancer report they have fewer friends than their peers (Yilmaz et al., 2014). These students feel isolated because of their battle with cancer. The students miss out on many social activities and peer interaction. They can also fear rejection and bullying due to their cancers and the changes the cancer may cause. Female adolescents express dismay over the loss of their hair and other changes in appearance. Students who have cancer may miss out on many social milestones such as sports, dances, and field trips because of cancer (Prevatt et al., 2000).

Parents have concerns regarding school reentry because they fear secondary illnesses and medical emergencies happening at school (Prevatt et al., 2000). Approximately 51% of parents also reported they are unprepared for school reentry (Ruble et al., 2019). Parents are naturally overprotective for their childhood cancer student worrying about peers' reactions, accidents, and compromised immune systems. Parents may in fact encourage their child to chronically miss school. (Prevatt et al., 2000).

Educators can also be apprehensive about school reentry for the student with childhood cancer because they worry about having a critically ill child in their classroom and school (Prevatt et al., 2000). Educators do not have pedagogical knowledge about working with students with life-threatening illness and they lack the skills to deal with the emotional and social effects of cancer (Brown et al., 2011). They worry they do not know how to help the child. Educators may feel like they are

not prepared because they are not given information from the hospital or information received from the parents is confusing or ambiguous (Prevatt et al., 2000). Educators of childhood cancer survivors have a multifaceted job. They must first assess post-treatment needs by addressing the child's missed academic content and possible neurological and physical changes. Then they must direct remediation at those affected areas (Donnan et al., 2015).

Successful school reentry is important because a failure can affect the rest of a child's life. Dumas et al. (2015) report that chronic childhood illness has resulted in lower socioeconomic status in adulthood. School support must begin at reentry and continue through a child's career to monitor academic success and possible late effects of cancer (Thompson et al., 2015). Donnan et al. (2015) state that "research suggests that regular education for children on cancer treatment is associated with a better quality of life 10 years later" (p. 25). Students with cancer and childhood cancer survivors face many problems as they return to school. Educators need to be trained about cancers and their effects on long-term survivors. Problems may not appear until years following treatment (Herrmann et al., 2011).

**Purpose**

This capstone project developed modules that would inform educators on childhood cancers, their treatments, cognitive side-effects, physical side-effects, social/emotional side effects, peer education including grief and loss, and school reentry. The modules were designed in 30-minute informative online sessions.

Brown et al. (2011) stated that online training programs for educators could help them feel better and gain an understanding of the student's situation. Online programs allow the educator to work on when it is needed and at their convenience. It is the goal of the modules to train a multidisciplinary team at the school to plan the school reentry of the student with cancer.

Educators need to be aware of the needs of children with cancer. It is the aim of these modules to train educators by giving introductions to the different types of childhood cancers and how they are treated. Following this introduction, focus shifts to types of long term-effects these cancers and their treatments can cause for children. Once those long-term effects are identified, then the interventions and accommodations are listed to help the child affected by cancer. Awareness is key to help children who have had cancer to obtain success in life after the disease.

Hermann et al. (2011) suggests that a school reentry plan consists of a multidisciplinary team meeting, training for school staff, short-term and long-term planning of support services for the student, and continued follow-up for the student. Peer education on cancer and the possible changes in the student with cancer should be planned (Prevatt, Heffer, & Lowe, 2000). School support must begin at reentry and continue throughout a child's career to monitor academic success and adapt to possible late effects of cancer (Thompson et al., 2015). Childhood cancer produces unique school difficulties for the children. That is why this capstone fits a specific need within a specialized population.



***Multidisciplinary team.*** The multidisciplinary team should consist of a hospital liaison, parent/guardian, school counselor, school psychologist, school nurse, special education teacher, teacher, and any other school support staff that may be required. The hospital liaison is the person who connects with the child's doctors to make the school aware of possible issues that may arise at school. The hospital liaison is the bridge between the hospital and the school. It is not optimum for the parent to be the go-between for the hospital and school (Irwin et al., 2015). Northmann et al. (2018) found that parents who do not have the support of the hospital liaison find that the child does not have as much success as students who do not have a hospital liaison. Hospital liaisons can help identify accommodations that may be needed for the student (Gorin & McAuliffe, 2008).

School counselors and psychologists can be the first contact of the hospital liaison. School counselors can provide support to the family to help find local resources, counsel the student with childhood cancer, and counsel peers. School counselors can work with the student to prepare a presentation for the class about the student's cancer. This helps the student talk to the counselor about their illness (Bauman, 2010). School psychologists are essential to multidisciplinary teams because they can evaluate the returning student for any cognitive effects that may require accommodations (Hermann et al., 2011).

School nurses should be included in the multidisciplinary team because they need to be able to develop a medical emergency plan and be aware of any medical conditions that may arise (Yilmaz et al., 2014). Teachers are very important to school

reentry they support the student while at school. They model behaviors that peers will mimic and can provide a respite from all the medical personnel in the life of the child (Yi et al., 2016).

As the multidisciplinary team plans the school reentry they should focus on the child and the environment that the child will enter which includes family, school, and peers (Gorin & McAuliffe, 2008). Communication is key in the planning for school reentry. The school must be diligent in communicating with the hospital and parents to be ready to meet the needs of the student with cancer.

***Online staff training.*** The modules developed to facilitate school reentry will provide the educators information about the medical aspects of cancer, side-effects of cancer, and the cancer treatment. Modules will provide information school personnel can use to set realistic learning expectations and realistic physical expectations for the student. Modules will also address how to present the information to peers and even address grief. Brown et al. (2011) identified these topics for educators to help facilitate a successful school reentry. School should not be a burden to the child and family. Instead, the school should provide a sense of normalcy and even hope to the survivor (Herrmann et al., 2011).

### **Guiding Questions**

The guiding questions for this capstone project were as follows. What are the implications of childhood cancer on the education of the survivor? How can educators gain professional knowledge on issues related to childhood cancer (cognitive side effects, physical side effects, and social/emotional side effects) and school reentry?

Nearly every childhood cancer survivor has at least one long-term side effect. The severity of the side effect and quantity of side effects varies from child to child. Also, educators can gain professional knowledge through online professional learning on issues related to childhood cancer.

Modules were further developed with guiding questions. What type of accommodations and assistance students with cancer will need once they return to school? How can school facilitate a school reentry plan for the student? How can educators ensure school reentry addresses all the needs (cognitive, physical, and social/ emotional) of the student?

### **Review of Literature**

Childhood cancer is a devastating diagnosis for any family. No matter the type of cancer parents must make the difficult decision to treat their child with treatments and drugs that may harm their future development. Childhood cancer can have many different side effects and children can be affected in varying severity. Interventions can help improve the quality of life for childhood cancer survivors.

***Childhood cancer and treatments.*** Acute Lymphoblastic Leukemia (ALL) is a cancer of the blood. It is a prevalent form of childhood cancer. It affects the white blood cells, which places the child at risk for devastating infections. The cancer cells may also affect platelets and red blood cells as the “blasts” create junk in the bloodstream. Blasts are non-functioning cells in the bloodstream. Low platelets cause bleeding and bruising. Anemia is the result of low red blood cells (Armstrong et al., 1999).

The second most prevalent form of childhood cancer are brain tumors. Brain tumors grow on or in the brain, exerting pressure on the organ. Seizures, hydrocephalus, vision problems, and nausea/vomiting may occur from brain tumors. Brain tumors may be treated with surgery, cranial radiation, and/or chemotherapy. The surgery required to intervene may affect the development of the brain. Additionally, brain tumor cancers typically require cranial radiation therapy (Armstrong et al., 1999).

***Surgery.*** Brain tumors may require surgery for their removal. “The size, location, tumor involvement may have a significant role in the functional capacity of children after treatment” (Armstrong et al., 1999, p.195-196). Shunting may cause even more cognitive impairment. Motor skills, vision, and speech could all be affected by the surgery. A neurosurgeon will advise parents on what structures of the brain will be affected by the surgery (Armstrong et al., 1999).

***Cranial Radiation Therapy (CRT).*** A breakthrough in treatment occurred with the addition of cranial radiation therapy (CRT). CRT is used on brain tumors and acute lymphoblastic leukemia when cancer cells are found in the spinal fluid. Prophylactic central nervous system (CNS) treatment improved the 5-year survival rate (Kanellopoulos et al., 2016). CRT is a CNS prophylactic treatment that uses radiation on the brain and spinal cord to kill the cancer cells. “CNS prophylactic treatment is necessitated because a sanctuary for leukemia cells is created by the blood-brain barrier that effectively prevents chemotherapeutic agents from reaching the CNS” (Moleski, 2000, p. 605). CRT patients are also treated with chemotherapy

drugs such as methotrexate. “Specifically, cranial radiation and intrathecal/intravenous methotrexate have been identified as the most toxic risk factors for neurocognitive deficits among survivors of brain tumors or acute lymphoblastic leukemia” (Lehmann et al., 2017, p.1869).

Moore et al. (2013) stated that cranial radiation causes neurocognitive deficits in attention, processing speed, memory, organization, and processing speed. Age of diagnosis also can indicate the severity of the neurocognitive deficits, the younger the patient the more severe the deficits and reduced cognitive functioning.

In recent years, oncologists have worked to make treatment protocols less toxic to the survivors. ALL was originally treated with CRT, which decreased deaths but resulted in neurocognitive sequelae or impairment of neurocognitive functions. Current treatments only call for CRT for high-risk cases of ALL and a lower dose of CRT than in original protocols. In non-high-risk ALL cases CNS directed chemotherapy was developed to lessen the neurotoxicity (Rey-Casserly & Meadows, 2008).

***Intensified CNS Directed Chemotherapy.*** A new less toxic protocol was formed which does not use CRT for standard-risk ALL patients (Kanellopoulos et al., 2016). “Central Nervous System (CNS) directed therapy is an essential part of acute lymphoblastic leukemia (ALL) treatment” (Kanellopoulos et al., 2016, p. 1). Prophylactic CNS-directed treatment with cranial irradiation (CRT) has been left in favor of intensified CNS-directed chemotherapy. These treatment protocols include

intravenous (IV) and intrathecal (IT) methotrexate as the primary way to treat CNS cancers instead of CRT (Kanellopoulos et al., 2016).

Intensified CNS directed chemotherapy consists of high doses of methotrexate, intrathecal (delivered directly into the spinal fluid) and intravenous (delivered directly into the blood stream) methotrexate, cytosine, hydrocortisone, doxorubicin, and asparaginase, which are given during treatment. Modes of dosing the various chemotherapy drugs include intrathecal, intravenous, and oral (van der Plas, 2017).

The five phases of ALL treatment for CNS directed chemotherapy are induction, consolidation, interim maintenance, delayed intensification, and long-term maintenance (Moleski, 2000). Induction is an intense phase whose purpose is to rapidly eliminate leukemia cells from the bone marrow and blood (Butler & Mulhen, 2005). Consolidation and delayed intensification have high concentrates of these chemotherapy drugs. Interim maintenance and long-term maintenance have chemotherapy drugs given at the highest dose tolerable to the patient. Drugs during this period are mercaptopurine and oral methotrexate (Moleski, 2000). ALL treatment for males can be a year longer than females. Females are treated for two and a half years. Boys who are at higher risk for relapse have longer treatment period due to a higher prevalence of relapse in testicles (van der Plas, 2017).

Methotrexate is used to bypass the blood-brain barrier and helps to prevent a CNS relapse. ALL patients routinely receive to methotrexate during treatment (Wen et al., 2018). Repeated intrathecal methotrexate can cause neurotoxicity in cancer

patients (Moleski, 2000). Intrathecal methotrexate is delivered directly to the spinal fluid called a lumbar puncture. Research has indicated that methotrexate changes the white matter in the brain, which in turn causes neurocognitive deficits (Wen et al., 2018).

### **Long-term effects of childhood cancer treatments.**

***Brain irregularities.*** Chemotherapy and cranial radiation alter the developing brains of cancer patients. The brain has two different types of matter, grey and white. White matter in the brain is the most sensitive to cancer treatment (Moleski, 2000). Askins and Bartlett (2008) found in cancer survivors that white matter is lower in density than when compared to a control group. The white matter shrinks because of the cancer therapy. This could indicate that toxicity in the white matter caused the brain tissue to atrophy. White matter of the brain controls much of the communication in neural network of the brain (Askins & Bartlett, 2008). Cognitive deficits have been correlated with the amount of white matter damage. The amygdala, thalamus, striatum, and corpus callosum are the regions of the brain that also showed the irregularities from treatment. This correlated with the deficits in working memory that cancer survivors exhibit (van der Plas, 2017).

As deficits accrue over time with cancer survivors, Armstrong et al. (1999) believed it is because of the interruptions of growth and development of the brain. Chemotherapy that targeted the CNS like methotrexate and cranial radiation interrupt the myelin sheath that covers the axons in the brain. This caused the brain structures not to develop correctly. It also explained why many cancer survivors' neurocognitive

problems mimic those of a traumatic brain injury. Cancer survivors do not lose prior knowledge but do lose the ability to learn as they did before treatment. These specific deficits are tied to regions of the brain that control these aspects of neurocognitive ability (Moleski, 2000).

Sleurs et al. (2017) found that in ALL survivors, treated with CNS intensified treatment, IQ scores did not differ from a control group. However, there was an IQ difference for ALL survivors diagnosed at a younger age. It is believed that the younger the treatment age, the more neurocognitive effects and the more severe the effects will be on the ALL survivor (Sleurs et al., 2017). Most diagnosis of childhood cancers occur between the ages of one and four. This is also a very important time for the brain's development. Neural networks are susceptible to the tumors and toxicity of chemotherapy (Rey-Casserly & Meadows, 2008).

***Focused attention effects.*** Early studies (Soni et al., 1975, Meadows et al., 1981, Mulhern et al., 1987) were limited due to the focus on intellectual and academic outcomes they did not study neurocognitive deficits the survivors were experiencing. Butler and Haser (2006) indicate the specific neurocognitive deficits survivors must cope with in daily life. Survivors' have difficulties with information processing, particularly focused attention. Focused attention is the ability to focus on activity for a period of time. These deficits in attention are likely to impact math and reading skills. Children who receive intrathecal methotrexate, IV methotrexate, and dexamethasone are all at a higher risk for impaired cognitive functioning. Children who received treatment for brain tumors show declines in IQ over time (Butler &



Haser, 2006). This decline is more severe the earlier a child is diagnosed with a brain tumor. Survivors of brain tumors often experience language, sustained attention, visual-spatial, executive function, and memory problems in varying degrees and combinations (Butler & Haser, 2006).

Focus encode and focus execute are two specific functions of attention. Focus encoding is the ability to store in your brain the information learned. Focus execute is the ability to use the new knowledge stored in the brain. In ALL survivors it was discovered that this ability is significantly lower when compared to their siblings. However, the ability to shift attention is at a similar level when compared to the sibling control. Focus encode and focus execute skills could be hampered by the decreased speed of information processing. This causes the child to have difficulty choosing the correct strategy to solve the problem. "Our study indicates that difficulties at school may result from an inability to focus attention" (Rodger et al., 1999, p. 322).

***Working memory effects.*** Brain development continues through adolescence into early adulthood. Neurocognitive sequelae may not be apparent until years after treatment. There is little information available on childhood cancer survivors who have lived more than 10 years off treatment. Kanellopoulos et al. (2016) investigated neurocognitive outcomes concerning the toxicity of treatment for very long-term ALL survivors. For this study, 112 ALL survivors who did not receive IRT were chosen for this study and compared to an age and gender-matched 100-member control group. This study compared the neuropsychological tests of the participants.

Kanellopoulos et al. (2016) found that while IQ was similar between the ALL group and the control processing speed, executive functioning, working memory, and verbal learning and memory were all considerably slower in the ALL group. The ALL group scored 23% lower on processing speed, 31% on executive functioning, 34% for working memory, and 16% for verbal learning and memory. "Working memory is one of the first cognitive functions to decline with age, chemotherapy has been associated with early aging in various organs, including the brain" (Kanellopoulos et al., 2016, p. 5).

In a study by Schatz et al. (2000) it also found ALL survivors had poorer working memory and slower processing speed than the control group. ALL survivors also may use less effective problem-solving strategies, which also hinder cognitive abilities. "Difficulties with working memory may be an important factor in explaining the delayed onset of IQ deficits in children treated with CRT" (Schatz et al., 2000, p. 198). Slower processing speeds and working memory deficits may help to explain why ALL survivors do not make appropriate academic progress in higher grades.

***Information processing effects.*** Information processing is the brain's ability to recall, process, and analyze information. This includes the functions of attention, working speed, memory, and executive functions. Rey-Casserly and Meadows (2008) reported that long-term cancer survivors "have an increased risk for poor academic performance, thought to evolve from their cognitive deficits, which can involve attention, speed of processing, engagement, fluid cognitive skills, and executive functions" (p. 244). Intrathecal methotrexate and cranial radiation increased the risk

of being enrolled in special education programs by 23%. In fact, in a study by Wengenroth et al. (2015), survivors score lower than their siblings in information processing, especially in the areas of concentration, working speed, and memory. Survivors treated with cranial radiation are the most severe cognitive problems when compared to their siblings. These deficits in attention, working memory, and concentration underlie the declines in IQ and academic achievement over time (Mulhern et.al, 2004).

Mennes et al. (2005) found “children treated for ALL with chemotherapy only are impaired in selective aspects of cognitive function” (p. 484). These selective functions are encoding, memory search letter, focused attention 4-letters. Processing speed and attention are required for all of these tasks. Cognitive processing tasks prove to be difficult for ALL survivors. These deficits in processing speed and attention cause ALL survivors to struggle with success in school (Mennes et al., 2005).

***Psychological effects.*** In a study by Roberts et al. (2014), researchers studied the psychological issues of childhood cancer survivors in South Australia. Approximately 40% of the 70 participants were survivors of ALL. The subjects were surveyed with the Strengths and Difficulties Questionnaire (SDQ), which is an assessment of psychological problems. SDQ was used with the participants to determine any psychological issues. The childhood cancer survivors had a significantly higher score than the normative data meaning; the survivors had more psychological problems than the general population (Roberts et al., 2014).

Psychological disorders reported by the participants included anxiety, depression, conduct problems, attention deficit, and social problems. Interesting to note that female survivors had more psychological problems than male survivors (Roberts et al., 2014). Female survivors are more likely to have depression and somatic distress. Childhood cancer survivors who received cranial radiation therapy “also had fewer or no close friends” (Rey-Casserly & Meadows, 2008, p. 244).

Many cancer survivors have reported that they are closer to their families than their peers. This may be related to the experiences shared during treatment (Winterling et al., 2015). Posttraumatic stress disorder is a problem for cancer survivors and their families. Cousino et al. (2017) found that family burden is increased when late-effects are greater. The greater number of late effects in survivors increases the chance of PTSD symptoms. A child with cancer will have a different view of illness than their peers, this may manifest in a fear of illness. Learning to cope with this fear will affect the outcome of the survivor's life (Stokes, 1999).

Childhood cancer survivors are changed by their life experiences during treatment. Despite the hardships that childhood cancer survivors face during treatment and struggles with late effects, 86.5% of childhood cancer survivors report a positive change after their diagnosis in their life (Yi et al., 2015). In a quality-of-life study conducted by Tonsing and Ow (2018), it was found that cancer survivors rate their spiritual life the highest. It is suspected that these spiritual coping behaviors that help the participants survive the cancer influence the belief in a higher power. The

belief in a higher power could also be the reason most childhood cancer survivors report a positive change in their lives after diagnosis.

***Physical long-term effects.*** Along with the neurocognitive sequelae, many cancer survivors have suffered from the physical effects of their childhood cancer treatments. Around 62% of cancer survivors report excellent health. The others report physical problems such as renal, endocrine, hormonal, and cardiovascular problems (Maunsell et al., 2006). Tonsing & Ow (2018) also reported that childhood cancer survivors rate their physical quality of life as low, with fatigue, aches, and pains as the chief complaints. One childhood cancer survivor reported, “I had fatigue in the upper grades of elementary school. I was not as good as my friends in physical activities” (Kim et al., 2018, p. 131).

***Psychosexual effects.*** Lehmann et al. (2017) found that neurotoxic treatments for childhood cancers impact later sexual relationships. Survivors in the Lehmann et al. (2017) study reported fewer sexual partners. In a study conducted by Zebrack et al. (2010) they found that 52% of female survivors and 32% of male survivors report some problem with sexual functioning. Female cancer survivors can have issues with ovary function or menstrual irregularity, and or vaginal dryness (Kim et al., 2018). Yet, the male survivors rate their sexual problems as more distressing than the female survivors (Zebrack et al., 2010). Survivors of brain tumors and those that received the higher doses of treatment were least likely to be sexually experienced, in a relationship, or have children. Neurotoxic treatments for childhood cancers impact later sexual relationships (Lehmann et al., 2017).

***Education attainment.*** Koch et al., (2004) studied the educational attainment of 2,384 childhood cancer survivors in Denmark. They were compared to a randomly selected control group. It was found that non-CNS treated (no cranial radiation) survivors attained similar levels of higher education as the control group (Koch et al., 2004). CNS treated (cranial radiation) children had a lower chance of completing higher levels of education. Specifically, survivors with brain tumors that were treated with CRT were found to have the lowest educational outcomes of childhood cancer survivors (Koch et al., 2004). Conversely, it was found by Dumas et al. (2015) that cancer survivors had a reduction in initial human capital, therefore had a lower subsequent socioeconomic status in adulthood. Further, they found that male cancer survivors would avoid physical blue-collar jobs due to health impairments.

### **Need for interventions**

Childhood cancer survivors will reenter school and normal social activities once their oncologists approve it. School professionals must equip themselves with the knowledge of the issues of childhood cancer treatments. Educators must be aware so they can prepare to aid the student in the long-term effects that may or may not get worse as the survivor ages (Armstrong et al., 1999). Difficulties may arise once the childhood cancer survivor has reentered school. They may endure extended absences and have missed work that has put them behind even without the neurocognitive deficits (Prevatt et al., 2000).

As survival rates for childhood cancers increase, the long-term effects of cancer treatments are becoming more obvious. One factor that influences the daily

life of childhood cancer survivors is their academic performance at school. Sleurs et al. (2017) report that school performance declines after a cancer diagnosis. As previously discussed, neurotoxicity of the chemotherapy causes neurocognitive problems in childhood cancer survivors. ALL survivors are more likely to require special education services and are evaluated lower on academic abilities. These deficits may not all appear until the survivor has been off treatment five or more years (Moore et al., 2013).

During treatment, education is often neglected due to health complications. Childhood cancer survivors may miss up to two years of school, which leaves them behind in more than just academic subjects. They often miss out on social and sporting activities. Cancer survivors may lose friends as well (Wakefield et al., 2010). French et al. (2013) report that childhood cancer survivors “have absenteeism rates that are more than double those of children with other chronic illnesses” (p. 160).

Donnan et al. (2015) surveyed parents about the education challenges their children face when they return to school. Around 62.3% of the parents reported that their child required extra services at school that were covered in an Individualized Education Plan (IEP) or Section 504 Plan. The highest needs reported were in fine motor skills, mobility, and hearing/vision. The parents also reported that they saw a decline in math grades, concentration, memory, writing, and confidence.

Parents and families of the survivor are burdened with the diagnosis and treatment of childhood cancer. Approximately, 48% of parents report that they did not receive adequate information for cognitive effects of treatment, further 51% of

parents report that they do not feel adequately prepared for their child's school reentry (Ruble et al., 2019). In a study by Patel et al. (2013) results indicated that parents of children with severe long-term effects were more stressed and needed more support than those parents whose children did not suffer from severe long-term effects. Empowering parents with information allows them to support their child. Three key areas that need to be addressed for parents of childhood cancer survivors are knowledge about the late effects, educational support, and advocacy to meet the needs of their children at school (Donnen et al., 2015).

**Interventions.** Interventions are important for childhood cancer survivors. Interventions are therapies or accommodations that improve the quality of life for the survivor. Interventions can help the survivor overcome a deficit or adapt in ways to overcome the deficit. As neural pathways may have been damaged during treatment, interventions can work to undo the damage caused. "For survivors who show neurocognitive decline following cancer treatment, rehabilitation similar to that used for survivors of traumatic brain injury have shown some effectiveness" (Askins & Bartlett, 2008, p. 11).

How interventions work to change the brain is not understood at this time, but Moore et al. (2012) hypothesize that interventions increase the plasticity and neural pathways of the brain. This allows for complex neurocognitive skills. Another theory states that interventions help the brain make connections between the white and grey matter of the brain (van der Plas, 2017). Grey matter is where the information is stored in the brain and the white matter is the communication between the areas of



matter. The sooner the interventions, the better the chance to minimize the atrophy of white and grey matter in the brain. Neurocognitive interventions need to be multifaceted to address the complex needs of the childhood cancer survivor (Skidmore, 2014).

Developmentally appropriate interventions can provide help at the right stages of development. Developmentally appropriate interventions are intellectual age based. Pharmacological interventions include medicines that can help the side effects of childhood cancer. For example, many survivors are later diagnosed with Attention Deficit Disorder (ADHD) and pharmacological drugs can help control these symptoms.

Multiple cognitive interventions are being developed. Cognitive remediation therapy, bottom-up and top-down interventions, and online cognitive interventions are three research based cognitive interventions. Over time more survivors with different needs will respond to different cognitive interventions. Psycho-social interventions are used to address any mental and social side effects treatment has caused. Counseling for the survivor and family may be necessary to help them cope. Finally, school interventions which include a multidisciplinary team who can address the whole child and accommodations at school to help level the playing field for the child.

***Developmental interventions.*** One model of intervention suggests that a multidisciplinary approach be pursued based on the child's developmental stages. Rey-Casserly and Meadows (2008) state that early childhood (3 to 8 years old)

intervention should target cognitive, language, motor, and sensory development.

Cognitive interventions often take a back seat to medical treatment at this stage if the child is undergoing treatment for childhood cancer. Individualized interventions like speech therapy, physical therapy, or occupational therapy can provide developmental gains if the whole family is involved. Parents may struggle with structured schedule for these children who are battling cancer, and this can impede developmental gains (Rey-Casserly & Meadows, 2008).

In middle childhood (9 to 11 years old) survivors see difficulties in adapting across the curriculum. Survivors can have problems with gaining new skills, integrating multiple processes, and application of skills (Rey-Casserly & Meadows, 2008). Research has been done on targeted interventions during this stage of development. Moore et al. (2012) used a mathematics intervention program to proactively intervene in mathematics skills. Intervention participants improved in calculation skills and applied mathematical problem-solving and it was found that skills continued to improve two years after the intervention (Moore et al., 2012). Self-regulation should be considered during middle childhood. Social isolation can also occur during this stage and social activities should be used to address this issue (Rey-Casserly & Meadows, 2008).

Adolescence (12 to 18 years old) brings a higher order and abstract thought processes. Survivors have problems with these skills. Survivors also have difficulties connecting with peer groups. Interventions for this age group can include social skill training and learning development skills (Rey-Casserly & Matthews, 2008). Targeted

intervention for adolescents is a SWAT IT process. "SWAT IT is a mnemonic process where you 1 state the problem, 2 identify what can be done, 3 ask themselves what the pros and cons about each option are and 4 try out the best choice" (Patel et al., 2009, p. 672). Then, the adolescent would evaluate if the option worked or not.

Cognitive reserve is also important for adolescents to develop. Helping the adolescent develop cognitive reserve will help the adolescent deal with the learning disability. "Reserve is the cognitive and psychological contextual resources available to the child developmentally to compensate for the impact of the brain injury" (Rey-Casserly & Matthews, 2008, p. 245). Being aware of the strengths and weaknesses of the adolescent will help them know when to ask for assistance and gain confidence with their successes. Developing cognitive reserve can be done through cognitive interventions such as the cognitive remediation program.

Emerging adulthood (18+ years) presents new problems. Coping with cognitive deficiencies as a result of treatment can be challenging to the survivor. There is limited research on this age group, emerging adulthood, as survivorship rates increase. These survivors can have problems with executive functioning and cannot successfully transition independence. Interventions should include an education advocate to help them develop self-advocacy skills. Emerging adult survivors need to understand their cognitive disabilities and adapt for success. Many long-term care clinics offer social services to help these survivors adapt to adulthood (Rey-Casserly & Meadows, 2008).

***Pharmacological interventions.*** Methylphenidate is a stimulant used to treat Attention Deficit Hyperactivity Disorder (ADHD). Since attention and concentration deficits are common in childhood cancer survivors and often have the same behavioral symptoms methylphenidate has been found to help these children (Butler & Mulhern, 2005). Mulhern et al. (2004) found that methylphenidate in childhood cancer survivors improved their attention and behavior as reported by their parents. In the study, of the 93 participants, only 9 had adverse side effects and had to discontinue the drug. Methylphenidate is a drug that has few adverse side effects. The drug takes effect within 30 minutes and is effective for about four hours (Mulhern et al., 2004).

In addition to methylphenidate three drugs are being tested to improve cognitive functions in childhood cancer survivors. Modafinil a central nervous stimulant has shown promise to improve visual memory and spatial planning capacity in participants (Castellino, et al., 2014). Donepezil, a drug for Alzheimer's and dementia, is in trials to determine its usefulness for childhood cancer survivors. Donepezil improves cognitive function (Castellino, et al., 2014). Recombinant human growth hormone was found to improve cognitive functions and attention in ALL survivors (Castellino, et al., 2014).

***Cognitive interventions.*** The cognitive remediation program is a tripartite treatment, which draws from three disciplines to provide interventions for childhood cancer survivors. In the original study, Butler and Copeland (2002) pulled techniques from brain injury rehabilitation, special education/educational psychology, and

clinical psychology. “The theoretical basis for cognitive remediation can be traced to the work of Alexander Luria (1963). He proposed that the brain is not a static organ and that functional reorganization of neural pathways can occur after a CNS insult” (Butler & Mulhern, 2005, p. 68).

In cognitive remediation therapy, participants focus on a learning task for 15 minutes. Then participants take part in a fun activity. This helps them develop stamina over a set period of time. Participants must score 50% on each activity. If 50% is not obtained, then the participant is put back a level and must get 80% to get to the next level. The cognitive remediation program used 15 metacognitive strategies. Strategies include task preparation strategies such as warm-up my brain, on-task strategies such as talk to myself and ask for a hint, and post-task strategies such as check your work (Butler & Copeland, 2002). The other key part of the cognitive remediation program is providing psychotherapeutic support for the participants, where they learn to reframe their struggles and learn their strengths and weaknesses. One of the most important parts of the program is learning to ask for help to overcome difficulties (Butler & Copeland, 2002).

There have been several studies testing the efficacy of the cognitive remediation program. In the first study, Butler and Copeland (2002) found that participants improved in attention. They were able to concentrate for a longer period of time with the skills taught. Zou et al. (2012) tested the cognitive remediation program. Where they conducted an fMRI three times on survivors to determine if the treatment worked on the neurocognitive function of the participants. fMRI is a

working brain MRI; the brain is performing specific activities during the MRI. The MRI captures images of the blood flow from targeted part of the brain. Zou et al. (2012) found that the brain had no activation in the targeted areas before the cognitive remediation program. After the program, there was some activity in these extrastriate visual areas of the brain. Six months after the program, even more activity in the extrastriate visual areas of the brain (Zou et al., 2012). This is an excellent indication that the cognitive remediation program and others like it can help survivors reverse some of the late effects of treatment.

Bottom-up and top-down interventions are neurocognitive interventions designed to increase the connection between the white and grey matter in the brain. Bottom-up interventions are rote practice drills. Where the students are asked to work at memorizing and recalling information. Top-down practices are focused on the performance of the work. The act or the steps of problem-solving are the focus to promote neurocognitive performance (Skidmore, 2014). Moore et al. (2012) used a mathematics intervention program that used top-down activities. They focused on problem-solving skills that they found translated to gains in other subjects as well as their intended math goals.

Cognitive rehabilitation comprises restoring impaired functions through strategy training and/or repeated skills practice. Cognitive rehabilitation programs are lengthy and require many sessions. However, computer-based cognitive rehabilitation programs have been shown to be just as effective as traditional approaches (Kesler et al., 2011). Many families live too far away from their medical centers to travel for

weekly interventions. Moscato et al. (2019) report that the feasibility and satisfaction of online programs are very high among cancer survivors. The appeal of an online program is that it can be completed from home and at any time of the day.

*CogmedRM* is an online program tested with survivors that had deficits in attention and working memory. Hardy et al. (2013) found that participants showed some improvements with use of the program with parents and participants rating the program very highly. Online cognitive programs like *Captain's Log* can provide in-home training to improve memory, attention, concentration, listening skills, and self-control. Childhood cancer survivors who used *Captain's Log* showed improvements in working memory, attention, and concentration. Three months after the intervention the participants were still improving in working memory (Hardy et al., 2011). Kesler et al. (2011) found that processing speed, cognitive flexibility, and memory scores improved with computer-based cognitive rehabilitation programs. Feasibility for programs such as these may make them preferable interventions for parents (Hardy et al., 2013).

***Psychosocial interventions.*** Social isolation is a real fear of adolescent and young adult childhood cancer survivors. Childhood cancer survivors are at risk for anxiety, somatic concerns, depression, and behavior issues (Roberts et al., 2014). Counseling services individually or groups may be needed to address these psychosocial issues. Coping issues with the disease and school reentry should be addressed in these counseling sessions (Hermann et al., 2011). The childhood cancer survivor may be reluctant to return to school out of fear of teasing and rejection of the

peers (Prevatt et al., 2000). Group counseling sessions with the survivor and the peer group to discuss the emotions and feelings around the diagnosis should be addressed. This can facilitate peer support for the survivor, which can lessen the psychosocial distress (Hermann et al., 2011).

***School-based interventions.*** A hospital liaison program offered by the hospital can be instrumental in providing needed information about the child returning to school. A hospital liaison has access to a child's medical records and has the responsibility of contacting the child's school. They can help by bridging the divide between the hospital and the schools. Hospital liaisons can provide support to the parents to ensure advocacy for the student returning to school with neurocognitive deficits (Northman et al., 2018). Hospital liaisons have several patient-specific tasks such as consultation with the medical team and parents, preparation time which includes gathering data about the child and illness, and school meetings such as IEP and 504 meetings (Irwin et al., 2015). However, the hospital liaisons are only available at the larger oncology units and are no longer provided once the child finishes treatment.

Parents report higher levels of understanding, greater abilities to advocate for their children, and informed access to services with hospital liaison programs (Northman et al., 2018). The hospital liaison can help coordinate the care and provide school-specific support to the parents and children (Irwin et al., 2015). Hospital liaisons can also work with the school nurse to help further collaboration between the



school and hospital. The school nurse can be a good resource for medical problems that may arise while at school (Yilmaz et al., 2014).

“Successful school reintegration for children diagnosed with cancer is best facilitated by a coordinated effort between and within the home, school, and hospital ecosystems” (Hermann, et al., 2011, p. 258). Yet, in the excitement of school reentry, many school professionals overlook the fact that the children have new cognitive deficits that were not there before the illness. The recommendation is that hospital and schoolwork together to coordinate the school-based interventions needed by the child.

School personnel workshops, which educate the school personnel about the needs of childhood cancer survivors help to lessen the fears of teachers and staff. Cancer survivors who have the support of the teachers have greater scholastic success upon school reentry (Yi et al., 2016).

Brown et al. (2011) developed training modules to instruct teachers on childhood cancer. A multidisciplinary team of medical personnel, psychologists, and educators created the modules around topics such as successful school reentry, general medical information, effects of cancer treatment, psychological impact, learning issues, and grief and loss. Teachers rated the program high for its content and delivery format.

School counselors can also play an important role in school reentry for childhood cancer survivors. School counselors can work as a local resource to facilitate a connection between home, hospital, and school. School counselors can

work with the students to help prepare them for the cancer survivor's return to school (Bauman, 2010).

Peer education programs can help peers understand what has happened to their classmates. It can help ease the survivor's reentry into the school (Prevatt et al., 2000). "Peer relationships are critical for establishing healthy self-identity among childhood cancer survivors" (Yi et al., 2016, p. 264). Yi et al. (2016) found in their study of childhood cancer survivors, that all survivors feared returning to school. Some of the participants reported being bullied and isolated from peers. Others reported that they had close peers that made the transition easier. Yi et al. (2016) found that those individuals who received peer support found greater academic success.

School-based interventions can be implemented through a 504 or Individual Education Plan (IEP). These accommodations are available for any students that meet the qualifications in the programs. Cancer survivors may receive accommodations for fatigue, working memory, executive functions, and processing speed. These accommodations can be shortened school days, modified assignments, modified tests, extended time, technology, and preferential seating away from distractions (Gorin & McAuliffe, 2008). Accommodations are not the same for every cancer survivor and are based upon the child's deficits. The goal of the accommodations are to help level the playing field so that the childhood cancer survivor can succeed in the classroom and beyond.

**Conclusion.** Neurocognitive impairments remain a significant risk despite advancements in childhood cancer treatments. Oncologists work diligently to reduce the toxicity of chemotherapy while trying to cure the child of cancer. During treatment, a delicate balance between too much radiation and chemotherapy, or too little radiation and chemotherapy must be maintained. Too much results in cognitive deficits, and too little can lead to fatality. Interventions need to treat the whole child, which will require a multidisciplinary, team working together, to create individualized treatments for cancer survivors. Further research is needed on the specific interventions that help this special population living with the late effects of their cancer treatment.

Childhood cancer is a life-threatening disease. Its diagnosis places fear in all those it affects. Students struggling with the disease or its aftereffects need the support of the school. They need the normalcy of going to school. However, the school does not need to be a burden on the student. To find that healthy balance, educators need to have basic knowledge of cancer, cancer treatment, and its long-term effects on the student. Educators need to be prepared to offer support and quickly develop plans to give interventions and accommodations as necessary. That is the underlying purpose of this capstone project: to give educators the basic understanding of childhood cancer that will allow them to work as a multidisciplinary team to develop successful interventions for the student upon initial school reentry or in their long-term school career.

The capstone project consists of five modules- Module One (see Appendix A) covers an introduction to childhood cancer and its treatments. Module Two (see Appendix A) covers the cognitive late effects of childhood cancer. Module Three outlines the social and emotional effects of childhood cancer. Module Four outlines the physical effects of childhood cancer. Module Five examines how to facilitate a successful school reentry for the student. These topics are ones that educators have little knowledge of, and the rarity of childhood cancer means that there is not a lot of experience dealing with childhood cancers. It is the aim of the capstone project to educate the educators on providing quality education with interventions and accommodations for the childhood cancer survivor.

**Who is the capstone meant to impact?**

The capstone is meant to impact the education community. There is information in the capstone project that can be used by teachers, school support personnel, and administrators. The return to school for the critically ill child is a complex process with many team players involved. There will need to be input from many- from the child, the parents, teachers, school nurse, school counselors, and the doctors. All who are supporting the survivor need to have basic understanding of the disease and treatment. They need to be aware of the changes that this disease has had on the individual student. They need to work together to create a plan that allows the student to have success in school both emotionally and academically. The school needs to ensure that the student also feels safe and happy in the school environment.

The goal is to provide the opportunity for teachers and other educators to learn the basics about childhood cancers. The modules are designed to present basic information about the childhood cancers and their possible side effects in a language that a non-medical person may understand. While the modules are geared primarily toward educators, there is a possibility that parents may find information within these modules beneficial.

**Overview of modules.** The information provided within Module One gives information about the most common childhood cancers. Section 1 is an introduction to childhood cancer and includes a video that explains why childhood cancer is different (St. Baldrick's Foundation, n.d.). Section 2 of the module covers the common types of childhood cancers and their treatments. Additional links are provided to aide in the search of more uncommon pediatric cancers. Section 3 includes information about possible side effects of the treatments and typical drugs used to treat the various cancers. Surgery, chemotherapy, radiation, stem cell therapies, immunotherapies, and targeted therapies are explained. Section 4 is the reference section for the module. Section 5 includes a link to a quiz that will allow the participants to print for their records of the module completion. This would be beneficial if a school district was awarding professional learning credit for the micro credential course. The last two sections of Modules 1-4 are the references and quiz respectively.

Module 2 provides educators with detailed information on cognitive side effects of childhood cancer. Section 1 discusses the cancer treatment effects on the

brain. This section also includes graphics and a video on treating brain tumors (Nationwide Children's Hospital, 2017). Section 2 includes material about how information processing and working memory are affected by the childhood cancer treatment. A video discussing neurocognitive late effects is included (Centers for Disease Control, 2018). Section 3 discusses the IEP vs. 504 Plan. This can help teachers and multidisciplinary team members have a better understanding of what the child might need on the return to school. Section 4 is about cognitive interventions. Cognitive interventions are different than accommodations that many schools provide. Cognitive interventions are re-training the brain to work at its best. This section provides tasks that educators can incorporate into daily lessons. It also includes accommodations that may be appropriate for cognitive disabilities and cognitive side effects.

Module 3 outlines information for social and emotional side effects. The student is more than just academic achievement, educators must be prepared to address the social and emotional issues that may occur due to childhood cancer. In section 1 of this module, information about psychological and social problems that may be present in survivors due to childhood cancer. A survivor's first-hand account of the difficulties of childhood cancer are also included in Section 1 (American Cancer Society, 2015). Section 2 discusses interventions and accommodations that may be appropriate for the survivors who are experiencing these side effects.

In Module 4, physical side effects of childhood cancer are addressed. Many children can have visible ravages of the cancer. These can affect their mobility,

hearing, vision, and self-esteem. Section 1 covers the long-term physical side effects of cancer. Videos are included that highlight osteosarcoma (John Hopkins Medicine, 2017) and retinoblastoma (St. Jude Children's Research Hospital, 2017). Section 2 covers the short-term side effects of childhood cancer specifically hair loss (alopecia), mouth sores, and appetite problems. These are short-term side effects are important to school reentry because they not only affect the student physically, but emotionally as well. Section 3 gives educators ideas about interventions and accommodations that might apply to the cancer survivor.

Module 5 has outlined the procedure a school can follow to develop a school reentry plan for the student. This module should only be completed after educators have done the other modules and have a basic understanding of the effects of childhood cancer. Section 1 is a detailed list of people that should be included in the multidisciplinary team that can facilitate school reentry. It also details the roles of the team members. Section 2 is an outline of the first meeting for the multidisciplinary team. It includes talking points to cover with the parents including the health management plan for the school, physical accommodations, and possible referral for a 504 Plan or IEP.

Section 3 discusses how to make a presentation to the peers of child with cancer. The presentation should be personally tailored to the child but should have certain basic elements at age-appropriate levels. Grief counseling is also covered in this section. Section 4 has a comprehensive list of appropriate accommodations and interventions for the child. These can be offered as part of a 504 Plan or IEP. This

capstone is intended as an introduction for educators to become familiar with aspects and issues of childhood cancer. This will allow a more comprehensive plan to be developed for the child and allow greater successes at school. Section 5 is the references. Section 6 is a checklist for the chairman of the multidisciplinary team.

**Context of the capstone.** Many educators have experience with adult cancers but are unaware of how childhood cancer is treated. For this reason, educators need to information about the disease, its treatment, possible side effects, and possible interventions and accommodations. The population of students is small, so the professional learning series needs to be available to those who need it. It may not be a school wide professional learning topic but a topic necessary to those who will be in contact with the student. The online platform will allow educators the opportunity to learn when they have time and as they need it.

### **How was the capstone project implemented?**

**Development.** The development of the modules was a process of adapting information from peer-reviewed journals and reputable internet sites such as St. Jude Children's Research Hospital, American Childhood Cancer Organization, and St. Baldrick's Foundation. These resources and others were used to create the content of the modules with relevant and current information. Videos are available on YouTube and were evaluated on their relevancy, information and published date.

The five professional modules were built using Open Author, an Internet application used exclusively on OER Commons. OER Commons is an open educational resource library that has free instructional materials. The intended



audience is educators who have a student with childhood cancer. The modules were developed using the principles of andragogical learning theory for adults. In Knowles learning theory, he stated that adults learn differently from children. Adults learners already have a concept of themselves as learners and are motivated to learn what is necessary to do their job (Harrop et al., 2018). The modules are self-paced and provide information at the discretion of the educator. The educator can decide to do all the modules or just the ones that pertain to their situation. Each module includes text, graphics, videos, and a short quiz at the end to check for understanding. The multi-media modules can be accessed on any computer or browser. The modules are followed by a link with a quiz that the educator can complete for a certificate of completion.

**Next steps.** The professional learning modules will be offered to the educational cooperatives within the state of Kentucky to list on their website as a potential professional development course. The intent is that districts and school can use the training when they have a student newly diagnosed with a childhood cancer or if they have a student with cancer that is encountering problems. The information will also be shared with parent resource groups for childhood cancer within social media platforms like Facebook. As the training will be included in the OER Commons library, it will appear in searches with key words childhood cancer, school reentry, childhood cancer late-effects, and cancer interventions and accommodations. This will allow a wider range of educational professionals to find the resource.

**Why were this capstone and related strategies selected?**

The research for children with cancer is very hard obtain. The guidance on returning to school for these children is narrowly focused. For this reason, the modules were developed to allow educators to find the information quickly. Medical information was combined with current special education guidance to develop accommodations and interventions that can be used in the schools. The capstone was developed to help guide educators in dealing with childhood cancer survivors. Educators cannot treat the cancer; however, they can provide the child with a safe and comforting experience at school while on treatment. Off treatment they can offer interventions and accommodations to battle the long-term side effects of cancer. This capstone project provides information to inform the school personnel with a basic understanding of childhood cancer, its treatments, its side-effects, and the interventions and accommodations that can be provided to the childhood cancer survivor.

**When was the capstone implemented?**

Development of the capstone began in August of 2020 and continued through January 2021. In February 2021, the modules were built on OER commons. Once the capstone is accepted and approved emails will be sent to the educational cooperatives requesting it to be included on their list of professional learning resources. At the same time, information will be passed onto childhood cancer support groups found in social media platforms such as Facebook.

**Limitations of the Study**

Some of the limitations of this capstone are the brief amount of time that was allowed to develop the project and implement it. This constrained the type of multi-media resources available for use. Videos could not be developed specifically for the project. The project was also limited because of the type of platform used to launch it. There were formatting issues and limiting features of Open Author that compromised the quality of the project in order to publish in the OER Commons.

**Reflections**

The development of these modules has been an intense investment of time. The information found through the literature review process and the development of the modules were very beneficial and applicable to the education of critically ill children. Most research articles focus on the medical aspects of childhood cancer and very few focus on the consequences of childhood cancer treatments on school. The need for educators to understand this special population is great. The capstone project fills the gap for educators. It delivers information about the disease and treatment itself. Modules also give interventions and accommodations that will help educators help their students. That is the first goal of an educator to help students succeed.

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# Module 1- Introduction to Childhood Cancers and Their Treatments



## Introduction to Childhood Cancer

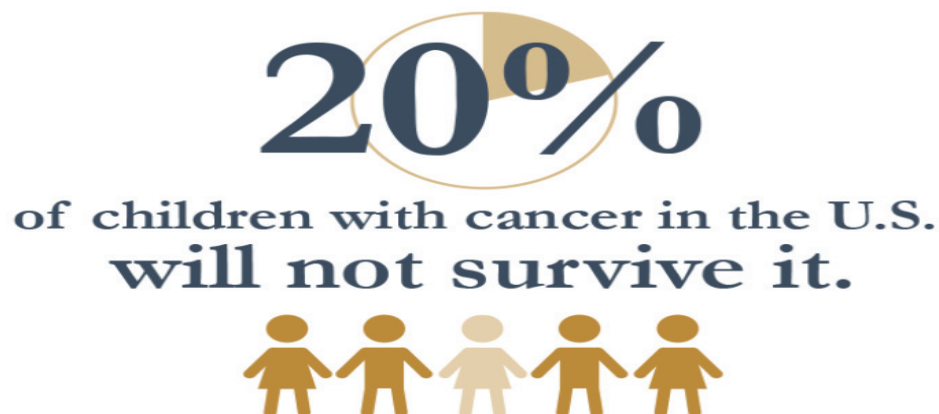
A childhood cancer diagnosis is devastating to a family. The world figuratively drops away. Yet 1- 2 children in 10,000 children each year are diagnosed with some form of the disease (Butler & Haser, 2006). In 1960 the survival rate for Acute Lymphoblastic Leukemia (ALL) was 57.2%. In 2014 the 5-year ALL survival rate increased to 90% (Noone et al., 2018). This has led to a growing population of survivors that has to deal with the late effects of cancer treatments. “Many survivors experience at least one long-term adverse effect of cancer and its treatment” (Roberts et al., p, 2014, p. 153). Each childhood cancer survivors’ story is different, but they share many of the common late effects, which include attention problems, concentration difficulties, working memory deficits, and processing speed. ALL

survivors often find themselves with declines in neurocognitive functioning several years following treatment (Moore et al., 2013).



Source: American Childhood Cancer Organization (n.d.)

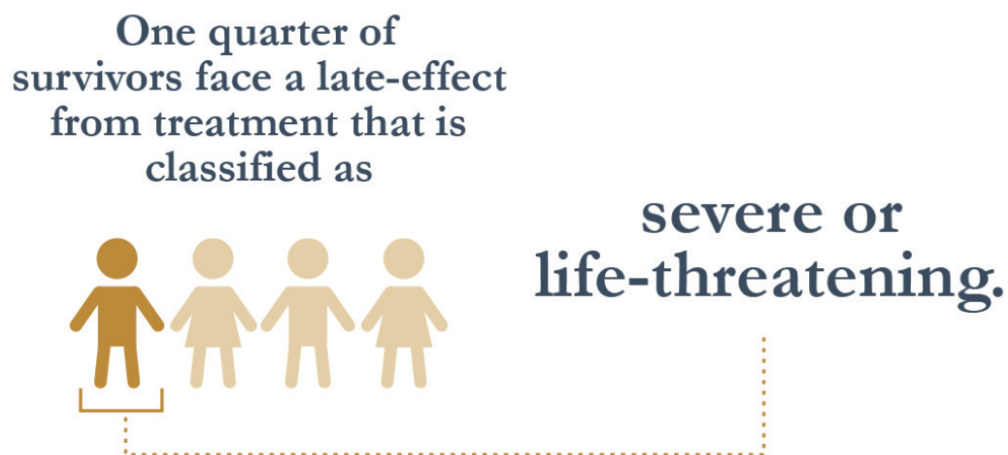
Childhood cancer is a life-threatening disease. Children who undergo treatment are exposed to chemotherapy and possibly radiation depending on the type of cancer. The long-term effects such as attention deficits, cognitive delays, and processing speed may be severe and affect their academic performance in school. It may also affect their physical and psychological health. Cancer treatment causes children to miss out on social activities with their friends and family. Effects of the cancer treatment can be even delayed years after treatment.



Source: American Childhood Cancer Organization (n.d.)

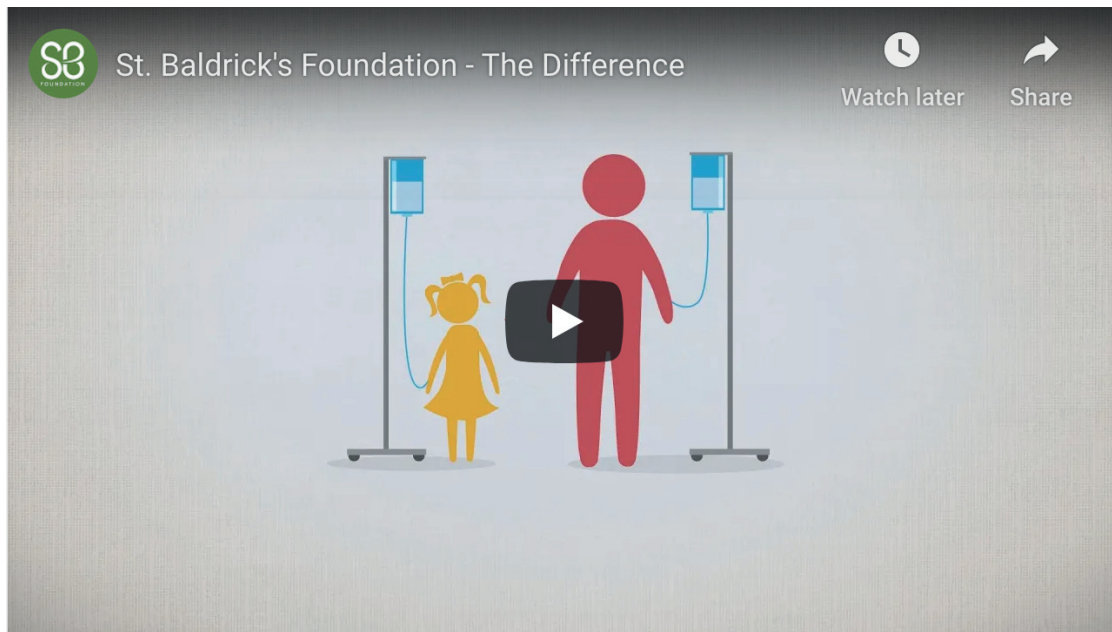
Identification of the difficulties that survivors experience is important to gain insight into the needs of childhood cancer survivors. These needs vary as each survivor has different long-term effects and levels of severity. As more children survive cancer, schools are going to have to prepare to accommodate this special population.

As survival rates increase for childhood cancer the long-term effects of cancer are becoming more evident. Sleurs et al. (2018) report that school performance declines after a cancer diagnosis. Neurotoxicity of the chemotherapy causes neurocognitive problems in childhood cancer survivors. ALL survivors are more likely to require special education services and are evaluated lower on academic abilities. These deficits may not all appear until the survivor is five years off treatment (Moore et al., 2013). Donnan et al. (2015) report that students may have trouble in school with motor skills, mobility, hearing, and vision. Other areas where survivors struggle is concentration, memory, writing, and confidence. The high absenteeism in cancer survivors also causes them to miss out on sports and social activities (Wakefield et al., 2010).



Source: American Childhood Cancer Organization (n.d.)

In this module we will discuss the different types of childhood cancers and the type of treatments for these cancers.



Source: *Why Childhood Cancers are Different*. (St. Baldrick's Foundation, 2015 September 2, <https://youtu.be/H26LATUEzgs>)

Transcript of Video (St. Baldrick's Foundation, 2015 September 2)

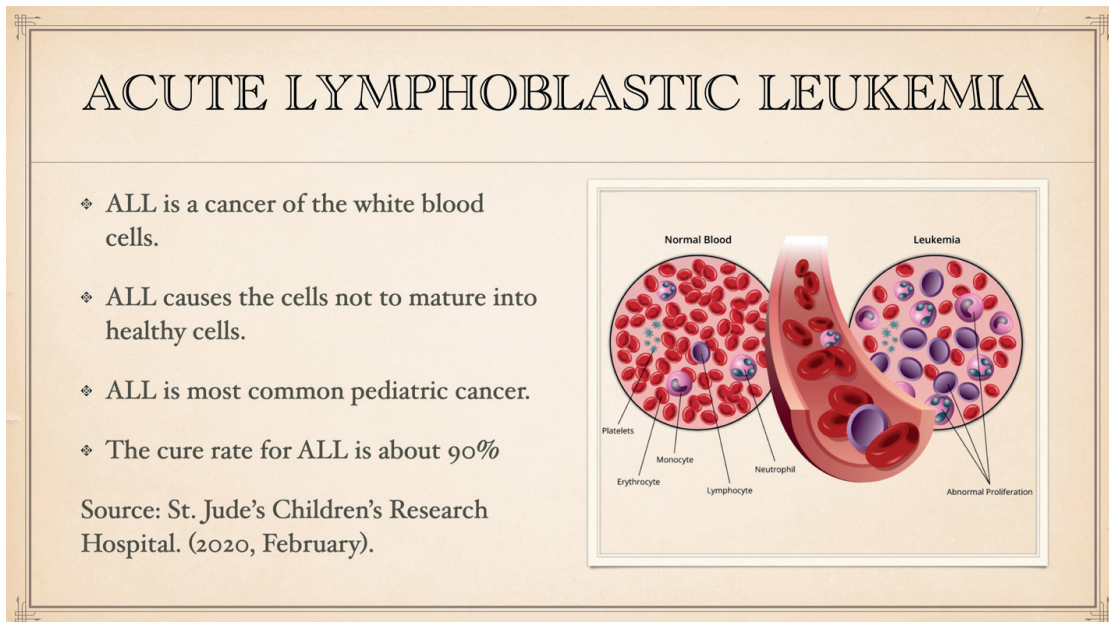
Kids are treated differently in everyday life. A child's education adjusts to their abilities. They have special laws protecting their safety, even restaurants treat them to their own menu but when children have cancer a different treatment is crucial. The kinds of cancers they get vary greatly from adult forms and the therapies they need are just as unique even when a child survives cancer their life is still forever changed. The medications that care them are often a toxic assault causing damage to their developing bodies that affects the rest of their years. Survivors are seven times more likely than the regular population to die from heart problems, 15 times more likely to die from new cancers later in life and her twice as likely to die from other countless health problems. At the St. Baldrick's Foundation, we believe a different outcome is possible- a healthier longer life beyond the disease by investing in the world's best research we can treat childhood cancers with kid-friendly cures. Give today for a better tomorrow.



## Types of Major Childhood Cancers

### Leukemias- Acute Myeloid Leukemia (AML), Acute Lymphoblastic Leukemia (ALL)

ALL is the most common childhood cancer. These cancers make up for approximately 80% of childhood cancers (Hoffman, 2013). ALL is a cancer of the blood and it is a prevalent form of childhood cancer. It affects the white blood cells, which places the child at risk for devastating infections. The cancer cells may also affect platelets and red blood cells as the “blasts” create junk in the bloodstream (Armstrong et al., 1999).



Acute Myeloid Leukemia (AML) also affects the blood and bone marrow. AML specifically affects the granulocytes which is a type of white blood cells. These are a different type of white blood cells than what ALL affects. AML is less common than ALL (Hoffman, 2013).





Source: Cincinnati Children's (2017, June 27, <https://youtu.be/UXfANnRyStM>)

Transcript for *What is Leukemia?* Cincinnati Children's (2017 June 27)

“What is Leukemia? Our bodies are made of millions of tiny, little things called cells. That's more than the tiny little grains of sand of a small beach. Actually cells are smaller than grains of sand. A million cells can be the size of one grain of sand. Not only are cells very tiny but we have different types of cells in our bodies. We have cells in our hair, in our body, and in our blood. Blood cells are made through a special process inside your bones by soft, spongy material called bone marrow. Bone marrow is like a factory that builds cells. These cells come out as red blood cells, white blood cells, or platelets. They each have a different job to do. Red blood cells give energy to your body. White blood cells fight off disease. Platelets help your body stop bleeding if you get a cut. Some cells don't grow up as expected. These cells are known as cancer cells. And they don't behave like normal cells.

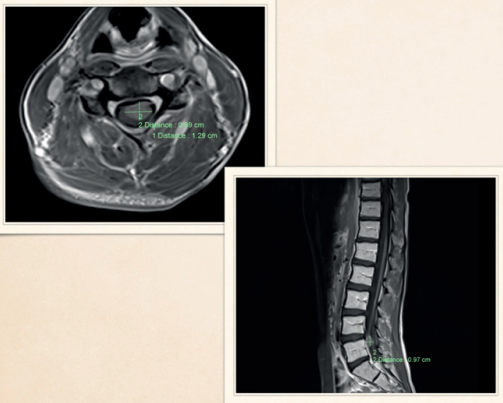
Leukemia and white blood cells, the ones that fight off infection, are the ones who don't grow and do their jobs properly. When they multiply and divide, they do not know when to stop or when to die off. And they will destroy good cells close to them. To help you get better, doctors will give you medicine called chemotherapy to get rid of all the unhealthy cells. You can get this medicine through something called a central line or as a pill. The medicine is very strong and can destroy some healthy cells too. Which can make you feel tired and weak. You can also

lose some of your hair. This is ok though because your bone marrow can always make more healthy cells and your hair will grow back. The important thing is making sure all the unhealthy cells are completely gone so that you can feel better again. Now that you know the basics about leukemia there are few important things to remember. Your cancer is not contagious. And its not your fault. Many other kids have leukemia too, even other doctors and nurses helping you get better may have had leukemia. Cincinnati Children's is here to answer your questions so don't be afraid to ask."

### Brain and Spinal Cord Tumors

Brain and spinal cord tumors can be a form of childhood cancer. The most common type of pediatric tumors occurs in the brain. Tumors are abnormal cells that accumulate together and do not follow a normal cell life cycle. The location of these tumors makes it difficult to treat them. Even non-malignant tumors are considered dangerous because they can be located in critical areas of the brain making removal life-threatening or even impossible. Survivors of this type of pediatric cancers often see the most severe of the late-effects of treatment (Hoffman, 2013).

## BRAIN AND SPINAL CORD CANCER



- ❖ The brain and spinal cord make up the Central Nervous System (CNS).
- ❖ Brain and Spinal Cord tumors can be malignant (cancerous) or non-malignant (non-cancerous). However, both types of tumors may cause death.
- ❖ 2nd most prevalent type of pediatric cancer
- ❖ Leading cause of pediatric cancer deaths.

Source: St. Jude Children's Research Hospital (2018, June).

### Hodgkins Lymphoma and Non-Hodgkins Lymphoma

Lymphomas are cancers of the lymph system. Lymph nodes store the colorless liquid called lymph that can be found in every organ of the body. Lymphocytes are the cells of the lymph system. Hodgkin's and Non-Hodgkin's lymphomas attack different types of cells in lymph system. Hodgkin's lymphoma is more commonly diagnosed in teens (Hoffman, 2013).

## LYMPHOMA

- ❖ Two types- Hodgkin Lymphoma, Non-Hodgkin Lymphoma
- ❖ Lymphomas are cancers of immune system they impact lymph nodes, lymphocytes.
- ❖ Hodgkin Lymphoma is more common in teens than young children.

Source: St. Jude Children's Research Hospital, 2018 , June

The diagram illustrates the lymphatic system in a human figure. Labels include: Cervical nodes, Tonsil, Lymph vessels, Axillary nodes, Thymus, Diaphragm, Spleen, and Inguinal nodes. The source 'together.stjude.org' is noted at the bottom of the diagram.

## Neuroblastoma

Neuroblastoma is a cancer of nervous system. The system that carries instructions from the brain to the rest of the body. Neuroblastoma often takes the form of solid tumors in the abdomen near the spinal cord. This cancer is found predominately in children under the age of five (Hoffman, 2013).

## NEUROBLASTOMA

Tumor Location	Symptoms
Eye	Bulging eye, dark circles ("raccoon eyes"), blindness, Horner syndrome
Neck	Lump or swelling, Horner syndrome
Abdomen	Lump, loss of appetite, vomiting, constipation
Pelvis	Change in toileting behavior; bowel or bladder problems
Spinal	Weakness, paralysis

- ❖ Neuroblastoma grows from immature nerve cells.
- ❖ Neuroblasts forms tumors at the end of the nerve cells.
- ❖ It typically grows in the abdomen.
- ❖ It commonly occurs before a child is five years old. It accounts for 50% of cancer in infants.

Source: St. Jude Children's Research Hospital (2018, June)



## Osteosarcoma

Osteosarcoma are cancers of the bone. They typically appear in the joints of the knee and shoulder. Osteosarcoma can even appear in the bones of the skull. Osteosarcoma is one of the most hard-hitting forms of childhood cancer. Often, a child will have a relapse of osteosarcoma that is even more aggressive than the first. (Hoffman, 2013). Amputation is often the safest treatment of osteosarcoma to remove the bone which is diseased.

# OSTEOSARCOMA

- ❖ Osteosarcoma is a cancer of the bones. It usually forms in the wide ends of large bones.
- ❖ It can form inside the bone (central tumor) or on the bone (surface tumor).
- ❖ It is the third most common pediatric cancer.

Source: St. Jude Children's Research Hospital, 2018)

Locations:  
■ Most common  
■ Less common

Osteosarcoma

together.stjude.org

## OTHER CHILDHOOD CANCER TYPES

There are many other types of childhood cancers- Wilms tumor, rhabdomyosarcoma, retinoblastoma, Ewing sarcoma, soft tissue sarcoma, medulloblastoma, and astrocytoma. Many childhood cancer organizations provide information and treatment details about these rarer childhood cancers. If your student has one of these then please check the following resources for more information about these types of cancers.



### OTHER CHILDHOOD CANCER RESOURCES

- ❖ St. Jude Children's Research Hospital
  - ❖ <https://together.stjude.org/en-us/>
- ❖ American Childhood Cancer Organization
  - ❖ <https://www.acco.org/types-of-childhood-cancer/>
- ❖ St. Baldrick's Foundation
  - ❖ <https://www.stbaldricks.org/about-childhood-cancer>
- ❖ Children's Oncology Group
  - ❖ <https://www.childrensoncologygroup.org/index.php/patients-and-families>

## **Treatment Types for Childhood Cancer**

The main treatment types for childhood cancer include surgery, chemotherapy, radiation, stem cell therapies, immunotherapy, and targeted therapies. Directed treatment types are surgery and radiation. Chemotherapy, stem cell transplantation, and directed treatments affect all the cells of the body (Hoffman, 2013). In recent years, oncologists have worked to make treatment protocols less toxic to the survivors (Rey-Casserly & Meadows, 2008).

Childhood cancers often follow treatment protocols which is very different from adult cancers. This is because childhood cancers are rare. Doctors must work together to find cure. A clinical trial protocol may be testing a new drug or technique against the childhood cancer. It is estimated that 60% of childhood cancer patients are on a clinical trial (Curesearch, 2020). Clinical trials are managed by pediatric oncologists at larger pediatric hospitals.

### **Chemotherapy**

Chemotherapy battles cancer by using drugs to stop the growth or kill cancer cells. Normal cells divide and replicate in a pattern. Cancer cells divide and grow in unpredictable patterns. Cancer cells can fill up the blood with junk cells like in leukemia or cancer cells can form tumors. Chemotherapy stops the cancer cells from being able to grow and divide. Unfortunately, chemotherapy also causes normal cells to die. This causes hair loss, mouth sores, and suppresses the immune system (Curesearch, 2020).



Source: (Curesearch, 2015, December, 23, <https://www.youtube.be/2ZABO2xJ9JA>)

Transcript for *Children's Cancer and Chemotherapy* (Curesearch, 2015, December, 23)

Cancer is a collection of diseases where cells grow abnormally. They don't respond to the usual signals to limit growth but instead grow without those controls invading locally and spreading to other parts of the body. Cancer represents a problem with genetic function. Some gene or genes get changed somehow, either they are deleted or removed from the genetic composition of a cell or they are altered or mutated in some way. There are many types of cancer treatments. We tend to lump them together as chemotherapy. Chemotherapy is a combination of medications that we can give the patient than can be used to treat the cancer within the patient. There are four different types of chemotherapy that we can give to cancer patients. We can give it into the muscle as an injection. We could give into the spine, which is called intrathecal chemotherapy. We can give it as a pill, or we can give into the vein called intravenous chemotherapy. An infusion is when we give chemotherapy into the vein and we like to give chemotherapy into what's called a mediport or any type of central line. Some side effects of chemotherapy are nausea, vomiting, you see loss of hair. Some patients just become generally fatigued and lose their overall sense of just energy. Patients just have loss of appetite or you can see diarrhea or constipation as well. So, we're always looking for new ways to target diseases. Specifically, the idea of



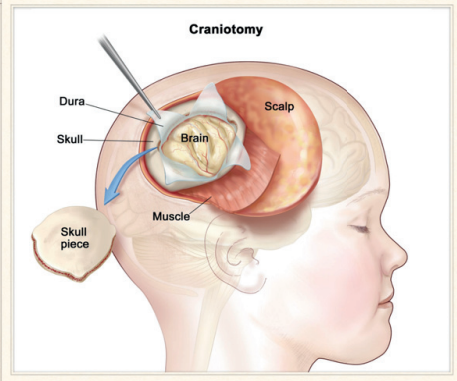
targeted therapy is that we can avoid a lot of the general side effects of chemotherapy that tend to cause damage to many different kinds of cells and the targeted therapy can home in on a particular abnormal cell within the body and kill it. In order to develop effective therapies for cancer, it requires research to determine whether any given drug will be safe enough at killing the bad cells but, not the good cells and actually work. A clinical trials research is performed on human subjects to determine if new therapy is safe and effective. Clinical trials are vital to the pediatric population because we need to come up with new novel agents that are less toxic but have the same efficacy. And it's not uncommon for pediatric oncology patients to enroll in a clinical trial. It's roughly estimated 60% participate.

## Surgery

### TYPES OF SURGERY

- ❖ Biopsy- a tiny sample of the tumor
- ❖ Debulking- removing part of the tumor to make it smaller
- ❖ Tumor removal- whole tumor removed
- ❖ Limb Salvage- removal of tumor and bone replaced with a donor bone
- ❖ Amputation- removal of bone and limb
- ❖ Enucleation- removal of the eye

Source: Hoffman, 2013



Source: National Cancer Institute, 2020

There are several ways surgery is used to battle cancer. Surgery can be used in the diagnosis of the pediatric cancer. Surgery can be used to remove part of the tumor or the whole tumor. Supportive care such as placement of direct line (port) for chemotherapy or the insertion of a feeding tube for nutrition (St. Jude Children's Research Hospital, 2018).

## Radiation

Radiation is used for a variety of cancer types. Radiation works by using a x-ray beam to destroy the DNA inside of a cancer cell. Radiation can be used in combination with chemotherapy and surgery (St. Jude Children's Research Hospital, 2020, July). The treatment plan is determined by the type of pediatric cancer.

### Radiation Therapy for Children with Cancer



Source: Curesearch (2013, December, 7, <https://youtu.be/SW5pxxP13t8>)

Transcript for Radiation Therapy for Children with Cancer  
(Curesearch, 2013, December, 7)

There are three basic ways we treat cancer. Chemotherapy which works all over the body cancer cells that may spread throughout the body. Surgery which tries to cut out remove tumors with a scalpel and then radiation therapies it's usually for localized areas where surgery might not be an ideal option or the person can't tolerate surgery. You would use something like radiation treatment. If we can use before or after surgery or instead of surgery. The most common reason we'd use it before surgery is if the tumor is located against some critical structure and the surgeon can't remove it cleanly. Giving anywhere from a week to five weeks of daily radiation treatment can shrink the tumor enough so that the surgeon can remove it cleanly. Sometimes we do it after surgery because when the

surgeon removed it and they reviewed everything under the microscope they realize there was a high likelihood of some tumor cells being left behind and you'll add radiation in addition to surgery to take care of those tumor cells in that local area what the surgery is not to get rid of them.

Oren is a young patient with early-stage Hodgkin's disease and now she's here to get ready to start radiation therapy simulation is like a flight simulator. We try to put the patient in the exact same position as they will get 24 daily treatment, we use typically use a high resolution cat scan pretty the same position and with that high resolution cat scan we try to design as effective and safe radiation as possible. We go behind the scenes in front of the computer where dosimetrist and physicists help us plan the radiation.

They figure out how to best deliver the radiation as safely as possible and then once that is done, we send a patient to the machine where the therapist physically put the patient on the table get some cat-scans get some x-rays to make sure we're lining up correctly. We turn the radiation beam on at the time the treatment and ranged anywhere from a week of treatment or five treatments to six or seven weeks I would say an average it's somewhere four to five weeks it's an outpatient therapy.

Ninety-eight percent of our kids walk in and out for their treatment. Many of them the vast majority continue with school and we want them to continue you know normal activities they can participate in sports it's not a type of treatment at least radiation because it's localized to one general small area it's not a type of treatment that knocks the kid out and they can't do the things they normally do.

During the treatment the parent can't be in the room, but neither can we because this radiation in the room once you start treating the patient. But the patient is on a TV monitor and there's complete audio connection so sometimes we'll be talking to the patient while they're going say the beam is on you're doing great you know words of encouragement the actual time the beam is on and the patient is in the room is minutes.

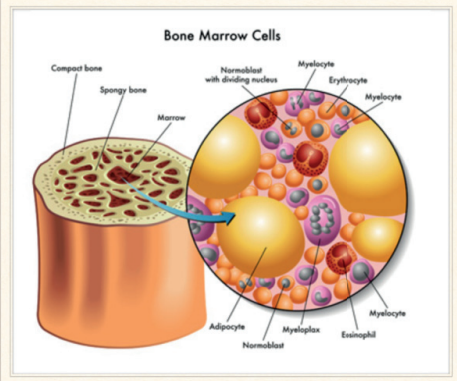
### Stem Cell Therapies

Stem Cell therapies are also known as bone marrow transplants. Bone marrow is soft spongy material inside of the bone. Bone marrow makes the blood of the body. BMTs replace the bone marrow with donor cells. The donor cells replace the diseased ones. BMT are used in severe cases where the patient is not responding to chemotherapy (Curesearch, 2020).

## STEM CELL THERAPIES

- ❖ Stem Cell Therapies commonly called Bone Marrow Transplant
- ❖ Allogenic- BMTs with donor cells from another person. This is for Leukemias and Lymphomas
- ❖ Autologous- BMTs with cells from the cancer patient that are frozen and then used at a later time. This is for neuroblastoma, Hodgkin disease, or solid tumors.

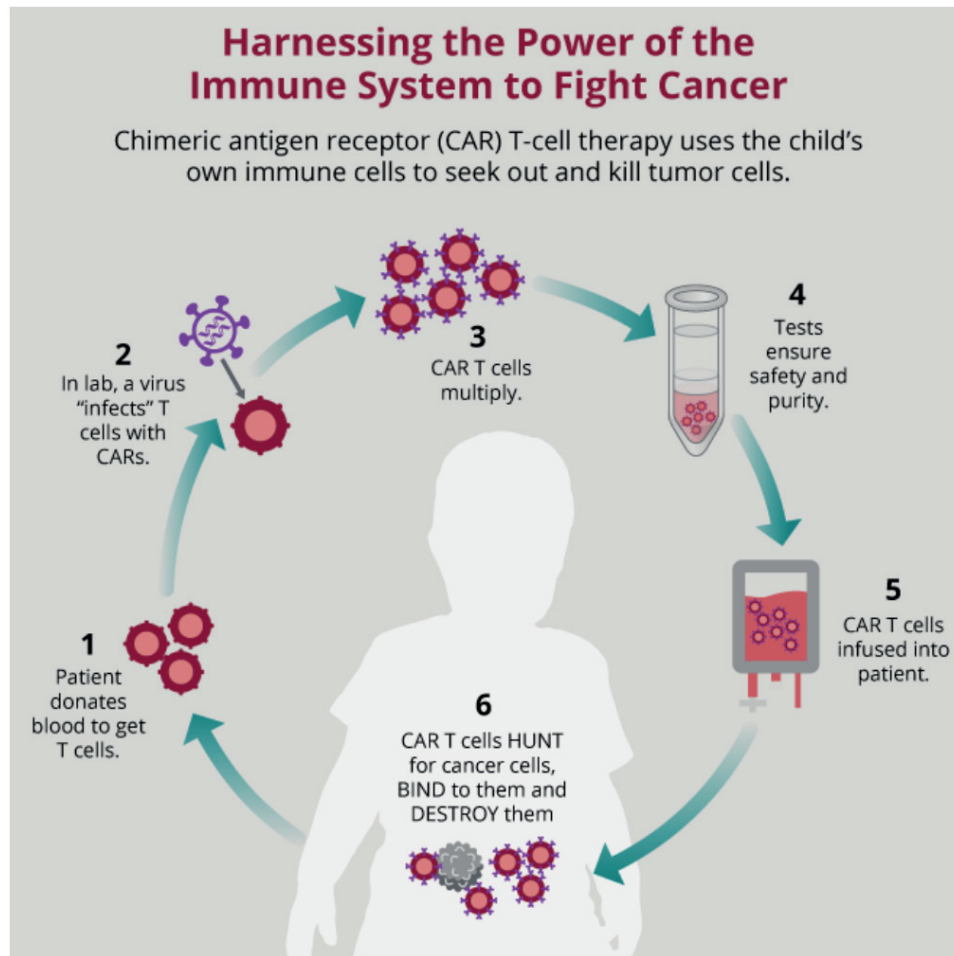
Source: Curesearch, 2020



The diagram illustrates the components of bone marrow. On the left, a cross-section of a bone shows the outer compact bone and the inner spongy bone containing the marrow. A blue arrow points from the marrow to a magnified circular view on the right. This magnified view shows various types of cells: a large yellow cell with a prominent nucleus labeled 'Normoblast with dividing nucleus', several red cells labeled 'Erythrocyte', smaller purple cells labeled 'Myelocyte', and other cells labeled 'Adipocyte', 'Normoblast', 'Myeloblast', and 'Eosinophil'.

### Immunotherapy

Immunotherapy uses the body's own immune system to fight the cancer. There are two types of immunotherapy cells. T Cell is adaptive therapies where the T Cell recognize the malignant cells and then attack them. T Cells can be programmed to find a specific type of cell or antigen. The other type of immunotherapy is natural killer cells. These cells just recognize foreign cells in the body and attack them (St. Jude Children's Hospital, 2018 June).



The diagram illustrates the power of the CAR T cells which are used to fight aggressive types of leukemia (St. Jude Children's Hospital, 2018 June).

### Targeted Therapies

Targeted therapies target specific cells to destroy or disrupt their replication process. This is a new type of therapy and a great interest to researchers. Targeted therapies can be used in conjunction with other cancer therapies. The targeted therapies can often increase the ability of these other therapies in their efficacy against cancer. Researchers also hope with targeted therapies they can reduce the number of side effects survivors experience due to their cancer treatment (Curesearch, 2020).



## Quiz

1. Childhood cancers are different than adult cancers.
  - a. True
  - b. False
2. What is the most common childhood cancer?
  - a. Acute Lymphoblastic Leukemia (ALL)
  - b. Acute Myeloid Leukemia (AML)
  - c. Osteosarcoma
  - d. Neuroblastoma
3. Leukemias target what type of blood cells and cause them to not grow properly?
  - a. Platelets
  - b. Red Blood Cells
  - c. White Blood Cells
4. Brain tumors may be malignant (cancerous) or non-malignant (non-cancerous).
  - a. True
  - b. False
5. Osteosarcomas cause tumors in which part of the body?
  - a. Nerve Cells
  - b. Bone Marrow
  - c. Brain
  - d. Bones, particularly the joints
6. Treatment protocols are standardized treatment for childhood cancers.  
\_\_\_\_\_ are considered experimental treatment for childhood cancer.
  - a. Clinical Trials
  - b. Chemotherapy
  - c. Immunotherapy

- d. Radiation
- 7. What type of therapy uses x-ray beams to destroy the DNA of cancer cells?
  - a. Chemotherapy
  - b. Immunotherapy
  - c. Radiation
  - d. Stem Cell Therapy
- 8. Therapy that uses the patient's own immune system to fight cancer is called \_\_\_\_\_.
  - a. Chemotherapy
  - b. Immunotherapy
  - c. Radiation
  - d. Stem Cell Therapy
- 9. Stem Cell therapy removes the diseased cells and replaces them with healthy cells. What is the name of these cells?
  - a. White Blood
  - b. Red Blood
  - c. Platelets
  - d. Bone Marrow
- 10. Chemotherapy cannot be targeted to only cancer cells and often also kills the healthy cells. What is the most common side effects of this type of treatment?
  - a. Hair Loss
  - b. Mouth Sores
  - c. Immune System Repression
  - d. All of the Above

Answer Key-

1. A, 2. A, 3. C, 4. A, 5. D, 6. A, 7. C, 8. B, 9.D, 10. D

## Module 2- Cognitive Late Effects of Childhood Cancer

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### **COGNITIVE LATE EFFECTS OF CHILDHOOD CANCER**



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### **Cancer Treatment Effects on the Brain**

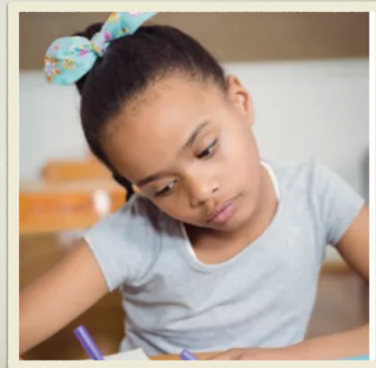
#### **During Treatment- Chemobrain**

Cancer patients during treatment have a decline in mental processes during treatment. This is called chemobrain. This occurrence happens because patients are given drugs that affect the mental function such chemotherapy drugs which cross the blood brain barrier and cortisteroids. Cancer patients with chemobrain complain of memory, attention, and thinking problems. These problems can be short-term or can be long-term (St. Jude Children's Research Hospital, 2019 April).



## Chemobrain Symptoms

- \* Slow Speech
- \* Confusion
- \* Cannot find the word
- \* Change in performance at school
- \* Poor Memory
- \* Short Attention Span
- \* (St. Jude's Children's Research Hospital, 2019)

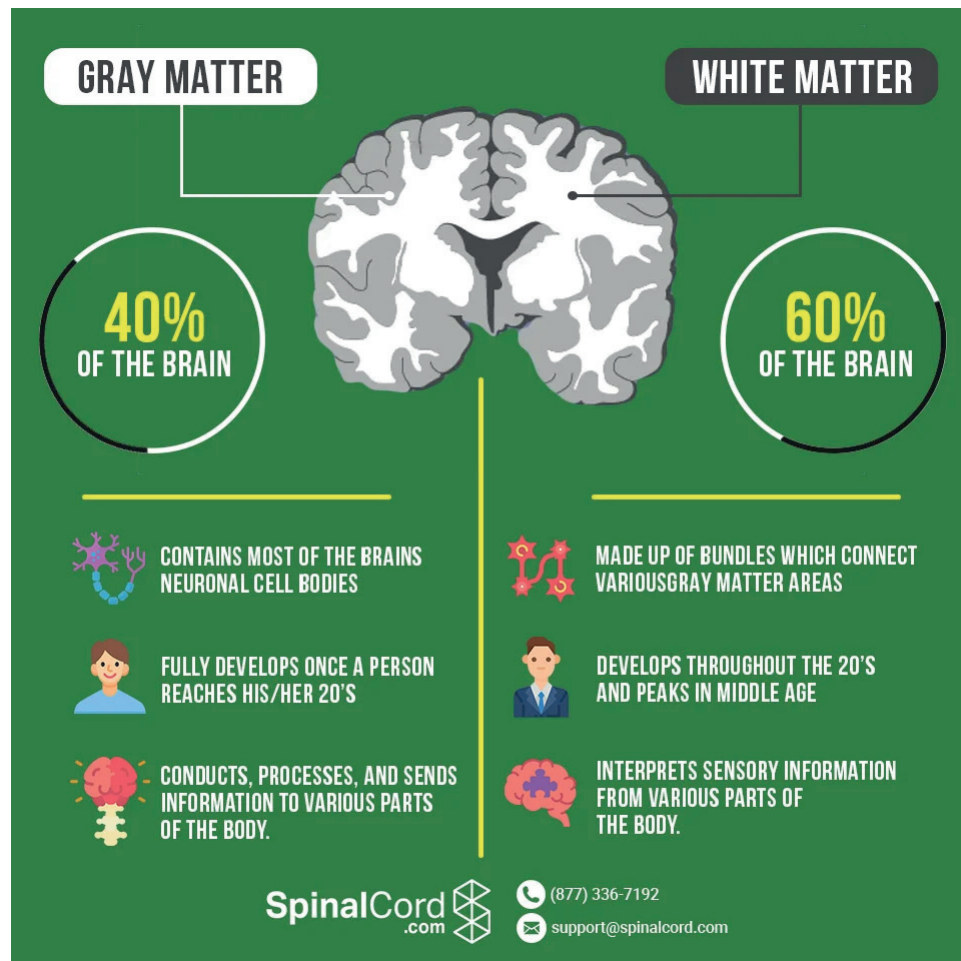


When you see signs of chemobrain be supportive. These difficulties often frustrate the student more than you. Changes in behavior and decline in quality of work should be noted but be understanding. The student is dealing with a health crisis in a potential life and death situation. School work is often one of the last things the student and family are thinking about. As educators, we should be aware of the situation and not add to the stress. However, if educators observe severe and dramatic changes in the student please make the parents and medical team aware.

### **Cancer Treatment Effects on the Brain**

Chemotherapy and intercranial radiation forever alter the developing brains of childhood cancer patients. The white matter in the brain is the most sensitive to the cancer treatment (Moleski, 2000). In fact, cancer survivors show lower density in white matter when compared to their same age peers. This could be connected to higher levels of toxicity in these parts of the white matter. Cognitive deficits have been linked with intrathecal methotrexate changes in the white mater of the brain which in turn causes the neurocognitive deficits (Wen et al., 2018). White matter is made of glial cells. Glial cells wrap around the neurons in the brain, chemotherapy

disrupts this process. White matter grows into the third decade of life. Chemotherapy and radiation are known to slow the growth of white matter and injure the existing white matter.



Source: (Villanes, Z., n.d.)

Some long-term effects on the brain are accrued overtime (Armstrong, Blumberg, & Toledano, 1999). This is because growth in the brain is interrupted by the cancer treatments. Chemotherapy that targets the central nervous system causes the brain to not develop properly. The treatments that have found to be linked with the most significant damage are methotrexate and cranial radiation (Armstrong, Blumberg, & Toledano, 1999). Brain shrinkage, blood vessel damage, and enlarged

ventricles are also known to be caused by chemotherapy and radiation treatment (Hoffman, 2013).



Source: (Nationwide Children's Hospital, 2017, Sept. 29,  
<https://youtu.be/aQsabHFJmPs>)

#### Transcript-

“Watching your kid be sick and in the hospital on going through chemo you can't even begin to imagine yourself in that position until you're there. When neurosurgery came in they told us that he had a large mass, they said that it was about a quarter of his head size and I feel like it was within minutes oncology came in Dr. Finley came in and he was like it's absolutely cancer.

Nathan not only presented with this tumor in his head this tumor had already spread throughout other parts of the brain and down the spinal cord that's very difficult. And we're talking about a child who was an infant at that time brain cancer is now the most common cause of death due to disease and kids.

One of the challenges it requires often radiation therapy, lots of different chemotherapy and so there's a lot of side effects. Dr. Finley is world renowned (doctor) people come from all around the world to

seek out the advice and opinion and care by our brain tumor team, our neural-oncology team.

It was kind of scary because we weren't really sure how his brain was going to react to having such a large mass removed. He tried to kind of prepare us, but I don't think you can really fully be prepared for something like that.

We decided to actually treat Nathan a little more like the current head stock for study. When I tell the families just by giving a year's worth of therapy at six days and then not give the radiation therapy is sort of the most devastating sledgehammer the side effects for a young and developing brain. Are very profound the question is can we substitute for it more intensive chemotherapy that doesn't damage the brain but can still heal.

Having a doctor like Dr. Finley that can do this whole protocol without using any radiation and still have a cure for us. I mean it was everything. When you mentioned we went global. We are now in a pretty novel situation here at Nationwide Children's Hospital with our Institute of Genomic Medicine. We're going to do a whole genome sequencing on the blood and the tumor of those children, address the question of who are the children with these tumors. Would like you to do well with one type of therapy versus another? You hear the term personalized medicine and this is an example of that, so my hope is that if Nathan is going to get another treatment we'll pick it up and we'll still be able to cure him.

I don't think we could have had a better oncologist for him you know from day one what it was and what treatment plan. We were going to have to follow it for anyone having their child second in the hospital is scary but ultimately through research and all the work that they're doing we want to find a cure” (Nationwide Children's Hospital, 2017, Sept. 29).

### **Age at Treatment**

A younger age at treatment is often found to be a serious risk factor for cognitive late effects. Children who are under the age of 8 experience immediate decline in general intelligence. Children over the age of 8 do not show a decline until approximately two years later. The development of brain at a young age is the likely reason for the immediate decline of intelligence (Hoffman, 2013).

### **Childhood Cancer VS. Traumatic Brain Injury**

It is interesting to note that long-term effects on the brain of pediatric cancer mimic the same neurocognitive problems of those with a traumatic brain injury. Cancer survivors do not lose prior knowledge but do lose the ability to learn as they did before treatment. This is caused by the disruptions of growth and development in the white matter and other crucial areas of the during treatment (Moleski, 2000).



## Information Processing and Working Memory

### Information Processing Effects

Childhood cancer survivors may find they have information processing deficits. Several research studies show that long-term survivors have declines in information processing (Kanellopoulos et al., 2015, Schatz, et al., 2000, Butler & Haser, 2006). These deficits can impact math and reading skills. Focus encode and focus execute are also impaired by cancer treatments. Oftentimes, childhood cancer patients have difficulty choosing the correct strategy to solve the problem (Butler & Haser, 2006). Cognitive processing tasks can prove difficult for pediatric cancer survivors. These deficits in processing speed and attention cause ALL survivors to struggle with success in school (Mennes et. al, 2004).



Source: (Understood, 2017, May 25, [https://youtu.be/HFa33hpMU\\_I](https://youtu.be/HFa33hpMU_I))

Transcript- "Processing speed refers to how long it takes for someone to get something done. Slow processing speed means that it takes a child longer to get the same things done that their peers may not

have any trouble getting done in a certain period of time. Processing speed can take different forms. It can be verbal, it can be visual, or it can be motor. A lot of the things that kids have to do in school rely on more than just one of those areas. So, a visual motor processing speed task might be how long it takes them to copy the notes from the board or copy their assignments down in their notebook.

Another kind of processing speed task might be how quickly they can do basic math facts in a minute. Every kind of task in school requires something to be done in a given period of time. Kids with learning and attention issues struggle with slow processing speed more than kids without learning and attention issues, and it can exacerbate some of the differences that they already have. So, a child with dyslexia who also has slow processing speed may have even more difficulty with reading fluency, meaning reading quickly or fluently.

Kids with ADHD who have slower processing speed may have even more trouble kind of paying attention and getting something done in a given period of time. Parents may feel like their child who has slow processing speed just is lazy, or not trying hard enough, and they need to remember that kids with slower processing speed are actually trying harder than kids without.

So, it can be frustrating for a parent of a child with slow processing speed. If they think though their child may have slower processing, one of the best things they can do is to get more information about that. They need to be able to quantify how long it is taking my child, and is there one issue, one of these areas that's more influential than others. Are they fast in the motor realm, but they have trouble processing in the verbal realm? Meaning, are they having trouble kind of hearing what someone is saying and then generating a response? The best thing a parent can do if they're questioning whether their child has slow processing speed is to get an evaluation, either done through their school system or through a private evaluator. And the evaluation should include a measure of processing speed, a measure of how quickly it takes for a child to get things done" (Understood, 2017, May 25).

## Information Processing

- \* Information Processing- how quickly your brain processes information
- \* Implications for Cancer Survivors- If your brain can not process information quickly or at a normal rate, it effects how quickly a student can recall information, how quickly they can answer questions, how quickly they can self-regulate, and how they maintain their attention.
- \* Information processing may not be an executive function but it does affect how well a child uses their executive functioning.
- \* (Rosen, n.d.)

### Working Memory Effects

Working memory is the memory available to remember a task and then transfer it to the long-term memory. Working memory in cancer survivors is found to decline as the brain develops through adolescence into early adulthood. These effects may not be apparent until years off-treatment. Declines in working memory point to early aging in the brain caused by chemotherapy (Kanellopoulos et al., 2016).

Long-term survivors have 23% more likely change to be enrolled in special education if they had intrathecal methotrexate and/ or cranial radiation during treatment (Wengenroth, 2015). Problems in concentration, working speed, and memory cause some cancer survivors to have decline in IQ and academic achievement over time (Mulhern et. al, 2004). There is little doubt that many of the treatments used to treat childhood cancers cause damage to the developing brains.



But, parents are left with little choices a treatment that may cause lasting damage or a disease that will ultimately cause death.



Source: (Centers for Disease Control and Prevention, 2018, Aug 7,

<https://youtu.be2ZBO2xJ9JA>).

Transcript- "Hello. I'm Dr. Lynne Padgett, and I'm a clinical health psychologist. I'm here today with Amelia Ballard. She's a childhood cancer survivor. Amelia and I are going to talk about some of the unintended side effects of cancer treatments. I'm sure you've heard people talk about chemo brain in referring to a group of cognitive impairments such as problems with learning, language, concentration, or memory during and after cancer treatment. These problems can profoundly affect survivors' daily functioning. So, Amelia, how did chemo brain affect your experience in school and in work?

Yes, so as you mentioned I am a pediatric cancer survivor. I was first diagnosed with leukemia when I was 17 months old and then relapsed when I was three years old. So, throughout my treatment process I received a lot of chemotherapy. As well as cranial and total body radiation. So, I think that chemo brain has definitely been one of

the things that I've had to deal with in my life. So, I would say during treatment it's hard to remember because I was so young especially in the hospital setting, but I remember outside of the hospital when I would be at home as a young child my mom would ask me to do basic chores, basic tasks, and that would take a lot of time. I did have cognitive testing throughout the chemo and radiation. I remember doctors would come in and ask me questions based on developmental milestones to make sure I was progressing and not deteriorating or to see what we needed to do to maintain my functioning. But other than that, I remember in my last battery test was when I was 15 years old and I have not had one since. So, I might be overdue for one of those. I need to ask my doctor about that.

And then you asked about how it affects my work and kind of education. Yeah. So, from the age of like 10 when I was in middle school and high school, I always had to take my test outside of the classroom. We kind of learned this the hard way when in the classroom I would get very easily distracted by any noises, any sounds. I would get very bad testing anxiety when my classmates were finishing way before me, they were turning in their test and so we found out that I would be able to take my test outside the classroom and this was very beneficial. I had the resources I needed, the time that I needed, and this continued through my high school and I think this really paid off with my academics.

Wow. That is a really compelling story. So, were there times where you found maybe when you were under stress or multitasking, that your symptoms felt worse? Definitely. I feel like when I am giving multiple tasks at hand or put under any pressure a lot of times this sounds crazy, but my mind just blanks. I feel like I definitely have a harder time with memory and concentration. Especially during multitasking and specific tests.

And I have a question for you, Dr. Padget. Okay. I'd like to ask what can patients do during and after treatment to help us cope with these symptoms? Great, well I'm glad that you asked. A lot of patients suffer chemo brain during treatment. And but then they are sometimes surprised when it continues after treatment. Sometimes, like you have experienced for years, so about 17 to 75%-- we have these large estimates of patients suffer some kind of cognitive symptoms. And one thing we want to encourage patients to do is tell their providers and identify these symptoms. If they are given an opportunity to and one of the ways they can do that is through what we call psychosocial distress screening. This is the way that patients can report psychological symptoms as well as symptoms associated with memory and attention to their providers. And it's important that they do that because there are

some things that we can do to help. One of the things we ask providers to do is to do this screening to elicit these symptoms from their patients to ask about them and then to ensure or see if they are continuing after treatment or after maybe they expected the symptoms to resolve. So, as we encourage providers to do that, then once they have identified them and how they are impacting the patient's quality of life and work in school, then they are able to take those symptoms and make referrals and those referrals may be in the cancer center or they may be out into the community. They may involve testing like you went through with the neuropsychologist. They may involve working with someone to learn coping skills. Or they may even involve medication to help mitigate those symptoms and to help cancer survivors successfully navigate their daily lives and work and school. Awesome.

It's good to know that there's resources out there. Yes, there are. Doctors and nurses have a real opportunity to reduce the impacts of problems like these and help cancer survivors like me live happy, healthier lives. Conducting recommended distress screening and advising your patients to receive treatment for psychosocial and neurocognitive concerns when they are indicated is an important part of their care. For access to training resources for healthcare providers and information about these topics, visit [cdc.gov/cancer](https://cdc.gov/cancer) and [cdc.gov/chronicdisease](https://cdc.gov/chronicdisease) dot org” (Centers for Disease Control and Prevention, 2018, Aug 7).

## Section 504 Plans and Individual Education Plans



Source: (Understood, 2015, Nov. 23, <https://youtu.be/A9TgDgHfdlY>)

Transcript: “There are many differences [Amanda Morin, Parent Advocate] between an IEP and a 504 plan. The first and most fundamental is they're governed by different laws. An IEP is governed by a special education law. 504 is governed under a civil rights law. And that makes a difference in what kinds of services and how an IEP plan and 504 plan come together.

To qualify for an IEP, you have to have one of 13 specified conditions or disabilities that are written in the law. For example, a specific learning disability, which would be something like dyslexia, would be a condition that a child would qualify for an IEP under. Having one of those 13 identified disabilities isn't enough to make sure your child gets an IEP. Whatever is going on with your child, whatever that disability is, also has to affect his performance in the classroom, and that's really important to know, because sometimes parents think that just having a disability qualifies for an IEP, but you also need to make sure that it's making a difference. It has what's called educational

impact—adverse impact—in the classroom for how your child's learning.

For a 504 plan, a child needs to have a disability that is getting in the way of his learning in the general education classroom. The difference isn't that he needs specialized instruction. It's that he needs some changes to get benefit from his education the same way as other kids in that classroom. And so kids who have ADHD often have 504 plans, and what happens is just changes are made to the environment. And those changes are called accommodations. And those changes are made in the general education classroom and don't require specialized instruction. So for example, a child with ADHD may need extra time to work on a test or to get his homework done.

So some people are concerned that a 504 plan isn't as good as an IEP. And the truth of the matter is that a 504 plan or an IEP can meet your child's needs. It just depends on how well it's put together. A well-written, well-implemented plan that everybody knows what's going to be happening and in place and is working on it can be very helpful for a child who doesn't need that specialized instruction. As long as there's a lot of follow-through and everybody's checking in to make sure it's working well, a 504 plan can be very helpful for kids in the classroom. Key Takeaways: An IEP is governed by a special education law. A 504 plan is governed by a civil rights law. A 504 plan covers kids with disabilities who don't require specialized instruction” (Understood, 2015, Nov. 23).

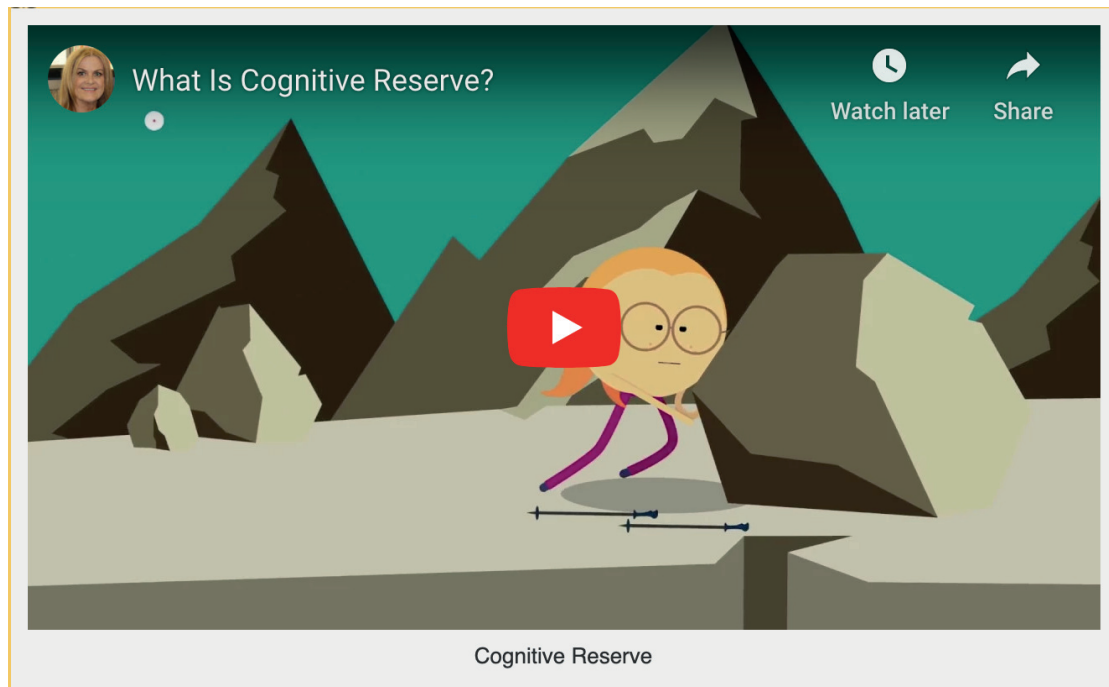
A 504 Plan or an Individual Education Plan may be needed to support the childhood cancer survivor once they return to school. If the survivor is experiencing difficulties that are adversely affecting their education, then it may be time to refer for either a 504 Plan or an IEP. If you believe that the student is experiencing a true learning disability, then it would be time for neuropsychological testing. This type of testing would determine whether the student had a learning disability and required specialized instruction. If the difficulties are not deemed a learning disability but have problems in the general learning environment, then they may need a 504 Plan. The accommodations in the 504 Plan can help the student overcome their difficulties and succeed in the general education environment.

Cancer survivors must meet the qualifications for either program which can be determined through an evaluation process. Cancer survivors may receive accommodations for fatigue, working memory, executive functions, and processing speed. These accommodations can be shortened school days, modified assignments, modified tests, extended time, technology aides, and preferential seating away from distractions (Gorin & McAuliffe, 2008). Accommodations are not the same for every childhood cancer survivor. Accommodations are based upon the child's deficits and help level the playing field so that they can succeed.

## **Cognitive Interventions**

Interventions are important for childhood cancer survivors. The aim of the interventions is to minimize the atrophy of the white and grey matter in the brain by increasing neural pathways in the brain. Neurocognitive interventions need to be multifaceted to address the complex needs of the childhood cancer survivor (Skidmore, 2014). A developmental intervention should be based upon the child's developmental stage. Early childhood interventions should focus on cognitive, language, motor, and sensory development (Rey-Casserly & Meadows, 2008). Middle childhood and adolescence bring more complex thinking. Targeted interventions should focus on higher-order thinking and abstract thought processes. Developing cognitive reserve is also important for these stages of development. Cognitive reserve is developing a toolkit of contextual resources for child to compensate for the impact of a brain injury (Rey-Casserly & Meadows, 2008). These survivors need to know their strengths and weakness and be ready to ask for help assistance when needed. Adult survivors also need to be aware of their capabilities and compensate for when they need help. Adult survivors need to stay connected to long-term clinic so that they may have access to resources for this special population.





Source: (Brenna, S., 2017, Feb. 13, <https://youtu.be/cLqWGVbPYuA>)

Transcript- “What is cognitive reserve? We all know people who are really resilient people who keep on keeping on no matter what life throws us. Well, our brain has the capacity for resilience to provided we give it a helping hand by living a brain healthy lifestyle. For example, when it's need like multiple sclerosis. Each attacks brain and spinal cord tissue causing communication problems within the central nervous system. It can lead to physical visual cognitive impairments. We know that some people with multiple sclerosis can tolerate more disease pathology than others while still retaining cognitive function.

Scientists believe that they're resilient in the face of disease pathology is linked to certain life exposure. Here's how they think it works. The brain has an inbuilt but finite resort called neurological reserve. This reserve allows the brain to reclaim function by reorganizing itself to compensate for brain atrophy and lesions. It reboots communication pathways to avoid damaged areas and adapt undamaged areas to take on functions of areas affected by disease.

Katrine is pretty fantastic but unfortunately it just can't keep pace with sustained activity. Eventually neurological reserve is exhausted from the cognitive deficit. But that's not the end of the story.

Neurological reserve has two components brain reserve which refers to the size of the brain. And cognitive reserve which is the ability to actively compensate to make more effective and efficient use of brain networks. Our lifetime experiences can increase cognitive reserve and help to maintain brain reserves. This gives us a better chance to hang on to cognitive function if life throws of the curveball. And the shape of a disease or injury all other things being equal people with multiple sclerosis with high cognitive reserve need less cover situation than those with less partnership reserve. For the extreme amount of claims ecology so give your brain a helping hand by maximizing your brain health” (Brenna, S., 2017, Feb. 13).

### **Cognitive Remediation Program**

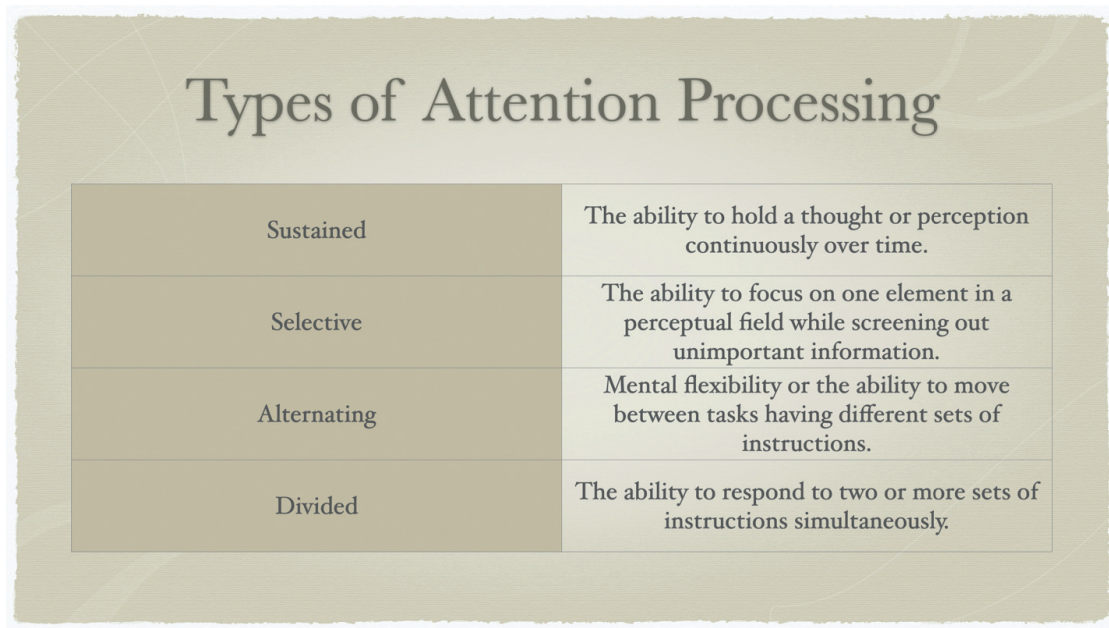
Cognitive remediation is a three-part program which draws from brain injury rehabilitation, special education/educational psychology, and clinical psychology. Butler and Copeland developed the program in 2002. They proposed that the brain is not a static organ but one that reorganize itself after damage has occurred (Butler and Mulhern, 2005). In cognitive remediation the participant does a learning task for 15 minutes and then does a fun activity. Before moving on to a higher level the participant must score 50% the first time or 80% on subsequent attempts. Strategies include warm-up my brain, ask for a hint, and check your work. A key component of the program is having the student learn their strengths and asking for help when they are stuck or need help.





Source: (Brainline, 2011, Apr 28, <http://youtu.be/stJyFeao1m0>)

Transcript- "We're seeing more and more research on the effectiveness of what we call cog rehab or comprehensive group interventions for folks with traumatic brain injury. The accumulating evidence is that that form of intervention is effective and is probably the most effective type of intervention that one can apply. I think we're seeing that some of the interventions that you can use such as using the computer by yourself at home are very effective. I think we're beginning to see that some neuroimaging techniques may be useful in helping to pinpoint an injury where the absence of injury had been observed before, but that's not-- I think we're looking at various biomarkers in terms of blood that may be signs of injury. So those are all diagnostics. Those are all issues that tell us whether or not somebody has been injured. I think, to date, in terms of improving cognitive function, there have been no magic pills that people can take. It's all a matter of re-learning cognitive skills and doing that in very structured ways with a tremendous amount of practice" (Brainline, 2011, Apr 28).

**Exercises to Improve Attention and Speed of Processing**

Sustained	The ability to hold a thought or perception continuously over time.
Selective	The ability to focus on one element in a perceptual field while screening out unimportant information.
Alternating	Mental flexibility or the ability to move between tasks having different sets of instructions.
Divided	The ability to respond to two or more sets of instructions simultaneously.

Attention Process Training (APT) trains the brain in cognitive flexibility. APT identifies four thought processes sustained, selective, alternating, and divided. APT has been around since the 1980's and currently now is on its third version. APT works not only on attention but on working memory. They train the individual to mentally juggle information. There are many different types of activities for the four types of attention. Tasks begin on an easy level and progress with the individual once 80% competence is achieved. Patients of APT are taught self-management especially with sustained attention activities. The patient must learn to stay attentive even when the tasks become stressful or boring (Hoffman, 2013).

## Quiz

1. Chemobrain is accompanied by slow speech, confusion, poor memory, and short attention span.
  - a. True
  - b. False
2. What part of the brain is the most sensitive to the chemotherapy and radiation treatments necessary to fight childhood cancers?
  - a. Corpus Callosum
  - b. Neurons
  - c. Grey Matter
  - d. White Matter
3. What age group is the most at risk for cognitive late effects?
  - a. Children under the age of 8
  - b. Children between 8-12
  - c. Adolescents between 12-16
  - d. Late Adolescents between 16-20
4. Cancer survivors can have problems with information processing. Often this manifests as slow processing speed. What might be an example of a student with slow processing speed?
  - a. Eric takes time with his assignments to make sure they are complete and accurate.
  - b. Jane often comes up with the correct answers, but it takes time for Jane to process the question and formulate the answer.
  - c. Iris often forgets what the question is because she has not been paying attention.
  - d. Peter struggles to not blurt out answers before he is called upon.
5. For a student to qualify for an Individualized Education Plan (IEP) they must meet what criteria?

- a. Be diagnosed with cancer
  - b. They must be failing all classes
  - c. Fit within one of the 13 disabilities covered in the IDEA act
  - d. Need extra help
6. What is the difference between an IEP and 504 Plan?
- a. An IEP is governed by disability laws and a 504 plan is governed by civil rights laws
  - b. For an IEP a student needs specialized instruction but on a 504 Plan the student does not need specialized instruction
  - c. Both A and B
7. Butler and Mulhern developed a three part program called Cognitive Remediation Program based upon the idea that
- a. The brain is static, and intelligence can only be gained through repetition
  - b. The brain can reorganize itself after trauma
  - c. The brain is not static but once trauma has occurred it cannot be repaired
  - d. The brain can learn after trauma but cannot re-learn new skills
8. Which type of attention processing allows mental flexibility to alternate between two tasks?
- a. Sustained
  - b. Selective
  - c. Alternating
  - d. Divided

Answer Key- 1. A, 2. D, 3. A, 4. B, 5. C, 6. C, 7.B, 8.C

## Module 3- Social/Emotional Effects of Childhood Cancer



### **Social/ Emotional Side Effects**

There are many challenges that affect the social and emotional health of the childhood cancer patient. These challenges can negatively impact their quality of life. Children can have difficulty dealing with the physical effects of treatment such as hair loss, weight loss or gain, and pain management. Many children and parents worry about their survival and their future. They worry they will not survive the illness and are scared. Older children miss their friends at school and do not like the separation from normal activities. The cancer treatment often overwhelms the patients and their family. Many students must travel to receive treatment so not only can they

not see their friends at school, but they may be separated from their family (St. Jude Children's Research Hospital, 2018 June).



Source: American Cancer Society (2015 Aug 15, <https://youtu.be/zaiovrRXPI>)

Transcript- "There's such a preoccupation with mortality and there's not much attention paid to what a child's life will be like after treatment. You know you've had these toxins pumped into this child for a year hard thing, bad things, poisons and you've had radiation and you've had surgeries all kinds of procedures. His nervous system has been stressed to the max. We were saying things that were significant after his treatment related to trauma and anxiety. For instance, he wasn't ready for kindergarten. He didn't have a chance to be a normal four-year-old.

Gabe is turning 21 and March and when we started going to the survivor clinic the psychiatric needs were very much dismissed. They really were ill-prepared to hear that and deal with it. You're a pioneer in many respects because there's not a lot of information and no one can really tell you. Well, it was at the surgery, was it the radiation, was it the chemo or is it this just his nature? And the answer probably is it's some of all of the above yet there's not the cookbook recipe for these challenges that you had with treatment of alveolar rhabdomyosarcoma.



There's a procedure there's a protocol you follow it. There is none for post cancer challenges particularly I think psychological challenges.

Just continue to advocate for your child. There may be things that you're not really prepared for and he might not be prepared for and no one has really prepped you that you know there may be some issues. The psychological evaluation as early as possible it's really important to know where your child is going in you have a baseline and then you can look at whatever the changes are from there. It's when the problems already arisen, and you begin evaluations that you don't know where you are when you started. This is an amazing, incredible trauma that these children have been put through and it would be unreasonable to expect a child to manage that emotionally or psychologically on his or her own" (American Cancer Society, 2015 Aug 15).

### **Psychological Late Effects**

Roberts et al. (2014) found that childhood cancer survivors have more psychological problems than the general population. Disorders reported by the participants included anxiety, depression, conduct problems, attention deficit, and social problems. Females report more psychological problems than males. Depression and somatic issues were indicated to be the biggest problem for females.

Psychological late effects permeate all aspects of the survivor's life. Many relive the traumatic events of treatment. They may be triggered by a smell, image, or just a random thought. Survivors have high levels of anxiety and often fear over their health. Any small change in their health and the survivors may worry about what that change means. A simple cold can have them worried that the cancer is back. Survivors may isolate themselves from friends. Pediatric cancer survivors may feel cut off from their peers either by choice or by lack of shared experiences. Many children miss key social milestones because they are in treatment. Especially, leukemia survivors which have almost three years of missed childhood experiences because of their treatments (Hoffman, 2013).

Many cancer survivors report that they are closer to their families than their peers. This may be related to their shared experiences of the family during the cancer

treatment (Winterling, et al., 2015). Post-traumatic stress disorder (PTSD) is a problem for cancer survivors and their families. The more severe the late effects of treatment the greater chance of having PTSD (Cousino et al. 2017). A child with cancer will have a different view of illness than their peers, this may manifest in a fear of illness. Learning to cope with this fear will affect the outcome of the survivor's life (Stokes, 1999).



Source: <https://images.app.goo.gl/AUL2UZrgytWuU3Z37>

### **Forged in the Fire**

Childhood cancer survivors are changed by their life experiences during treatment. Despite the hardships that childhood cancers survivors face during treatment and struggles with late effects, 86.5% of childhood cancer survivors report a positive change after their diagnosis in their life (Yi et al., 2015). In another study (Tonsino & Ow, 2018) found that spiritual coping was found to be the most helpful to cancer survivors. It is suspected that these spiritual coping behaviors help the participants survive the treatment and maintain good mental health. The spiritual coping behaviors can also be attributed to positive change after diagnosis and treatment.



## **Social/ Emotional Interventions**

### **Counseling**

There are many ways to help students to cope with the mental health concerns such as anxiety, fear, depression, and post-traumatic stress disorder. Counseling services are the first step to help the young survivor. Therapeutic counseling for the survivor should be performed in a clinical setting. Coping issues with the disease and feelings about school reentry should be addressed in these counseling sessions (Hermann et al., 2011).

School counselors can help with the transition back to school by touching base with the student. They can provide encouragement and help advocate for the student when they encounter difficulties in the classroom. Another counseling service a school counselor might consider is to offer group counseling to the survivor and their class. In these group sessions it would be beneficial to address the feelings of the survivor if they are apprehensive about returning to school. Emotions and feelings around the diagnosis can be addressed during the sessions. This can help facilitate peer support for the survivor, which can lessen the psychosocial distress for the survivor (Hermann et al., 2011).

**September is Childhood Cancer Awareness Month**

September is Childhood Cancer Awareness Month. Many schools host events in awareness to recognize these survivors. High school football games, volleyball games, have special nights that often use the phrase, "Go Gold." The players wear gold socks and decorate the venue in gold. These events bring awareness and celebrate the student survivors. Alex's Lemonade Stand Foundation has some excellent resources to help your school celebrate this special month. The resources can be found at <https://www.alexslemonade.org/blog/2020/09/9-ways-be-bold-and-go-gold-through-childhood-cancer-awareness-month>

### Monkey in My Chair

Monkey in My Chair is a program that helps the childhood cancer patient stay connected to their classmates to avoid the isolation that many feels when going through treatment. The program also promotes empathy among the classmates as they remember and stay in touch with their missing classmate.



Source: (MU Health, 2015, Nov. 24, <https://youtu.be/CgaW3fpM7m0>)

Transcript- “While Ryan Loose stays at University of Missouri Children's Hospital for cancer treatment, her friends go to school. As Ryan builds a castle in the hospital playroom somebody takes Ryan's seat in kindergarten class. The monkey will sit in her chair and it's to remind the class that she's still part of the class. Monkey in my chair is a national program aimed at helping young cancer patients stay connected with their school and in turn helping classmates better understand the challenges of fighting cancer. So with the monkey in the chair that actually lets the kids know at school that you're still being thought of that you're still there. You're just missing school for other reasons the monkey kit includes of course the monkey but also a backpack for teachers to send home Ryan's classwork and well wishes from her friends. And there's a book to help teachers explain the difficult situation giving teachers instructions about what to do

resources stories for the kids. Ryan named her monkey Bailey and Ryan's classmates make sure Bailey goes everywhere they go during school day. The monkey helps but her friends no life at school is not the same without Ryan because they're learning with this whole process. We wish this never had happened but with it happening it's the kids are learning compassion from the University of Missouri” (MU Health, 2015, Nov. 24).

## Quiz

1. Childhood cancer survivors can have emotional and social problems during and after treatment.
  - a. True
  - b. False
2. Anxiety, depression, conduct problems, attention deficit, and social problems have all been reported by survivors. According to research, which of the disorders is reported most frequently by female survivors?
  - a. Anxiety
  - b. Depression
  - c. Attention Deficit
  - d. Social Problems
3. How many years can leukemia survivors miss out on childhood experiences?
  - a. 1
  - b. 2
  - c. 3
  - d. 4
4. Who do cancer survivors report to whom they are closer?
  - a. Peers
  - b. Fellow Survivors
  - c. Family
  - d. Doctors
5. Fear of illness in the survivor, is a symptom of \_\_\_\_\_.
  - a. Depression
  - b. Post-Traumatic Stress Disorder
  - c. Social Problems
  - d. Attention Deficit
6. Therapeutic or clinical counseling should be performed by a school counselor.

- a. True
  - b. False
7. What month is Childhood Awareness Month?
- a. June
  - b. July
  - c. August
  - d. September

Answer Key- 1. A, 2. B, 3. C, 4. C, 5. B, 6. B, 7.D

## Module 4- Physical Side Effects of Childhood Cancer



### Physical Long-Term Side Effects of Childhood Cancer

Cancer can ravage the physical body of the child particularly; the osteosarcomas can leave a child without a limb and retinoblastomas can cause a child to lose an eye. These physical effects can leave a child disabled for life. Childhood cancer treatments often have the long-term physical side effects. While 62% report excellent physical health- 38% report side effects that substantially impact their lives such as renal, endocrine, and cardiovascular problems (Maunsell, et al., 2006). The most common physical long-term side effects of childhood cancer are nervous system effects, hearing and vision effects, internal organs effects such as a heart problem, immune system deficiencies, effects on the bone, and fatigue.



Source: (John Hopkins Medicine, 2017, <https://youtu.be/sZIZmGQ2irI>)

Transcript- "Jaliyah: My name is Jaliyah Mason. I'm 11 years old and I was diagnosed with a tumor at the age of 9.

Mom: She came home, and her ankle was swollen, and I said what happened? She said I fell.

Jaliyah: After a week later, I told my mom it was still hurting really bad.

Mom: So, the swelling didn't go down and the physician advised us to see an expert. The first option was amputation.

Jaliyah: I was like, what's amputated? And she says, when you don't have your ankle no more, when they just cut it off.

Mom: It was just a matter of finding the right surgeon that could do the surgery, she needed a limb-sparing surgery.

Jaliyah: My mom started looking at doctors, and then that's how she found Dr. Morris.

Dr. Morris: Amputation did not resonate with them and that she would have genuinely been unhappy if she hadn't at least tried this first.

Jaliyah: I wanna try to save my leg, first, before I get amputated.

Dr. Morris: The most nuanced part, I think, of what we do is matching the right operation with the right patient. There are lots of



- options out there and all of those options probably will work fairly well. But if the patient doesn't want the option, then it doesn't work at all.
- Jaliyah: 38t staples all the way up, cuz I was really interested how many staples I had. When my mom finally found Dr.Morris it was the best thing that ever happened to me. A doctor who could actually do this type of surgery on my ankle to save my leg, it was like a really good blessing.
- Dr. Morris: By far, the most important thing is to get rid of the tumor. We took out over 50% of the tibia bone, including all the way down to the ankle joint. We took the smaller bone in the leg, the fibula, transferred it over to where the tibia used to be, connected the remaining tibia down to the bone in her ankle called the talus. So, what we essentially did is we rebuilt the leg by fusing her ankle.
- Mom: It was very difficult surgery, but she made it so comfortable for me and my daughter. What really stands out is my daughter did not experience any tremendous pain after the surgery.
- Jaliyah: I'm glad I'll be able to walk because now when I'm walking it feels like a normal foot and I'm practicing being able to stand on one leg again. I love to dance, I'm self-taught, I just love to do that almost every day, and my big inspiration was Michael Jackson when he used to dance.
- Mom: What are you doing?
- Jaliyah: Michael Jackson”  
(John Hopkins Medicine, 2017).

### **Nervous System Effects**

The child sick with childhood cancer may undergo many physical problems during treatment. Nervous system effects include hydrocephalus, leukoencephalopathy, seizures, strokes, and peripheral nerve dysfunction.

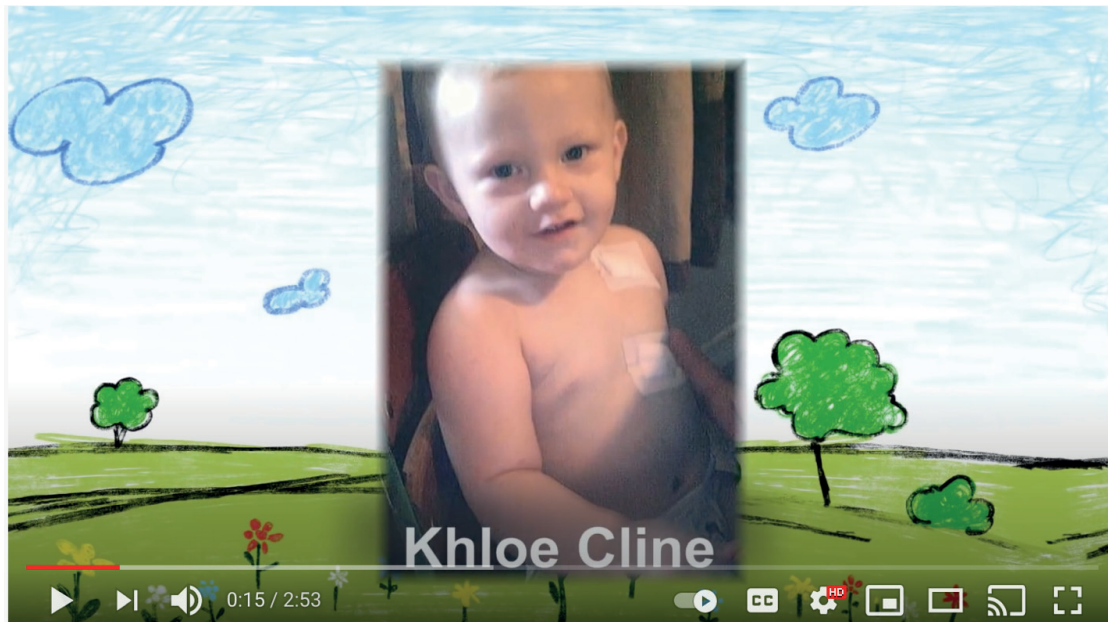
Hydrocephalus is commonly referred to as water on the brain because either a tumor or spinal fluid is putting pressure on the brain. Hydrocephalus is treated with a shunt. Teachers need to know about a student with shunt and the doctor should provide instructions on what types of activities are appropriate for the student.

Likewise, teachers should notify parents immediately if they suspect any problems with the shunt as it could be a life-threatening condition.

Leukoencephalopathy is distinguished by problems with the white matter of the brain. Cognitive deficiencies are caused by leukoencephalopathy. Seizures which are temporary electrical disturbances in the brain can occur because of treatment. They can be generalized- whole brain or focal which are specific parts of the brain. Seizures can be brought about by reactions to chemotherapy drugs. Peripheral nerve dysfunction is damage to the nerves. It can be temporary or permanent. Peripheral nerve dysfunction can cause fine motor and gross motor delays or disabilities (Hoffman, 2013).

### **Hearing and Vision**

Hearing loss is a common for survivors who had high dose radiation to their head. Young children are especially at risk for hearing loss. Cancer-related hearing loss often damage the nerves that interpret sound so hearing aids do not work. Decreases in vision can occur from tumors or the treatment itself. Many times, retinoblastoma survivors have lost an eye. Cataracts are also common for children who received cranial radiation. Most of students with hearing and vision disabilities will require accommodations to the learning environment (Hoffman, 2013).



Source: (Cincinnati Children's, 2014, Oct. 7, <https://youtu.be/pDBmKLAEH4Q>)

When Chloe Klein was a toddler her mother noticed something wasn't quite right with their vision. Alicia Gray would look into her daughter's eyes and see Chloe struggling to focus. The problem was more severe than Alicia expected. Doctors diagnosed Chloe with bilateral retinoblastoma, a rare cancer in the back of her eyes. "She had eleven tumors to start out with. Three of them were" "huge." Chloe began chemotherapy treatment at their local hospital in Indianapolis. Doctors told the family the next step would be radiation, which could destroy Chloe's eyesight. But they said specialists at Cincinnati Children's might be able to save her vision. There was not much hope given to her. Doctor Todd Abruzzo says he thought it was a long shot to salvage both of her eyes, but he developed a new technique targeting chemotherapy to the eyes using two catheters and a balloon in Khloe's arteries to direct blood flow so it would lead the chemotherapy directly to her tumors. It was absolutely, without a doubt terrifying. She had a phenomenal response. She had remission of both tumors and we were able to save both of her eyes. What color is this? Pink. When the alternative is to remove the eye, there's an incredible pressure and motivation to come up with something that will work.

Doctor Abruzzo says he hopes the method will one day become the first line of treatment for targeting chemotherapy in children with these kinds of high-grade tumors. When it does work, it's a eureka

moment. It's just like, you know, like wow. This procedure means families have another options, says doctor James Keller, a retinoblastoma specialist at Cincinnati Children's. We're fortunate in the United States that the overwhelming majority children do survive their cancer. Several of the other goals are that we try and preserve their vision and that we get them through their therapy and through their journey as comfortably as possible. For Chloe and her family it means Chloe, who wants to be a doctor when she grows up, can look forward to a bright future. She is 100 percent resilient and it's a good outcome. It is a good outcome" (Cincinnati Children's, 2014, Oct. 7).

### **Internal Organs**

Chemotherapy particularly the anthracyclines can cause damage to a child's heart. Problems with the way the heart pumps the blood and the heart's rhythm can be affected by the chemotherapy. Doctor's should develop a list of activities that are prohibited for the childhood cancer survivor. It is the duty of the parent to make sure the list gets to the school. School nurses should question parents as well to know what physical activities are limited for the child (Hoffman, 2013).

Kidneys can also be affected by the treatment or by the cancer itself. "Wilms tumor" leave a child with one kidney. Bladder control problems can be a result of chemotherapy. Diarrhea or constipation often accompany the myriad of chemotherapy drugs that a child may take. This can make it necessary for the children to have extra bathroom breaks, accommodations to use a more private bathroom than student bathrooms, and planning to have extra clothes available for the student (Hoffman, 2013).

### **Immune System**

Cancer, chemotherapy, and radiation all do harm to the child's immune system. The more severe therapies the weaker the immune system can be. This will cause the child to have frequent absences because of slight illness or the avoidance of illness that is occurring at the school. Many common childhood illnesses can cause major medical complications for the child who is on still on treatment or even the children off treatment. Many schools send a letter home to classmates that ask them

to report to the teacher when a student has illnesses such as flu or chicken pox. Then, the teacher (without divulging the other student's name) can tell the parent of the cancer survivor. This can allow the cancer child's parent to make the decision to keep them home (Hoffman, 2013).

**Bones**

Sometimes bones must be amputated, or pieces removed to rid the child of cancer. Low bone density can also be a side effect of high dose steroids. Low bone density can result in brittle bones that can fracture at any time. Doctors should identify what physical accommodations may be needed and what activities may be limited. These accommodations should be communicated to the school through either the hospital liaison or the parents (Hoffman, 2013).

**Fatigue**

Fatigue can be a problem long after treatment is over. Survivors who live with it since diagnosis may not realize that their energy levels are not the same as others. Doctors may not be able to find a clear cause. Exhaustion hampers attention, learning, and concentration. Students may just be too tired to function. Students may need breaks to rest during the day or extended time to complete assignments and tests. Survivors may need to have alternate schedules such as half days or a few days during the week. Survivors could also be accommodated by having all of their required classes such as Math and English in the mornings while concentration and fatigue are not as much of a problem.

## Physical Short-Term Side Effects of Childhood Cancer

### Hair Loss



Source: (CNN, 2011, <https://youtu.be/fnuZlbASAhg>)

#### Transcript-

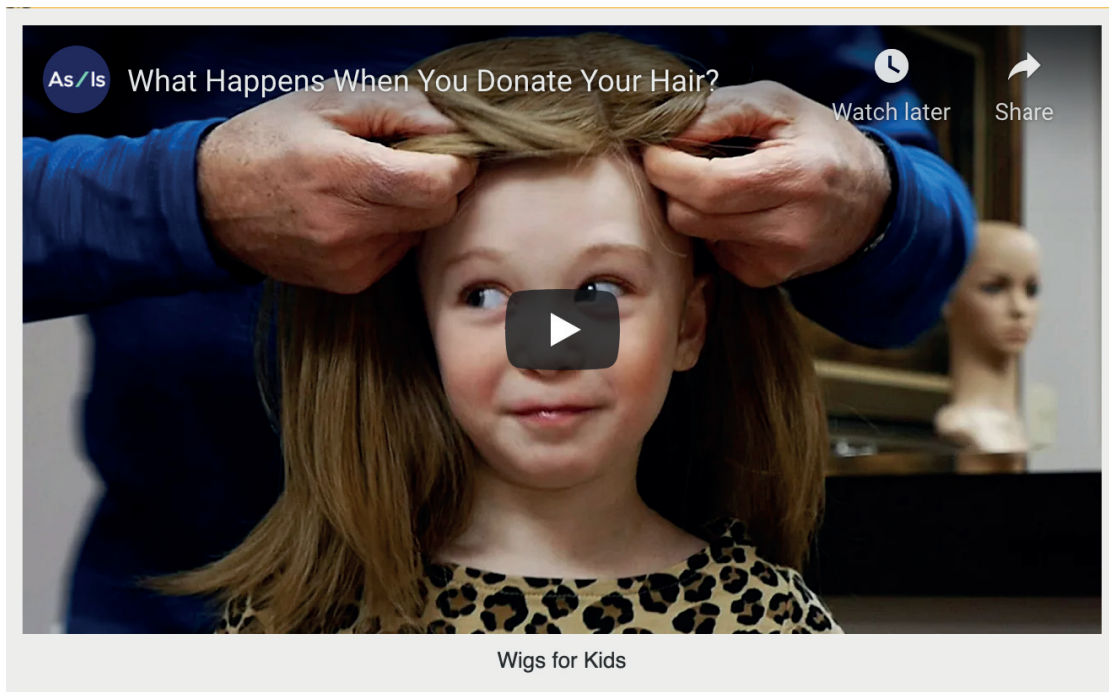
“Emma Wheeler loves to spend time with her friends and classmates. But, there was a time in her life when she did not like going to school. (Emma) Sorta embarrassing because people weren’t able to differentiate me from a boy or a girl. Emma was five when she was diagnosed with leukemia. She required chemotherapy for treatment and her hair fell out as a side effect. According to the American Cancer Society more than 11,000 children will be diagnosed with cancer this year. Teaching why kids lose their hair is the goal of their book *The Long and the Short of It*, which Emma is a character. (Nurse Dawn) Not having hair is the hallmark of being sick. (Reporter) Nurse Dawn Sty says how children cope depends on their age. Typically- (Nurse Dawn) Your younger school age kids deal with it right up front, it’s pretty traumatic when it does happen. But then they adjust pretty quickly. (Reporter) She sees its impact most on teenage girls. (Nurse Dawn Sty) They’re the most into their image.

And obviously, their hair and hairstyle are such a big part of that. So, it's really difficult. (Reporter) Once she was well Emma decided to grow her hair out long and donate to a charity that makes hair pieces for sick kids. For today's health minutes, I'm Susan Hendrick" (CNN, 2011).

Hair loss called (Alopecia) often occurs as a result of chemotherapy and radiation. It can occur multiple times over the course of treatment. Many children are bothered by their hair loss. The change in appearance and loss of hair sets them apart from their peers. It makes them feel isolated and afraid that other children may make fun of them.

There are many agencies that provide wigs free of charge for cancer patients. If your student seems to be struggling during treatment with hair loss encourage them to see their hospital social worker for help finding a wig. One agency is Wigs for Kids which provides hair loss options free of charge (Curesearch, 2020).





Source: (As/Is, 2015, <https://youtu.be/tNMKzZHX-J8>)

Transcript: This is Hannah. When she told us, she was thinking of cutting off and donating her hair, we asked if our cameras could come along. (Hannah) Yeah. This is Bridget. She has alopecia, which has caused her to lose her hair. Today Bridget is getting a new wig. What Happens When You Donate Your Hair? (Hannah) I am in a hair salon and I'm about to cut off 12 inches of my hair and donate it to Wigs for Kids. Where? I'm feelin' nervous, definitely, but mostly very excited. Here we go. Oh, she's doin' it. This is my hair. We just cut the first ponytail. Oh my god, this is crazy. So, I cut this off my head and now it's gonna go into a wig. I hope that my hair can help create a wig that is given to a girl that can give her confidence and make her feel beautiful.

We followed it from California to Ohio. First, the hair gets sorted hair that doesn't meet donation specifications is filtered out and usable hair is sent to the wig manufacturer. Then, the hair is brushed, and the shorter pieces are removed next, ponytails are sewn together and treated in a chemical bath. A custom cap is created for each wig based on the shape of the wig owner's head. Hair colors are blended to create a natural look. Hairs are hand-tied into the wig one at a time eventually, the wigs are completed. Wigs like these are given to kids like Bridget. [Voiceover] Are you excited to get a new hairpiece?



(Bridget) Yeah. She hasn't sit still all morning. Think I saw it in that room. [Voiceover] This is all the hair that was donated from some special people for you. Is that cool? It takes 20 to 30 ponytails to donate one wig. (Bridget) Wow. [Voiceover] Wow. You wanna brush it? Uh-huh. Now I got some new hair. Might not seem like a lot in the big scheme of things, but, you know, to, uh, you know, to a little girl it means a whole lot, so I really have to thank the people who donated. (Voiceover) Thank you, Hannah" (As/Is, 2015).

### **Mouth Sores**

Chemotherapy is not a targeted therapy. It kills all cells healthy or cancerous. Chemotherapy is especially harmful to cells that replicate fast. One type of cells that replicate fast is the cells in the lining of your mouth and esophagus. Chemotherapy kills these cells and it causes mouth sores. These mouth sores can line the mouth all of the way to the esophagus. They are extremely painful for the patient. If the mouth sores cause the patient to quit eating doctors will be forced to place a feeding tube to the stomach to provide nourishment. If you have a student with mouth sores encourage them to drink frequently. Make sure they avoid extreme temperature foods. Make sure they avoid acidic foods that may burn. The cafeteria should also be alerted that the child may have eating problems and diet restrictions. The child may need soft foods. This may avoid further pain for the child (Curesearch, 2020).

Children suffering from mouth sores may need to have special foods prepared for them specifically. They may also need to have liquids available at all times in the classroom. They will also need to have access to the school nurse as needed to help with the pain control.

### **Appetite**

The loss of appetite occurs in many cancer patients who are just too nauseous to eat. If this occurring for one of your students let them eat snacks as needed it can settle their stomach. Work with the parents to help provide snacks or treats that would provide high calories. Try to make lunch special each day for the child while they are at school. Maybe let them pick someone to eat with and go first. Possibly allow them

to eat in the room with you and bring a friend. Eating is very important for child to keep up weight and strength during treating. Teachers and staff can help encourage the student to ensure that they eat during the school day (Curesearch, 2020).

## **Interventions for Physical Side Effects of Cancer**

As educators, it is our job and desire to make our students feel welcome and comfortable at school. Many cancer kids who return to school enter scared. They are scared because the disease and treatment may have changed their bodies forever. It is up to the school faculty to help the student overcome these problems. The first thing that a school needs to do is reach out to the parents to find out what is going on with the student. Once this is accomplished, if the parent allows the communication, the school may need to reach out to the hospital educational liaison or social worker to help determine what needs the child may have once they return to school.

A child suffering from the physical effects of cancer may need accommodations to address those issues. These accommodations could be provided in the form of a 504 Plan or Individualized Education Plan. It should be determined on a case-by case basis and what the student qualifies for based upon federal and state guidelines. Whatever the disability or physical medicine condition there may be a need to have general physical, orthopedic, visual, and hearing accommodations.

### **General Physical Accommodations**

The child may need adjustments in the physical demands of the class. Do not require physically strenuous activities. The student may need time for rest breaks. The student may need a shortened or modified school schedule. If the physical disability limits mobility, provide extra time to transition between classes, or allow the students time to leave early to get to their destination. Make sure the physical environment is welcoming to the student, meaning if the student has adaptive or rehabilitation equipment make sure there is a convenient place to put it during class. Give the student access to the school elevator as needed. Allow students to keep a second set of school materials at home to avoid carrying books and heavy materials back and forth to school. Assign a locker close to classrooms and at a height convenient for the

student. If the student cannot access a locker then, make sure the student has a designated place in the school to securely store their items. If the student drives, allow a student parking space close to the entrance of the building. Provide assistance at lunch in the cafeteria line to take the student's tray to the table and prepare any foods they cannot open. For safety, have student accompanied to the school nurse by another student. All personnel should know emergency plans for the student and how to use any medical equipment necessary. Extended time for tasks, assignments, and tests should be given to help the student have time to complete all work.

**Orthopedic Accommodations**

Students who may need orthopedic accommodations may need a variety of tools to overcome their disability. The student may need assistive technology to utilize during the school day. Assistive technology is any device low- tech or high-tech that provides assistance, rehabilitation, or accommodates the child with a disability. Extended time to finish assignments.

Note-taking assistance for the student, if the student struggles with writing/typing. Provide special seating arrangements or a larger space if the student needs room for assistive technology and medical equipment. Ensure the school is ADA compliant by making sure physical surrounding are accommodating. For example, doors can be opened by the student, hallways and walkways are wide enough for the student to pass, and by increasing the size of wheels, dials, handles, and buttons on lab equipment if needed. Also, lower the whiteboard or interactive boards so that they may be accessed by all.

**Visual Accommodations**

Students with visual disabilities should have preferential seating for classes, assemblies, and sporting events. Allow the student to move closer and around the room as needed to see information being presented. Allow the student to have some time in the room without their peers to move about the room to familiarize themselves with the room arrangement. Do this anytime the furniture is moved. Remind students frequently to keep aisles cleared of obstructions. A staff member should be assigned

to accompany the student out of the building during emergencies. Classroom materials and tests must be available in a format suitable for the student- large print, braille, electronic. Assistive technology should aid instruction and is at student's eye level and avoids glare with limited visual clutter for the student. Assign someone to provide note taking assistance. As a teacher, use specific language used to aid the student. For example, "Look the left side and you will see a horse." Instead of "Oh, Look a horse!"

### **Hearing Accommodations**

Students with hearing disabilities should be provided with appropriate assistive technology for school. Videos, films, and web meetings should be closed captioned. Students with hearing disabilities should have preferred seating. Teachers should always remember to face the class while speaking. Many students with hearing disabilities have the ability to read lips. Teachers should make sure to prompt and cue the individual to gain their attention. The teacher should help reduce background noise and auditory clutter for the student. All instructions need to be written down and given to the students. Also, provide the student with assistance to take notes. This can be a copy of the notes or even a someone to write down the notes for the students.

These accommodations were developed from the author's personal experience and two print resources (Hoffman, 2013; Bateman, 2016).

## Quiz

1. This condition is commonly referred to as 'water on the brain' and is a physical side effect of childhood cancer.
  - a. Epilepsy
  - b. Hydrocephalus
  - c. Leukoencephalopathy
2. Retinoblastoma is a cancer that affects the eyes. Retinoblastoma can often cause a child to lose an eye. Which of the following accommodations would NOT be appropriate for a child with the loss of an eye?
  - a. Assistive Technology
  - b. Less Visual Clutter
  - c. Sign Language Interpreter
  - d. Preferential Seating
3. Wigs for kids provides wigs free of cost to children who have lost their hair due to medical conditions.
  - a. True
  - b. False
4. Osteosarcomas can result in limbs being amputated to remove the cancer. Which of the following accommodations would be appropriate for children returning to school with physical disabilities?
  - a. Access to the elevator
  - b. Aisles, Hallways Clear of Obstructions
  - c. Parking space located near the school or designated drop off and pick up location that is handicap accessible
  - d. All of the Above
5. Students with hearing disabilities may need instruction in sign language. Along with sign language what is another accommodation that would be

appropriate for a child with hearing impairment? (Assume the child has no other disabilities.)

- a. Subtitles on all videos, films and web meetings.
- b. Access to the elevator
- c. Reduction in visual clutter.
- d. Large print textbooks

Answer Key -

1. B, 2. C, 3. A, 4. D, 5. A

## Module 5- Return to School



### Multidisciplinary Team Assemble!

## CHILDHOOD CANCER AND SCHOOL

"MY BEST ADVICE FOR TEACHERS IS TO LISTEN WITH YOUR EARS AND YOUR HEARTS. THESE CHILDREN HAVE BEEN TERRIFIED BOTH PHYSICALLY AND EMOTIONALLY. THEY HAVE SEEN THEIR BODIES CHANGE, THEIR FRIENDS DISAPPEAR, AND THEIR PARENTS CRY. FRIENDS THEY MAKE IN THE HOSPITAL SOMETIMES DIE. IF THEY DEVELOP LEARNING DISABILITIES, THEY OFTEN REMEMBER AND GRIEVE THEIR LOSSES. EVEN IF THEY DON'T REMEMBER, THEY SOON NOTICE THAT THEY DON'T LEARN AS QUICKLY AS OTHER CHILDREN. IF THEY WERE ATHLETES, THEY DESPERATELY MISS PRACTICE AND THE CAMARADERIE OF THE TEAM. WHEN THEIR HAIR FALLS OUT, THEY ARE OFTEN TEASED. THEY HAVE MORE TO COPE WITH THAN ANY CHILD SHOULD. SO, TRY TO LEARN ABOUT THE DISEASE. TRY TO UNDERSTAND THAT THE FAMILY IS IN TURMOIL AND IT MIGHT BOIL OVER AT SCHOOL. BE KIND TO THE SIBLINGS. HELP REPAIR PEER RELATIONSHIPS BY BY ENCOURAGING COMPASSION AND INCLUSION. HAVE REALISTIC EXPECTATIONS BUT PROVIDE PLENTY OF ENCOURAGEMENT. YOU CAN BE AN ANGEL OF MERCY FOR THE FAMILY OR ANOTHER BURDEN. THE CHOICE IS YOURS" (HOFFMAN, 2013, BACK COVER).

-MOTHER OF CHILD DIAGNOSED WITH CANCER



Just like in the movie, *The Avengers*, a team of heroes needs to assemble to take care of the child upon school reentry. Team members should be the child's parents, doctors, hospital liaison, school psychologist, school counselor, teachers, school nurse, and special education teachers. The job of this team is to facilitate the successful school reentry for the student who is currently receiving treatment or has survived childhood cancer.

“Successful school reintegration for children diagnosed with cancer is best facilitated by a coordinated effort between and within the home, school, and hospital ecosystems” (Hermann, et al., 2011, p. 258). Yet, in the excitement of school reentry many school professionals overlook that the children have new cognitive deficits that were not there before the illness. The recommendation is that hospital and schoolwork together to coordinate the school-based interventions needed by the child. School personnel workshops, which educate the school personnel about the needs of childhood cancer survivor help to lessen the fears of teachers and staff. Cancer survivors who have the support of the teachers have greater scholastic success upon school reentry (Yi et al., 2016).

School counselors can also play an important role in school reentry for childhood cancer survivors. School counselors can work as a local resource to facilitate a connection between home, hospital, and school. School counselors can work with the students to prepare them for the cancer survivor's return to school (Bauman, 2010). Peer education programs help peers understand what has happened to their classmate. It can help ease the survivor's reentry into the school (Prevatt et al., 2000). “Peer relationships are critical for establishing healthy self-identity among childhood cancer survivors” (Yi et al., 2016, p. 264). Yi et al. in their study of childhood cancer survivors, all 31 participants feared returning to school. Some participants reported being bullied and isolated from peers. Others reported that they had close peers that made the transition easier. Yi et al. found that those participants who received peer support found greater academic success.

A hospital liaison has access to a child's medical records and academic records. They can help by bridging the divide between the hospital and the schools. Hospital liaisons can provide support to the parents to ensure advocacy for the student returning to school with neurocognitive deficits (Northman et al., 2018). Hospital liaisons have several patient specific tasks such as consultation with the medical team and parents, preparation time which includes gathering data about the child and illness, and school meetings such as IEP and 504 meetings (Irwin, Elam, & Marianos, 2015). However, often times these liaisons are only available at the larger oncology units and are no longer provided once the child finishes treatment. Parents report higher levels of understanding, greater abilities to advocate for their children, and an informed access to services with hospital liaison programs (Northman et al., 2018). The liaison can help coordinate the care and provide school specific support to the parents and children (Irwin et al., 2015). Hospital liaisons can also work with the school nurse to help further collaboration between the school and hospital. The school nurse can be a good resource for medical problems that may arise while at school (Yilmaz et al., 2014).

School based interventions can be implemented through a 504 or Individual Education Plan (IEP). These accommodations are available for any students that meet the qualifications in the programs. Cancer survivors may receive accommodations for fatigue, working memory, executive functions, and processing speed. These accommodations can be shortened school days, modified assignments, modified tests, extended time, technology, and preferential seating away from distractions (Gorin & McAuliffe, 2009). Accommodations are not the same for every childhood cancer survivor. Accommodations are based upon the child's deficits and help level the playing field so that they can succeed.

## **Multidisciplinary Team Meeting**

During the first meeting with the team several topics must be covered. The first thing the school team needs to express is empathy for the situation for the child. Letting the parents know that the health of the child comes first and foremost to the needs of the school. This is vitally important for children who will be attending school while on treatment. The family already feels isolated in the diagnosis and treatment, school does not need to be an extra burden for the family to shoulder. Be open and listen to what the parents are saying and if the child is present listen to what they are saying about their feelings upon returning to school.

The second item on the agenda is the need to develop a health management plan for the student. The school needs to formally request medical documentation with the parent and hospital liaison. If the hospital has not already initiated the paperwork, discuss the option of getting a HIPPA waiver so that the school may talk directly to the hospital liaison and the medical team. Discussions should include what limitations the doctor has placed on the child. This could be physical limitations or even dietary restrictions. Discussions should cover the current medical equipment the child may have to bring to school and any medical implants the child may now have. Children on treatment will most likely have a port or central line placed. The school needs to be aware of these items. Medicines that may be given by the school nurse and a list of prohibited medicines. Emergency numbers to call when the student is ill or needing to go home. Ask the parent if they want a letter sent home asking that they notify the classmates of the diagnosis of their peer. If they could notify the school when their child has the flu or other childhood illnesses so that the cancer parent may decide to keep their child home to avoid exposure. The hospital liaison and school nurse should also work together to develop a comprehensive health management plan for the student. Further resources can be found at CDC's Healthy Schools website <https://www.cdc.gov/healthyschools/healthconditions.htm>.

The third item that may need to be discussed is a modified school schedule. Children receiving treatment for childhood cancer may be fatigued. They may not be able to handle a full school schedule. Discuss options that the school district is able to offer prior to the meeting with school officials then, discuss with the parent. It is a better idea to have options that are already approved going into the meeting than to have options that are later denied by someone at the district level. Options that may work for the student could be a few days a week for the student, a half day schedule, or virtual instruction. Options could also be discussed to have a place for the child to rest at school if the child can handle a full schedule but sometimes needs a break. During this time also discuss the amount of time the child may be absent from school due to treatment and doctor's appointments. Plan a procedure for making the school aware of these absences.

It may be necessary to plan the physical surroundings for students who may return to school with an amputation. Plans will need to be developed if the student will need access to a special restroom, students need access to an elevator, bathroom accessibility, and even more space in the classroom due to medical equipment. Will the student need assistance to change classes, assistance in the cafeteria line, assistance carrying books and materials? The school should offer to provide a set of textbooks for home and hospital use. Discuss extra cleaning in the classrooms and areas that the child may use while at school. Discuss these plans in depth team members, brainstorming ideas to make the situation more accessible to the student who may be coming back to school with a new disability.

Dietary accommodations should be addressed. Discussions should cover what types of foods to avoid and what types of food may be needed. Discuss if there needs to be food and water always available for the child in the classroom and the frequency of the snacks. A plan needs to be developed on who would provide these snacks for the classroom and the child.

If the child needs to be referred for a 504 Plan or Individualized Education Plan. Conversation needs to happen about the differences in each plan and what plan

the child might qualify. Not all students will qualify for these plans as each should be tailored to what the student needs. For example, if the child opts to do virtual school many of these accommodations would not be needed. In many virtual programs the students work at their own pace so even extended time would not be needed. If the parent wants to refer the child, it would be a good idea to go ahead and set a date and time for the initial referral meeting of either of these processes.

Also, consider how the parents of the child with cancer would like the classmates told. The classmates may already know about the child's diagnosis but as the child gets ready to return to school, a plan could be developed to prepare the classmates for their peer's return. You could plan to have the student involved in the presentation or it could be as simple as the parent requesting the teacher to ask the students not to mention hair or weight loss. This will be different for each student. In the next section, there is an outline that can be used by teachers or school counselors to speak with the class.

End the meeting with support and caring words from the team. Make sure that the parents and child feel wanted in the building. Make sure to give parents contact information of school personnel and get contact information of the health liaison and parents. This meeting can give much needed reassurances to the parent and child that all medical, emotional, and academic needs are going to be met for the returning child.

### **Outline of Meeting Agenda**

1. Introductions of team members, expectations, and most importantly empathy.
2. Health Management Plan- medicines, emergency procedures, HIPPA waiver
3. Modified School Schedule, Absences
4. Physical Areas- What Physical accommodations may need to be in place before the return of the child.
5. Dietary Accommodations
6. Referrals for a 504 Plan or an Individualized Education Plan

7. Discuss telling the classmates about child's diagnosis.
8. Conclude the meeting. Make sure to provide contact numbers for school personnel and get contact information for the parent and hospital liaison.

## **Telling the Classmates**

Telling the classmates that their friend has cancer is very hard. There are not many resources that address this topic. For younger students, as previously mentioned Monkey in My Chair is program that helps develop empathy for the cancer patient. Not only does Monkey in My Chair have a stuffed animal that acts as a reminder it comes with materials for the teacher to teach the students about cancer. For more information about this program please visit <http://www.monkeyinmychair.org>. For older students the approach should be age appropriate. The feelings of these students may also be more intense. Classroom presentation should always be given at the age-appropriate level.

### **Classroom Presentation**

As a teacher developing a presentation to tell your class about a peer's cancer you may want to include several important facts. First begin by giving general information about the cancer. Define what cancer is and discuss the specific diagnosis. Then, discuss the myths about cancer. It is extremely important for students to understand that they cannot "catch" cancer. Let students ask questions and be open and honest with the students. Prepare the students for physical changes of the cancer patient. The cancer patient may have hair loss, medical equipment such a port visible, weight loss, a nasogastric tube for nutrition, scars, loss of limbs, and may need to use a wheelchair or crutches. Mention that the cancer patient may miss a lot of school due to a suppressed immune system and doctors' appointments (Hoffman, 2013).

Students will want to help the cancer patient. Discuss ideas with the class ways you can help the cancer patient. You can always create cards, a gift basket, a video, and other things to help the child. Students may want to act as a note taker for the cancer patient to keep them up to date on their work. Video conferencing may be a way for the student to still take part of classroom activities while not physically being present. Discuss what the students can do if someone tries to bully the cancer patient (Hoffman, 2013).

In the course of the presentation, someone will ask, "Can he/she die?" or "What if the treatment doesn't work?" Answer these questions honestly. Be optimistic with the children. Emphasize that cancer treatment has advanced in recent years. Tell the class the cancer patient is a fighter and that we are going to all help the cancer patient fight this disease (Hoffman, 2013).

#### **Outline of Presentation (Remember to Adapt for Age)**

1. Brief overview of cancer
2. Type of Cancer of the Classmate
3. Type of Treatment of the Classmate
4. Changes in the Classmate
5. How They Can Help
6. Questions

#### **Grief Counseling**

In the tragic event that a cancer child passes. Explain to the class in age appropriate terms. Say that the cancer patient died instead of ambiguous phrases such as, "gone to sleep" or "passed." Little children may need clarification such as the body has stopped breathing, stopped eating, stopped playing, etc (Cancer.net, 2018).

- Allow the children to express their grief. Encourage expression with art therapy, music therapy, or play therapy.
- Make sure little children understand that it is their fault that the cancer patient passed.
- Encourage the class to speak about the cancer patient.

- Older children may need to talk to someone outside of the class about their grief. They may need to see the school counselor.
- Explain to the students that their grief may come and go. They may get sad and get angry at the cancer. These are all natural parts of grief.
- It is very natural to feel sad over the death of friend.
- Keep all classroom routines. These constants help the students feel safe and secure.
- Reassure the class, that the cancer patient would have wanted them to continue to have fun. They did not want their classmates to be sad all the time.
- It may also be a good idea to have extra counselors on hand when the students find out about the cancer patient. This would allow more one-on-one attention for students who are expressing intense grief that may make other students scared or anxious (Cancer. net, 2018).



## **504 Plan and Individualized Education Plan Accommodations**

Listed below are accommodations that may be appropriate for the cancer patient returning to school with a 504 Plan or an Individualized Education Plan (IEP). These recommendations are compiled from my experience as educator and recommendations from Hoffman (2013) and Bateman (2016). All recommendations are not intended to be appropriate for all cancer patients. This list is generated with the idea that you pick and choose what is applicable to your student with childhood cancer.

While on treatment it would be a good idea to base grades on improvement rather than actual work. Grade what is completed not what is not completed. Give student credit for the effort of any work completed during this difficult time. Remember school should not be another burden to these students but rather an escape from the stark reality of their life.

### **General**

- Infection precautions developed for the classroom and school. For example, extra cleaning, child wearing a mask, nurse informing parent when infectious illness is in the school building.
- Attendance accommodations such as half days or modified schedules.
- Virtual School.
- Adjust schedule to provide rest breaks. A resting place in the school counselor's office, school nurse's station, somewhere the student may rest during the day.
- Attendance policies adjusted or not applied.
- Reduce the number of courses required.
- Homebound or hospital instruction if appropriate.

- Adjust activity level and expectations where physical activity is required. For example, student may not be required to participate in physical education class or field trips with class.
- Assistive technology- any hi-tech or low-tech device which provides assistance, accommodations, or rehabilitation to the student.
- Awareness training for all faculty and staff- discuss the disease, expectations, and pertinent medical information with faculty and staff who will come into contact with the child.
- Develop a multidisciplinary team to develop a health care emergency plan to deal with student getting sick at school.
- Preferential seating in the classroom- away from distractions, away from high traffic areas.
- Extended time- for assignments, tests, and projects.
- Monitor school reentry for any signs of problems. Once the student returns have someone designated for daily check-ins with the student, ideally this would be the school counselor.
- Allow a transition period for school reentry. This may mean a modified schedule at first for the student. Day in school and a day off school or several half days which slowly increase in time until the student is attending a full day of school.
- Educate classmates about cancer and the possible differences in their peer. See section on telling the classmates.
- Create a peer support group, gather friends and classmates, along with the child with cancer to discuss feelings and emotions around the disease.
- Allow students two sets of textbooks one for home and one for school. This keeps the student from carrying heavy loads to and from school. This would also keep germs from spreading to the cancer patient.
- Allow frequent restroom breaks.

- Allow unrestricted access to the school nurse. It may be a good idea to have the student escorted to school nurse when the student is feeling ill.
- Allow student to wear a hat or head covering.
- Allow student to eat and drink in the class.
- Allow student to bring in outside food and beverages.
- Student should be allowed to leave class early for transitions to lunch, recess, or another classroom. This will allow the child to avoid crowds and exposure to germs.
- Designated parking space close to the entrance of the school or be allowed to be dropped off right in front of the school entrance.
- Develop a health management plan for the child which would include a schedule for medicines to be given at school, limitations, emergency plans, and other information deemed vital by the multidisciplinary team.
- Personal Aide if deemed necessary by the school. They could be used to help the student get physically from location to location, monitor dietary concerns, monitor medical devices, and help the student in the classroom.

**Lesson Accommodations**

- Provide written notes or recordings of lectures.
- Use multi-sensory methods of instruction- multiple ways of delivering lessons- visual, spatial, auditory, etc.
- Small group instruction
- Prompting
- Cueing
- Reduced number of questions on assignments- shortened assignments as fatigue may be a factor for the student.
- Provide daily one-on-one tutoring with special education teacher. If the student qualifies for an IEP, special education instruction may be required.

**Physical Accommodations**

- Assistive devices needed to accommodate the student. These can be a computer, hearing aids, visual aids, scribe, etc.
- Special seating that will accommodate student's adaptive equipment this could mean a lowered table or a larger writing surface.
- Physical therapy in school
- Occupational therapy in school
- Make sure the student can easily travel to and from classes, cafeteria, gym. This may mean that the student will need someone to accompany them to these areas to help carry books, and equipment.
- Have the appropriate transportation to school to accommodate the physical needs. This could be a bus with a ramp.
- Adjust the size of wheels, dials, handles, and buttons on lab equipment if needed
- Provide oral or computer-based exams based on the need of the student
- Change of clothes at school in case of accident
- Adaptive equipment for restroom if needed. This could be lifts, larger bathroom stalls, or an alternative restroom for the child.
- Elevator access

**Hearing Impairment**

- Sign language interpreter
- Provide the student with Communication Access Real-time translation (CART)
- Assistive Learning Devices- any adaptive devices that can help the child hear the lesson better.
- Captioning for any videos
- Verbal testing
- Face the class while speaking rather than speaking to the whiteboard.
- Obtain the student's attention prior to speaking

- Reduce auditory distraction, no background music, ensuring class is quiet.
- Speak clearly with clear diction
- Repeat information as needed
- Provide the student with step-by-step instructions written and verbally.
- Wear a mask with clear opening over the mouth so the student may see the mouth moving while talking.

**Visual Impairment**

- Let the student move about the room in order to see the information as it is being presented.
- Allow the student to explore the room without any other students in it. Do this anytime the furniture is re-arranged.
- Adapt the room to fit the physical needs of the student. If the student needs a larger walkway make sure that is provided. If a student needs a different type of desk than other students make sure it is provided.
- Keep the floor clear of obstacles such as backpacks, books, etc. Remind other students not to place these items on the floor.
- Provide Braille Instruction
- Provide textbooks in large print or braille.
- Use high contrast color in student materials and in teacher-led presentations.
- Limit visual clutter in the room, especially on worksheets.
- Lay out materials in organized manner, let the student familiarize themselves with the arrangement.
- Allow for modified forms of writing tools
- Allow the student to use assistive technology. This can mean a computer and even low-tech devices such as a walking stick.
- Provide ample light.
- Use Arial font, which is the preferred font for those with visual disabilities.
- Assignments and tests in braille or large print.

- Electronic formats for assignments ensuring that the student can enlarge the print as needed.
- Classmate takes notes for the student.
- Provide written notes for the student.
- Explicit language is used such as, "pass papers to the left."

## Checklist for Planning School Reentry

- ☐ Contact parent about child. Use empathy and understanding if diagnosis is recent. Discuss options available in your district- home/hospital, virtual, etc. Discuss school reentry date for a future date at the parent's leisure.
- ☐ Set up multidisciplinary meeting to discuss school reentry.
- ☐ Initial Multidisciplinary Meeting
  - Develop Health Management Plan
  - Request Medical Information
  - School Schedule- Modified, Reduced, Alternate
  - Physical Areas- decide on accommodations needed, if any
  - Telling the Classmates
  - Referral for 504 Plan or IEP
- ☐ Prepare Peers for Re- Entry
  - Outline of Presentation (Remember to Adapt for Age)
  - Brief overview of cancer
  - Type of Cancer of the Classmate
  - Type of Treatment of the Classmate
  - Changes in the Classmate
  - How They Can Help
  - Questions
- ☐ 2<sup>nd</sup> Re- Entry Meeting (If needed)
- ☐ Re- Entry
  - Check in with student regularly
  - Follow- Up with School Nurse to check on health management plan
- ☐ Revisit plan and revise as needed, with input from all members.
- ☐ Keep track of referral status of 504 Plan or IEP Evaluation
- ☐ At the end of grading periods, check with teachers to determine if student is having any difficulties

## VITA

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