

PRACTICAL GUIDE TO SEEING A SPECIALIST

IF YOU OR YOUR LOVED ONE HAS OR IS SUSPECTED TO HAVE TOURETTE SYNDROME, YOU MIGHT ATTEND AN APPOINTMENT WITH A SPECIALIST AT SOME STAGE DURING DIAGNOSIS OR TREATMENT.

Whether you are seeing a specialist for Tourette syndrome for the first time or you have had a specialist appointment in the past, going to your appointment prepared with relevant medical and treatment history is important, as it helps the clinician understand your needs in the most efficient and accurate way.

This practical guide will take you through what to expect and what to bring to your specialist appointment and it contains a handy Treatment Record to help you keep track of your symptoms.

WHAT SHOULD I BRING TO MY SPECIALIST APPOINTMENT?



YOUR MEDICAL HISTORY

When visiting any new health professional for the first time, you may be asked about your medical history. New doctors may or may not have access to your full health records, but either way they will want to check details are correct. They will appreciate detailed information about dates things happened, previous doctors and any treatment or medication prescribed, including doses, names and the medication taken. It is likely that you will be asked about when the tics started, how they presented and, importantly, about other challenges that you or your loved one may have had alongside. This is very important for people with tics as they often have additional conditions, which can sometimes impact their lives even more than tics and may have gone undetected before the appointment.

TOP TIP: KEEP A DETAILED RECORD

We recommend you write down the details of your symptoms and, where possible, keep a detailed record of appointments and treatment. You could also record the past history as much as possible. You may have been sent copies of previous reports and these can also be filed away in your **Treatment Record**, which we've provided at the end of this guide. Although medical reports are helpful, other information such as school reports for children and employment information for adults can also be welcome. →



When seeing a specialist for assessment, a **Tic Diary** can be a helpful source of information. This could be notes on paper or notes on your phone of types of tics, frequency and when they started and any triggers or patterns you might notice. If possible, you could video record them to show the health professional. If you are a carer, parent or partner, it is important to consider whether consent should be sought from the person with tics before you take the recording.



YOUR PARENT(S)

If you are an adult patient going for an assessment with a specialist, it can be helpful to bring a parent along with you to the consultation, if possible. They may be able to help you with questions about any tics you had as a child and at what age, etc.

If you are bringing a parent along, it could be helpful to share this guide with them ahead of the appointment.

WHAT QUESTIONS WILL A SPECIALIST ASK DURING A MEDICAL ASSESSMENT FOR TOURETTE SYNDROME?

Below you'll find some questions you could be asked during a medical assessment for Tourette syndrome. Ahead of the appointment, you could jot down some answers in the space provided. Don't worry if you are not sure on some of the answers or if some questions don't apply – it's not a test you have to pass and every person's tics are different. The most important thing is to be as honest and accurate as you can. The health professional will look at the whole picture of symptoms, medical and family history in order to make a diagnosis and treatment plan.



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ABOUT THE TICS

- ➔ When did they start?
- ➔ Which tics started first?
- ➔ What age were they most severe?
- ➔ Are they very noticeable to other people?
- ➔ Can they be suppressed?
- ➔ Do you have a sensation before you tic?
- ➔ Does suppressing them eventually make them worse?
- ➔ Do they change over time and fluctuate in severity?
- ➔ Have you ever had the swearing tic or made rude gestures that you can't control?
- ➔ Do you copy what people say or do?
- ➔ If medications have already been used, what were they and what effect did they have?





MY NOTES

2

ABOUT OTHER POSSIBLE FEATURES OF TOURETTE SYNDROME

- ➔ Do you have obsessive compulsive disorder (OCD) or obsessions, rituals or unpleasant and intrusive thoughts?
- ➔ Do you have a diagnosis or suspected diagnosis of attention deficit hyperactivity disorder (ADHD)?
- ➔ Do you like counting in your head?
- ➔ Might you have features of autism?
- ➔ How is your mood currently?



MY NOTES

3

ABOUT YOUR FAMILY

- Do any other relatives have motor or vocal tics or both (including extended family)?
- Do you know if any relatives have OCD or ADHD?
- Have any family members had other neurological conditions or mental illnesses?

MY NOTES



4

ABOUT PAST MEDICAL HISTORY

- Any other medical conditions in the past (including operations)?
- Have you ever suffered from depression or other mental health conditions?
- Do you take any regular medications now (provide medication names and doses, including contraceptive pill if applicable)?
- For adults: Any history of smoking, drinking alcohol or taking recreational drugs?
- Have you had a lot of throat infections or streptococcal (a kind of bacteria) infections?

MY NOTES

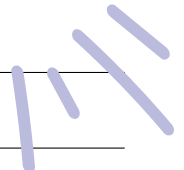


5

ABOUT CHILDHOOD DEVELOPMENT (QUESTIONS FOR PARENTS)

- Were the pregnancy and delivery typical or were there any problems?
- Did walking and talking develop at the normal time?
- How did you/your child do at school?
- How did you cope at school, college and if an adult how do you manage at work?

MY NOTES



It can be anxiety-provoking seeing a new specialist or accompanying a child, friend or partner to an appointment but the more helpful information you can bring, including an open mind about the assessment, the better it will be for you. Don't be afraid to ask questions, clarification and to let the professional know of any important additional information that they may not have asked you about directly. It is also important to ask when a written report following the consultation might be available so that you have details of the conclusion and diagnosis without having to remember it yourself.

MY NOTES



YOUR TREATMENT RECORD

Date:

Hospital:

Doctor (consultant):

Medication and doses:

Duration medication taken for:

Beneficial or side effects of medication given?

Any other medication at the same time?

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Any changes to treatment or medication should always be discussed with a healthcare professional.