



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

Tourette syndrome and treatment with medicines

Some of the symptoms of Tourette syndrome (TS) can be managed with medicines. The medicines we use commonly at Great Ormond Street Hospital (GOSH) are described on separate information sheets. We will give you the leaflet(s) that go with your medicine(s). Remember, if you have any questions about medicines, please ask your doctor, nurse or pharmacist for information.

What medicines are used to treat TS?

There are many different types of medicines used to treat TS. An important point to remember is that most of them were originally developed to treat other conditions, so the patient information leaflet in the packet might seem misleading. For instance, a medicine called clonidine was originally developed to lower blood pressure but was found to also help people with TS.

When you read the patient information leaflet you might also read that the medicine is not recommended for children and young people. This means that the drug company producing the medicine is not allowed to promote or advertise it to certain people. It does not mean that the medicine is not safe for children and young people and if it is prescribed for you, it will have been studied in children and your doctor considers that it might be beneficial. All children's doctors are very aware of unlicensed medicines and will not prescribe any medicine that is not safe for children and young people.

How do TS medicines work?

Most TS medicines interact with chemicals in the brain. Our brains constantly have chemical messages moving around, giving instructions for certain aspects of our behaviour. Different chemicals are thought to be involved in tics, attention deficit hyperactivity disorder (ADHD) and obsessive-compulsive disorder (OCD). The choice of medicine will depend on which difficulty needs help. Some children need more than one medicine.

Generic and brand names for medicines

Another important thing to remember is that medicines in the UK have two names: a generic name and a brand name. For instance, fluoxetine is a generic name and Prozac® is a brand name. Keep a list of which medicines you are taking and include both generic and brand names. If you are going abroad, the names for your medicines might be different to the UK ones. They may also be of different quality. Always take plenty of supplies when you're packing for your holiday abroad.

Side effects

Medicines may have side effects as well as their main effect. The majority of side effects are identified when the medicine is being tested, and they are all included in the patient information leaflet. This can make for worrying reading, but remember that some of the reported side effects are extremely rare.

If you think you are having side effects, please telephone your doctor but do not stop taking the medicines.

Stopping taking medicines

In many cases, TS medicines should not be stopped suddenly. This is because the body gets used to the medicine and stopping suddenly could cause problems. If your doctor decides you no longer need to take a medicine, he or she will gradually reduce the dose you are taking until it is safe for you to stop. This allows your body to get used to the reduced amount of the medicine over a period of time, so is less likely to cause problems.

Changing doses

Often, it can take a while to find the right dose for you that balances the effect on your symptoms with the side effects of the medicine. The doctors will start you on a moderate dose of the medicine, and then gradually increase it over time, unless they have reached the dose that effectively treats symptoms without causing too many side effects. Remember that many medicines are worked out on your height and weight, so your dose may increase, as you grow taller and heavier.

Taking medicines safely

Most medicines come in different formats and strengths. For instance, clonidine comes as a liquid or in two different strengths of tablet. Often, you can choose which format you want, but in some cases, the medicine only comes in one format. If you have trouble taking medicines, please look at our other information sheets for helpful suggestions.

Liquids are measured in milligrams per millilitre (mgs per ml) and tablets are measured in milligrams (mgs) and micrograms. It is really important to make sure you understand how much liquid or how many tablets you need to take each day and at what times. Many medicines can cause serious problems if too much is taken and your symptoms won't improve if you take too little. If you have any questions about your medicines, please talk to your doctor or pharmacist.

Storing medicines

- Keep all medicines in a safe place where children cannot reach or see them.
- Your medicines have been prescribed specifically for you – do not give them to anyone else.
- Most tablets should be stored at room temperature, but some liquids need to be kept in the fridge. Check with your pharmacist for storage instructions.
- Medicines should always be taken as directed by your doctor, nurse or pharmacist.
- If you forget to take a dose, telephone your local doctor for advice. Try to keep to your regular dose schedule, but never give double the dose.
- Remember to order a repeat prescription in plenty of time before you run out of medicine.
- If the doctor decides to stop treatment, return any remaining medicine to the pharmacist. Do not flush or throw them away.