Educating Peers About Tourette's Syndrome

Note: Some research suggests that children with tics are teased, and in some cases rejected, because of their tics. Preliminary research assessing whether a peer education program might make a different suggests that there could be some benefit if peers were educated about tics. The suggestions below are based solely on my experiences over the last 15 years conducting peer education programs and do not represent any formal research results. The suggestions are for a classroom presentation, but can be modified for use by parents who wish to educate their child's friends.

The length and depth of the program will depend on the age of the peers. Here are some things to keep in mind if you are running a peer education for children ages 7 - 11:

- Plan on doing a 20 - 30 minute presentation, but no more than that, and possibly shorter. Remember that their attention span is not that of an adult's. Occasionally, I've had groups that got so "into" the discussion that we actually ran longer, but in general, keep it short, sweet, and make sure you use vocabulary appropriate to the age group.

- The national Tourette Syndrome Association has some videotaped vignettes available that you might want to consider to show to the class as part of the peer education. You can find a description of these on their web site at http://tsa-usa.org. Danya International at http://www.danya.com also has a video made for peer education purposes. For very young children, you may also wish to read them a book such as "Taking Tourette's Syndrome to School" by Krueger (available at http://www.amazon.com).

- Remember to tell the kids that Tourette's Syndrome (TS) is not a fatal disease. We know that, but they don't, and they may get scared.

- Remember to tell the kids that they can't catch TS from a classmate. Again, we know it, but they won't unless you tell them.

- Be sure to explain that the tics will change, so that in the future, the class will have some basis for understanding why their classmate is now having symptoms other than what you talked about that day.

Be prepared for questions such as:

- "How did s/he get it?" I usually explain that the child inherited it (assuming that I know that there is a family history), just like all of the children got their eye color, hair color, talent, etc. from their parents.

- "Is there any cure for it?" My answer is a straightforward, "No, but the good news is that [child's name] will probably get better when s/he gets to be a teenager -- it may just be rough for a while now, if we can all hang in there and support [name]."

- "If I don't have it now, could I get it?" I usually answer that there's no way for me to know for sure, but if their parents don't have it, then they probably won't have it.

In explaining TS to young children, use examples that they can relate to -- like having the hiccups. I always ask the class how many kids have had the hiccups. When the all raise their hands, I ask them if they can stop the hiccups just because they want them to go away. And so we compare tics to hiccups -- you didn't plan on them, you don't want them, you can't really stop them, and they'll go when they're good and ready and not until then! The children can also relate to how uncomfortable they feel if they hiccups hurt or last too long.

One of the main purposes of the presentation is to develop empathy, but not pity. I usually ask the children how they'd feel if they had to make loud noises or strange movements. Then I ask them how they'd like others to react to them if they had to make noises or movements. Most kids will generate the strategy of "I'd like them to ignore it." To which I enthusiastically respond, "Excellent!! That's the best strategy -- just ignore the tics!"

Occasionally, I've encountered children who would rather their peers not ignore the tics but make some understanding comment if they're going through a rough time. Whenever possible, I talk with the child for whom the peer education is being conducted *before* the presentation to find out what s/he wants the class to understand and what s/he would like in terms of reaction. I wouldn't "push" a child to be present at a peer education program, but I would encourage it. Some kids are terribly anxious about how their peers will react and would rather not be there. If the child is nervous about having a peer education program, I would delay it until they give you the go-ahead. I don't personally believe in "outing" kids, and we can't really guarantee them that everyone will be understanding or supportive. Let's recognize that there may be kids in the class who once they know about the TS, may use that knowledge to tease or torment the child. And let's also remember that in talking to the class about a peer's TS, we are revealing confidential medical information about that child and parental consent is required.

If the child would like to help teach or run the peer education program, that's terrific, as it helps them learn how to advocate for themselves. But again, I would never "push" a child to do that -- even if they're in the room. I tell them privately beforehand that I won't call on them unless they want me to but if they want to chime in or explain something, I'd love to have their help.

If I show a film, it's only after I've prepared them for it. And after the film, we discuss what they saw and handle any questions or comments. I usually try to tell the class about some famous people who have TS and I tell them about kids with TS whom I know and what they CAN do.

The message is simple: kids with TS come in all shapes and sizes just like every other kid, but they just have this tic condition that may seem weird if you don't know what it is. But now that they know what it is, they'll know that the best thing is to just ignore it or to be supportive of their peer.

Following a peer education, you will probably notice a "honeymoon" effect where peers are nicer to the child for a while. But keep track over time and see if the peers' behavior actually changes towards the child. Is the child now getting included in more activities on the playground? Are they getting invited to more birthday parties? You may need to conduct some "booster" awareness sessions at different points during the school year.

Finally: although I have conducted numerous peer education programs on Tourette's, I actually prefer not to do a program on "just Tourette's" as there are so many conditions affecting children. If your school or district can create an "embrace diversity" program, students can be exposed to a number of conditions – and the more children who are affected by one of the conditions, the more likely they may be to accept another student's differences.