CHILDHOOD CANCER EDUCATION TOOLKIT PARENT SECTION











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In 2018, approximately 325 children in Virginia were diagnosed with childhood cancer.

While treatment plan and length of treatment vary depending on the type of childhood cancer, the desire for normalcy and concern for education are common themes expressed by parents, children, teens and young adults. Hopefully, this educational toolkit will answer many of the questions parents may have when transitioning their child back to school following treatment.

When first diagnosed, the child or teen is usually placed on homebound services and receives educational services at home when too sick or blood counts are too low to attend school. However, as the child gets through the induction and consolidation phases and blood counts recover, the physician allows the child to return to school, either for a partial day or full-time. This is when a meeting must be scheduled to address the transition back to school. While the meetings and process of returning to school can be overwhelming, this toolkit will answer many of the questions.

The parent and school sections of this toolkit address many of the same concerns in regard to the physical, cognitive, psycho-social emotional and spiritual late effects or challenges. Therefore, the parents and school team can have open communication regarding the late effects and accommodations needed in the school setting. It is very important that parents feel comfortable sending their child back to school following treatment and that they know their child will feel safe and that his or her needs will be met.



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 when faced with these challenges?

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

• School health plan

Each school division may have its own school health plan, but each plan does address the diagnosis, 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.

• Networking with local and state agencies, non-profit organizations, and businesses in the community

MOST COMMON PHYSICAL CHALLENGES

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- 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 student have an extra set of books in the 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 are common challenges they may face:

- Slower Processing Speed
- Short Term Memory Loss
- Inability to Focus or Concentrate for Long Periods of Time
- 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 and 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 indepth 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 with 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. The student 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



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 and 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

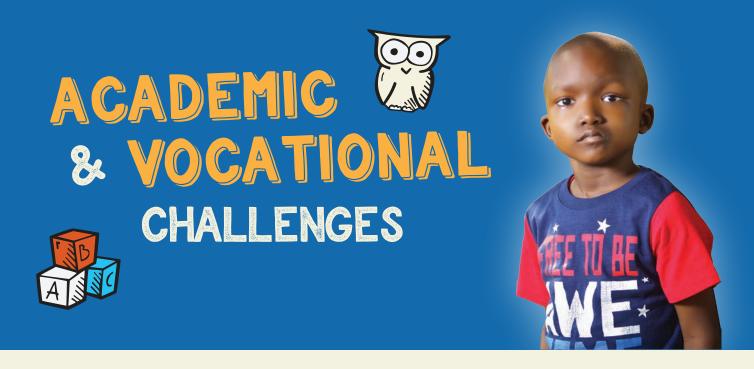


MOST COMMON SPIRITUAL CHALLENGES

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.



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.







Prior to the child transitioning back to school, parents need to meet with the school nurse to obtain a copy of the School Health Plan and then have their child's physician complete the plan.

The School Health Plan is important because it:

- States the diagnosis and medical condition
- Lists medications given at school
- Outlines medical procedures that will be performed at school
- States feeding and nutritional needs at school
- Lists physical accommodations needed in the school setting
- Provides information regarding emergency contacts and procedures

Why Is an Educational Plan Important?

Most children and teens returning to school after a cancer diagnosis need an Educational Plan to accommodate for the side effects and challenges associated with treatment.

What Educational Plans are Available?

- Section 504 of the Rehabilitation Act of 1973
- Individuals with Disabilities Education Act

What is Section 504?

It is a civil rights law that prohibits discrimination based upon disability.

What constitutes a disability?

- When a person has a mental or physical impairment which substantially limits one or more major life activities
- When a person has a record of such an impairment or is regarded as having such an "impairment"

*The clinic or hospital dictation can serve as the record of the impairment. Parents need to obtain the dictation from the clinic or hospital prior to attending the school meetings to discuss educational plans and the need for accommodations.

What is defined as an "impairment"?

Any disability, long-term illness or disorder that substantially reduces or lessens a student's ability to access learning in the educational setting because of a learning problem, behavioral issue or health-related condition.

*Parents, keywords here are "long-term illness" and "health-related condition." A diagnosis of childhood cancer is definitely an illness that lessens a student's ability to access learning in the educational setting because of a health-related condition. Attendance, the ability to sit for an extended time, concentration due to the chemotherapy or treatment and just overall thinking are a few of the major life activities that might be impacted.

What are considered Major Life Activities?

- Self-Care
- Thinking
- Manual Tasks
- Learning
- Walking
- Breathing
- Seeing

- Concentrating
- Hearing
- Interacting
- Speaking
- Working
- Sitting

*Parents, please note that children and teens who are making good grades and are academically successful can still be eligible for a 504 Plan. Many children and teens who are in gifted programs, taking accelerated classes or Advanced Placement classes may have a 504 Plan if the impairment substantially limits one or more major life activities. Even students who are in college may have a 504 plan. Many times, the student may need extended time due to slower processing or a scribe to take notes if attention or concentration is an issue. Late effects of treatment can substantially limit the major activity of learning.

What is the Individuals with Disabilities Education Act (IDEA)?

IDEA, Individuals with Disabilities Education Act, is a federal law that ensures that all children with a disability are provided a free appropriate public education that is tailored to meet their individual needs. Each child who is found eligible for special education services under IDEA has an IEP, Individualized Education Program, that is written specifically for his or her unique learning needs.

Children must be evaluated to determine if they qualify for special education and related services under IDEA.

Evaluations can include:

- Medical
- Psychological
- Educational
- Social History
- Speech Language
- Physical Therapy Evaluation
- Occupational Therapy Evaluation
- Assistive Technology Evaluation
- Classroom Observation

While there are 13 handicapping conditions under IDEA, children with childhood cancer who need special education services often qualify under the handicapping condition of Other Health Impairment. Of course, if the child is exhibiting cognitive deficits due to treatment, the handicapping condition of Specific Learning Disability, Speech or Language Impairment or another may be used.

*Parents, please note that this process for evaluation can be lengthy. The school district has 65 days to complete the evaluations. Sometimes it is beneficial to put accommodations in place under a 504 Plan due to the medical condition so that the child will not fall behind during the evaluation process.

For more information, please reference Virginia Department of Education (VDOE) VDOE Evaluation and Eligibility.

HELPFUL Accommodations

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



PARENT HOMEWORK



Parent Homework Prior to Transitioning Child Back to School

Step 1: Call school and request a School-Based Team Meeting

*A referral to a school-based team can be verbal or written, but a written referral is good documentation that the referral has been made, requesting a meeting. The school has ten (10) days to respond with a meeting date.

Step 2: Obtain a copy of the latest clinic dictation or medical summary so that the school will have documentation of diagnosis, treatment and other pertinent medical information.

Step 3: Attend the School-Based Team Meeting and discuss the following:

- Diagnosis
- Treatment
- Side Effects or Challenges (physical, cognitive & psycho-social emotional)
- How the side effects of treatment and challenges have impacted learning
- What accommodations may be needed in the school setting
- What evaluations may be needed in order to better serve the child
- Whether or not a class in-service is needed in order to answer questions and make the child more comfortable with peers
- Information regarding emergency contacts and procedures

*Parents should request that the school nurse and all teachers working with the child be present at the meeting. If the school-based team recommends that additional evaluations are required, then they have sixty-five (65) business days to complete all evaluations.

After the evaluations are completed, the team will determine if the student is eligible for accommodations under a 504 Plan or for special education under an Individualized Education Program (IEP). They then have 30 days to write an IEP or 504 Plan.

Why a Class In-Service is Important

Determine whether or not a class in-service is needed in order to answer questions and make the child more comfortable with peers.

- Answers questions
- Makes children less curious
- Makes children less afraid
- Makes children feel more comfortable
- Offers helpful hints and suggestions on how to be supportive and a good friend



The class in-service should be given at an age-appropriate level. The educational consultant, social worker or child life therapist at the medical center where your child is treated may be the one to facilitate the in-service. Otherwise, it may be a teacher, school counselor or school nurse at your child's school. Of course, an in-service is at the discretion of the parents. Suggestions are:

- A short description of the diagnosis and treatment is always a good way to begin followed by pictures, diagrams and big words like "chemotherapy" on the board.
- Then use the puppets to show where the Port-A-Cath is placed and how the medication is given.
- Next, side effects such as hair loss, fatigue, and low stamina can be discussed.
- Classmates and facilitators can discuss ways to be a good friend.

Puppets, pictures and medical devices to share with the children such as a Port-A-Cath, and children's books are always helpful when doing an in-service. Classmates need to know why their friend is frequently absent, is allowed to wear a hat, cannot play contact sports such as dodge ball at PE or recess, and may need a rest period.



Advocating for Your Child

- 1: Parents need to remember that they know their child better than anyone. This includes the medical center and the school.
- **2:** Parents may want to start at a young age teaching self-advocacy skills. A few suggestions for this are:
 - Encourage your child to start early thinking and learning about who he or she is.
 - Help your child learn his or her strengths and challenges.
 - Teach your child to communicate effectively with teachers, medical staff, friends and others about his or her strengths and challenges. He or she should never be ashamed or embarrassed to talk openly and freely about the diagnosis, treatment, challenges and needs.
- 3: As children and teens reach their goals and become more independent, stay involved and know that at each transition period, whether to middle school, high school, college or a new job, parents may need to hold their child's hands a little longer. Straddling the line between childhood, adolescence, and adulthood can be scary.
- 4: When a teen transitions to college, meet with the Office for Students with Disabilities at the college or university to discuss 504 accommodations needed at the post-secondary level. Accommodations to consider are extended time for exams, hard copy of notes or lectures, a scribe to take notes, use of assistive technology, etc.
- **5:** Explore community and state resources that are available. For teens and young adults who need assistance in regard to their disability and post-secondary education needs, the Virginia Department of Aging and Rehabilitative Services, otherwise known as DARS, offers wonderful programs that include vocational counseling and training, work adjustment, independent living skills training, assistive technology consults and evaluations, driver's education, job coaching and placement and others. Each high school is assigned a DARS counselor that can work with the student before leaving high school and assist with planning of post-secondary education goals.





"My daughter is currently enrolled in the Vocational Training program at Woodrow Wilson Rehabilitation Center in Fishersville, Virginia. They are preparing her for workforce readiness, and she gets evaluated and trained during her internships in the community. She has successfully completed PERT: Post-Secondary Education, Rehabilitation and Transition, Vocation Evaluation, and PREP, Preemployment Readiness and Education Program - each time, living independently away from home as a resident. This fall, she is scheduled to attend the Behind the Wheel program for a driver's license at WWRC: Wilson Workforce Rehabilitation Center.

Our first tour to WWRC was somewhat overwhelming. It's a wellrun machine but a big campus, much like a small college. It's in a beautiful setting in the Shenandoah Valley. I immediately noticed the campus police station and security cameras everywhere that gave me instant relief. Students and staff are polite and respectful. There are activities galore in the recreation hall - bowling, swimming, pool tables, arts & crafts, TV, computer games, etc. The external features include tennis, basketball, and lake activities. During spring and summer, they have field trips such as camping, Kings Dominion, etc.

My daughter has blossomed in ways I didn't think possible at WWRC. She is far more confident and outgoing than when she first began. She lives independently, navigates her daily schedule including getting up for class/work on time, signs up for extracurricular activities, shops for her basic needs by taking the Brite Bus to Walmart or CVS, does her laundry, and even manages her daily meds within her room (but the clinic is available if needed). We stay in touch via FaceTime and visit her about every 3 weeks. She has free internet access on campus so she can use her phone freely. She has a ton of friends there and participates in their bowling league. She's very comfortable in her environment and feels very safe. WWRC is a stickler about bullying, respect, and following the rules including curfew. They have weekly room inspections which keeps her on top of her game with cleanliness. There is a lot of shared space and bathrooms so she has to work in a team to keep things clean. Dorm staff, counselors, nurses, are available 7 days a week. The cafeteria serves balanced meals (starting as early as 6:30 am) and you can get food off hours in the Grill if you miss the scheduled hours.

I think what she enjoys most about WWRC is the many activities available each week and being amongst young adults that have similar disabilities. She can be herself with her speech delays and learning challenges and still be accepted. She doesn't have to try to "fit in" or avoid situations like she did in high school. What I like most is her content, growth, and happiness at WWRC. We are so fortunate that this highly specialized training facility exists in VA. If she never gets to attend college, this is the next best thing to that experience!"

From Pam Hill, parent of young adult survivor



(804) 658-5910 5211 W Broad St Suite 102, Richmond, VA 23230 www.askccf.org