

Tics

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Workbook for Parents

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Introduction

You are the parent of a child that has tics and is going to follow a behavioral treatment aimed at reducing tics. The purpose of this workbook is to give you information about tics and the treatment. Your child will receive its own workbook, which also includes information and exercises. In addition, your child's workbook contains information for school, which can be given to the child's teacher. Both during the sessions and at home, your child will have to do a lot of practicing. As a parent you will be involved in the treatment by recording your child's tics and helping your child with homework assignments. More information about how this works can be found in this workbook.

1 • Tics and tic disorders

Tics are sudden, rapid, non-rhythmic movements of for example eyes, head, neck and shoulders. Examples of tics are eye blinking, throwing the head into the neck or shoulder-shrugging. In addition, tics are sometimes sudden sounds, such as coughing, throat-clearing or peeping noises. Tics may also be more complicated movements or sounds that seem more purposeful such as jumping, touching things or repeating what someone has said. Or, a child may have cognitive tics that may be expressed as mind games, such as counting words or stairs of reading backwards. Many children have tics; about one in ten children do tics during shorter or longer periods of time. Usually, the tics disappear spontaneously. But some tics do not go away; in that case it is possible that the child has a tic disorder.

A well-known tic disorder is the Gilles de la Tourette's syndrome or Tourette's syndrome. Children with this syndrome have more than one movement tic (also called motor tic) and at least one sound tic (also called vocal tic) for at least a year. In that year, the tics are not absent for more than three consecutive months. Research shows that the syndrome is present in 0.5-1 percent of the population, more often in boys than girls. Another tic disorder is chronic tic disorder. This disorder involves having either movement tics or sound tics for more than a year, but not both types of tics as is the case with Tourette's syndrome. When the tics disappear within a year, the term temporary tic disorder is applied.

Children that have a tic disorder often experience a lot of activity in their heads. They are more likely to express hyperactive behavior and have attention deficit hyperactivity disorder (ADHD) than other children. Also, repetitive behavior (also called compulsive behavior) such as checking locks or turning lights on and off is possible. Sometimes it is hard to differentiate between tics and compulsive behavior. An important difference is that compulsive behavior is usually expressed to reduce fear, whereas tics are not linked to fear. They are more linked to so-called impulsive actions.

Many children that have tics can suppress their tics for shorter or longer periods of time. How long they are able to do so varies from person to person. Something that seems to play a role in how well a child can suppress their tics is that in many children a tic is preceded by an unpleasant feeling. It is as if the tic is announced by this feeling. Some children experience a sensation similar to an itch, tension, pressure or burning feeling, on their skin, muscles, bones or joints. Children sometimes compare the feeling they get to insects, mice or little people that are walking or crawling inside their body. A tic can also be preceded by a feeling of being cold or warm, or other more specific, mostly nasty feelings. During your child's treatment we will refer to these sensations as tic-alerts because they announce that a tic is coming on. However, not all children experience these sensations and sometimes they become aware of them during the treatment.

We do not yet fully understand what causes tics, tic disorders and Tourette's syndrome. Tourette's syndrome is a neuropsychiatric disorder in which genetic factors play a role. In addition, there are indications that the immune system and infections play a role in the development of the syndrome. The nature and the severity of tics and tic-related symptoms tend to change over time. It is not known what causes these changes. What is known is that tics usually increase or decrease in specific situations. Tension and fatigue can make tics worse and tics tend to become less when a person is relaxed, sleeping or concentrated. Usually, tics will become less severe in adulthood.

If you would like to know more about tics and tic disorders, suggestions for further reading can be found in appendix 3 of this workbook.

2 • Behavior therapy to manage tics

Scientific research has shown that there are two types of behavior therapy that can be effective in the treatment of tics: 1) exposure and response prevention and 2) habit reversal. Both methods are described in this chapter. Exposure and response prevention is called 'holding back tics' in your child's workbook. Habit reversal is referred to as 'using a competing response'. Together with your child's therapist, you will choose which method your child is going to use. Exposure and response prevention consists of twelve sessions and is often applied if your child has many different tics. Habit reversal includes ten sessions and is often used if your child has a few different tics. If there is only one or a couple of tics, the treatment may be even shorter than ten sessions. If there are many tics involved, it is more likely that there will be a reduction in the severity and number of tics, than that the tics will disappear completely. At the start of the treatment, sessions are weekly. Later on there may be more time between sessions. If the chosen method does not help sufficiently, the therapist may suggest trying the other method in consultation with you.

Your child will be assigned exercises to do at home. Depending on the child's age and level of independence, you will be involved in these exercises. Also, you will be asked to record your child's tics daily during a period of fifteen minutes. This is to determine the efficacy of the treatment. Paragraph 2.3 explains how this recording is to be done.

After the treatment methods have been completed, there still may be tics in particular situations. The first step is to study in which situations your child still expresses a lot of tics. Then together with you and your child, the therapist will come up with possible solutions for these situations. Sometimes this will involve relaxation exercises for your child or maybe your child needs extra help to do its homework. The next chapter contains information about these additional interventions.

There is no cure for tic disorders and even after treatment it is possible that tics will return or get worse. This is why a relapse prevention plan will be made before the treatment ends. This plan describes what your child can do to prevent the tics from coming back or getting worse after the treatment has ended. The relapse prevention plan also sets out what your child can do if the tics come back or get worse anyway. You, your child and the therapist will draft this plan together. In your child's workbook, the plan is referred to as the "Keep-the-tics-away" plan.

2.1 Exposure and response prevention

Chapter 1 explained that many children who have tics or Tourette's syndrome experience unpleasant sensations (tic-alerts) in association with their tics. These sensations play an important role in maintaining tics. If doing a tic makes the unpleasant feeling go away, the body learns that expressing a tic helps it to get rid of the unpleasant feeling, the tic-alert.

Exposure and response prevention is a method that aims to help your child get used to tic-alerts. The association between the tic-alert and the tic is broken when your child does not react to a tic-alert by expressing a tic. Thus, by suppressing tics, the child can learn to tolerate the alerts. Tic reduction is the result. The situation can be compared to a mosquito bite that itches. If you keep on scratching the itchy place, the itch disappears for a moment, but the skin is damaged and the itch will keep coming back. If you are able to tolerate the itch and not scratch the bite, the itch will eventually go away, as well as the mosquito bite. Then scratching is no longer necessary. It sounds quite simple, but how does it work in practice?

The treatment begins with two training sessions. During these sessions your child will learn to suppress the tics for increasing amounts of time. This is called response prevention. Your child will be encouraged to do its best not to express tics. Through training, the time your child can do this will be increased; first one second longer, then a minute and so on. The therapist will give your child lots of compliments to motivate it to stop the tics from being expressed for an increasing amount of time. Sometimes your child will work on suppressing all the tics at once, and sometimes it will focus on one particular tic that is often expressed. Once your child has been trained sufficiently in suppressing tics, the accent shifts to what is called 'exposure'. While suppressing tics, your child will learn to notice the unpleasant sensations that usually become less after a tic is expressed. This is a tough exercise, because no one likes to focus on an unpleasant feeling. However, to be able to learn to get

used to that feeling, it is necessary to expose your child to it. The exposure will be done separately for each of the five most prominent tics. The underlying rationale of this treatment is that the unpleasant sensations will eventually disappear even when the tic is not expressed, just as a mosquito bite that is not scratched will disappear eventually. This process is called habituation.

You can help your child with this treatment by making sure it will practice suppressing tics at home too. Your child and the therapist will agree on a certain amount of time for this. In appendix 2.2 and 2.3 of your child's workbook you or your child will write down how many tics have slipped through and how severe the tic-alerts were every five minutes on a worksheet. Make sure your child brings this worksheet to each session. The results will be plotted in a graph, to visualize the effect of all your child's efforts.

2.2 Habit reversal

Habit reversal tackles tics one by one. For each individual tic, a so-called competing response is chosen. The competing response is also known as an incompatible response to the tic, because doing the response makes it impossible to express the tic. To be able to use a competing response, your child will first have to become aware of when it is doing the tic. If your child does not notice a particular tic, it will first learn to recognize the tic, by observing the tic and recording it. An important part of this process is learning to analyze the tic together with the therapist. How does the tic start, is there a tic-alert, which groups of muscles are used in the tic and in which order? From beginning to end the tic is described. Once there is a clear picture of the tic, a competing response is chosen. For eye-blinking for example, it helps to keep the eyes wide open and focused on a fixed point. Doing this response makes it impossible to do the eye-blinking tic. Another example is pressing lips together to prevent the tongue from being stuck out. Though it may involve some creativity, it is possible to come up with a competing response for each tic. The therapist will help your child to find suitable competing responses.

After a competing response has been identified, your child's treatment will involve practicing this response. As soon as your child feels the tic coming on (once the tic-alert has gone off!), it will do the competing response during (for one minute or as long as it takes for the tic-alert to become less severe. The tic cannot be expressed now. If your child was 'too late' and the tic has already been started or expressed, the competing response is done anyway. This procedure is repeated for each individual tic. In this way, your child is able to control the tics so they will occur less often.

It is important that your child practices the strategies it is learning at home to maximize the treatment's profit. Together with the therapist, your child will agree on a time for practicing. Your child and if needed you will use the worksheet (appendix 3.2 Workbook for Children) to record the tics that have "slipped through". Your child should bring this worksheet to each session. The results will be plotted in a graph, to visualize the effect of your child's efforts and when it is time to tackle the next tic.

2.3 15-minute tic frequency recording

During the entire treatment, you will be asked to record daily the number of tics your child expresses during a fifteen minute period. This is an important homework assignment for parents; the records are used to measure the results of the treatment. The tic frequency recording worksheet at the back of this workbook (appendix 1) can be used to write down the frequencies.

Because of the fluctuating character of tics, tic registration must be done at a set time each day during a fixed activity. For example, every evening at 7 p.m. while the child is watching television, using the computer or eating dinner. The recording must always be done by the same parent. A hand counter can be helpful to do the counting as you can push the button after each tic. Alternatively, you could use tally marks on a piece of paper. If your child has quick and consecutive tics, it may be easier to count ten tics at a time and then make a mark.

Once you have gained some experience in recording the tics, you may become more able to recognize certain tics or series of tics. It is important that you do not change your method of counting during the treatment. For example, if at the start of the treatment you count pulling the mouth and squinting the eyes as one tic, this should remain so during the entire treatment. Otherwise it will seem as if the number of tics is increasing, while

what actually has happened is that you have changed your counting method. Some children find it unpleasant when their parents record their tics because they feel they are being watched more closely than usual. Other children will try to do their best to stop the tics during the recording time. Try to observe your child as subtly as possible. If the observations are causing problems, discuss them with the therapist.

Write down here which parent will be recording the tics daily for 15 minutes, during which activity and at which time of the day.

Who is registering:

Time of day:

Activity:

Make sure to bring the tic frequency recording worksheet (appendix 1) to every session. Each week the therapist will plot the average tic frequency for that week in a graph to visualize how much and at what rate your child's tics are becoming less.

2.4 Helping with practice and giving rewards

It is important that your child practices the exercises at home. During the sessions with the therapist, you and your child will agree on how often, how long and when the practicing at home will take place. Later on in the treatment your child will also be asked to practice in other situations where tics usually occur. Here are some tips to help you support your child as best as possible. Naturally, if your child is a little older, you can expect it to be more independent and in principle teenagers should be able to practice without your help.

- └ Practice at a set time, in the same place during a fixed activity you have agreed on with the therapist and your child. Predictability and being clear about practicing will increase the chance that your child actual does practice and prevent that you will have to engage in a daily struggle to get your child to practice.
- └ Stay with your child while it is doing the exercises. Children often find it easier to practice during a session than at home. During a session they have the complete attention of the therapist, who is encouraging them to practice and keeping them focused on what they are doing.
- └ Give your child lots of compliments and do not be too strict if tics 'slip through'. Suppressing tics is not an easy thing to do. Try to emphasize something positive: "It is really good that you are practicing so hard!" Encourage your child not to give up when it has a tough day with a lot of tics. If there are a lot of tics, there is a lot of stuff to practice with!
- └ Reward your child when it does its best. Construct a reward system together with your child: make clear agreements about how often and how long your child must practice to receive a particular reward. You can also give a reward after a session. For young children, small short-term rewards are more effective, e.g. staying up five minutes longer, choosing their favorite thing to eat or being able to watch a television program. Older children can save (using points or small amounts of money) for bigger long-term rewards. Also agree on a reward for when the treatment ends, for example doing something fun together like going to an amusement park. The therapist can help you develop a reward system.

Write down below what you and your child have agreed to. When does your child get a reward? What is the reward? Discuss this with the therapist.

.....

.....

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.....

.....

3 • Additional help for remaining tics

It may be that after practicing exposure and response prevention or habit reversal, there are still specific situations in which lots of tics occur. For example, when your child feels tense or nervous, when your child has a fight with a brother or sister, or when your child comes home from school. You, your child and the therapist may decide to devote a few extra sessions on managing tics in these specific situations.

3.1 Situations in which tics still often occur

A tic recording exercise will help you understand which factors contribute to the maintenance of tics in specific situations. These factors may precede or follow the tics. You and your child will be asked to pay close attention to the moments in which lots of tics still occur: Where is your child then? Who else is there? How does your child feel at that moment? How do other people (children and adults) react to the tics? Do they laugh or tell your child to stop the tics? Or do they encourage your child to keep on doing the tics? What is your own reaction and how does the rest of the family react to your child's tics? Do you get angry and punish the child? Or do you go easy on your child just because you feel sorry for it? All your information can be collected in the 'Getting an overview of tic situations' worksheet in appendix 2 of your workbook. Your child has its own worksheet (appendix 4.1 Workbook for Children) to fill in.

Using the inventory, the therapist, you and your child will come up with solutions and think of a strategy to help reduce the tics further. For example, if your child has more tics when it is doing homework, the therapist may help to find out if your child dreads doing homework or that it would rather be doing something else than homework at that time. The next step is to discover how to help your child dread doing homework less. Maybe as a parent, you can help to do homework, or you can temporarily connect a reward to doing homework or maybe you need school to help on this. And if your child has more tics when it comes home from school then maybe your therapist will advise the child to have a quiet moment in its own room to do some of the exercises learned during the treatment before joining the rest of the family. The strategies you will need to agree on are specific to the situation and what is needed.

In your child's workbook, there is space to write down the strategies to deal with tics that have been agreed on: What can you or your child do to prevent that your child gets into a situation in which it has a lot of tics? If the situation cannot be prevented, what can your child then do to reduce the tics in that situation? If tics seem to be maintained by the attention your child gets from other people (for example people pity your child or make a remark) or by avoidance (for example escaping a task, not having to go to school, delaying bedtime), what can be done to change this? Any other possible solutions to prevent the tics from increasing that the therapist, you and your child come up with are written down in your child's workbook. Make sure that the agreements are easily accessible, for example by hanging them up in a place at home where you and your child can both see them.

3.2 Breathing and relaxation exercises

Most children express more tics when they are excited or nervous about something. If your child is tense or nervous it can help to do a breathing or relaxation exercise. A breathing exercise helps to calm you down because you become aware of your breathing. A relaxation exercise is an exercise to become more calm and relaxed by reducing the tension in your muscles. If your child experiences an increase in tics when stressed, the therapist will do breathing and relaxation exercises with your child. It is very likely that the tics will become less or disappear during these exercises!

In the breathing exercises, the therapist will teach your child to breathe deeply and calmly using its stomach. Your child will breathe in through the nose and out through the mouth. In the relaxation exercise the therapist will help your child learn to relax its body. To teach your child to feel the difference between muscles that are relaxed and tense, the therapist will ask your child to contract and relax different muscles in its body one by one. While doing this, the therapist will ask the child to pay attention to its breathing. To increase the feeling of relaxation, the therapist will then ask your child to think of something pleasant, a happy memory or a moment when your child felt calm and relaxed. The therapist will record the exercise, so that the exercise can be practiced at home.

Appendix 1 • Tic frequency recording worksheet

Name of child:

Week: from (date) to (date)

Follow-up to session:

You can keep track of how practicing went on this worksheet.

Day	Time from to	Number of tics	Counted by
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			
		Total:	
		Average:	

Average number of tics per time unit day:

$\frac{\text{total number of tics}}{\text{counted days}} = \dots\dots\dots$

Appendix 2 • Getting an overview of the tics worksheet

Day – time	Situation – What is happening? – Where is your child? – What is your child doing? – Who is with your child?	Feeling? – How does your child feel? Angry, scared, happy or maybe sad?	Result? – What reaction follows the tics? – What do you do and what do others do?

Appendix 3 • For further reading

Robertson, M., & Cavanna, A. (2008). Tourette Syndrome: the facts. Oxford: University Press

<http://www.tsa-usa.org/>

<http://www.tsa-usa.org/People/kids/kids.html>

<http://www.tourettes-action.org.uk/>

TSA is the official website of the US Tourette Syndrome Association and Tourettes-action is the official UK website. These websites contain a lot of information about tics and Tourette's syndrome, both for you and your child.