

Chronic Illness and Education: *Helping Teens Soar*

By Dayna Fladhammer and Annaben Kazemi

The World Health Organization, in 1948, defined health as “a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity.” Successfully living with chronic illness is a true testament to the above. No longer should we think of health as being “not sick,” but, rather, as our emotional, physical and social well-being. This is especially true of chronically ill teenagers and the school system. Combine this idea with a parent’s support and a school system that is willing to explore accommodations, and you enable a teen with a chronic illness not only to survive, but to thrive in the school setting.

Joan Fleitas, EdD, RN, and associate professor of nursing, Lehman College, created a website just for students with chronic illnesses, called Band-aides and Blackboards. The website began as part of her dissertation, and the work gave her great insight into the minds of ill teens. Now the site helps teens manage the challenges of attending school with a chronic illness.

Through her website, Fleitas has come to realize that not all teens with chronic illness are the same, nor will they respond the same way to similar situations. “Kids are as different with chronic illness as they are without it, some quite resilient and accepted by most, and others quite vulnerable, both physically and psychosocially.”

The role of parents of a teen with a chronic illness is no less challenging than the teen’s. The parents’ job is threefold: to help their teen know his or her limitations and abilities; to help their child find what works for him or her; and to be their child’s best advocate. These three factors contribute significantly to a teenager’s success in school.

Maintaining Social Connections

While not allowing teens to be defined by their illness, a parent must also be aware of the psychosocial “bumps” that a teen with a chronic illness can encounter. Fleitas believes that the single most important success factor for a teen with a chronic illness attending school is “acceptance of the student by classmates and teachers.”

One of the challenges of having a chronic illness and continuing in school is finding a balance that sustains a child’s social life. It is essential to keep up with schoolwork,



but it is equally—if not more—important to continue to “have a life.” Teens rarely thrive without this.

Absenteeism, a frequent occurrence for many chronically ill teens, can directly affect the social life of a student, straining relationships within his or her social circle, especially if the absences are of extended lengths. Often, the teen returns from an absence to changes in the social circles or common experiences that he or she has missed—anything from a party to a sporting event, or even a prom. While many teens will be able to pop right back into their social positions, some will find it problematic, experiencing difficulties with some peers or feeling isolated.

Parents must observe their teen carefully, keeping an eye out for any signs that the child might be experiencing difficulties with his or her social circle that could lead to depression. One intervention parents can consider is allowing their teen to continue socializing when they are home sick or hospitalized. While it is important to consider your teen’s personality and comfort with “exposing” him or herself in this way, it is also important that a teen with a chronic illness experience as little isolation from peers as possible. Including peers in the teen’s experience with his or her illness can actually be a powerful bonding experience.

One cautionary note: Faking sickness to get out of school is a possibility with any teen, regardless of his or her health status, but your familiarity with your child’s disease and its symptoms should help you make astute determinations.

Achieving Academic Success

Chronic illness in an adolescent can present complex challenges to acquiring an education. Fleitas has advice for

parents in the academic arena: "In terms of academic success, parents need to support their youngsters, rather than 'do for' them as they confront the demands of school. [This] makes for much better self-esteem and achievement."

There are many different ways to help your teen learn to do for themselves, and you can provide support by identifying options that work for your teen's individual personality, style and needs. (As tempting as it may be, though, doing your child's assignments is not a good option.)

Traditional schooling is not geared toward students with the complications presented by chronic illness. Therefore, teenagers dealing with such complications may find themselves in situations in which they do not fit or cannot meet the expectations of a traditional schedule and workload. Parents, doctors and educators can help a student develop a plan for balancing the illness and the education.

Developing a Plan

The student's educational, social and psychological needs at school must all be considered when developing a plan. It can be helpful to review a variety of options to determine which best fits the needs of your student, but whatever you do, do not feel bound by the traditional route. While some schools may not have extensive experience in dealing with chronic illness, you can educate them and suggest options that might not otherwise have been offered. Regardless of the school's experience, your child's potential should not be limited, and you will need to advocate for this.

There are various legal requirements for accommodating students with special needs that schools must honor (see "Special Education Plans," Page 22, and "IDF School Guide," Page 27). However, even if your teen is determined to be eligible for any of these accommodations, you must continue to be an avid advocate for the best education your child can receive. Make sure the unique characteristics of your child's illness are reflected in his or her education plan. Fatigue, for example, is common to many diseases, and it can be accommodated with schedule and course load adjustments. Students are not required to take six core classes a semester—there is always summer school or community college classes (often awarded double the high school credits!), which can allow a student to work at his or her pace, but still graduate with peers. A combination of traditional classes and independent study can help some students manage fatigue and still keep up. And, some students may simply need an extra semester or two to complete high school requirements. Remember that the goal is to graduate, so present taking extra semesters as an option early on, so it doesn't feel like failure to your teen.

Developing a Sense of Self

Teenagers suffering a chronic illness must deal with a lot, both the problems the illness presents and also the burden it adds to the normal adolescent struggle for self.

While it is critically important that school staff are well informed about your child, it is also essential that a teen's right to privacy in the school setting be respected. While some teens will talk freely about their illnesses and struggles, others will not. It is important to respect the wishes of the child in this case. Teens will choose their own ways to communicate about their illnesses—who they will tell about their disease, when they will share it and in what way. Their willingness to reveal such information can be affected by how comfortable they are in their peer groups, their personalities, how long they have been diagnosed, and their parents' reactions to their illness. Let your teen take the lead on this one; it is an area in which he or she can enjoy some control and, hence, some beneficial self-determination.

Sometimes teachers can unintentionally draw unwanted attention to the differences between a teen with a chronic illness and his or her peers by doing something as simple as asking publicly for a volunteer to help orient a student who has returned to class after a long absence or openly offering a student special consideration or accommodation. If this occurs and it is unwanted, it should be addressed with the teacher immediately, either by the teen or the parent.

Teens can learn some creative and proven ways to deal with their diseases and the demands of school in peer support groups, but this may not be for every teen. Fleitas explains, "Support groups are effective for the kids who need a peer group, [but they are] not for everyone. In fact, some youngsters with pretty serious medical conditions would die before they'd participate in something that further marks them [as different]."

Ask your teen if you should seek out others with similar conditions, but do not push it if he or she is not interested. Of course, you can always repeat the question in a few months, in case things have changed for your child, but respect the answer you receive.

As hard as it is, with or without a chronic illness, teenagers are still teenagers. Your job is to provide them with healthy options, but they must be given room to spread their wings and the freedom to make mistakes, while at the same time have a safety net so they don't fall too far or too hard. ■

Visit Band-aides and Blackboards at
<http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/>.