

What next?

If you require any tests, they will mostly be performed on the same day as the clinic. The results of your tests will be reviewed by the Doctor and we will inform your GP and you by letter if any action is required.

Your follow-up appointment will be sent to you by post so you don't need to book this separately after your consultation.

If you need to contact the service

If you can't make an appointment or want to contact the service before you come to the hospital please contact 0121 627 2000.

Useful websites:

Turner Syndrome Support Society

www.tss.org.uk

Explain Turner Syndrome

www.explain.me.uk

If you have any questions regarding this clinic or your condition, please make a note below, and we will try and answer them when you attend the Turner Syndrome Clinic.



The Trust provides free monthly health talks on a variety of medical conditions and treatments. For more information visit www.uhb.nhs.uk/health-talks.htm or call 0121 371 4323.

ENDOCRINE

Queen Elizabeth Hospital Birmingham
Mindelsohn Way, Edgbaston
Birmingham, B15 2GW
Telephone: 0121 627 2000



**Queen Elizabeth
Hospital Birmingham**
– Turner Syndrome Clinic

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To see all of our current
patient information leaflets please visit
www.uhb.nhs.uk/patient-information-leaflets.htm

Introduction

Welcome to the Turner Syndrome Clinic.

What is the Turner Syndrome Clinic?

This clinic is a dedicated service for women with Turner Syndrome (TS). The clinic is run by Dr Andrew Toogood and Dr Helena Gleeson, both Consultants in endocrinology (hormones), and is supported by a Nurse Specialist. Some women who attend this clinic have known that they have had TS for many years and have been transferred from a children's service; some may have been diagnosed later, even as an adult, and are still coming to terms with the diagnosis.

Why have a dedicated Turner Syndrome Clinic?

Women with Turner Syndrome (TS) are on the whole exceptionally well, however careful screening is recommended to pick up some conditions that are more common in women with TS than in women without TS. We feel, as do the Turner Syndrome Support Society, that this is better done in a dedicated clinic.

One of the most important of these is the health of your heart and your aorta. In this clinic we monitor this carefully. Every woman gets an initial check up with our cardiology (heart) team when they join the clinic and detailed pictures of your heart and aorta are taken at least every 4 years or more frequently if necessary. We also perform blood pressure measurements and check lipids (fats) in the blood and screen you for diabetes every year to ensure that your risk of developing any heart or aorta problems remains as low as possible.

Most women with TS also face some specific challenges, particularly those that want to have children. We can give you advice about the risks of having a pregnancy if you have TS. We can also refer you to the fertility specialist, Mrs Lynne Robinson, at Birmingham Women's Hospital, who works closely with the heart doctors to ensure that any pregnancy is as safe as possible.

Other areas that will be discussed are oestrogen replacement and hearing and any other concerns that you bring to the appointment. A general screen of thyroid function, kidney and liver function and for coeliac disease will be performed

What will happen during my initial appointment?

Once you have booked in at reception the nurse will take your observations including your blood pressure, heart rate, weight and height. Before you are seen by the doctor, you will be asked to complete a simple Holistic Needs Assessment Questionnaire to help us identify the issue that matters to you the most. You will then be seen by a doctor. It is your choice whether you go in to see the doctor by yourself or whether you bring your parent, partner or a friend.

Following that, you will be seen by the Nurse Specialist who will introduce him/herself to you and provide you with relevant information about Turner Syndrome and the clinic. They will also explain what support may be available for you. The Nurse Specialist will be able to give you advice about other areas, such as education and employment and also healthy living. Some useful information leaflets will be given to you to take home. You will also be given the opportunity to access your medical record from home if you wish to via the myhealth@QEHB system.