Caring for Students with Sick
A chronic illness is one that has no cure, but does not necessarily result in death. Chronic illnesses prevalent among children and adolescents include asthma, allergic disorders, digestive disorders, heart conditions, diabetes, cancer, hemophilia, sickle-cell anemia, and epilepsy (Newacheck and Halfon 1998).

**Students with Chronic Illness**

The most obvious consequence of chronic illness is increased absenteeism. Approximately half of all children diagnosed with a chronic illness are absent from school up to four times more frequently than their healthy peers, and are sometimes absent for extended periods of time. Asthma, the leading cause of school absence in the United States, accounts for 14 million absences annually (Riverside County Childhood Asthma Program 2005).

Students with chronic illness experience many challenges as they attempt...
to keep up with their peers while dealing with their illness. Students undergoing radiation and chemotherapy for cancer will have suppressed immune systems and may feel tired and nauseous. Students with rheumatoid arthritis or sickle-cell anemia may experience severe joint pain that will limit their ability to write or participate in physical education. Younger students may not possess the self-monitoring skills to know when they need help. For example, students with asthma may not seek help from the teacher or school nurse until their condition has progressed to a serious stage, and students with diabetes may be unable to concentrate on schoolwork long before their symptoms of low blood sugar are noticeable to others.

Whether due to increased absences or the consequences of their illness or treatment, students with chronic illnesses experience more academic and psychosocial difficulties than their peers. Forty-five percent of students with chronic illness report falling behind in their schoolwork and therefore having negative attitudes toward school (Theis 1999). Some medical conditions or treatments can cause impaired visual scanning, spatial abilities, attention, and memory (Thompson and Gustafson 1996), resulting in difficulties with reading, math, and problem-solving.

The goal is to help students stay in school in spite of their illness and the challenge in achieving this goal is to find ways to respond to a unique population of students who are capable of learning, but who are at risk of failure because their bodies do not allow them to be engaged enough to learn to high standards.

Ten Critical Questions
What practices and policies do you have in place to address the needs of your students with chronic illness? Responding appropriately may require a variety of accommodations. These may be informal agreements between parents and teachers or may be as formal as a school health plan, a school re-entry plan (Kaffenberger 2004), a 504 plan, or an individualized educational plan (IEP) (U.S. Department of Health and Human Services 2004).

Here are 10 questions that can help you assess your school’s policies and practices related to students with chronic illnesses:

**How do you support their families?**
Families with few social supports and those already under stress will struggle to respond to the ongoing needs of the child with a chronic illness. The school should make early personal contact with the parents. Allowing them time to tell their story will help you understand how they are coping and what are their child’s specific needs. Identify someone at school to be the primary contact with the family, and discuss what services and support the school can provide.

**How do your teachers respond?**
Teachers have a variety of responses to students with chronic illness. Some teachers are very sensitive to these students’ needs; others are unsure of what is expected of them. Teachers can help chronically ill students be accepted by peers and succeed in school (Fotland 2000), but they need accurate and timely information about the ongoing medical and academic needs of these students.

**Do you provide appropriate training for your teachers?** There is clear evidence that when teachers and school staff are provided with information and training about the needs of students with chronic illness, they feel more equipped to work with the students and their families, and are more sensitive and responsive to individual needs (Prevatt et al. 2000). Teachers report that what is most useful to them is accurate information about a student’s medical condition, an understanding of the social and behavioral impact of the illness, and someone who can answer specific questions.

**Do you provide information about students’ chronic illness to their peers?** The classmates of a student with chronic illness often don’t know how to respond. Having no information about the illness, they may unintentionally make the student feel uncomfortable or isolated (Papadatou et al. 2002). A workshop or classroom presentation providing peers with accurate information, answering their questions, and learning how they can help can go a long way toward helping chronically ill students make a successful return to school (Peckham 1999).

**How do you support the student’s siblings?** Siblings are often the forgotten family members in chronic illness situations (Kaffenberger 1999). Parents already under tremendous stress are sometimes unaware of their other children’s needs, resulting in feelings of isolation, resentment, and fear that can lead to increased behavioral and emotional problems (Barbarin et al. 1995; Kaffenberger 1999). Teachers and the school counselor can provide siblings with social support, acknowledging the stress they are experiencing.

**How do you review the medical needs of your students?** Every school should have a confidential list, updated each year, which identifies every child with any kind of medical need. A school health committee, which may include the principal, school nurse, school counselor, school social worker, a clinic assistant, a special education teacher, and a classroom teacher, should review the needs of students on the list, develop support plans, and make recommendations for staff training.

**What are your district’s homebound policies?** Students with chronic illnesses often require some type of homebound instruction and school districts typically have policies that determine
their qualification. Some policies are quite restrictive, requiring a student to be out of school for 30 days before qualifying. Other policies state that students who are receiving homebound instruction cannot attend school, and that once they return to school they no longer qualify. Most students with chronic illness need much more flexible support (Kaffenberger 2004). It is important to review these policies and develop procedures that allow a student to be in school part-time while receiving homebound instruction.

Do you use technology to support students with chronic illness? School districts are using technology in a variety of ways to connect the homebound child to the classroom. Through computers, e-mail, and computer cameras, students with chronic illness can stay connected to the classroom, communicate with peers and teachers, and keep up with classroom assignments.

What roles do school counselors and social workers play? Your school counselor and social worker are positioned to coordinate the support needed to help students with chronic illness stay connected to school. It is often the responsibility of the school social worker to arrange for homebound instruction when a child is going to be out of school for significant periods of time, while the school counselor can serve as the liaison between school and the student’s home, explaining school services to the parents and helping the student manage illness-related consequences, schoolwork, and peer relationships.

What resources do you have to provide medical information and support? The first resource for medical information about a child with a chronic illness is the child’s parents. If the child is under a physician’s care, the school should get permission to obtain information from the physician. If the physician is a specialist, there may be printed information available describing the specific illness, its physical symptoms, and the needs of affected children. The school nurse is another source of accurate medical information and resources, and may be the best-qualified team member to communicate with physicians.

Finally, building a library of resources, including books and Internet resources, for teachers, students, and parents is another way of showing that yours is a school that understands, cares about, and wants to help students with chronic illness.

References


Peckham, V. C. “Children with Cancer in the Classroom.” Teaching Exceptional Children, Fall 1993: 27–32.


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http://www.rivcoph.org/healthed/asthma/page2.html


http://www.hhs.gov/ocr/504.html

Carol J. Kaffenberger is an assistant professor of counseling and development at George Mason University in Fairfax, Virginia. Her e-mail address is ckaffenb@gmu.edu.

WEB RESOURCES

The student-friendly Web site Band-Aids and Blackboards was created by a nurse educator to help children and adolescents cope with chronic illness and the challenges of returning to school.

www.lehman.cuny.edu/faculty/jfleitas/bandaides

The Brave Kids Web site has online resources, including information about camps, support groups, and a message board for children and adolescents with chronic and life-threatening illnesses.

http://bravekids.org

The Candlelighters Childhood Cancer Foundation has a Web site with resources and support for children and families.

www.candlelighters.org

The Children With Diabetes Web site has resources and information for children and families.

www.childrenwithdiabetes.com/index_cwd.htm

DNA Interactive is a Web site on genetic disorders, such as hemophilia, sickle-cell anemia, and cystic fibrosis, with resources and information for parents and teachers.

www.ygyh.org/?syndrome=hemop