

Connective tissue disorder clinic

This leaflet offers further information on the connective tissue disorder clinic, including what happens there and who should attend. If you have any further questions or concerns, please do not hesitate to contact a member of your healthcare team.

Where is the clinic held?

The clinic is held on Thursday afternoons in the cardiac outpatients department at St Thomas' Hospital. You should have received a detailed map of St Thomas hospital.

What is a connective tissue disorder?

Connective tissue is like the cement in a building which holds the bricks together. In the same way, connective tissue holds the muscles, skin and bones in place. Some people can have unusual connective tissue which means that their joints and bones move around more freely making them 'hypermobile'. Sometimes this hypermobility is associated with other features which together make up a connective tissue disorder. Some connective tissue disorders have specific names, such as **Marfan syndrome**, **Ehlers-Danlos syndrome** and **Loeys Dietz syndrome**.

Who attends the clinic?

A number of different people are invited to this clinic, including:

- people with a connective tissue disorder that may have a genetic (inherited) basis
- people with a family history of connective tissue disorder
- people who need an assessment to help their doctors decide whether or not they have a connective tissue disorder.

The clinic is run by:

- a consultant geneticist
- an adult cardiologist
- a paediatric (children's) cardiologist
- adult echocardiographers.

There are sometimes medical students and other people observing in the clinic. Please let us know if you do not wish to have an observer in your session.

What happens at the clinic?

We recommend that you allow two hours for all your tests to be completed.

Usually, you will have a heart check first called an echocardiogram. This is an ultrasound scan of the heart. During this test, the echo technician will put some cold jelly on your chest and will

move a sensor across your chest. The sensor uses sound waves to build a detailed picture of your heart.

You may also have an electrocardiogram, which monitors the electrical activity of the heart. Small sticky patches will be attached to your skin and these patches sense the electrical activity.

Both of these investigations are painless. After your investigations you will meet with the geneticist.

During the appointment the geneticist will:

- examine you carefully, (particularly your hands, feet, back and face)
- take a detailed personal and family history
- explain the purpose of the heart check and the results
- explain what the results of the examination and heart check mean for you and your family
- give you a chance to ask questions
- make a follow-up plan with you.

How can I prepare for my appointment?

It may be helpful to write down any questions you have prior to the appointment and bring these with you. The geneticist will be interested in your family history and you may have received a family history questionnaire when you were first given your appointment. If you did, please complete the questionnaire and bring it with you.

If you are unable to attend your appointment, please let us know as soon as possible so that the appointment can be offered to another patient.

What is the advantage of the clinic?

Coming to clinic means that you can have your heart check at the same time as meeting with the geneticist. It also means that families can be seen together if required. Finally, because all of your assessments are done at the same time, you will have a better understanding of your condition and you can have all your questions answered by the doctors there and then.

After the appointment

You will be sent a letter which summarises the appointment. Specific recommendations will be made for you and your doctors in the letter. You may be referred for further investigations such as an eye examination or another type of scan, known as an MRI, if the geneticist feels this will help you to manage your condition.

Contact us

If you have any more questions about the **connective tissue disorder clinic** or what will happen at your appointment, please feel free to call the department on **020 7188 1364** and ask to speak to the genetic counsellor responsible for the clinic. We are always pleased to hear from you.

For more information

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

Patient Advice and Liaison Service (PALS)

To make comments or raise concerns about the Trust's services, please contact PALS. Ask a member of staff to direct you to the PALS office or:

e: 020 7188 8801 at St Thomas' **t:** 020 7188 8803 at Guy's **e:** pals@gstt.nhs.uk

Knowledge & Information Centre (KIC)

For more information about health conditions, support groups and local services, or to search the internet and send emails, please visit the KIC on the Ground Floor, North Wing, St Thomas' Hospital.

t: 020 7188 3416

Language support services

If you need an interpreter or information about your care in a different language or format, please get in touch using the following contact details.

t: 020 7188 8815 **fax:** 020 7188 5953

NHS Direct

Offers health information and advice from specially trained nurses over the phone 24 hours a day.

t: 0845 4647 **w:** www.nhsdirect.nhs.uk

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

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Membership is free and it is completely up to you how much you get involved. To become a member of our Foundation Trust, you need to be 18 years of age or over, live in Lambeth, Southwark, Lewisham, Wandsworth or Westminster or have been a patient at either hospital in the last five years.

To join, please call 0848 143 4017, email members@gstt.nhs.uk or visit www.guysandstthomas.nhs.uk