



Highlights from the IG Living Teleconference, May 21, 2014

Topic: **Teens living with chronic illness or disability**

Guest expert: **Miriam Kaufman, a pediatrician, public educator, head of the division of adolescent medicine at SickKids in Toronto, Canada, and a professor at the University of Toronto.** Dr. Kaufman's main interest is young people with special healthcare needs. She is the author of *Easy for You to Say: Q&As for Teens Living with a Chronic Illness or Disability*.

- Young people with chronic illness, whether common or less common, often feel they are the only person in the world with their condition. Many changes happen in teens' lives that take them from being a child to being an adult. Some of these things happen without them having any control over them, like puberty. Other things happen somewhat under their control, although often not consciously — things like developing a set of ethics and morals, what they believe is right or wrong.
- Kids' emotions get richer as they get older. For instance, little kids get sad, mad or glad, but as they go through adolescence, they have a much more emotional repertoire. One of the big emotional changes that develop as a teenager is a sense of identity — a subconscious process that develops through meeting people and comparing themselves to those people — thinking, "In what ways am I like that person or not like that person? What are the things I don't like about that person?"
- A teen's identity also comes from experiences. A chronic health condition can affect a teen's identity in both negative and positive ways. Some may feel there is something wrong with them, which can lead to a lot of difficulties in life. Others might feel lucky since, 100 years ago, they would have died from their condition, and instead, they now have options open to them.
- A teen's identity also comes from parents' expectations. Sometimes, young kids with health conditions are seen differently in their households. For instance, parents may think that a chronically ill teen needs to be more taken care of, or that they shouldn't have the same responsibilities as the other young people in the home. And, this can lead to an identity of being somebody special in not such a positive way — somebody who doesn't have to contribute at all to the family or to family life, or to the world in general.

- There also are all kinds of practical things that teens have to deal with when developing their identity. For instance, they may worry about how to tell people they have a condition, or how to plan for college. Or, they may worry about whether they can use every form of birth control available to them, whether they are going to be able to have children, and what the chance is that their children will have what they have.
- Finally, young people with a chronic illness may feel that their parents are trying to stop them from doing the things they want to do. That often occurs because parents want to be sure their children are safe. However, there is a real dividing line between keeping their children safe and protecting them from learning experiences. We all make mistakes, and one of the points of growing up is learning from those mistakes so we're not making the same ones over and over again.