



Parent Handbook – Children’s Neuroblastoma Cancer Foundation

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Identification and Interventions for Cognitive and Academic Difficulties in Pediatric Neuroblastoma Survivors

Children who undergo treatments for cancer are at risk for cognitive late-effects of treatment due to the potential neurotoxicity of anesthesia, steroids, chemotherapy and irradiation. This section provides information on types of cognitive and academic difficulties neuroblastoma survivors may be at risk for, signs and behaviors you may observe in a child experiencing cognitive difficulties, and interventions to support neurocognitive challenges.

- **Why are children at risk for cognitive difficulties after treatment for neuroblastoma and what types of difficulties are most common?**
 - While less research has been done on the late-cognitive effects of neuroblastoma compared to other types of cancer, general research on the impact of chemotherapy on cognitive functioning have demonstrated difficulties in “cognitive proficiency skills” that include aspects of attention, processing speed, and executive functioning for survivors treated with chemotherapy (Trapiani & Murdaugh, 2022). This is thought to be due to the impact that chemotherapy has on white matter networks throughout the brain, which interferes with the brain’s ability to efficiently send messages between brain cells and execute complex cognitive tasks (van der Plas et al, 2020). Patients who undergo certain types of chemotherapy (e.g., vincristine) can also experience difficulty with fine-motor coordination and dexterity due to peripheral neuropathy, which can lead to numbness, tingling or weakness in the hands and feet (Phillips et al., 2021).
 - Patients with neuroblastoma have higher rates of high-frequency hearing loss following treatment due to exposure to platinum-containing chemotherapies such as cisplatin and carboplatin. Hearing loss is most common in patients under five years old and leads to more detrimental impacts on language compared to hearing loss onset in school-aged children (Meijer et al., 2022; St John et al., 2020). Hearing loss can impact language development by making it difficult to discriminate the variety of sounds in speech, which can lead to a reduction in language exposure and acquisition. Over time, this can interfere with expressive and receptive language skills, reading and writing abilities, as well as mastery of other academic skills. Childhood survivors with hearing loss have higher rates of learning disabilities, problems with reading and math skills, and use of special education services compared to survivors without hearing loss (Gurney et al., 2007). There can also be social

- challenges that can arise as a result of high frequency hearing loss when individuals are in large group settings, making it sometimes difficult to hear and participate in conversations.
- Patients with high-risk neuroblastoma may also be at risk for greater cognitive difficulties if their treatment requires irradiation to treat their illness (Zhao et al., 2020). The impact of radiation on cognitive functioning is mixed: studies involving radiation to the brain have demonstrated a link between weaknesses in attention, memory, and learning while others have found no cognitive differences in neuroblastoma patients who underwent total body irradiation as a preparative regimen for a transplant (Carpentieri & Diller, 2005).
 - The average age of neuroblastoma diagnosis is between one and two years old and about 90% of neuroblastoma occurs prior to five years of age (American Cancer Society, 2023). Children who are younger at the time of their diagnosis and treatments are at a higher risk of cognitive and psychological difficulties (e.g., anxiety, depression, oppositional behaviors, social challenges) due to the important period of brain development children undergo in the first few years of life (Krull et al, 2018). Interruptions to early brain development can impact the development of brain pathways that are the foundation for processes related to thinking and learning.

- **What are the signs and symptoms of neurocognitive difficulties that one might observe in neuroblastoma survivors in daily life?**

Cognitive Domain	Your child may ...
<p>Attention (ability to selectively focus on specific information in the environment)</p> <p>Working Memory (ability to hold and manipulate information in the short-term)</p>	<ul style="list-style-type: none"> ● have difficulty concentrating on homework or in conversation ● tend to become distracted by interruptions to work and have a difficult time returning to the task ● frequently appear to daydream or “zone out” ● often make careless errors on tests or homework ● demonstrate trouble remembering instructions in multi-step tasks
<p>Processing speed (rate at which one responds to information or performs a mental task)</p>	<ul style="list-style-type: none"> ● be unable to complete tests or school assignments within the expected time limit for their age ● take a long time to verbally respond to questions or in conversation ● take longer than typical to complete household tasks
<p>Executive functioning (set of cognitive skills used to control and coordinate behavior to complete goals including initiation of a task, inhibition of behavior or thoughts, mental and emotional flexibility, planning, organization, shifting between tasks, self-awareness)</p>	<ul style="list-style-type: none"> ● have difficulty keeping track of assignments ● tend to routinely lose or misplace personal items ● often have a messy room or backpack

	<ul style="list-style-type: none"> • have challenges with planning how to approach complex or long-term assignments • have poor time management or a tendency to procrastinate • demonstrate trouble controlling behavior (e.g., impulsivity) or emotional reactions (e.g., tantrums) • have difficulties problem-solving
<p>Language</p> <p><i>Expressive language:</i> the “output” of language; one’s ability to produce communication through speech, writing, or nonverbal modes (e.g., sign language)</p> <p><i>Receptive language:</i> the “input” of language; one’s ability to understand and comprehend spoken language that is heard or read</p>	<p><i>Expressive Language Difficulties:</i></p> <ul style="list-style-type: none"> • demonstrate difficulty expressing their thoughts or ideas in speech, • have a limited vocabulary compared to same-aged peers • tend to make grammatical errors in speech or have speech that is confusing/illogical • dislike spelling or writing <p><i>Receptive Language Difficulties:</i></p> <ul style="list-style-type: none"> • have difficulty understanding lengthy or complex explanations • frequently ask for repetition of directions from teachers/parents • find reading and/or reading comprehension challenging
<p>Higher rates of learning disorders (characterized by persistent impairment in at least one of three major content areas – reading, writing, and/or math; may be specific to one subject or across content areas)</p>	<ul style="list-style-type: none"> • receive low grades across classes or in one particular subject • avoid homework in a specific subject matter <p><i>Reading:</i></p> <ul style="list-style-type: none"> • read slower or with more errors than typical for their age • problems sounding out words or recognizing sounds/letters • difficulty understanding what they have read <p><i>Math:</i></p> <ul style="list-style-type: none"> • demonstrate challenges with math concepts (e.g., counting, arithmetic) • challenges counting forward and/or backwards

	<ul style="list-style-type: none"> • difficulty with telling time or making sense of money <p><i>Writing:</i></p> <ul style="list-style-type: none"> • poor handwriting • frequent grammatical, punctuation, or spelling errors in written work • challenges organizing thoughts while writing
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- **What do I do if I am concerned about my child’s cognitive or academic functioning?**

- *Ask medical team or psychosocial providers for a referral for a neuropsychological evaluation*
 - If time allows, it may be possible to have a neuropsychological evaluation before treatment begins in order to have a baseline of your child’s cognitive and academic abilities, as well as social-emotional functioning.
 - Neuropsychological evaluations can also be requested after treatment ends. After an initial evaluation, your child may have an evaluation every one to three years to assess cognitive changes, and ensure they have appropriate supports in place at home and at school.
 - It is important to note the difference between psychological, psychoeducational, and neuropsychological evaluations to ensure you are getting the most appropriate assessment for your child; it is acceptable and encouraged to ask any evaluator (whether it be through the school or an outside provider) what type of testing they are conducting; schools commonly provide psychological or psychoeducational testing but not a full neuropsychological evaluation.
 - *Psychological testing* can include diagnostic interviews or metrics to help identify and diagnose psychiatric and developmental disorders such as anxiety, AD/HD, autism spectrum disorder, etc.
 - *Psychoeducational evaluations* typically include a measure of general intelligence (e.g., IQ) and academic abilities (e.g., reading, writing, spelling) but does not include measurement of other cognitive domains or social-emotional functioning.
 - *Neuropsychological testing* provides a comprehensive evaluation of an individual’s general intelligence, as well as their abilities across multiple cognitive domains such as attention, language, reasoning skills, processing speed, and memory. Assessment of social, emotional, and behavioral functioning is also typically included. Neuropsychological testing can provide insight into a child’s learning style and psychological functioning, and provide individualized recommendations based on their personal strengths and weaknesses.
- *Contact child’s school to access supports*
 - Under the “**Individuals with Disabilities Education Act**”, children with disabilities are guaranteed access to a free public education and related supportive services until their high school graduation or age 21 (whichever comes first). This also

includes early intervention services to infants and toddlers up to age 3. This law also ensures that children have the right to an evaluation through their school that assesses their functioning and need for various services; the IDEA act requires that the evaluation is done within 60 calendar days if the school agrees that your child needs an evaluation. Evaluations can also be conducted privately such as with a neuropsychologist at your medical care center.

- After the evaluation, children with qualifying disabilities will have an **Individualized Education Plan (IEP)**. An IEP is a written document that is created from collaboration between parents, school administration, teachers (both general education and a special education teacher), school psychologists, and other medical providers (e.g., oncologist, psychiatrist, neuropsychologist, etc.). The IEP outlines the type of classroom and curriculum that is most appropriate for a child, along with related services they will receive through the school. An IEP is most appropriate for when a child's disability affects the child's educational performance and/or their ability to learn from a general education curriculum. It is for when children require specialized instruction or services to make progress in school (e.g., smaller classrooms, speech/language therapy).
- After your child has completed a neuropsychological evaluation, what's next?
 - For children with disabilities who do not qualify for IEP, a **504 plan** is an option for students with disabilities who can participate in a general education curriculum, but who would benefit from accommodations in order to do so. A 504 plan provides changes to the learning environment that enable students to more effectively learn alongside their peers (e.g., sitting a child towards the front of the classroom, or providing extra time on tests or assignments). For children actively on treatment, 504 plans can provide a child the opportunity to take breaks as needed due to fatigue, to visit the school nurse, or use the bathroom. They may also be allowed to use the school elevator or have the assistance of a health paraprofessional to accompany them throughout the day if mobility or energy due to treatment is a concern.
 - A comprehensive explanation of the difference between IEPs and 504 plans can be found at Understood.org: <https://www.understood.org/en/articles/the-difference-between-ieps-and-504-plans>
 - Accommodations or services that might be available to your child through an IEP include:
 - Testing accommodations: Your child may be able to have extra time to take tests or complete assignments, both at school and for state or district-wide assessments. They may also be able to take tests in a separate setting outside the classroom with minimal distractions and other services such as having someone read questions to them or being able to ask questions.
 - For children with difficulties in specific subject areas, additional instruction in reading, writing, or math can be provided one-on-one or in small groups.
 - Specialized therapy to support your child's development in areas that may have been delayed during or after their treatment can also be provided

- individually or in a group. This may include speech and language therapy, occupational therapy, physical therapy, or auditory and hearing services.
 - Adaptive technology evaluations can also be requested through an IEP to assess the need for assistive devices that mitigate difficulties with hearing, language, fine-motor difficulties, and processing speed (e.g., dictation devices, laptops, audio recording tools, etc.).
 - For children with emotional or behavioral difficulties, counseling services or the provision of a paraprofessional can be provided to support the development of coping strategies and behavior management at school.
- *Collaborate with mental health professionals*
 - In addition to school services, connecting with mental health professionals outside of school can provide additional support for your child’s social, emotional, and behavioral functioning. Psychologists can help to:
 - Assist children and parents in developing strategies to improve attention and executive functioning skills that help them stay focused in school and organized in their work
 - Help children with anxiety, depressed mood, or emotion dysregulation challenges develop coping skills during or after treatment to ensure emotional distress does not interfere with their ability to engage in schoolwork or enjoyable activities
 - Offer parent training to help families learn effective behavior management strategies
 - Provide psychoeducation on the clinical presentation and trajectory of your child’s symptoms, information on treatments, and support on how to navigate school accommodations
 - Parents can also work with an educational advocate to navigate the procedures of their local school district, assist with completing paperwork, identify appropriate services, and help intervene if school districts are not providing agreed upon services. Some cancer centers offer educational liaisons who will assist in connecting your child with appropriate services as your transitions back to school after treatment.
 - For attention difficulties or emotional challenges that do not improve with school or behavioral supports, consultation with a child psychiatrist or psychopharmacologist can provide information on medications that safely improve attention, anxiety, depression, and emotion regulation difficulties in children.

Additional Resources

Websites that can provide additional information about common psychological disorders, treatment options, navigating school services, and at-home strategies for optimizing functioning include:

- Understood.org
- Childmind.org
- ADDitudemagazine.com

Books for children with attention or executive functioning difficulties:

- “*Smart but Scattered*” by Richard Guare & Peg Dawson.
- “*Thriving with ADHD Workbook for Kids: 60 Fun Activities to Help Children Self-Regulate, Focus, and Succeed (Health and Wellness Workbooks for Kids)*”

Books for children with speech and language difficulties:

- “*The Parent’s Guide to Speech and Language Problems*” by Debbie Feit
- “*Helping Your Child with Language-Based Learning Disabilities: Strategies to Succeed in School and Life with Dyslexia, Dysgraphia, Dyscalculia, ADHD, and Processing Disorders*” by Daniel Franklin & Louis Cozolino

Books for children with mental health struggles:

- “*CBT Toolbox for Children and Adolescents*” by Lisa Phifer
- “*Helping Your Anxious Child: A Step-by-Step Guide for Parents*” by Ronald Rapee
- “*Anxiety Relief for Teens: Essential CBT Skills and Mindfulness Practices to Overcome Anxiety and Stress*” by Regine Galanti

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