



Parent Roadmap: Kids with Cancer Still Need School

Third Step on the Journey into Survivorship: Return to School Part-Time During Treatment

Even though your child is still in treatment, more days may feel back to normal. You know the basic schedule of treatment visits, & you have a pretty good idea of how your child is tolerating treatment. This is probably a good time for your child to return to school part-time. Although this may sound a little scary, it is an important milestone and a reason to celebrate.

Health Care Related

Checklist of Things to Ask or Do

- Will it be OK for my child to return to school part-time? Can we continue Home & Hospital at the same time?
- Start talking about the possible impact your child's cancer therapy may have on his/her neurocognitive function. Consider getting a neuropsychological assessment if this hasn't already occurred.
- What precautions should I take to avoid infection when my child is at school? (examples: Will my child need to wear a mask? What should be done if a classmate has an infectious disease at school?)
- If your child has a central line, what precautions should be taken at school?
- Are there any activities associated with school that you think my child should avoid? (examples: participation in physical education, contact sports, field trips)
- Make a calendar that maps out when you think your child will have good counts (absolute neutrophil count and platelets; ask your oncology team for help). These would be good days to attend school. For example, most treatments have a low point about 7-14 days after chemotherapy.
- Add known appointments and priorities for school attendance to the calendar and use this to set up a schedule. If your child would really like to attend school half-days on Mondays, Wednesdays, & Fridays, work with his treatment team to see if his outpatient visits can work around these times.
- Identify someone on your health care team that can communicate with school staff and answer questions.

School/Community Related

Checklist of Things to Ask or Do

- Set up a communication link for emergencies and include a back-up. Let your child's school team know the best way to contact you.
- Discuss your child's health status with the teacher and school nurse; include the precautions your health care team advised. Suggested areas include:
 - a. What to do if your child develops a fever, what temperature means a fever. What if there is bleeding?
 - b. What is your child's typical energy level, and will he/she need to have rest breaks during the day?
 - c. What has your child's appetite been like? Share any food or fluid restrictions (or efforts to increase fluid intake).
 - d. Share any specific concerns about toileting routines, including how often your child may need to use the restroom. Ask about allowing your child a special hall pass, if needed.
 - e. Share any physical disabilities that may require assistance for your child at school (for example, does your child have any difficulty walking or require a wheelchair?)

School/Community Related: a few more Things to Ask or Do

Checklist of Things to Ask, Do, or Consider (continued):

- Share the calendar from column 1 and update as needed.
- Discuss how your child wants to handle coming back to school and seeing friends. Suggested topics include:
 - a. Does your child want the teacher/parent to talk to the class before he/she returns? What information would your child like to have shared with classmates? How can you support connections with friends?
 - b. If your child has had hair loss, discuss wearing a hat and whether other children can wear them in support.
- Discuss any concerns you or your child may have about bullying. Ask the school team to develop a plan to monitor your child more closely
- Establish joint goals for the time your child is at school and update them frequently. (For example, at first your child may just want to come to school and re-establish social connections; as time goes by, academic goals will become more important.)
- Be flexible, be prepared for some hiccups (For example, if your child has a fever s/he should stay home).
- Request a 504 plan to meet any needs your child has at school, including physical and academic supports. (See definitions below)
- If you haven't already, ask if you can sign a release of information to permit communication between the school and hospital teams.

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

You learned a lot of new words about cancer. Here are new words about school procedures you may need:

What is a 504 Plan?

- A 504 Plan is a way to ensure that your child has equal access to school activities, including learning and physical activities (sitting, mobility, alertness). This access is protected by a civil rights law that is part of the Rehabilitation Act. There is no cost to the family for 504 supports or accommodations.
- Your child's 504 Plan is designed to remove any barriers and allow for supports that will allow him/her to learn in school alongside their peers.
- An accommodation is a change in *how* your child is taught – it does not change *what* they are taught. Some relevant 504 accommodations include:
 - Extended (extra) time for test taking, especially if writing or responding quickly is difficult
 - Reduced length of assignments or a reduced number of problems to be completed, so your child can complete his/her work in the same amount of time as other students
 - Additional copies of textbooks to keep at home
 - Rest breaks during the day
 - A hall pass or elevator access if s/he tires easily or balance/walking is affected
 - Use of speech-to-text software to reduce handwriting demands
 - Access to teacher notes or another student's notes, if note-taking is slowed or difficult

Helpful resources:

<https://www.understood.org/en/school-learning/special-services/504-plan/understanding-504-plans>
<http://w3.cerebra.org.uk/help-and-information/guides-for-parents/returning-to-school-a-teachers-guide-for-pupils-with-brain-tumours-during-and-after-treatment/>
<http://media.chop.edu/data/files/pdfs/oncology-oncology-teacher-guide-school-reentry.pdf>

Next step on the Journey into Survivorship: Returning to School after Treatment