



# Parent Roadmap: Kids with Cancer Still Need School

## Fourth Step on the Journey into Survivorship: Returning to School after Treatment

Congratulations! Your child has completed therapy or s/he may be in maintenance therapy. So far, your child's medical issues have been your priority. They will still be important. After cancer treatment, some children learn differently from how they did before. Especially if this is true for your child, you may need to be very involved in their schooling to be sure s/he is able to get the additional school supports that they have a legal right to receive.

### Health Care Related

#### Checklist of Things to Ask or Do

- What does my child's post-therapy follow up look like? What kind and how many medical visits will there be?
- Does my child need any physical rehabilitation services? Are there lingering side-effects that may impact his/her ability to fully take part in school such as being tired or having muscle weakness? (For example, your child might need PT for rehabilitation or OT for weakness/hand writing difficulty.)
- Should we monitor for long term neurocognitive changes after my child's treatment?
- Should my child have a(nother) neuropsychological assessment\*? How do I access this service?
- Identify who on your health care team has expertise in long term neurocognitive changes and resources for supporting survivors at school. This may be one or more of the following: psychologist, neuropsychologist, social worker, child life therapist or advanced practice provider. Some institutions may have a School Liaison Program; your oncology team will know if this is available and can connect you.
- Talk to your oncology team about school performance at each follow up visit. Even if the primary aim of the visit is to follow up on cancer, how your child is doing in school after treatment is important and they will want to know about it. Also talk about these issues during visits with your child's regular pediatrician.

\*The First Step: Diagnosis page has information about this term.

\*\*The Third Step: Return to School has information about this term.

### School/Community Related

#### Checklist of Things to Ask or Do

- If your child has a 504 Plan\*\*, discuss how to continue or modify the plan or if an Individual Education Program (IEP; see reverse side) is more appropriate.
- If your child has had neuropsychological testing, talk to the neuropsychologist about using the results to help your child with school. Share the report of the evaluation with your child's school team.
- Get to know the people on your child's school team. Many families report that finding someone in the school that has experience with childhood cancer or who is motivated to learn about it helps things go more smoothly.
- Reach out to parents with similar experiences. The best advice can come from someone who has also been touched by cancer. This may be someone you met in the hospital waiting room or a neighbor whose child has a similar health condition. You can also ask your treatment team or local foundations to connect you.
- Tap into community resources. Ask your oncology team, your child's school, or others in the community for suggestions. For example, you might find local tutoring programs or advocacy organizations such as the Special Education Parent Teacher Association/Organization (SEPTA/O).
- At the end of every school year, ask how your child's teacher/school administrator plans to transition and communicate your child's supports to the next grade. This is particularly important when transitioning to middle school and high school. Reach out to upcoming teachers so they are aware of your child's needs.
- Support your child to be engaged with social and extra-curricular activities as much as possible.

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

This page explains critical terms about school processes and tools you might need.

### What is an IEP?

- IEP stands for an Individualized Education Program, a plan that allows your child to receive special education supports, services, and modifications, if needed.
- IEPs are mandated by the Individuals with Disabilities Education Act (IDEA), a federal law that ensures that all children have access to a free and appropriate public education. In other words, this law ensures children with disabilities have equal access to education and schooling, including special education when needed. This law applies to public schools only. Private schools do not have to provide special education. However, you should still check to see what resources are available for your child if they attend private school.
- Children may be found eligible for special education under a variety of specific disability categories: in many cases, the categories of *Other Health Impairment* or *Traumatic Brain Injury* are often most appropriate for children with a history of cancer and related treatments. The categories of *Specific Learning Disability* or *Intellectual Disability* may also apply in some cases.

### How do I know if my child needs an IEP?

- Your child may need an IEP if the effects of cancer and related treatments are causing your child to learn, behave, or otherwise function differently –and if s/he is having more trouble in school as a result. In other words, if you notice your child begin to struggle, you should consider whether your child may need additional supports beyond a 504 Plan.
- If you have concerns, consider a meeting with your child’s teacher; ask how your child is performing and whether s/he is working on grade level.
- After talking with the teacher, the first step towards an IEP is to request an IEP Team meeting, by sending a written request or letter to the principal. The IEP Team involves a group of educators and administrators who follow a legal process defined by IDEA; the first step is to set up a meeting to discuss your child’s performance and health, and your specific concerns. If you have a report from a neuropsychological assessment, consider sharing it with the team in advance of the meeting to help them understand your child’s medical history, strengths, and needs.
- At the meeting, you and the IEP Team will discuss your child’s current performance and whether there is a need for the school team to complete additional testing to determine whether your child meets eligibility criteria for an educational disability category. You may be asked to sign consent for additional educational, cognitive, language, motor, or behavioral assessments.
- The team has 90 days to complete testing, determine eligibility, and if eligible, develop IEP goals to address any identified areas of need.
- You can always bring a partner, friend, neighbor, or other advocate to the meetings with you. See the link below for the Council of Parent Advocates and Attorneys.

### Helpful Resources:

<https://www.understood.org/en/school-learning/special-services/504-plan/understanding-504-plans>

<https://www.understood.org/en/school-learning/special-services/ieps/what-is-an-iep>

<http://www.copaa.org/> (Council of Parent Attorneys and Advocates)

**Next step on the Journey into Survivorship: Survivorship – the Journey Continues**