

How to Be a Teenager and Cope with a Chronic Illness

By Erika Lawrence, PhD

These coping strategies for dealing with parents, friends, caregivers and even themselves can better help teens to navigate these difficult years.

Being a teenager is hard enough. There is tremendous pressure to fit in, to be “normal,” to conform with peers. There are few people who don’t look back on high school and shudder. It is a time when teens feel like outsiders, like they don’t belong, like they’re different in some (bad) way.



Teens also feel like they have absolutely no say over their own lives. They're constantly answering to their parents, teachers or friends. It is one of the most challenging times of their entire lives.

Imagine how much harder it is when they add to all that a chronic illness. One of the questions teenagers often ask is: "How do I deal with people who 'just don't get it'?" Parents, friends and even doctors can be infuriating at times. That's why it's important for teens, as well as their caregivers, to understand the unique challenges they face when coping with a chronic illness, and to be armed with some strategies for dealing with these situations.

Dealing with Parents

People with a chronic illness know how challenging and frustrating it can be to get family members to understand the unique, complicated and unpredictable nature of their disease. They also know how difficult it is to get others to be supportive in a way that is helpful, rather than hurtful or aggravating.

But, while adults have some power in their relationships because they are on equal footing with their spouses and friends, teenagers have very little power in their relationships with their parents. Instead, they have to struggle to balance some newfound independence with their dependence on parents for food, shelter and clothing, as well as for love and support. What's more, teens with chronic illnesses also are dependent on their parents and caregivers for help with their medical care. They have to be driven to doctors' appointments, have their medications paid for and be helped with infusions. When they infuse in the home, parents either have to assist teens or at least supervise them to ensure the infusions are being done. When teens infuse in the hospital or clinic, parents often have to drive. As a result, teens with chronic illnesses often wind up feeling even more dependent on their parents.

Another challenge faced by these teens is dealing with parents' reactions to having a child with a chronic illness. In some cases, parents can be as critical or dismissive as other people in their lives. However, the more common situation is for parents to become overly protective and/or extremely anxious. This makes sense, of course. Parents want to protect their children, and they worry about them and want to keep them safe. However, adolescence is the time when this feels the most suffocating and unhelpful.

So how do teenagers gain some control over their lives when they depend on their parents to stay healthy? How do they deal with overprotective parents? First, keep in

mind that parents may have a hard time accepting or coping with their children's illness. Teenagers should set aside some time to try to talk to their parents about this. Parents need a chance to tell their children how scared they are for their safety and health, how guilty they feel that they have this illness (yes, parents often blame themselves for their children's health problems), or how much they want to lock them in their room so nothing bad can happen to them. Teenagers, in turn, need to empathize with their parents, who are feeling and/or behaving this way out of love for their children and out of a desire to be a good parent — not because they want to make their children's lives miserable.

Second, teenagers need to ask their parents to really listen to what they say things are like for them. They need to tell their parents that they understand why they are so protective or anxious (or that they are trying to understand), but that the protectiveness and anxiety adds another layer of stress and difficulty to an already challenging situation (being a teenager with a chronic illness).

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Third, once teenagers have had a chance to say how they feel, they should try to come up with a small change that both they and their parents can live with. For example, if teenagers feel a lot of pressure to stay home Friday and Saturday evenings instead of going out with friends, perhaps it could be agreed upon to go out Friday night for a few hours (perhaps two to three hours instead of five or six). Then, when they come home, they can let their parents know how much they appreciate their parents letting go a bit. If that works, they can talk again about what another step forward might be. Over time, they'll be able to have more of the types of freedoms that other teens have, and their parents will become increasingly comfortable (or able to tolerate) giving them more freedom.



Last, if that does not work, teenagers should request that they all meet with a counselor for a few sessions. It can help a lot to have a third party to help navigate these types of discussions and move forward.

Dealing with Peer Pressure and High School

High school is all about fitting in — being normal. Having a chronic illness makes teenagers feel different or deficient in some way. There may be peer pressure to drink, which is particularly dangerous for teens who are on medications or getting infusions. Dating and becoming sexually active is more challenging with physical health problems. There also is tremendous pressure to be strong and not show vulnerability, for both teenage boys and girls. Bullying is a huge problem in schools, causing tremendous stress and depression for victims. All of this can cause stress and depression, which can worsen symptoms of chronic illness, leaving teenagers feeling more vulnerable and more like outsiders.

So how can teenagers find support and fit in at high school? First, they should identify one or two friends whom they really trust and tell them about their illness. They should do the same with one or two authority figures at school that they trust, such as a teacher, counselor or coach. Knowing they have a few people in their corner who can look out for them can make it easier to navigate everything else. This is particularly important if bullying is an issue.

Once they have identified people they can trust, teens need to figure out *how* to tell them. Most people want to understand, but they simply don't know a lot about chronic illnesses. Teenagers need to educate them about their

illness and how it affects them on a day-to-day basis. They also should encourage them to ask questions, and ask if they would like something to read about their illness.

It is important for teens to take their cues from the other person. They should be careful not to overwhelm others with information, but rather provide as much information as they seem interested in hearing about or able to take in at the time. They can always teach them more the next time they talk about it.

Teenagers should know that, at times, they might disappoint their friends. There are so many demands that are already put on them as teenagers. When managing a chronic illness is added to that, teens have only so much time and energy to do everything that they need and want to do. Therefore, they should be assertive and tell their friends if they cannot go out with them on Friday night because they need some time to take care of themselves. It's OK for them to say "no." They can also let their friends know how disappointed or frustrated they might be about that and offer an alternative that they can live with (e.g., getting together for a movie on a different night). Real friends will understand.

Dealing with Doctors and Nurses

It can be so frustrating for patients when doctors and nurses don't know much about their chronic illness. And, finding a medical professional who is an expert — or at least knows a bit — about their specific illness is not always an option. Even if one is found, is that

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person within driving distance? Does he or she take the patient's medical insurance? Is it possible to get an appointment?

Most people with a chronic illness are stuck trying to educate their doctors about their own illness, and how their illness

affects whatever symptom or problem they are experiencing that day. How do patients teach the “experts”?

Doctors can't be expert in everything. No one can be. However, most doctors and nurses do want to understand what patients are going through, and how they can help them feel better. It is OK for patients to bring a pamphlet or sheet of information about their specific illness to their appointments. Patients also can give permission to all their doctors to speak to the specialist treating their chronic illness. It also helps to bring to each appointment a list of all their medications, the dosage and why they are taking them.

Changes in the Healthcare System

One of the key features of the current administration's healthcare plan is to treat patients and their families; in other words, to treat the “home.” This means that people with a chronic illness will have a team of healthcare professionals to help the entire family system cope with the illness, the ways in which family members are affected, and how family members affect each other. For example, in Vermont, patients have a “healthcare coordinator” who helps families design unique care plans. This approach has been used for decades in England when women have babies, and it has been shown to be highly effective at helping individuals and families cope with changes, stressors and health problems.

Finally, Take Time for Self-Care

It is perfectly normal for teenagers to feel scared, angry, sad, disappointed, guilty and distressed at times. And, it's OK for them to feel that way. All patients should allow themselves to have those feelings when they arise.

However, it's important for teenagers to not let those feelings take charge. They should ask themselves these questions: “Am I so depressed that I am having trouble living my life on a day-to-day basis, or having trouble getting out of bed?” “Am I so anxious that I am not connecting with people or not going out and having fun?” “Am I so mad that I am taking it out on everyone else?” If the answer is yes to any of these questions, they need to talk to someone: a school counselor, teacher, parent, doctor or nurse. Depression, anxiety and irritability can be successfully treated; it's not necessary to feel that way.

How can teenagers best take care of themselves?

1. Identify one or two authority figures and two to three close friends they can really talk to about how they feel.

2. Give themselves a break. Everyone feels like an outcast in high school at times. They are not alone and it is not forever.

3. Join a support group for teens — either in their community or online.

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4. See a counselor for a while to have a place to get things off their chest and to have a sympathetic ear.

5. Find an outlet for their feelings and thoughts so they don't get stuck in their heads. They can try keeping a journal, drawing or painting, listening to music or playing an instrument, or whatever works for them.

Adulthood Is Just Around the Corner

As hard as life can be for a teen, it is even more difficult for one suffering from a chronic illness. But by gaining a better understanding of how to deal with what they feel and how to reach out to their parents, friends and caregivers, they can get through this difficult time in their lives. They can grow out of their teenage years before they know it with a healthy and sound psyche. ■

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