

## Real Feelings

Whenever you go to the mall with your brother, Joshua, who has Down syndrome, and your mom, you feel really embarrassed. You don't really want to be seen with them because so many people stare at Joshua. You're also nervous because it feels like Joshua could get loud or do something to embarrass you at any moment, and you don't want to be around for that. At the same time, though, you feel guilty for feeling these things. What can you do?

Imagine you're the parent of two sons, one of whom has Down syndrome and the other does not: Your daughter, Kristen, who is in middle school, gets so impatient with her brother, Leo, who has Down syndrome and is just a year younger than her. Kristen always complains that Leo takes forever to do just about anything, including eating dinner. She seems very frustrated with him and has been spending very little time with him lately. What do you do?

You are fifteen years old and studying for your highly-anticipated driver's permit exam. Your sister, Summer, is sixteen years old and wanting to drive, as well. Summer also has Down syndrome, and you don't think she will pass the exam and be able to drive a car. Summer keeps talking about how she's going to study for the test and pass it and the drive. She won't stop. It begins to make you really upset because you know Summer likely won't pass the test, but you likely will. You don't want her to be jealous or mad at you, so you decide you just won't take the test at all—at least not for now. What else could you do in this situation?

Here are some notes on these:

- Visit the “Topics” section of the site to read about issues of embarrassment. Joshua's parents should talk to him about why he feels so embarrassed and help come up with solutions to the situations that cause these feelings. It may also help Joshua to talk to other brothers and sisters of people with Down syndrome.
- It may be helpful for Kristen to participate in a Workshop like this where she can experience some activities that will help her understand life from Leo's perspective. Also, if Kristen is feeling so angry about the extra time Leo takes, it's probably because Leo is taking that time away from her when she could be spending that time alone or with her parents or friends. She should talk to her parents about needing some time without Leo, perhaps independently with her parents, and that may help with her feelings of resentment. There is a section about this under “Topics.”
- Summer's feelings of guilt are normal, but she should also know she doesn't have to feel guilty. It will be important to focus on all of the things Mariah will grow up to do that will make her happy and help her to find fulfillment and meaning in her life. You can also discuss ways to find a compromise for this situation. For instance, yes, Mariah may not be able to drive right now, but Mariah will be able to ride around with Summer in her car! Mariah will find great joy in that independence and quality time with Summer.
  - For more information, check out Dr. Brian Skotko's and Sue Levine's book, *Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters*, Chapter 6, Detour Ahead: sorting out your feelings, pages 132-134, pages 135-136, as well as Chapter 8, Are We There Yet: looking toward the future, page 171, as well as pages 175-176!