



Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Young People

The Tourette syndrome clinic at GOSH

This information sheet explains about the Tourette Syndrome (TS) clinic at Great Ormond Street Children's Hospital and what to expect when you attend an appointment. It forms part of our TS information pack for young people and families.

Getting a referral to the clinic

In most cases, children and young people will have been referred to the clinic by their paediatrician (specialist children's doctor), paediatric neurologist (doctor specialising in brain and nervous system disorders) or child and adolescent psychiatrist (doctor specialising in mental health problems affecting children and young people). They will have sent a referral letter to the doctor in charge of the Tourette Syndrome (TS) clinic at Great Ormond Street Children's Hospital, who will then have sent an appointment.

Most children and young people with TS in the UK do not need to come to GOSH, as they can be looked after by their local team. Some children and young people are referred to us by their local team, if the issues are especially complicated, the TS is very severe, or the diagnosis is uncertain.

Who attends the clinic appointment?

The TS clinic is multidisciplinary, that is, various health care professionals make up the team. The main team consists of a child psychiatrist, paediatric neurologist and clinical psychologist, but other healthcare professionals will attend your appointment if needed. As GOSH is a teaching hospital, you may see student nurses and doctors in training, but they will be supervised at all times by a qualified member of staff.

What happens at a clinic appointment?

Before the appointment, you will receive a pack of questionnaires to be completed and returned by post and/or by the Internet. All information is secure. This information helps us to plan your appointment in detail before we meet you.

In most cases, the appointment will start with an assessment, that is, the team asking how you are doing and whether there are any specific areas of concern. It can be helpful to make a list of questions beforehand and bring them to the appointment. The professionals will ask you about the severity of your tics and how often they occur. If you are taking medicines to help with the symptoms of TS or associated problems, they will ask you how well you think they are working.

Afterwards, you and your parents might have separate sessions with other members of the team for further discussion of some issues related to TS. For instance, the clinical psychologist might talk to the child separately about family, school and social life.

What happens after a clinic appointment?

We always aim to keep other members of your local health care team involved and informed, so we will write a report of the clinic appointment and send it to your family doctor (GP) and the doctor who originally referred you. This will give details of any changes to treatment, such as medicines. We will also send you a copy to read and keep. If you agree, we will also keep your school informed, so that they can help, perhaps by updating your individual education plan (IEP).

The TS Clinic is a national, specialist service and we aim to help your local service carry on giving you regular care but to be available for advice when needed. How often you need to come to clinic depends on the support you need. Some children and young people will need to visit us again following the initial assessment and others will not.

We often ask to contact schools after our assessment meeting to find out more information and offer teachers support and advice.

Where can I find more information about TS?

If you have a specific question or concern, talk to a member of the TS team. The following organisation may also be able to offer support and advice:

Tourettes Action

Helpline: 0845 458 1252

Monday to Friday from 9am to 5pm

Web: www.tourettes-action.org.uk