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AID FOR STUDENTS WITH CHRONIC ILLNESS

Chances are, your school has students with chronic illness. Do you know who they are and how you can help?

BY CAROLYN A. BERGER, PH.D.

Samantha is an 11-year-old sixth-grader who was recently diagnosed with diabetes. Samantha has always excelled academically, but her new lifestyle is causing her stress. Her regimen now consists of pricking her finger six or more times daily, eliminating most of her favorite foods from her diet and regularly receiving insulin injections. Samantha’s social life has been compromised due to issues that present themselves when going to friends’ houses and parties. She has had to cut back on her favorite activities — soccer and gymnastics. Samantha feels like her diabetes controls her life, and although her grades are still excellent she feels unhappy most of the time. She visits the school nurse daily and complies with her treatment, but she feels embarrassed and alone.
Jamison is a 16-year-old 10th-grader who was diagnosed with sickle cell anemia as an infant. He has been hospitalized extensively throughout his school years due to extremely painful episodes, and he averages 15 missed days of school each year. Due to his absences, Jamison has fallen behind in his education. He does not have any friends and does not enjoy coming to school. His GPA is 1.9, he recently failed the state standardized test required for graduation, and he is considering dropping out.

Samantha and Jamison are just two examples of how chronic illness can affect students in our schools. About 15 percent to 20 percent of students in the United States live with some form of chronic illness. Therefore, regardless of where you work, you will have a student with some form of chronic illness in your caseload. Sometimes these students do not appear to have any difficulties, and educators may not even be aware of their health condition. However, regardless of whether or not a student with chronic illness is able to manage his/her academic standing, the needs of these students cannot be ignored. Students with chronic illness often feel isolated from their peers because of their conditions. They may not have the strong peer connections due to frequent hospitalizations and limited extracurricular activities. These students may dread holiday or birthday celebrations because often they cannot partake in the festivities due to diet restrictions caused by their illness. Students with chronic illness might live in fear of pain or death. Mental health concerns such as depression, anxiety and social withdrawal are more common for students with chronic illness.

In addition to social/emotional concerns, approximately one-third of students with chronic illness have academic problems. These problems are most often due to lower school attendance, but they may also stem from neurocognitive deficits caused by the chronic illness. Short-term memory impairment and distractibility are often present in students with certain chronic illnesses (e.g., seizure disorders, sickle cell anemia, leukemia). Sometimes the treatment or medications required to manage the chronic illness can also cause neurocognitive deficits.

Regardless of whether or not a student with chronic illness presents with significant academic or social/emotional problems, these students need to feel supported in their school environment. School counselors play a key role in supporting students with chronic illness. It is critical that school counselors take a strong leadership role to help meet these students’ needs. In this leadership role, school counselors will collaborate with a wide variety of stakeholders and advocate for the students’ needs. School counselors can provide direct services while in the school environment to assist the student. So the question is: How can you begin to work toward meeting the needs of students with chronic illness?

**Step One**
The first step you need to take in advocating for these students is to educate yourself about which students in your school suffer from a chronic illness. You may run into issues with obtaining this information because of concerns with adherence to FERPA (and sometimes HIPAA) guidelines. To learn more about compliance with FERPA and HIPAA guidelines in schools, access the document developed by the U.S. Department of Health and Human Services and U.S. Department of Education regarding student health records (http://www2.ed.gov/policy/gen/guid/pcodoc/ferpa-hippa-guidance.pdf). This document explains that student health records cannot be shared without written parent/guardian consent unless the disclosure is to school officials with legitimate educational interests.

Once you have the students’ names, you can access the students’ achievement and achievement-related data. Thoroughly review the students’ academic records and files, including grades, test scores, attendance, discipline and promotion/retention information. Does the student have an IEP or 504? What services are already being provided to the child? Sometimes you will find students are already well-supported, most likely due to a strong parent/guardian advocate. However, other times you may find a student has a wide variety of needs not being addressed adequately. In addition to reviewing school records, meet with the students with chronic illness individually to assess their needs. Consultation with the students’ families and teachers during this process is essential. Hearing from students, parents and teachers will help you gain a broader perspective of the students’ needs and concerns.

The next step is to assess the gaps in meeting these students’ needs. Consider needs such as: counseling services to connect students with their peers, development of a system for managing absences/hospitalizations, strengthening connections with families, educating teachers/staff on chronic illness, management of 504 plans and many more. Once you determine the necessary services, this is when you get to actually advocate. Speak up on behalf of the student. Talk to administrators, school nurses, parents, teachers, cafeteria workers, whomever necessary to begin implementing services that will better meet these students’ needs.

You may find that despite your best efforts, the system continues to fail to meet the needs of students with chronic illness. This may be due to school district policies or a lack of school resources. For example, a school district may have a rule that a student must be absent at least 10
times in one school year prior to receiving any hospital or homebound services. This is a reactive vs. a proactive policy. Why wait until a student with chronic illness has been out of school for two whole weeks before initiating services? This is when you have to escalate your advocacy efforts, and you will need to advocate beyond the school level. Enlist the support of your administrators, teachers and parents to take the concerns to the school district and/or school board.

**Assign a Coordinator**

Systematically evaluating the needs of students with chronic illness and ensuring that these needs are met is a schoolwide effort. It is essential that one leader within the school be coordinating these efforts. Each school needs to identify a point person to focus on meeting the needs of students with chronic illness (i.e., a chronic illness coordinator). A chronic illness coordinator would work with parents, teachers, health professionals and agencies that can assist with meeting the students’ needs.

The chronic illness coordinator will work hand-in-hand with all stakeholders to ensure students are regularly identified and needs are evaluated. The coordinator’s duties would include: maintaining a list of students with chronic illness, setting up parent/student meetings at beginning of year, documenting that teachers are informed of student needs and accommodations, coordinating trainings/workshops for faculty on the chronic illness, advocating for students and communicating with administration on needs of students. The coordinator’s duties are similar to that of an IEP or 504 coordinator, and therefore these efforts could be combined. However, not all families of students with a chronic illness want their child to have an official 504 plan, and these students cannot be left out of the monitoring process.

The chronic illness coordinator should set up meetings with families of students with chronic illness at the beginning of the school year. Ideally, this meeting would include the student, his/her parent/guardian, the student’s teachers, school counselor and school nurse. During this meeting, the chronic illness coordinator should discuss any of the following that apply:

- school policies and resources (e.g., 504 plans, hospital homebound, etc.)
- an absenteeism plan (e.g., collection of make-up work on a regular basis)
- a plan for transitioning back to school when longer absences occur
- methods of communication with teachers and other pertinent school staff
- communication with health care professionals outside of school
- the student’s academic standing
- any concerns parents might have (e.g., student’s well-being, social concerns, etc.)
- referrals that may be needed (e.g., school counselor, mental health counselor, tutoring)

A plan for meeting student’s needs should be decided upon by the student, family and chronic illness coordinator. Each school faculty member will play a role in the implementation plan. School counselors play an important part in the implementation, and two things you should consider include: collaborating to increase belongingness and provision of direct services.

**Collaborating to increase belongingness:** Regardless of the student’s specific academic and social/emotional concerns, a key focus should be to increase the students’ sense of belongingness. Students with chronic illness often feel different, misunderstood and isolated. One way to reduce these unpleasant feelings is to collaborate with the family to participate in school events. Invite the family to talk with faculty about what their child’s life is like on a daily basis, and ask the student to play an active role in this discussion. Teachers may not understand the struggles this student experiences and therefore may misinterpret students’ behaviors. Bringing the family in to explain these issues will reduce confusion and misunderstanding. If students with chronic illness are comfortable with the idea, they could also share with classmates about their experiences. For example, a student with cystic fibrosis might need to carry an oxygen tank to help her breathe. The student could teach her peers about her condition and show her classmates how the tank works. This can help reduce peer teasing and isolation of the student with chronic illness.

Connecting school faculty to the school nurse as well as outside health care professionals is beneficial to educate the faculty about the chronic illness. Faculty may not understand why the student needs access to a note-taker or frequent bathroom breaks. The nurse and health care professionals can help faculty understand the medical need for these accommodations. National or local health associations or foundations might be able to provide on-site trainings, webinars or resources for free to your faculty, so collaborating with these groups can also be beneficial.

Another reason to connect with community associations and foundations is to conduct fundraising efforts and/or events that show support for the child who experiences the chronic illness. You could coordinate a fundraiser for the National Children’s Cancer Society and benefits could either go to the association, or if the family agrees, the funds could go toward the child’s treatment. Showing the family that the school faculty and students care about the student’s well being is critical, and having a schoolwide event for a chronic illness foundation would be one way to show the family support.

A special note to make is that each individual student’s situation is unique and must be treated as such. Not all students with chronic illness and their families would welcome the spotlight of presenting information to faculty. Many families might shy away from being the focus of a fundraiser. Therefore, be sure you know the student’s and family’s preference before staging these types of events.

**Providing direct services:** In addition to helping increase the student’s sense of belonging, school counselors need to closely consider the academic, career and social/emotional needs of students with chronic illness. Of course you already do this for every child, but students with chronic illness are used to trying to blend in. Therefore, these students may mask their needs better than other students. Academic needs might include absenteeism/progress monitoring, providing tutoring services and making sure academic accommodations are being followed in
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the classroom. Students with chronic illness may have unique career concerns that are not addressed in the regular classroom career lessons. Students with chronic illness may worry about how they can manage going to college and getting a job due to the demands of managing their illness. If necessary, teach students about the Americans with Disabilities Act so they can advocate for their needs as an adult. Assertiveness skills could be incorporated into the career training for students with chronic illness, as they are going to have to assert themselves at times to best self-advocate.

Pay close attention to the social/ emotional needs of students with chronic illness. As mentioned earlier, depression, anxiety and isolation are some of the mental health concerns for these students. Students experiencing mental health concerns should be referred to a mental health counselor. However, monitoring students even if they receive outside services is crucial, and students should have easy access to you as needed. Regular check-ins with the students would benefit them if they have a history of social/emotional concerns. These check-ins will help you establish a strong rapport with the students so they know they have an adult ally at school. Group counseling in the school and helping the students make positive peer connections are other potential services for students with chronic illness.

Chronically ill students need our attention but often get left out of critical planning. Systemic issues and lack of resources are obstacles, but they aren’t insurmountable. A school counselor who strongly advocates and collaborates can help these students increase their academic achievement and feel like they belong.

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