

Adolescents and Chronic Illness

By Robert H. Phillips, PhD

Introduction

Most books and articles written about chronic illness are targeted for adults with diseases. Much information is given about the particular disease, such as its symptoms, treatment and lifestyle changes necessitated, all of which is very valuable. But there is a unique population that is not addressed often enough in this written material: the adolescent with chronic illness.

Although children and adolescents may experience many of the same problems living with chronic illness that adults do (such as pain, other physical symptoms, or medication side effects), certain problems are more exclusive for adolescents.

This article will address a sampling of the problems that may affect adolescents with chronic illness. Rarely will an adolescent with chronic illness experience every psychological consequence of a chronic illness; however, it's important for everyone involved- parents, friends, educators and healthcare professionals- to be aware of, and sensitive to, these difficulties.

Denial

It is interesting that adolescents, more than virtually every other age group, have a common, non-verbalized (and sometimes loudly verbalized) belief about their medical status: "I'm fine!" They don't want to *feel* sick; they don't want to *be* sick; and they don't want to be *different*. But chronic illness may throw a monkey wrench into that.

What makes it especially difficult, though, is that unless a chronic illness is affecting the young person to such a degree that they are literally unable to function, in many cases the young person's attitude will *continue* to be "I'm fine". This can be frustrating for other family members, who are trying to be protective and helpful, and for healthcare professionals, who have more difficulty treating a young person if the answers to questions about symptoms are evasive or denying.

School

Adults who work generally have a clear sense of their responsibilities and obligations at their jobs; they know that if they don't work, changes will result- many of which can be difficult and unpleasant. The adolescent's primary "job" is to go to school. For adolescents with chronic illness, the attitude about school varies. Some are upset and frustrated if their illness interferes with consistent school attendance and schoolwork performance. Others see school as less important and may have few or no qualms about missing excessive time in school.

Adolescents with chronic illness may have a more difficult time in school if they have to deal with hostility or criticism from their classmates or friends ("Why can't you go out with us tonight?") or the ignorance of teachers ("You've missed too much school work; either get with the program or you're going to fail.") In addition, because of chronic illness, adolescents may find themselves ostracized and even excluded from activities that were once within their physical capabilities.

Peer pressure

Peer pressure may also affect young people with chronic illness. The need to "fit in"- at its strongest during adolescence- can be devastating to someone who has a chronic illness with noticeable physical effects (e.g., rashes, bloating, hair loss, disfigurement, etc.) and behavioral effects (slower, more painful movements, etc.).

It is heartwarming to hear stories of young people with chronic illness whose friendships continue despite their illness. Yet it is sad to hear of other stories in which the adolescent with chronic illness is ridiculed and even abandoned by former friends.

Parents

Adolescents with chronic illness may have difficulties with parents being overprotective ("Stay inside, the sun is out"), not protective enough ("You want to go to the beach? Do whatever you want"), or

insensitive to their needs (“Stop complaining about your pain already. Get up and finish your school work”). With adolescents trying to break free of childhood and enter the world of adulthood, any of these parental reactions may be difficult for them to understand.

Parents may be concerned about the effects their child’s chronic illness will have on the family, such as financial issues, problems with or neglect of other children, or even feeling like their independence is being inhibited. Any of these concerns can likewise affect the young person with chronic illness. Already unhappy because of having chronic illness, but feeling responsible for problems within the family or with the parents, an adolescent may feel guilty to the extent that it interferes with physical... and emotional... health.

For example, the young person may not tell parents about a serious physical symptom, knowing it might mean another trip to the doctor or even the possibility of hospitalization.

Siblings

Brothers and sisters of an adolescent with chronic illness may be very resentful. Being less able to understand the physical impact of the disease, they may dislike the added “attention” being directed at their sick sibling. They also may not like getting less attention, and may act out in an attempt to regain their “share” of parental interactions.

Their resentment toward their sick sibling may be manifested in many hurtful ways, such as anger, ignoring instructions, spiteful behavior, concealing important information from their parents, etc.

A final note

It is difficult enough for anyone to live with chronic illness, but the adolescent with a chronic illness has added, age-related problems. Being aware of the potential impact of chronic illness in young people does not eliminate these problems. But increased awareness can pave the way to a better understanding of the unique needs of adolescents, and can lead to methods for better alleviating the problems that may occur.

Some Helpful Suggestions

- **Be sensitive to the adolescent’s unique needs.** Chronic illness can be difficult to live with, especially for an adolescent who has less “life experience” and consequential coping strategies in place. Don’t assume that the young person has the emotional strength or the social support network to handle chronic illness-related problems successfully.
- **Communicate appropriately.** Try to look at any chronic illness-related issues through the eyes of the adolescent. See what they see. Feel what they feel. Issuing commands, or using anger and aggressiveness in “forcing issues” is rarely productive. Calm, constructive discussion is a much more positive way to address chronic illness-related issues.
- **Try to treat the adolescent as an adult.** Plan together the appropriate ways to treat, and live with, chronic illness. The more you treat the adolescent like an adult, the more likely it is that this will generate adult-like behavior in return.
- **Educate significant others.** Any individuals who are not familiar with living with medical problems, including family members, friends and teachers, can be obstacles to successful living with chronic illness. This is especially important in school, since the adolescent is going to spend a good number of hours there each day. Provide pamphlets and other information to teachers, guidance counselors and even classmates, so that school can truly be a “home away from home”.

About Dr. Robert H. Phillips - Dr. Robert H. Phillips is the founder and director of Long Island, NY’s *Center for Coping* (www.coping.com), a multiservice organization that specializes in helping individuals and families improve their ability to cope with medical illnesses, stress, family concerns, and other life problems. Dr. Phillips is a charter member of AARDA’s Scientific Advisory Board and serves on its Board of Directors.

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