

# Coping with Tourette Syndrome

A Workbook for Kids with Tic Disorders

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### *Directions*

Plan a script to explain your TS. You can fill in the blanks below or write your own script on a separate piece of paper.

I have Tourette syndrome. Have you noticed that I \_\_\_\_\_?  
That's part of my TS. There are other things my body and brain make me do, too. Sometimes I can stop for a little while, but then I can't concentrate on anything else. Trying to stop takes a lot of energy, and it is very hard. I'm sorry if I'm bothering you. TS is something I would like to control, but I can't. I would if I could.

When do you think this script would work for you? \_\_\_\_\_

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Practice the script with your parent, counselor, or another adult until you feel comfortable saying the words without looking at them. Next, choose a relative that you talk to a lot. Ask if you can practice your script together, in person or over the phone. When you feel good about that practice, share it with another relative or friend.

Use the log on the next page to keep a record of your practice.

*What is your best advice for kids who have very noticeable tics that make people stare at them?*

Don't let the stares bother you. Get used to it. After a while, you will actually get used to the stares. When I go out in public, my friends and family get more upset by the stares than I do. I guess since I have lived with TS for so long, I'm used to it. I have tried to live my life just like anyone else, and I don't allow the stares from other people to get in the way of me living my life to the fullest!

# Helping Others Experience TS

## Activity 11

One day, Jackson's health teacher brought a wheelchair to class. The kids in the class took turns sitting in the wheelchair. They had a chance to feel what not being able to walk might be like. Another day, they each kept their eyes closed for an entire class period to see what being blind was like.

Jackson had practiced his TS script with his parents and shared it with other people, but he wished that his classmates, his friends, and his family could experience what having TS was like. He knew that if other people understood about his TS, he would feel more relaxed. He would be able to express his tics without worrying about what others thought. He met with his school psychologist to come up with an idea. Together, they created "The Tourette Syndrome Game." That night, Jackson played the game with his mom. She said it really helped her understand.

### *Directions*

You can play The Tourette Syndrome Game with a parent, a relative, a friend, a teacher, or anyone who has a few minutes to spare. All you need is a timer, or you can use a clock or a watch. Before you play, fill in the blanks below:

One of my vocal tics is \_\_\_\_\_.

One of my motor tics is \_\_\_\_\_.

My favorite number under ten is \_\_\_\_\_.

Then read the following out loud, inserting your answers:

The Tourette Syndrome Game can help you understand what having TS is like. You must follow the rules and then tell me how you feel at the end. When I say "Go," you will start singing "Happy Birthday." You will keep singing for two minutes. Each time you sing the word "happy," you will do my phonic tic, which is \_\_\_\_\_. Each time you sing the word "birthday," you will do my motor tic, which is \_\_\_\_\_. Each time you sing the word "you," you will clap your hands as many times as my favorite number, which is \_\_\_\_\_.

Read the directions twice and then start timing. If other players ask you to read the rules again, you can, but don't stop timing. You can't help them, but you can correct them. At the end of two minutes, say "Stop."

Then ask the other players the following questions.

1. How did you feel before you started playing this game?
2. How did you feel in the middle of the game?
3. How did you feel at the end of this game?
4. Were you able to sing "Happy Birthday" as many times as you expected?
5. Was it harder than you thought it would be?
6. Is there anything else you want to share with me?

Who is another person you would like to play this game with? \_\_\_\_\_

Have you ever tried to not sneeze or to not hiccup? Sometimes you can actually make sneezes or hiccups less noticeable, but a lot of times you can't. Have you ever thought about your tics in the same way? There are times when you feel comfortable expressing your tics. There are other times when you might be more embarrassed and want to cover them up. There are also places where it is best to cover up tics and places where it doesn't matter as much.



***Directions***

Here are some more ideas to try that can help you use humor. Put a check next to the ones you would like to try.

- 1. Each weekend, learn a few good jokes and tell one immediately after an embarrassing tic. This won't always work at school, especially if you are taking a test!
- 2. Ask your teacher to help when you make a big sound or noise that you can't control. Your teacher can say, "Bless you!" as if you had sneezed.
- 3. Turn a "bad" word into a different word or sound. For example, if you say "butt" as a tic, turn it into "butter."
- 4. Take a drama class and become a real comedian!

Write your own ideas here. \_\_\_\_\_

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