



Educational Issues after Cancer Therapy

Neel S. Bhatt, MBBS, MPH
Assistant Professor, Clinical Research Division
Fred Hutchinson Cancer Center, Seattle, WA

Outline

- 1 Spectrum of long-term complications after cancer therapy
- 2 School & educational issues after completion of cancer therapy
- 3 How to prevent or mitigate school & educational issues

Why is Childhood Cancer Survivorship Important?

- More than 500,000 childhood cancer survivors living in the United States
- Almost all of the survivors face at least one complication after therapy
- Complications are due to any specific treatment exposure or general cancer experience



Long-Term Complications After Completion of Therapy



Physical



Psychological



Social/ Financial



Secondary cancer

Importance of School & Education

- At personal level:
 - Cognitive & emotional growth
 - Social development
 - Employment and income
- At societal level:
 - Workforce participation & economic growth



School Reintegration is Part of Recovery After Completion of Therapy

School reintegration could provide:

- A sense of normalcy
- Feeling of being in control
- A self-esteem boost
- Social support



School & Education-related Challenges after Therapy

Low School Attendance

- Due to clinic visits
- Due to illnesses



Poor Social & Behavioral Outcomes

- Poor interpersonal experiences with teachers
- Concerns for being teased or bullied by classmates
- Adverse classroom behavior such as aggression or withdrawal
- School disengagement

Adverse Academic Outcomes

- Repeated or failed grades
- Attended learning disabled/ special education program
- Educational attainment

Factors Associated with Educational Challenges

- Type of cancer and treatment
- Impact of treatment on developing brain
- School & educational issues before starting cancer therapy
- Type of school patients are returning to after completion of therapy
- Support provided by everyone involved in the return to school process



Challenges from Patients' Perspective

Physical

"I changed [schools] after the first month because **my legs were sore** from a couple of the chemo and there was lots of stairs in the building."

"Most of the time, it was **hard to concentrate** just because I felt crummy."

Social/ Emotional

"Because I hadn't really done much schooling for six months, **I had issues with stress and stress management** and freaking out over exams."

"But because I missed [so much], I never used to, but I'd get real stuttered sort of and couldn't talk, I don't know why but. I think it was probably **the loss of friends making me nervous.**"

Academic

"Just the couple days I'd miss, and then next thing I know **I'm behind a bunch of assignments and I keep getting more assignments** as the days come."

"**I was very clueless sometimes** because I really didn't get some of my work."

Challenges from Parents' Perspective

Communication Challenges

“It was so frustrating because **none of the teachers communicated** [among themselves]. Like, they did not even know he had leukemia before, they had no idea. I mean it was just like, is not that something you would talk about in a meeting, when you are handing over?”

“**I kind of feel like that [school-related challenges] wasn't fully divulged.** I do not think it was on purpose, but I am sure the medical team does not want to tell you you have been through all of this awful stuff and now it's going to get worse.”

Lack of Knowledge

“Because **I did not understand one word of what was being said in these meetings [at school]**, the terminology, the acronyms, the testing, the educational components ... [I was] completely out of my element.”

“[Teachers] were very intimidated, **they were so scared that they might do something wrong**, and they were like “well, do I need to sanitize the whole room before he comes in?”

What Helped with the Return to School Process?

“The teachers were really supportive. Because of my arm, I couldn’t write, so they let me bring my computer, so that was really good. Anything that I need help with, the teachers are happy to give up their lunchtime to help me.”

“Her team was communicating via email...sending [the school nurse] her medication list...and helping to put in place [an emergency] plan.”

“It was not easy starting high school, as a freshman, **but once he started returning to school and making friends, it was easy for him.** He loved being in school, being with people, being out of the house after being locked up for so long.”

“We had a daily regime. **We read self-help and devotional books, we exercised to stop sad and negative thoughts.**”

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How to Prevent or Mitigate School & Educational Issues after Completion of Therapy

Before Returning to School: Plan Early

- Discuss timing of return to school
- Inquire about inpatient / homebound education & school re-entry resources
- Assess medical/ emotional readiness, address cognitive challenges, fatigue, pain
- Reach out to school & arrange a meeting

Step 1:	Talk with your medical team about possible short-term and late effects of treatment.
Step 2:	Work with your medical team to communicate your child's needs to the school staff. If your child needs accommodations to succeed at school, ask for a meeting with a team that may include the principal, teachers, school counselor, school nurse, a treatment team member, and anyone you choose, such as a friend or family member. The team may suggest strategies that can be tried for a period of time (about 4 weeks).
Step 3:	If the strategies are not successful, request in writing that your child be evaluated for either an IEP under IDEA or a Section 504 plan. Members of your treatment team (physician, social worker, or psychologist) can help you write this letter.
Step 4:	In a timely manner, the school must set up and conduct an evaluation of your child. Be sure to keep track of all dates in this process to keep it moving along.
Step 5:	Ask for a meeting to share the results of the evaluation and to develop a plan for accommodations. The law requires that you be informed of all results and recommendations. You must agree to any accommodation before it is put in place. You have the right to a second evaluation.
Step 6:	Watch your child closely to see how the accommodations are working. If different accommodations are needed, talk with the team members to change your child's IEP or Section 504 plan. These plans are "works in progress." As your child's needs and abilities change, the plans can be changed appropriately.

Information to Share with the School

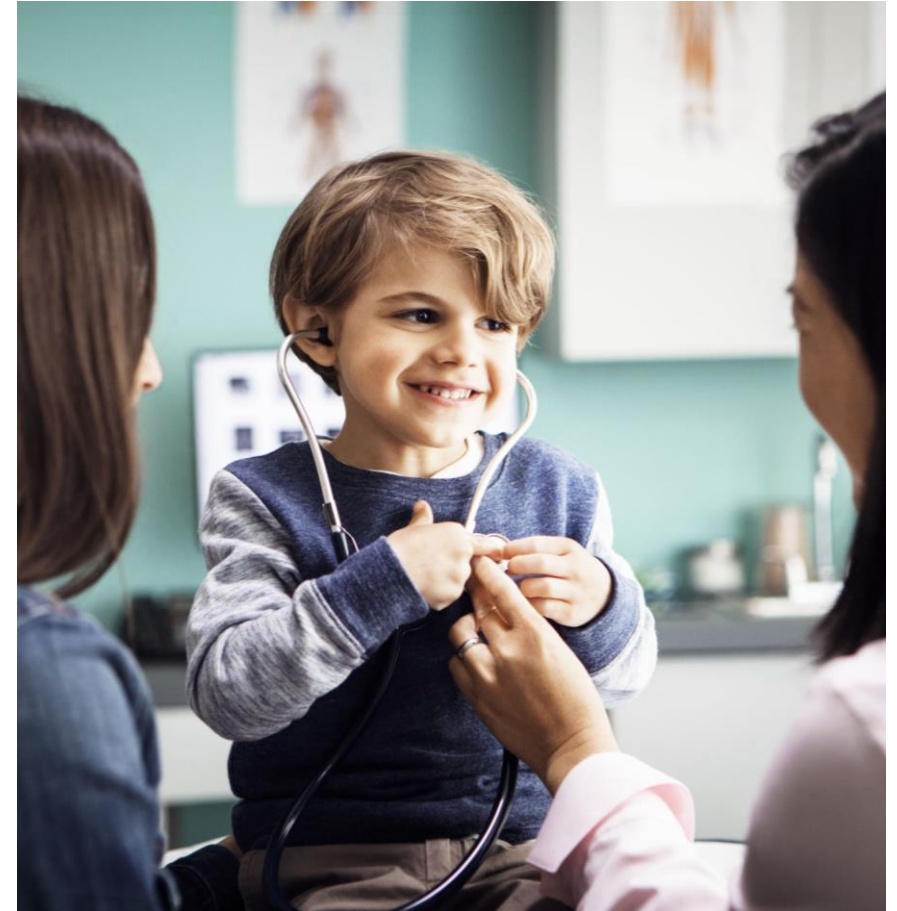
- Details of the medications
- Any medical conditions/ limitations and criteria for notifying
- Special precautions
- Emergency management/ contact information
- Need for IEP/ 504 plan and additional accommodation

Classroom presentation to educate friends/ classmates

- Is cancer contagious? How did my classmate get cancer?
- Will the cancer go away? Will it ever come back?
- Does my classmate still have to do homework?
- What can we do to help?

Ongoing Assessments after Return to School

- Regular assessment of educational progress
- Referral to psychiatrist/ psychologist, PT/ OT, neurocognitive testing as needed
- Develop & revise individualized health plan
- Communication with school in case of concerns
- Survivorship clinic visit at least once a year



Other Recommendations

- Learn to embrace and adapt to the changes in educational needs
- Try to continue social interactions with classmates whenever possible
- Ask for help (school or healthcare teams) if navigating the process becomes too burdensome

Return to school resources



Leukemia & Lymphoma Society: The Trish Greene Back to School Program For Children With Cancer

American Cancer Society: Returning to School After Cancer Treatment

Livestrong: Learning & Living With Cancer: Advocating for your child's educational needs

NCCS: The Other Side of The Mountain



Thank you