CHILDHOOD CANCER EDUCATION TOOLKIT SCHOOL SECTION
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While the method of treatment varies depending on the type of cancer, so does the length of treatment. One child may have surgery and then require no further treatment while another child may have surgery, followed by chemotherapy, radiation, and sometimes a bone marrow transplant. The cure rate for childhood cancer is better than ever before, with some types of cancer being at a 95% success rate or better. Unfortunately, treatment can be long, rigorous, and debilitating, making the process even more challenging than ever anticipated. Following treatment, both children and teens can suffer from late effects of treatment that include many physical, cognitive, psycho-social and emotional challenges. These challenges must be addressed prior to transitioning back to school.

The transition back to school can be very difficult. However, with the medical team, parents, and school team working together in a strong partnership, both children and teens can successfully reintegrate back to school. This educational toolkit is designed to assist school personnel, parents, and the medical team with information and forms that will make the transition easier than ever before.

In 2018, approximately 325 children were diagnosed with childhood cancer in Virginia.
Who has these Challenges?

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

• **Strong support system and partnership between medical team, school team, parents and child**

• **School health plan**

Each school may have its own school health plan which addresses the diagnosis and medications that may need to be given at school, procedures that may need to be addressed at school, and accommodations needed in the school setting for the medical condition.

• **Educational plans such as a 504 Plan or IEP, Individualized Education Program**

A 504 Plan may be beneficial when a student is successful in a general education setting, but is exhibiting some of the late effects related to the medical diagnosis and treatment.

An IEP, Individualized Education Plan, is needed when he or she is needing specialized instructions due to the physical, cognitive, or psychosocial emotional challenges he or she is experiencing following treatment.

• **In-service for school staff and classmates**

An in-service is an informational session for classmates to discuss their friend’s return to school. This will help explain why they may need accommodations and how to make them feel welcome.

• **Transition goals**

Transition is a difficult time for all students, but especially for students who have experienced the diagnosis and treatment of childhood cancer. Helping them achieve small, attainable goals is always beneficial.

• **Networking with local and state agencies, non-profit organizations, and businesses in the community**
Most Common Physical Challenges

- Fatigue
- Muscle Weakness & Low Stamina
- Neuropathy
- Mood Swings
- Altered Physical Appearance
- Unsteady Gait
- Hearing & Vision Loss
- Gross & Fine Motor Skill Deficits
- Nausea & Vomiting
- Pain
• **Fatigue:**

Fatigue is a side effect of chemotherapy and radiation that can last for an indefinite period of time following treatment. It may require that the child or teen only attend school for part of the day or that he or she may need a rest period during the school day.

• **Muscle Weakness & Low Stamina:**

Muscle weakness and low stamina affect the amount of activity the child can handle during the school day. Does he or she need to be exempt from physical activity at recess or during physical education class? Does he or she need extra time to walk to his or her next class? Should the child have an extra set of books in his or her classroom so he or she does not have to carry the heavy backpack?

• **Neuropathy:**

Neuropathy is weakness, pain, numbness or tingling in the hands or feet that might impact walking, climbing stairs, completing fine motor skill tasks or writing lengthy assignments. Pain and discomfort can interfere with attention, concentration and the ability to successfully complete academic tasks.

• **Mood Swings:**

Mood swings are often a side effect when taking steroids, which are included in numerous treatment protocols. Children may be extremely tearful, irritable and sad. Temper tantrums or emotional outbursts may be exhibited. Steroids can affect sleep, as well as appetite. Children and teens may require additional snacks at school when taking steroids, as well as a rest period.

• **Altered Physical Appearance:**

Children and teens are often sensitive to their altered physical appearance following diagnosis and treatment. Hair loss or thinning of hair is often a side effect of chemotherapy. Weight loss or weight gain can be the result of medication and treatment. Surgery, placement of a Port-A-Cath or an internal catheter placed for medication purposes can all result in scarring. Therefore, students may need permission to wear a hat or scarf, a desk suitable to body size, or a private shower stall in which to change clothes for PE class.
• **Unsteady Gait:**
  Children and teens recovering from a brain tumor can experience difficulty walking or have an unsteady gait. They may return to school in a wheelchair or with a walker. For a younger child, a personal aide or assistance from an adult might be needed. Children and teens in middle school and high school may need to leave class early to avoid the crowded hallways.

• **Hearing & Vision Loss:**
  Hearing and vision loss can occur during or after treatment. If problems are suspected in the school environment, visually impaired and/or hearing impaired coordinators for the division should be contacted to evaluate the child.

• **Gross & Fine Motor Skill Deficits:**
  Gross motor skills are those that involve the large muscles of the body. Children with gross motor skill deficits can have difficulty with running, hopping, skipping, riding a bicycle, carrying a heavy backpack, and even everyday skills needed for dressing. Fine motor skills involve the small muscles in the hands. Children with fine motor skill deficits may have difficulty with everyday skills such as buttoning their clothes, tying their shoes, opening food items, and even feeding themselves. Academic skills are affected with the fine motor skill deficits due to difficulty with handwriting, coloring, cutting, and construction (lego bricks, puzzles, etc.).

• **Nausea & Vomiting:**
  Children and teens often experience nausea and vomiting due to the side effects of medications and treatment, particularly chemotherapy. These children may require a late arrival to school to accommodate the morning sickness. If it continues throughout the school day, the school nurse should be consulted.

• **Pain:**
  Chronic pain is associated with numerous types of childhood cancer. Pain medications can be administered through the school nurse.
I couldn’t play sports or do anything physical because of my Port-A-Cath. Inside it hurt, but it made me more determined to overcome cancer. In school, my cancer had a different impact on me. It took me much longer to understand concepts. I’d have to have things repeated to me a couple of times where other students understood right away.

- Essay from Leukemia Survivor
Cognitive deficits can sometimes be subtle and difficult to recognize in children. The following reviews their common challenges:

- **Slower Processing Speed**

- **Short Term Memory Loss**

- **Inability to Focus or Concentrate for Long Period of Times**

- **Poor Organization**

- **Difficulty Multi-tasking**

- **Visual-Spatial Deficits**

- **Difficulty with Word Retrieval**

**Slower Processing Speed:**
Children and teens with slower processing often appear unmotivated or even lazy, when, in fact, they do not have enough time to process the information and complete their work. These children may suffer from anxiety due to the slower processing. They are nervous and afraid of being called upon in class and not having enough time to respond.
• **Short Term Memory Loss:**
  Children with short term memory deficits can study their spelling words the night before and know them, but do poorly on the test the next day. These same children might do poorly on math assignments even after a review; the math skill or concept may appear new on a daily basis to the child who has short term memory loss.

• **Inability to Focus or Concentrate for Long Periods:**
  Many children and teens may experience attention and concentration issues following treatment. Steroids and other medications can affect attention and concentration, as well as pain and overall discomfort. Frequent breaks, as well as subtle reminders, may be needed to help the child focus.

• **Poor Organization:**
  Executive functioning is the ability to plan, organize and complete tasks. Children and teens may need assistance from teachers and parents with writing assignments in their agenda book, completing assignments, preparing for upcoming tests and projects, and keeping their notebooks and backpack organized.

• **Difficulty Multi-tasking:**
  Due to the late effects of chemotherapy and radiation, processing in-depth information and multiple steps at one time might be very difficult. Giving both oral and written directions, with one or two steps at a time may be beneficial, as well as the teacher checking for clarification and understanding of the tasks.

• **Visual-Spatial Deficits:**
  Since visual-spatial processing is the ability to tell where objects are in space, this can affect a child’s progress in both math and reading, as well as physical activities. The use of visuals, manipulatives, and hands-on activities can help strengthen these deficits.

• **Difficulty with Word Retrieval:**
  Difficulty with word retrieval can occur following chemotherapy. The child or teen knows what he or she wants to say, but has difficulty finding the words and speaking. He or she often just needs additional time to formulate his or her thoughts.
MOST COMMON
PSYCHO-SOCIAL & EMOTIONAL CHALLENGES

It is like a dangerous roller coaster ride with upside down loops, gravity defying drops and steep upward hills. And much like a roller coaster ride, once finished, you look back on it as the scariest, most challenging, yet somewhat vitalizing time, and come away a stronger and wiser person.

- Robyn Dillon, Licensed Clinical Social Worker for Pediatric Hematology/Oncology
It is like a dangerous roller coaster ride with upside down loops, gravity defying drops and steep upward hills. And much like a roller coaster ride, once finished, you look back on it as the scariest, most challenging, yet somewhat vitalizing time, and come away a stronger and wiser person.

- Robyn Dillon.

Licensed Clinical Social Worker for Pediatric Hematology/Oncology
Psycho-social and emotional challenges can wax and wane for children facing cancer diagnosis and treatment. The following list addresses some of their most common challenges:

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

Children and teens returning to school following diagnosis and treatment need a safe haven in the school building. This place is one to which the child can go when feeling anxious, sad, afraid, or angry. A special teacher, coach, school nurse or counselor can be the one person the child turns to when faced with challenges during the school day.
Special clubs or support groups, facilitated by the school counselor or other school professionals, can be beneficial for children with special health care needs or psycho-social emotional issues. These groups can allow students to express their feelings and concerns, as well as let them know they are not alone.

All children and teens need a time to feel extra special and shine. Showcasing artwork, performing in the school play, making morning announcements, being an office aide, or serving as an assistant on a sports team can make a child returning to school feel wanted and accepted.
Remember that when you are having a bad day, there is always a good part of it. It shines through the events of your day, you just have to find it. This is what everyone going through cancer, young or old, should know.

- Hodgkin’s Lymphoma Survivor
The diagnosis of childhood cancer provokes many questions. The answers to these questions are difficult for adults; therefore, what do parents, teachers, medical providers, and loved ones say when asked these tough questions by children? Is there a correct answer or do the answers vary depending on the individual?

- Why me?
- What did I do so wrong to deserve this?
- Where is this all loving God?
- Why do bad things happen to good people?
- Who is watching over me?

Bernie Siegel, MD, writes, “Spirituality means the ability to find peace and happiness in an imperfect world, and to feel that one’s own personality is imperfect but acceptable. From this peaceful state of mind come both creativity and the ability to love unselfishly, which go hand in hand. Acceptance, faith, forgiveness, peace, and love are the traits that define spirituality for me.” Citation: Love, Medicine, and Miracles; Harper and Row, 1990.
ACADEMIC & VOCATIONAL CHALLENGES

The Physical, Cognitive, Psycho-Social Emotional and Spiritual Challenges impact academic success. Therefore, it is crucial that we consider Academic and Vocational Challenges.

- Curriculum and Scheduling
- Standards of Learning
- District and State Engrossments/Testing
- Type of Diploma—Standard vs. Advanced
- SAT & ACT Testing
- Career Goals
- Transition Issues
- College and/or Vocational Planning
The physical, cognitive, and psycho-social emotional challenges greatly impact academic and vocational success. In fact, there are numerous academic and vocational challenges that are frequently not identified until the child or teen returns to school and resumes his everyday activities in the school setting. Therefore, it is imperative that the parent and child work closely with the school counselor to discuss curriculum and scheduling prior to returning. While the younger child may transition back only for a partial day, it is important that the major core subjects, such as reading, math, science and social studies be taught during his or her time at school. Homebound services can be offered when the child or teen is absent from school for clinic visits or hospitalizations or when just not feeling well.

Many parents have concerns regarding whether or not their student should take district and state assessments or participate in SOL testing. This is a difficult question because while we want to know what skills the child has mastered, we also do not want to put worry and stress on the child. Therefore, this is a discussion that should be had between the teachers and parents to determine if SOL or district assessments should be given. For a teen in high school, careful monitoring to make sure that the teen has the required verified credits for graduation is crucial.

Discussion concerning whether the teen is pursuing a standard diploma or advanced diploma is also of utmost importance. A child or teen should never feel that he or she cannot pursue a gifted program, advanced placement classes or an advanced diploma because of having cancer and experiencing some setbacks.

The key is to have open communication and frequent meetings, perhaps quarterly, to discuss pertinent information regarding all aspects of the child’s education. For the teen or college age student, discussions regarding SAT and ACT testing, career goals and transition to college would be helpful. Papers coming home announcing SAT testing and College Night are sometimes lost in the shuffle when parents are trying to resume getting back to work on a regular basis while simultaneously handling all the medical appointments and financial obligations.
HELPFUL ACCOMMODATIONS

The following checklist can be used on the 504 Plan or IEP when student is exhibiting physical, cognitive, psycho-social and emotional challenges:

☐ Two sets of books or instructional materials; one set for home and one set for school
☐ Permission to carry a water bottle throughout the school day
☐ Mid-morning and afternoon snack breaks
☐ Bathroom privileges when needed
☐ Rest period when needed
☐ Use of a 2-way agenda book in which parents and teacher can communicate on a daily/weekly basis
☐ Clarification of both oral and written directions
☐ Hard copy of notes, power-points and study guides
☐ Scribe to take notes
☐ Chunking of assignments and tests into small parts
☐ Extended wait time for responses due to slower processing
☐ Extended time to complete assignments and tests
☐ Repeat or rephrase key information of study unit to allow for additional processing
☐ Preferential seating, free of distractions
☐ Use of visual aids and manipulatives when learning new tasks
☐ Use of assistive technology to address reading and writing difficulties
Divider or study carrel to block visual distractions when completing tests, quizzes, and individual class assignments

Frequent breaks during lengthy class periods and assignments to mitigate fatigue and improve mental stamina

Modified workload with emphasis on quality versus quantity

Study guide or bank of possible questions at the beginning of each study unit

Small group or individual setting for testing, quiet and free of distractions

Teacher prompts and reminders to submit classwork and homework

Use of a voice-to-text reader to improve oral reading comprehension

Use of noise canceling headphones to reduce demands on sustained attention

Use of multi-modality learning in which auditory, visual, and tactile hands-on activities are incorporated

Use of formula bank and word bank to assist with word retrieval and memory issues

Exempt from strenuous exercises, contact sports, and long distance running in PE class

Exempt from the Presidential Physical Fitness Testing in the Fall and Spring

Participation in physical education activities as tolerated

Permission to wear sunscreen and hat when going to recess or PE

Permission to wear a hat or scarf due to hair loss or feelings of discomfort

Allowed to leave class 3-5 minutes early to avoid the crowded hallways

Peer buddy when transitioning from class to class

Elevator pass when school has multiple floors

Locker assignment close to classes

Parking space close to school entrance

Partial day school with intermittent homebound services when unable to attend for a full day

*In Virginia, homebound services are provided to elementary-age students at a maximum of 5 hours per week. High school students receive a maximum of 10 hours per week. A homebound form must be completed by a licensed physician, clinical psychologist or psychiatrist.
When classmates are not educated, they are often persistent in asking redundant questions or fabricating stories to get an answer. A class in-service can be beneficial in the following ways:

- **Answers questions**
- **Makes one less curious**
- **Makes one less afraid**
- **Makes one feel more comfortable**
- **Offers suggestions on how to be a supportive and compassionate friend**

Puppets, children’s books, doctor kits and other visuals can be used to educate children at their age-level. These in-services must be consented to by the parent or legal guardian. While some hospitals have staff to facilitate these in-services, they can also be facilitated by the school counselor, teacher, school nurse or other staff member from the home school.

Of course, an in-service should be done at the discretion of the parent.
Trauma Toolkit

**Trauma** is a disturbing or distressing event that impacts you physically, emotionally and psychologically.

**Acute Trauma:**
Events that occur at a particular time and place. These events are usually short lived; such as a job loss, sudden loss of a loved one or natural disaster. Acute trauma typically causes overwhelming feelings of terror, horror or helplessness.

**Complex Trauma:**
Exposure to repeated trauma over long periods of time, such as continual sexual abuse or domestic violence. Complex trauma usually causes intense feelings of fear, loss of trust in others, decreased sense of personal safety, guilt and shame.

*For a child with cancer, there are numerous moments throughout the course of treatment and afterwards that one might characterize as being traumatic.*

- Loss of Hair
- Hospital stays & clinic visits
- Not going to school
- Lack of consistent contact with friends
• Surgery/Needles
• Changes to body due to medication/surgery/ transplant/muscle atrophy, etc.
• Initial diagnosis & follow-up scans
• Concern for parents and siblings
• Death of friends who also have been diagnosed

**Long-term Implications of Trauma**

Consider a time that was particularly traumatic for you, such as a job loss, separation/divorce, loss of a pet, illness/injury to self or loved one, natural disaster, etc. It could have been one month, one year, or even ten years ago.

**Go back to that moment in your mind...**

**What do you hear around you?**

**What do you smell?**

**Who/what do you see?**

**What can you touch?**

**What were you feeling in this moment?**

**What are you feeling now?**
For many individuals, traumatic experiences can be triggered based upon any one of the five senses...a smell of food similar to the hospital, a noise that mimics when they were engaging in treatment, years ago.

A study completed by the Children’s Hospital of Philadelphia (CHOP) found that 30-45% of parents and siblings and 15-20% of childhood cancer survivors experience traumatic symptoms years after treatment has ended. Pre-existing vulnerabilities, prior behavioral and emotional concerns, and personal opinions about the event can all contribute to the outcome of traumatic stress symptoms in children and adolescents. **

**https://www.chop.edu/centers-programs/cancer-center/posttraumatic-stress-pediatric-cancer

How do we Manage Trauma in the Classroom?

For individuals with trauma, it is important to create an environment that feels safe and secure. One mechanism for promoting safety is to create a ritual. Rituals can be established for the entire class in the form of:

• Morning Meeting

• 5-minute drawing/coloring sessions at the start of each day

• 5-minute morning stretch break at the start of the day

The more you can promote a sense of safety and security among classmates, the more likely you will manage the trauma symptoms in the class.
Individual Safety Plans

When a student does have a moment where they are triggered or emotionally charged/reactive due to a traumatic memory, it is helpful to have a plan already in place to implement quickly. An individual safety plan consists of three to four ideas that help to decrease anxiety and feelings of stress in the moment. Some ideas for safety plans may consist of:

• 5-minute check in with the school nurse or identified school staff/administration

• Water break

• 5-minutes of listening to calming music

• Calling home to caregiver to check-in and say “Hello”
  Remember that this is a check-in, not an appeal to go home. It is important to coach the parents when the safety plan is being established on setting a boundary and talking about “weather topics,” or things that are mundane to assist in take the student’s mind of the trauma.

• Take a walk around the building

• Visit the school counselor

• Draw or color for 5-minutes
Anxiety Toolkit

To promote an environment that is grounded in safety, it is helpful to have an anxiety toolkit or station in the classroom that all students know they can access in moments of worry, stress, frustration, fear, etc. Having a station designated for all students assists in helping the student with cancer feel they are typical to their peers; put simply, they can feel “normal.” Anxiety toolkits may include:

- **Crayola Model Magic** (found in most stores with arts and craft supplies)
- **Velcro dots or strips to place on desk**
  
  Students can rub both sides of Velcro to help with focus and re-engagement in classroom activities and learning
- **Felt strips to be cut into shapes that students can keep in their pocket**
- **Bubbles**
- **Coloring sheets or adult coloring books for adolescents**
- **Lotion in a calming scent**
- **Small MP3 player for music**
- **Easy-to-read books or comics (Books that are fun!)**
- **Sticker books**
- **Stress balls**

Trauma & Anxiety Toolkit by: Ashley Soukup, Licensed Marriage & Family Therapist
Lessons Learned when working with Childhood Cancer Patients and Survivors:

**Kids Have Worries, Too**

Even though children and teens have been medically cleared to return to school there may be days in which that student may appear preoccupied or unable to focus. They may often worry about relapse, upcoming scans that are scheduled or how the good friend at the hospital is doing with his or her treatment. As an educator, if you see that the student is having a particularly bad day it may be beneficial to find some quiet time to ask if everything is okay. They may share with you their fears, concerns and worries. Sometimes these worries are too big to carry alone!

**It’s Okay to Cry**

Working with children and families who have experienced a devastating medical condition, trauma and even loss is not easy. In fact, it is really hard! What do you say when a child, teen or family shares their soul about past or upcoming medical treatment or another family crisis that is occurring? You talk with them and let them know you really care. And yes, it is okay to cry with the child or family that is hurting. We are all human and emotions are part of being human.
The Need for Normalcy

Just as adults get up and go to work each day, children and teens get up and go to school. When they are no longer able to attend school daily due to medical reasons they feel a great loss. Therefore, once transitioning back to school they will need accommodations, but subtle accommodations so they do not feel so different from their peers. Such accommodations may include a peer buddy with whom to play board games when others are participating in recess or physical education activities that are too strenuous or demanding, or eating lunch with a peer buddy when crowded lunchrooms must be avoided. This is a time when school personnel must be creative and help the child or teen find normalcy at school despite the limitations he or she might be experiencing.

Belonging

Many changes come with a medical diagnosis. Teens who were once star athletes are sometimes told they can no longer play football, basketball, soccer or other contact sports. Others who have spent hours practicing or rehearsing for a role in the dance recital or upcoming performance no longer have the energy to perform. When these children return to school, they often feel that they no longer have a social group in which to belong. They feel a loss and the loss is great. As an educator you may want to encourage the child or teen to try other activities such as art, band, chorus, theatre, robotics team or chess club. Schools today offer so many extra-curricular activities that there are many options. If the student does not seem interested in the school activities then community involvement such as church youth group, scouts or volunteering at a shelter or for a non-profit organization may be an option. The key is finding a social group in which to feel a part and belong!