



NHS

Great Ormond Street Hospital for Children NHS Foundation Trust: Information for young people and families

Tourette syndrome and the future

This information sheet explains about Tourette syndrome in young adulthood and what you might expect when you grow older. It forms part of our TS information pack for young people and families.

Will I always have Tourette syndrome?

We know that Tourette syndrome can be a life long condition, but we also know that many people have fewer or less noticeable tics as they grow older. Tics are usually at their worst between the ages of seven and 12. After this age, they generally get less noticeable and happen less frequently. Following late-adolescence a lot of children may stop having tics or only get them occasionally.

Obsessive-compulsive symptoms may carry on into teenage years, or start for the first time around adolescence. One study reports that about one third of adults with TS also have obsessive-compulsive disorder (OCD). In some people, OCD symptoms may not have been noticeable during childhood, so regular check ups are needed to identify obsessive-compulsive disorder in adolescence and adulthood.

Will I be able to go to college or university?

There is no reason why you should not go onto further education. Many people with TS do not need special help in education, although it is often worth letting someone at college know you have TS. If you do have special needs, some colleges offer extra support, so it is worth checking

what is available when applying.

Many young people with special needs of all kinds can have a successful and fulfilling time at college.

Are there any jobs I should avoid?

People with TS do all sorts of jobs. Having TS should not stop you from doing anything that you want to do. We know people with TS who are doctors, footballers or accountants. If you have troublesome ADHD or are taking medicines that make you drowsy, this could affect your work. You will need to talk to your doctor about this. In rare cases, severe tics can make some physical tasks difficult.

What about relationships and having children?

Some people might worry about telling their girlfriend or boyfriend about their TS. We have met lots of people who found it helpful to confide in the people to whom they are closest.

Tourette syndrome seems to run in families. There is an increased likelihood of developing TS if a parent has it, but it is still more likely that a child of someone with TS will not have TS.

Where do I go if I need to a clinic appointment when I'm older?

Most people with TS do not need to go to a specialist adult service for TS. If they have mental health needs, such as OCD or depression, their local adult mental health team can provide support and treatment. If the tics are a problem, usually a neurologist will advise. In a few cases, an adult with TS may need to be referred to a TS specialist, of which there are a few in the UK.

Notes

Further reading

You might want to read the following book:

Nix your tics: eliminate tic symptoms: a how-to guide for young people by Duncan McKinlay - available from *Life's a twitch publishing* - www.lifesatwitch.com/nixyourtics_book.html



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