



Parent Roadmap: Kids with Cancer Still Need School

Beyond the Fourth Step: Survivorship - The Journey Continues

The year after treatment finishes can be full of unexpected and difficult challenges. The focus on getting through treatment is replaced with a life-long shift to a new normal. And that new normal can keep changing. It is possible that you and your child may discover new learning differences especially in the higher grades, including high school or college. School assignments may get more challenging, social situations can be more complex, and these can present new issues. But there are many things that you, your health care team, your school, and your child can do to make things better.

Health Care Related

Checklist of Things to Ask or Do

- Ask your child's oncologist about whether the hospital has a Survivorship or Late Effects clinic. Ask when your child's care may be transferred to this new clinic or provider.
- Prepare a list of questions or concerns ahead of each visit with the oncologist, including your child's school performance as well as any health concerns.
- Should my child have a(nother) neuropsychological assessment*? How do I access this service?
- If your child is a teenager (age 14 and over), ask about guidance to support your child in learning to become responsible for his or her own healthcare needs. In some hospitals, children transition from pediatric clinics to adult care clinics when they turn 18. Health care processes (consent for treatment, who shares information, how parents are involved) change when youth turn 18. Ask about transition planning.
- Ask the healthcare team for a referral to a counselor or psychologist if needed. As time passes after treatment, children sometimes become reluctant to share their worries with parents, but you may notice that your child struggles to adjust. Cancer is hard, and sometimes children need help adjusting after the dust settles.

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

School/Community Related

Checklist of Things to Ask or Do

- Check-in with your child about how they are adjusting to their new normal and be willing to discuss any social challenges associated with survivorship.
- Remember to let your child's teacher(s) know when s/he will need to miss school for follow-up medical visits. Make a plan for how missed work and assignments will be communicated. Clarify when missed work is due.
- 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 to ensure they are aware of your child's needs.
- Meet regularly with your child's teacher(s) to monitor his/her progress, ask about his/her performance, and ask whether s/he is working on grade level. Children who were treated with brain radiation are especially vulnerable to slowed academic progress and greater school difficulty over time. It is important to monitor progress for all survivors, however!
- Ask about any needed accommodations for standardized testing (such as state-wide testing, SAT, or ACT) and whether your child will need any new assessments to obtain accommodations on such testing, if needed.
- If your survivor is thinking about college, ask the high school counselor about schools with strong disability support programs. Your survivor, rather than you, will need to take the lead in seeking any accommodations in college.

Survivorship - The Journey Continues: Knowledge you need and resources that can help provide it

On this journey, you have learned so much about how to help your child. As your survivor matures, it is important to teach him/her how to help themselves. When they are young adults, this will help them be independent in college and can also help them deal with the long-term health risks that are a part of survivorship. You can start by helping your child talk with adults about what s/he needs to succeed in school.

Late Effects:

- Over time, as children's brain develop and school gets harder, learning difficulties may start to appear in some survivors—even if they didn't show up earlier. This can be due to the effect of certain cancer treatments on brain development, the more complicated demands for managing tasks and materials placed on students as they move into middle and high school and beyond, or both. A "gap" might appear between the survivor's ability to complete class work or homework and his/her peers' skills—which can be frustrating for everyone!
- While frustrating, it is never too late to reach out to your oncology team or neuropsychologist for advice or a neuropsychological evaluation. Having updated information about how your child learns and what might be getting in the way can identify ways to better help and support.
- As your survivor approaches 18, it will be important to discuss the transition from pediatric to adult medical care, and how to help your survivor actively participate in and learn to take charge of his/her own care. See the links below for ideas!

Legal Resources:

- As noted earlier, your child might need additional supports in school, which could be provided through a 504 Plan or IEP. See the First Step: Diagnosis page for information about a 504 Plan and the Third Step: Return to School page for information about an IEP. These are relevant through high school. The ADA law still protects students' access to learning beyond high school, which means that survivors moving into college, community college, or other vocational training programs also may be able to obtain needed supports or accommodations after leaving high school.
- You can always ask to be connected with a parent advocate, find an educational attorney, or find out whether your state has a legal agency designated to support youth with developmental disabilities. The state Division of Rehabilitative Services or Developmental Disabilities Agency may also be helpful.

Helpful resources:

<http://www.wrightslaw.com/video/wrightslaw.provides.answers.to.your.questions.mp4> (video about how to use this legal rights website: Wrightslaw.com)

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

<http://www.gottransition.org/> and <http://www.gottransition.org/youthfamilies/> (Guidance for Transition from pediatric to adult healthcare)

Survivorship – the Journey Continues

As you and your child continue on this journey, stay in touch with the school and health care teams, and help them stay in touch with each other.