About Navigating School While Chronically III

Approximately 30% of U.S. children aged 5-17 live with a chronic health condition.

UCLA Health (2023)

health. For students, it shapes engagement with learning, relationships with peers, and their self-image. And too often, rather than being a supportive place, they find school a toxic environment.

While the physical effects of chronic conditions are widely documented in medical literature, the internal impact on students' psychological development and educational access is under-examined. Drawing from a review of the literature and personal interviews with several high school nurses (see references), what follows highlights barriers at school that often marginalize this population and the urgent need for a more accommodating and collaborative system of supports.

Barriers to
Academic
Accommodations
& Psychological
Support

Available evidence indicates that students with chronic illness encounter a wide range of institutional barriers that interfere with their academic progress and psychological well-being. Although legal protections (e.g., the Individuals with Disabilities Education Act) exist to support diagnosed students, the policies are inconsistently applied. Even when a student's medical diagnosis indicates a chronic condition, delays frequently occur because schools wait for serious learning, behavior, and emotional problems to arise before responding. Chronic illnesses that are invisible or fluctuate in severity, like Postural Orthostatic Tachycardia Syndrome (POTS) or lupus, are especially prone to dismissal by educators.

As a result, the burden of advocacy falls to families – many of whom may lack the resources, awareness, or language access to navigate school systems effectively. As interviewed nurses reported that a student's plan often is initiated only after repeated absences and depend heavily on whether a parent can provide sufficient information and advocate effectively for their child. This trend generally works against underresourced and non-English-speaking families.

In general, although widely acknowledged, the relationship between health and academic success is not well attended to in school policy and practice. While there are exceptions, teachers and student support staff generally lack sufficient training, systemic guidance, and protocols for supporting chronically ill students. School nurses tell us that staff shortages often result in them dealing with thousands of students across multiple schools, leaving little capacity for contacting medical providers, addressing the health needs of many students, coordinating care, or training staff. In too many instances, health plans focus narrowly on concerns, such as medication administration or attendance policies, without acknowledging the emotional strain students endure while managing chronic illness.

The material in this document was produced by Leena Aziz as a participant with the national Center for MH in Schools & Student/Learning Supports at UCLA in 2025.

The center is co-directed by Howard Adelman and Linda Taylor and operates under the auspices of the School Mental Health Project, Dept. of Psychology, UCLA. Website: https://smhp.psych.ucla.edu/

Psychological Strain and Social Isolation

Chronic illness leads to secondary conditions. These manifest as learning, behavior, and emotional problems. For example, chronically ill students often struggle with negative feelings about self and others. They may feel set apart from their peers and stigmatized because of visible physical changes and being behind academically. They may feel less competent and experience a disconnection from others. All this can be further aggravated for those returning from hospitalization and prolonged absences.

The absence of a structured reintegration plan can exacerbate the situation and further weaken self-image and heighten social anxiety and withdrawal.

School Environment, Policies, Practices, and Inequities

It is not surprising that most school staff lack awareness about chronic illnesses. Rules and policies at a school may lack flexibility and contribute to an environment that feels unaccommodating.

Illnesses may be dismissed entirely during periods when symptoms are not outwardly apparent. Nurses report that it is common for students without continuous visible symptoms to be disproportionately subject to increased stigma and a lack of support that students with more outwardly apparent illnesses might not.

In this sense, teacher perceptions significantly shape whether chronically ill students receive meaningful support. Attribution bias (a cognitive tendency to explain someone's behavior based on internal character rather than external circumstances) can lead educators to interpret symptoms like fatigue or frequent absences as laziness rather than legitimate illness. This misjudgment often leads to reduced accommodations and punitive responses, with studies showing that educators are more supportive when a student's condition is visibly physical or well-documented. Without proper training, many teachers rely on assumptions, perpetuating stigma and weakening trust between students and school staff.

In addition, race, socioeconomic status, and illness visibility are seen as factors increasing inequities confronting chronically ill students. Low-income families and students of color often face reduced access to healthcare and support services. Non-English-speaking parents struggle to communicate with schools.

Disruption During Pediatric-to-Adult Care Transitions

The pediatric-to-adult care transition poses another major challenge. As students age out of pediatric services, they are expected to independently manage appointments, insurance, and medication adherence, often without adequate preparation. Unstructured transitions increase the risk of emergency flare-ups and can also disrupt eligibility for accommodations during post secondary schooling. Without coordinated transitional planning, vulnerable students are left unsupported and unsure about how to advocate for their academic needs.

What Student and Learning Supports are Recommended?

Our literature review and nurse interviews make it clear that too many students with chronic illnesses face stigma, delayed accommodations, emotional isolation, and institutional gaps that fail to address the complexities of their conditions. To address their needs, the following strategies illustrate what is commonly recommended:

1. Individualized Education and Health Planning

- Develop Individualized Education Programs (IEPs) or 504 Plans tailored to the student's medical, academic, physical, and emotional needs.
- Create Individual Health Plans (IHPs) in collaboration with healthcare providers, families, students, school nurses, and other student support staff.

2. Flexible Learning Options

- · Homebound or hospital instruction for students unable to attend school.
- · Online or hybrid learning models to maintain continuity.
- Modified schedules or reduced course loads when needed.

3. Academic Support and Accommodations

- Breaks, extended time on assignments and tests, seating accommodations.
- Modified assignments and/or alternative assessments.
- · Note-taking assistance or recorded lessons and access to assistive technology.

4. Emotional and Social Support

- · Counseling to address emotional problems.
- Peer understanding/support to maintain social connections and counter stigma.
- Staff training that fosters empathic understanding and actions.

5. Communication and Collaboration

- Regular collaboration of school staff, family, and healthcare providers.
- Case management to coordinate interventions and monitor progress.
- Designated point person (e.g., school counselor or nurse) for the student.

6. Health and Safety Measures

- · Facilitate access to medication & medical and self-care during the school day.
- Emergency action plans for flare-ups or complications.
- · Safe and accessible environments, including rest areas.

7. Transition Planning

- Support for re-entry after hospitalizations or long absences.
- Gradual reintegration into school routines.
- · Post-secondary planning that considers health needs.

A Note from the Center Co-directors

As with other students who need a supportive school environment, those with chronic illness require a well-designed and implemented student/learning support system that personally addresses their well-being medically, psychosocially, and educationally.

Schools must prevent and ameliorate many types of learning, behavior, and emotional problems each day. Fortunately, the ways in which such problems overlap means that similar strategies and interventions often can be used for a variety of problems, rather than approaching each as a separate entity (Adelman & Taylor, 2017).

Given this and based on many years of research and development, our Center stresses embedding interventions for problems, such as chronic illness, into a unified, comprehensive, and equitable system (Adelman & Taylor, 2022).

References Used in Preparing this Resource

- Adelman, H.S. & Taylor, L. (2017). *Addressing barriers to learning: In the classroom and schoolwide*. Center for MH in Schools & Student/Learning Supports at UCLA.
- http://smhp.psych.ucla.edu/improving_school_improvement.html
- Adelman & Taylor (2022). A brief guide for moving in new directions. Center for MH in Schools & Student/Learning Supports at UCLA. https://smhp.psych.ucla.edu/pdfdocs/briefguide.pdf
- Almazroui, K. (2023). Learning as the best medicine: Proposal for SMART schooling for hospitalized children, Heliyon, 9, e16845. https://www.sciencedirect.com/science/article/pii/S2405844023040525
- Becker, G., & Newsom, E. (2003). Socioeconomic status and dissatisfaction with health care among chronically ill African Americans. *American Journal of Public Health*, 93, 742-748. https://pmc.ncbi.nlm.nih.gov/articles/PMC1447830/
- Berkelbach van der Sprenkel, E.E., Nijhof, S.L., Dalmeijer, G.W., Onland-Moret, N.C., de Roos, S.A., Lesscher, H.M.B., van de Putte, E.M., van der Ent, C.K., Finkenauer, C., & Stevens, G. (2022). Psychosocial functioning in adolescents growing up with chronic disease: The Dutch HBSC study. *European journal of pediatrics*, 181, 763-773.
- Cobham, V.E., Hickling, A., Kimball, H., Thomas, H.J., Scott, J.G., & Middeldorp, C.M. (2020). Systematic Review: Anxiety in Children and Adolescents With Chronic Medical Conditions. Journal of the American Academy of Child and Adolescent Psychiatry, 59, 595-618. https://pubmed.ncbi.nlm.nih.gov/34595612/
- Davis, A.M., Brown, R.F., Taylor, J.L., Epstein, R.A., & McPheeters, M.L. (2014). Transition care for children with special health care needs. *Pediatrics*, 134, 900-908. https://pmc.ncbi.nlm.nih.gov/articles/PMC4533283/
- Education Law Center. (2023). Accommodating health needs in school: 504 Plans. Author. https://www.elc-pa.org/wp-content/uploads/2023/09/Accomodating-Health-Needs-in-School-504-Plans-2023.pdf
- Gray, W.N., Schaefer, M.R., Resmini-Rawlinson, A., & Wagoner, S.T. (2018). Barriers to Transition From Pediatric to Adult Care: A Systematic Review. *Journal of pediatric psychology*, 43, 488-502. 488-502.https://pubmed.ncbi.nlm.nih.gov/29190360/
- Hen, M. (2022). Mothers' and teachers' experience of school re-entry after a child's prolonged absence due to severe illness. *Psychology in the Schools*, *59*, 1122-1134. https://onlinelibrary.wiley.com/doi/full/10.1002/pits.22666
- Jackson, J.L., Misiti, B., Bridge, J.A., Daniels, C.J., & Vannatta, K. (2015). Emotional functioning of adolescents and adults with congenital heart disease: A meta-analysis. *Congenital heart disease*, 10, 2-12. https://pmc.ncbi.nlm.nih.gov/articles/PMC4145051/
- Keehner Engelke, M., Guttu, M., Warren, M.B., & Swanson, M. (2008). School nurse case management for children with chronic illness: health, academic, and quality of life outcomes. *Journal of School Nursing*, 24, 205-214. https://pubmed.ncbi.nlm.nih.gov/18757353/
- Kennedy Krieger Institute. (2023). Barriers to education for children with chronic health conditions: A systems-level analysis. Center for Innovation and Leadership in Special Education. https://pmc.ncbi.nlm.nih.gov/articles/PMC7712821/
- Logan, D.E., Catanese, S.P., Coakley, R.M., & Scharff, L. (2007). Chronic pain in the classroom: Teachers' attributions about the causes of chronic pain. *Journal of School Health*, 77, 248-256. https://onlinelibrary.wiley.com/doi/10.1111/j.1746-1561.2007.00200.x
- Rao, S., & Passi, V. (2021). Impact of chronic illness on academic performance and social confidence in youth: A comparative analysis. *School Psychology Quarterly*, *36*, 101-115. https://pmc.ncbi.nlm.nih.gov/articles/PMC6158376/
- Shi, L., Chen, C.-C., Nie, X., Zhu, J., & Hu, R. (2014). Racial and socioeconomic disparities in access to primary care among people with chronic conditions. *Journal of the American Board of Family Medicine*, 27, 189-198. https://pubmed.ncbi.nlm.nih.gov/24610181/
- Suris, J.C., Michaud, P.A., & Viner, R. (1995). Chronic illness and emotional distress in adolescence. *Journal of Adolescent Health*, *16*, 414-419. https://pubmed.ncbi.nlm.nih.gov/8863088/
- Surís, J.C., Parera, N., & Puig, C. (1996). Chronic illness and emotional distress in adolescence. *Journal of Adolescent Health*, 19, 153-156. https://pubmed.ncbi.nlm.nih.gov/8863088/