



Parent Roadmap: Kids with Cancer Still Need School

First Step on the Journey into Survivorship: Diagnosis

Your child has just been diagnosed with cancer and may be starting treatment. You and your family are making a lot of adjustments and absorbing a lot of new information. School may be the last thing on your mind but there are a few things to get started on now that will help your child adjust and prepare you for important steps down the line. Use this roadmap to help you ask important questions, be sure to record information to refer back to later.

Health Care Related

Checklist of Things to Ask or Do

- What are possible impacts of treatment on school/neurocognitive function?
- How long can I expect my child to be out of school?*
- Should my child have baseline neuropsychological* testing? If yes, check with you insurance company regarding coverage.
- Meet with treatment team to discuss neurocognitive* issues and possible school effects
- Meet with child life or social work to discuss approaches to talking to your child about missing school.
- Ask the treatment team to identify one or more people who will be able to be the primary contact who will communicate with school team members as needed.
- Ask to sign a release of information to permit communication between school and hospital.

*see reverse to learn more about these terms.

**If your child is not school aged, ask about early intervention services s/he may be eligible for even before they start pre-school

School/Community Related

Checklist of Things to Ask or Do

- Inform the school that your child has a newly diagnosed illness and provide an estimate of how long s/he is expected to be out of school.
- Talk to teacher about what you want your child's classmates to know about the illness.
- Ask to identify one or more people who can be a primary point of contact to communicate with you and with the hospital. Let this person know the best way to contact you/how you prefer to be contacted.
- Connect the primary points of contact from hospital and school to each other if possible. This could mean starting an email conversation including contacts from both hospital and school.
- With your child, identify classmates that he/she wants to stay in contact with so missing school is not so socially isolating (consider both virtual or in-person hospital visits if appropriate).
- Consider supporting your (younger) child to have a virtual presence in their classroom, or introducing the school to "Monkey in my chair" <http://www.monkeyinmychair.org/program>

First Step: Knowledge you need and resources that can help provide it

You will be learning a lot of new words about cancer and cancer treatment. It might be surprising, but you might also need to learn some new words about school and learning.

What are neurocognitive skills or abilities?

- Neurocognitive abilities is a term for skills we use to pay attention, understand what people say to us, think about our own actions or answers, and respond to others or complete tasks.
- These skills can be affected by cancer itself (such as brain tumors) or by the methods used to treat the cancer (such as chemotherapy given with a spinal tap or radiation to the brain).

Why is this a concern for my child?

Many of the treatments given to treat childhood cancer can affect the brain and its development. This is especially true for children treated for brain tumors or leukemia (because the central nervous system may harbor leukemia cells, it requires specific treatments). But all children treated for cancer are at risk for changes in neurocognitive function. Other physical changes like hearing loss and fatigue may accompany treatment and make learning more difficult. To understand if there are changes in your child's neurocognitive function, you may want to request neuropsychological testing. You do not have to do this right away – some families wait until the child is ready to return to school.

What is neuropsychological testing?

- Neuropsychological testing is a way of measuring the effects of disease or treatment on a person's behavior and performance through a set of specific tasks.
- You may also hear people call these tests *neuropsychological assessments*, *neuropsychs* or *neuropsych evals*.
- The testing involves attention, language, motor (such as muscles required for balance or writing), reasoning (how someone thinks about things to come to a decision), problem-solving, and memory tasks, given one-on-one to a person by a neuropsychologist. The process also usually includes interviews and questionnaires to determine how the child functions in their day to day life, how the child is coping, and what changes might have occurred over time. For children, the tasks are usually somewhat similar to school or "brain teasers," so children are usually comfortable once they get started. **Be sure to check with your insurance company about coverage.**

Helpful resources:

<https://theaacn.org/pediatric-neuropsychology/>

<https://www.understood.org/en/learning-attention-issues/treatments-approaches/working-with-clinicians/pediatric-neuropsychologists-what-you-need-to-know>

Next step on the Journey into Survivorship: Starting Home and Hospital Teaching