

## SPECIALIZED RESOURCES



Specialized Resources is a column designed to share books, websites, apps, and other resources that may be helpful for child life specialists working with a specific population. This column represents only the personal views of the author, and the Association of Child Life Professionals does not endorse or sponsor the products or services mentioned. In addition, the authors of this column verify that they have no affiliation with the companies or organizations related to the products and services mentioned in this article.

### School Re-entry with a Chronic Illness

Elizabeth Anderson, CCLS

HUNTSVILLE, AL

Children living with chronic illness face several different challenges when attending school. Chronic illnesses affect at least 10-15% of American children (U.S. Department of Health & Human Services, National Heart, Lung, and Blood Institute, 2014). Addressing and attending to the needs of students with chronic conditions in the school setting requires a thoughtful, multidisciplinary approach. While child life specialists are not always present in the school to assist with school re-entry, there are many resources available to guide the process and help support parents and caregivers as they prepare for their child's return to school.

#### REFERENCE

U.S. Department of Health & Human Services, National Heart, Lung, and Blood Institute. (2014). Students with chronic illnesses: Guidance for families, schools, and students. Retrieved from <https://www.nhlbi.nih.gov/files/docs/public/lung/guidfam.pdf>

#### RECOMMENDED RESOURCES

**Books:** These resources include children's books that can be utilized by parents, caregivers, and teachers to educate both the child with a chronic illness and their peers, as well as a guide for parents and teachers on educating children with cancer.

- Gosselin, K. (1998). *Taking asthma to school*. Bohemia, NY: JayJo Books.
- Gosselin, K. (2001). *Taking cancer to school*. Bohemia, NY: JayJo Books.
- Gosselin, K. (2004). *Taking diabetes to school*. Bohemia, NY: JayJo Books.
- Gosselin, K. (2001). *Taking seizure disorders to school: A story about epilepsy*. Bohemia, NY: JayJo Books.

These colorfully-illustrated books are intended to teach elementary school children about students who have been diagnosed with chronic illness, and how these illnesses are managed in school. These books help foster empathy among children who may have a classmate with a similar diagnosis.

- Henry, C. (2000). *Taking cystic fibrosis to school*. Bohemia, NY: JayJo Books.  
Appropriate for school-age children, this book explains cystic fibrosis and how people with the diagnosis take care of themselves.
- Hoffman, R.I. (2013). *Educating the child with cancer: A guide for parents and teachers* (2nd ed.). Beltsville, MD: American Childhood Cancer.  
A comprehensive resource meant to provide education and encourage communication between parents/caregivers, educators, and medical personnel on the educational issues facing children diagnosed with cancer.

**Organizations and Resources for Patients, Parents/Caregivers, Educators, and Medical Personnel:** This is a wide range of resources for anyone working with school-age children who have chronic illnesses. These resources are meant to provide information, guidance, helpful tips, and emotional support.

- *14 Things that can Make High School with a Chronic Illness Easier*. This list of items, suggested by members of The Mighty community, an online resource for those with health challenges and their caregivers, aims to help make attending school with a chronic illness easier. <https://themighty.com/2018/01/high-school-disability-illness-supplies/>
- *American School Health Association*. The American School Health Association is a multidisciplinary organization that aims to create safe and healthy school environments for all children. [www.ashaweb.org](http://www.ashaweb.org)
- *Cancer.Net: Doctor-Approved Patient Information from American Society of Clinical Oncology*. This organization offers several resources, including:
  - *Cancer and School*. This article includes information for school-age children and adolescents on navigating school with a cancer diagnosis. <https://www.cancer.net/navigating-cancer-care/teens/family-friends-and-school/cancer-and-school>
  - *Just for Teens - Cancer and School*. This podcast for teenagers with cancer focuses on balancing school and treatment. <https://www.cancer.net/blog/podcasts/just-teens-cancer-and-school>
- *CF and School*. This section of the Cystic Fibrosis Foundation website is an instructional guide with additional resources intended for teachers working with a student who has CF. <https://www.cff.org/Life-With-CF/Daily-Life/CF-and-School/>
- *Crohn's Disease and Ulcerative Colitis: A Guide for Teachers and Other School Personnel*. A comprehensive guide from Crohn's and Colitis Foundation, for educators to provide information, guidance, and resources related to the student with Crohn's or colitis. <http://www.crohnscolitisfoundation.org/resources/guide-for-teachers.html>
- *Epilepsy Foundation*. The Epilepsy Foundation offers many programs and resources to support students with epilepsy, including:
  - *Epilepsy in High School*. This article provides helpful advice to students with epilepsy about navigating high school with this diagnosis. <https://www.epilepsy.com/living-epilepsy/youth/epilepsy-high-school>
  - *Managing Students with Seizures: School Nurse Training Program*. This program provides education about epilepsy to school nurses as well as strategies and resources needed to better manage its care. <https://www.epilepsy.com/living-epilepsy/our-training-and-education/managing-students-seizures-school-nurse-training-program>
  - *Seizure Training for School Personnel*. This free, interactive course provides education to school personnel and promotes a positive social and educational environment for students with an epilepsy diagnosis. <https://www.epilepsy.com/living-epilepsy/our-training-and-education/seizure-training-school-personnel>



- **Take Charge: Classroom Epilepsy Education Programs.** Take Charge offers three different programs for K-12 students designed to help them understand and support their classmates who live with epilepsy. Each program uses age-appropriate language and teaching tools, educates students about epilepsy and seizures, helps students identify and learn about different types of seizures, and teaches students what to do and not to do when someone is having a seizure. <https://www.epilepsy.com/living-epilepsy/our-programs/take-charge-classroom-epilepsy-education-programs>
- **Genetics Education Materials for School Success (GEMSS).** GEMSS is an organization that provides resources for and encourages collaboration between families, schools, and medical professionals to help all children with genetic health conditions succeed in school. <https://www.gemssforschools.org/>
- **HEAL: The Hospital Educator and Academic Liaison Association.** HEAL is a professional organization that supports and connects multi-disciplinary professionals who work with students with medical and mental health needs. Their overall goal is improving educational outcomes for these students. <https://www.healassociation.org/>
- **HopeCam.** HopeCam uses technology to help children in Pre-K to 12th grade stay connected to their classmates. HopeCam works with both the family and school to make sure all necessary technology elements are provided. [www.hopecam.org](http://www.hopecam.org)
- **KidsHealth.** This is an extensive website with age-appropriate information for children, teens, and parents to learn about many different medical conditions and health issues. [www.kidshealth.org](http://www.kidshealth.org)
- **LearnWell.** LearnWell works with hospitals and school districts to facilitate academic instruction for children who have a prolonged absence from school due to health concerns. <https://learnwelleducation.com/>
- **LIVESTRONG at School.** These are age-appropriate lessons for grades K-12 to help educators teach their students about cancer. <https://www.livestrong.org/what-we-do/program/livestrong-at-school>
- **Monkey in my Chair.** Monkey in my Chair is an organization that helps preschool and elementary aged children with cancer stay connected to their classmates. <http://www.monkeyinmychair.org/>
- **National Heart, Lung, and Blood Institute.** Several resources are available through this organization for supporting children with asthma in school:
  - **Asthma and Physical Activity in the School.** An easy-to-read booklet for teachers, coaches, and families who want to help students with asthma participate in sports and physical activities. <https://www.nhlbi.nih.gov/health-topics/all-publications-and-resources/asthma-and-physical-activity-school>
  - **How Asthma-Friendly is your School?** This is a two-page resource that helps determine how well a school can manage the needs of a student with asthma. <https://www.nhlbi.nih.gov/health-topics/all-publications-and-resources/how-asthma-friendly-your-school>
  - **Managing Asthma: A Guide for Schools.** This resource provides guidance for schools on how to implement effective management of asthma. <https://www.nhlbi.nih.gov/health-topics/all-publications-and-resources/managing-asthma-guide-schools-2014-edition>
- **Returning to School after Cancer Treatment.** The American Cancer Society shares helpful information for parents/caregivers about their child's return to school after a cancer diagnosis. <https://www.cancer.org/treatment/children-and-cancer/when-your-child-has-cancer/after-treatment/returning-to-school.html>

*continued on page 50*

## Specialized Resources: School Re-entry with a Chronic Illness

- **Safe at School.** The Safe at School Campaign, sponsored by the American Diabetes Association, shares several resources available to help parents/caregivers, educators, and medical personnel coordinate the safest and most appropriate care of children with diabetes in the school setting. <http://www.diabetes.org/living-with-diabetes/parents-and-kids/diabetes-care-at-school/>
- **Sickle Cell Disease: A Practical Guide for Teachers.** This resource provides an easy-to-understand overview of sickle cell disease for educators. <https://www.aboutkidshealth.ca/Article?contentid=652&language=English>

**IEPs and 504 Plans:** This section includes helpful websites that provide information on the laws that require schools to meet the individualized learning needs of children who have special needs and/or disabilities.

- **Durheim, M. (2018).** A parent's guide to Section 504 in public schools. Retrieved from <https://www.greatschools.org/gk/articles/section-504-2/> This article gives an overview of the civil rights law Section 504 and answers basic questions about its implementation in school settings.
- **Understood.** Understood is an organization that offers support to parents of children with learning and attention issues. Their website provides many helpful resources, including the following:
  - **Individuals with Disabilities Education Act (IDEA): What you Need to Know.** This resource explains the legal process that must be followed for children who require special education services. <https://www.understood.org/en/school-learning/your-childs-rights/basics-about-childs-rights/individuals-with-disabilities-education-act-idea-what-you-need-to-know>
  - **Learning about IEPs.** This article explains IEPs, which are individualized programs and written plans for children with special education needs in school settings. IEPs are required under the special education law, the Individuals with Disabilities Education Act (IDEA). <https://www.understood.org/en/school-learning/special-services/ieps/what-is-an-iep>
  - **The Difference between IEPs and 504 Plans.** This chart provides an overview of the similarities and differences between IEPs and 504 plans, both of which offer formal help for children in Grades K-12 who have individualized learning needs. <https://www.understood.org/en/school-learning/special-services/504-plan/the-difference-between-ieps-and-504-plans>

**Child Life/Professional Resources:** The following resources are for child life professionals who support the importance of thoughtful, individualized planning for children attending school with a chronic illness.

- **Canter, K.S., & Roberts, M.C. (2012).** A Systematic and quantitative review of interventions to facilitate school reentry for children with chronic health conditions. *Journal of Pediatric Psychology*, 37(10), 1065-1075. This article explores the effectiveness of interventions for children re-entering school with a chronic condition, specifically looking at efforts to increase knowledge of teachers and peers and encouraging positive attitudes towards children with chronic illnesses.
- **Soejima, T., Sato, I., Takita, J., Koh, K., Maeda, M., Ida, K., & Kamibepu, K. (2015).** Support for school reentry and relationships between children with cancer, peers, and teachers. *Pediatrics International*, 57(6), 1101-1107. This study shares responses from children with cancer and their guardians about their school re-entry experiences.
- **Thompson, A.L., Christiansen, H.L., Elam, M., Hoag, J., Irwin, M.K., Pao, M.,... Patterson Kelly, K. (2015).** Academic continuity and school reentry support as a standard of care in pediatric oncology. *Standards for Psychosocial Care for Children with Cancer and Their Families*, 62(S5), S805-S817. This is a literature review, completed by a multidisciplinary team, about school re-entry support for children and adolescents with cancer.
- **Weiner, P. (2005).** Bridging the gap: Education services within the scope of a child life program. *Child Life Council Bulletin*, 23(3), 5-8. This article in the *Child Life Council Bulletin* outlines the ways child life specialists can support children and families as they navigate their child's schooling while in the hospital and deal with a diagnosis or illness.

---

*Liz Anderson has been a child life specialist for 9 years, working with a variety of populations. She currently lives in Huntsville, AL. Liz previously worked with several different chronic care populations, including oncology, hematology, gastroenterology, and endocrinology, and has experience helping children within these populations navigate school while dealing with their chronic illness. She can be reached at andersone0813@gmail.com.*