



Parent Roadmap: Kids with Cancer Still Need School

What about Toddlers and Preschoolers?

Your child has been diagnosed with cancer. Cancer and its treatments can affect a child's development, including ways s/he grows, learns, feels, or thinks. Sometimes this can create challenges later in school. Even though your child may be too young for school now, acting now can make things easier later. Your child may be able to get help from state programs like "Early Intervention." This Roadmap provides you with information that may help you do things now that can help with school later.

Health Care Related

Checklist of Things to Ask or Do

- What are possible effects of treatment on my child's development?
- Ask if your child might need physical therapy to help muscles develop/stay flexible and/or help managing behavior –especially during treatment.
- Should my child have neuropsychological* testing? If yes, check with your insurance company regarding coverage and ask the oncologist to make a referral.
- Ask the treatment team to identify one or more people who will be your primary contact for any developmental concerns and if your child's primary care provider will be involved.
- Talk regularly with your contact person about what to watch for in terms of how your child is growing, learning, and behaving. Make sure to report any concerns you may have.
- Meet with a representative from Child Life or a Social Worker to discuss how to access *Infants and Toddlers* or *Early Intervention/Preschool* Special Education Services in your state.

* Neuropsychological testing for your young child can give useful information about things like how s/he speaks, moves, pays attention, thinks, and solves problems. This can help you know if getting services now will be important to help prepare your child for school later. It can also help provide a baseline so you can compare how your child develops skills over time.

Home/Community Related

Checklist of Things to Ask or Do

- If your child is in day care or preschool, talk with the health care provider about his/her diagnosis and any concerns about attending day care/preschool. Share information from the healthcare team about any necessary health precautions with the day care/preschool staff.
- Ask who can be your primary point of contact(s) at day care/preschool so you always know who you can talk with about how your child is doing and any concerns for your child's development.
- If you can, help connect the primary contacts from hospital and preschool/day care to each other. This could mean starting an email conversation between the contacts.
- If you can, keep up normal routines and activities. Doing things with friends is important for your child's development. Treatment can make families and children feel isolated, so try to find community/social activities and ask your oncology provider if they are safe for your child/family.

First Step: Knowledge you need and resources that can help

Can having cancer or treatment now affect development and school later?

- Cancer or its treatment can affect how your child develops and reaches their milestones. Examples of milestones include walking, talking, taking turns, learning to share, and using the toilet. These skills are important for being ready for school.
- These skills can be affected by cancer itself (such as brain tumors) and/or the methods used to treat the cancer (such as chemotherapy given with a spinal tap or radiation to the brain). Since their brains are still developing quickly, young children are at risk for developmental changes during and after treatment. This means that treatment can have an effect now, and can affect the way the brain develops skills later.
- Cancer and treatment can also cause physical changes like hearing loss and muscle weakness. These can affect how well children can do everyday activities, like talking or walking.
- Everyday activities like crawling and playing can help your child grow and prepare for school. If everyday activities aren't enough to help your child develop school readiness skills, your child may be eligible for services now to help address negative effects from cancer or its treatment.

What can I do now to help make school easier later?

You may want to request neuropsychological testing (see first page) and/or seek an evaluation from the Infants and Toddlers/Early Intervention services. This can help you make a decision about whether just doing everyday activities will be enough or if getting extra services will be important to help your child reach milestones they need to be ready for school.

What Early Intervention services or resources are available to help me or my child?

Infants and Toddlers Program: directs a family-centered system of early intervention services for young children with developmental delays and disabilities and their families. These programs are composed of local departments of education, health, social services, and other public and private providers in each county or state. Intervention plans are called Individual Family Service Plans (IFSP). Services may include: audiology, physical therapy, occupational therapy, transportation, speech-language pathology, family training, special instruction, assistive technology, and home visits. For more information visit: <https://www.cdc.gov/ncbddd/actearly/parents/states.html> or in Maryland, <https://referral.mditp.org/index.html>.

Preschool Special Education Services: provides specialized instruction and related services, including speech-language, physical, and occupational therapies, to young children, ages 3 through 5, who are eligible under the Individuals with Disabilities Education Act, and in accordance with State special education regulations. Intervention plans for preschoolers are called Individualized Education Programs (IEP). For more information visit:

<http://marylandpublicschools.org/programs/Pages/Special-Education/MITP/PreschoolServices.aspx>

More helpful resources to check out:

<https://www.understood.org/en/learning-thinking-differences/treatments-approaches/early-intervention/what-to-expect-during-an-early-intervention-evaluation?>

<https://www.understood.org/en/school-learning/special-services/ieps/getting-an-iep-for-your-very-young-child?>