

# Turner Syndrome Clinic

## 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

## Information for Patients

---

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**.

### Do I have to come to the hospital for my appointment?

We now also offer video appointments which you may prefer rather than travelling to hospital. Your first visit will normally be at the hospital, but let us know if you prefer video. After this, your follow up visits will normally be through video, a visit at the hospital or a telephone consultation / chat. Let us know which you prefer.

### What next?

If you require any tests, they will mostly be arranged or 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 also be sent to you by post.

If you need to contact the service please feel free to contact the hospital in between appointments if you have any questions or concerns.

If you want to rearrange your appointment or you have a question about when your next appointment is contact the Endocrine.

Secretary Team:

Email: **EndocrineSecretaries@uhb.nhs.uk**

Tel: **0121 371 6947**

If you have a health concern you want to ask about, contact the Endocrine Clinical

Nurse Specialist Team:

Email: **EndocrineNursesQEHB@uhb.nhs.uk**

Tel: **0121 371 6950**

### Useful websites:

Turner Syndrome Support Society

[www.tss.org.uk](http://www.tss.org.uk)

Explain Turner Syndrome

[www.explain.me.uk](http://www.explain.me.uk)

Please use the space below to write down any questions you may have and bring this with you to your next appointment.

---

---

---

---

---

---

---

---

---

---

## Information for Patients

---

---

---

---

---

---

### Endocrine

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

If you require this information in another format, such as a different language, large print, braille or audio version please ask a member of staff or email [patientexperience@uhb.nhs.uk](mailto:patientexperience@uhb.nhs.uk).