



THE EDUCATION ROADMAP FOR CHILDREN WITH CANCER

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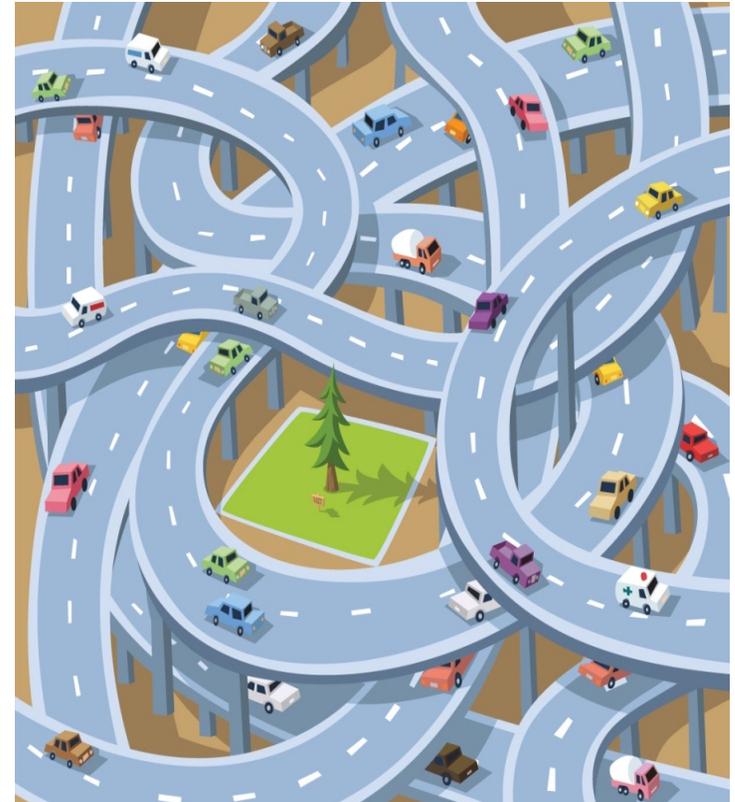
CAC2 Summit
June 22, 2022



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THE CANCER JOURNEY ...

“Cancer is not just a single event with a certain end but an enduring condition characterized by ongoing uncertainty, potentially delayed or late effects of the disease or treatment, and concurrent psychosocial issues.”

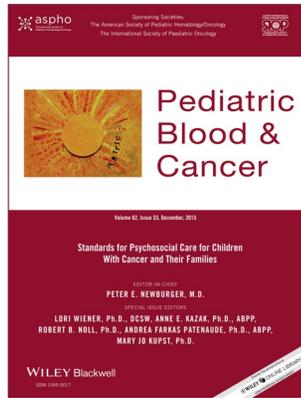


EDUCATION IS IMPORTANT

- Successfully progressing through school is one of the most important tasks of childhood and early adulthood
- Childhood cancer can disrupt this developmental process by interfering with school engagement and negatively impacting academic achievement
 - At-risk survivor groups achieve diminished educational attainment compared to the general population
 - Maintaining pre-illness academic achievement and participation in school-related activities is related to enhanced quality of life
- With survival rates for childhood cancer exceeding 80%:
 - The importance of understanding the school experiences and academic needs of youth treated for cancer has never been higher

INTRODUCTIONS

STANDARDS FOR PSYCHOSOCIAL CARE



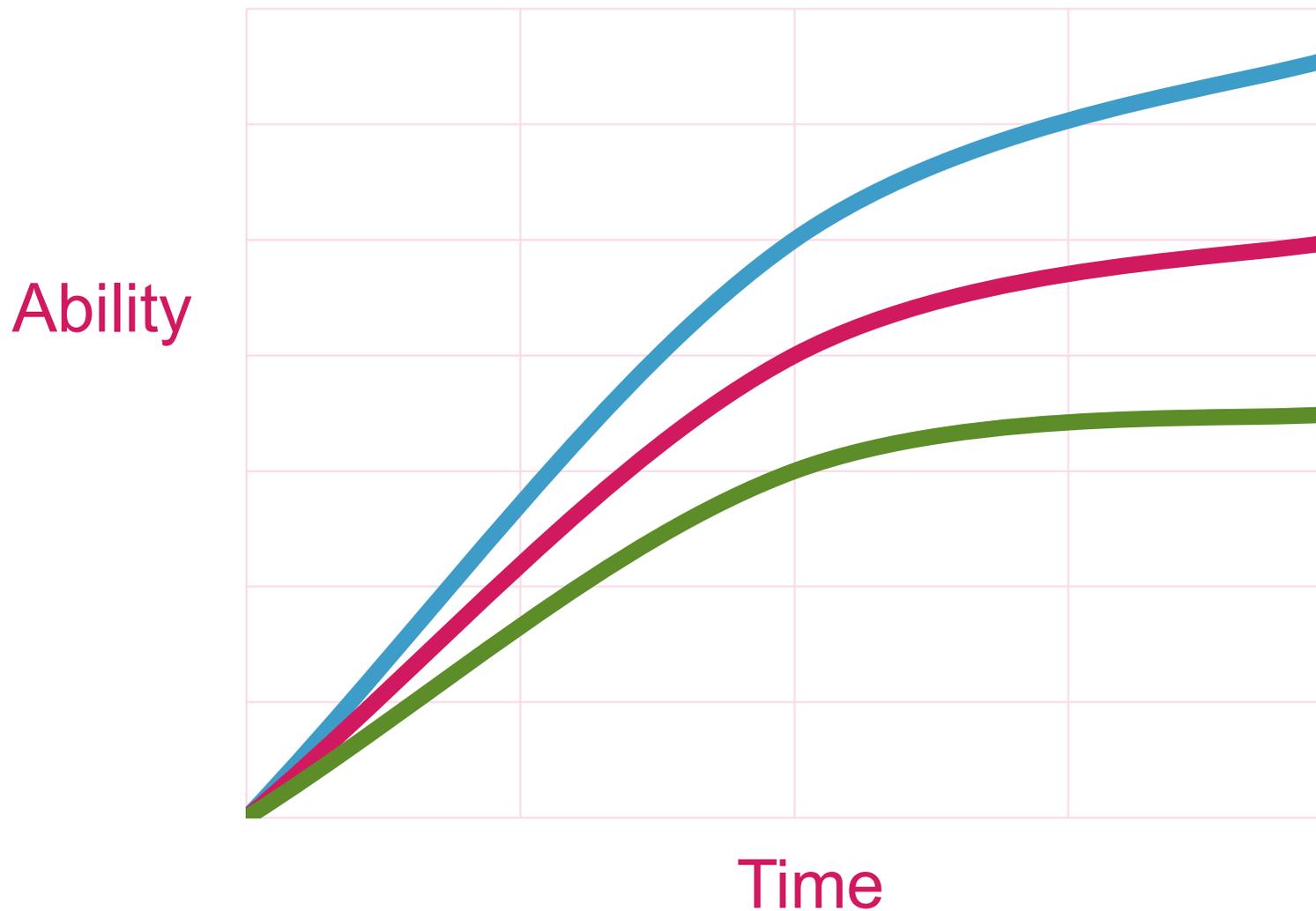
- U.S. Congressional Briefing
- Two think tanks
- Multidisciplinary workgroup
- Consumer involvement
- Clear process for drafting the standards (AGREE II) + evaluating rigor (GRADE)
- Peer Review
- 1217 studies, 16 Papers, 66 Authors

1. Assess psychosocial health care needs of youth and families
2. Monitor neuropsychological deficits
3. Screen long-term survivors
4. Provide psychosocial support and intervention
5. Assess financial risk
6. Assess and intervene on caregiver mental health
7. Offer psychoeducation, information, anticipatory guidance
8. Provide developmentally appropriate preparatory information
9. Offer opportunities for social interaction
10. Provide supportive services for siblings
11. Support school re-entry
12. Assess and monitor adherence
13. Introduce palliative care
14. Maintain contact with family after child's death
15. Practice interprofessional care, document services, and train providers

STANDARD 2: MONITORING AND ASSESSMENT OF NEUROPSYCHOLOGICAL OUTCOMES

- Children with brain tumors and others (leukemias) at high risk for neuropsychological deficits should be monitored during and after treatment
- Risk is proportional to the intensity of therapy
 - Longer treatment with higher cumulative doses of radiation, higher doses of chemotherapy, and multimodal therapies increase the risk of late effects
- Neuropsychological late effects of cancer and cancer therapy may not manifest for years, requiring ongoing health surveillance

NEUROPSYCHOLOGICAL OUTCOMES





GOALS OF NEUROPSYCHOLOGICAL ASSESSMENT ARE TO HELP:

- Caregivers and teachers better understand the child's cognitive development after cancer diagnosis and treatment
- Caregivers advocate for their child in the school (IEPs or 504 Accommodation Plans)
- Identify need for additional resources and/or interventions
- Plan for the child's future

504 PLAN VS IEP

| 504 Plan: Accommodation | IEP: Modification |
|--|---|
| A strategy used to help a student with learning needs access the same curriculum as their peers. | A strategy used to help a student with learning needs achieve the same curriculum as their peers. |
| Curriculum learning expectations and outcomes are the same. | Curriculum learning expectations and outcomes are different. |
| Occurs in the general education classroom. | Occurs in the general education classroom. |
| Tools, materials, technology, visual aids, physical space, and timing are used to help the student <i>access</i> the curriculum. | Tools, materials, technology, visual aids, physical space, and timing are used to help the student <i>achieve</i> the curriculum. |
| Grading is the same. | Grading is different and appropriate to the student's specific developmental level and learning needs. |

STANDARD 11: SCHOOL

- School age youth diagnosed with cancer should receive school re-entry support, providing information to school personnel about the patient's diagnosis, treatment, and implications for the school environment
- Pediatric oncology programs should identify a team member who will coordinate communication between the patient/family, school, and the health care team

EDUCATIONAL NEEDS AND RESOURCES

- Parent report of educational needs of patients and survivors:
 - Significant ongoing concerns regarding academic achievement and social functioning
 - Patients with brain tumors most at risk for ongoing educational challenges
 - 63% of children never evaluated and 55% did not have formalized educational accommodations
 - Support needed for negotiating with schools on accommodations and obtaining school evaluations, 504 plans and IEPs—during and after treatment

EDUCATION PROGRAMS IN PEDIATRIC CANCER CENTERS

- Survey of Children's Oncology Group (COG) institutions:
 - 42% had a formal program; 52% had some services
 - 54% have support from the hospital or department; 20% from donations or grants
- Programs offer home tutoring; communication between school, medical team and family; education for parents and children regarding going back to school; school staff consultation at the time of reentry; advocacy information for parents and individual education plan (IEP) help; neuropsychological evaluations; and class presentations
- Another study of support services available to cancer survivors within National Cancer Institute (NCI)-designated comprehensive cancer centers found only 19% of centers have school re-entry programs

ACADEMIC ROADMAP



Pictured here are the milestones children need to reach to get to the next step. Not on track? Check out the resources provided on the following pages.

Roadblocks to avoid Resources available Financial milestones

Birth-3 years

1

Get \$100 from the state to start a PA 529 education fund.

Read with your children for at least 20 minutes a day to build language and literacy skills.

You promote your children's learning when you talk about everyday activities, encourage them to be curious and explore, ask open-ended questions, and offer plenty of time for imaginative play.

Third graders who read at grade level can read independently for at least 20 minutes, read aloud smoothly "with expression" that shows understanding, figure out the pronunciation of new words using what they know about phonics, and answer questions about the meaning of a grade-level book.

3rd grade

3

Not reading at grade level by 3rd grade

Students take the state PSSA tests in English Language Arts and Math in grades 3-5, and Science in grade 4.

When students are identified for special education services, parents must be invited to participate in creating their Individualized Education Plan (IEP). The school is responsible for providing the education outlined in the plan.

Pre-k/
Kindergarten

2

Kindergartners who don't miss much school are more likely to become proficient readers by 3rd grade.

Resources:

The Pittsburgh Learning Collaborative and Family Hotline

Led by A+ Schools, the Pittsburgh Learning Collaborative (PLC) is a coalition of more than 80 regional organizations and individuals across Pittsburgh's learning community. The PLC serves as a coordinated asset for families.

The **PLC Family Hotline** is a resource line available to all families. Call **412-256-8536** if you have questions about your child's school, tutoring or homework help, getting access to technology or the Internet, youth workforce opportunities, food and school supplies distributions, or other support for academic or personal needs.

Calls can be received 24/7. When the line isn't staffed, you can leave a voicemail. Expect a reply within 48 hours on weekdays.

Additionally, **A+ Schools staff** have over 15 years of experience navigating the district and individual schools. If you have a question, big or small, about your child's education or school choice, or if you need resources, please reach out by contacting info@aplusschools.org or by calling the Family Hotline number above.

See pages 26 and 27 for more resources to help your child.

Middle school

4

Students take the state PSSA tests in English Language Arts and Math in grades 6-8, and Science in grade 8.

Algebra 1

Taking Algebra 1 in middle school allows more time for taking advanced courses required for post-secondary STEM majors.

The Pittsburgh Promise: Eligible students can receive up to \$5,000

Suspension

If your child was suspended, we can help. See page 27.

Keystone exams

Students take the state Keystone exams in Algebra 1, Literature, and Biology.

Graduation

6

FAFSA:

Find out how much federal student aid your child might receive.

SAT/ACT tests

Students take the PSAT (Preliminary SAT) in the fall of sophomore or junior year, and the SAT or ACT in the spring of junior year and/or the fall of senior year.

Taking low-level courses in high school

High school

5

Chronic absenteeism

Good attendance in middle school—or even improving one's attendance—is a key predictor of high school success.

RESOURCES

- **Supporting the Student with Cancer: A Comprehensive Handbook for your School Community**
 - <https://media.chop.edu/data/files/pdfs/supporting-student-with-cancer-booklet.pdf>
- **Facilitating Your Child's School Reentry**
 - <https://media.chop.edu/data/files/pdfs/oncology-oncology-parent-guide-school-reentry.pdf>
- **Psychosocial Services Resource Guide for Adolescent and Young Adult Survivors of Cancer**
 - <https://media.chop.edu/data/files/pdfs/oncology-aya-survivorship-manual.pdf>
- **Survivorship Roadmap**
 - <https://www.kennedykrieger.org/patient-care/centers-and-programs/neuropsychology-department-outpatient-clinics/oncology-clinic/cancer-survivorship-schooling-resources/roadmaps>

QUESTIONS?

