

The cystinuria clinic

The aim of this leaflet is to answer any questions you may have about the cystinuria clinic. If you have any further questions or concerns, please phone 020 7188 7415 or 020 7188 6788 or email UrologyAppointments@gstt.nhs.uk.

You can also contact the stone nurse practitioners. Their contact details are at the bottom of this leaflet.

What is the cystinuria clinic?

This clinic has been set up to provide a more efficient service for patients with cystinuria. The unique benefit of the service is that it brings members of the healthcare team (doctors, specialist nurses and dieticians) to one place, so that you do not have to travel around the hospital for different appointments and tests.

Where is the clinic?

The clinic is held in the Urology Centre, first floor, Southwark Wing (the light blue zone), Guy's Hospital. Please ask for directions at the reception desk in the main entrance if you are unsure of how to find us.

Travelling to Guy's Hospital

London Bridge underground, rail and bus station is very close to the hospital.

If you are a registered disabled driver and hold a blue badge, parking is free on the day of your appointment. You will need to show your appointment letter to security staff to receive an exit ticket. Although parking is very limited, we do our best to help disabled patients arriving by car. If the car park is full when you arrive, security staff can direct you to an NCP car park close to the hospital (charges apply).

Who will I see in the clinic?

You will be seen in the clinic by a urology consultant and kidney consultant, a dietician and specialist nurse. You may also be seen by a radiology consultant or a sonographer. Please do not hesitate to ask questions at any time if you have any queries or concerns.

How long should I expect my appointment to last?

Appointments can last up to three hours, depending on the number of tests that you need to have in order to diagnose your problem.

Will I have to wait?

At this clinic most patients will be having tests as well as a consultation with the consultant. Inevitably, this entails some waiting. As a specialist service we treat a large number of patients from the surrounding area as well as local patients so our clinics are very busy. We will keep you informed about waiting times at regular intervals. Please speak to the clinic receptionist if you require more information or have any concerns about waiting times.

What can I do while I am waiting?

You may wish to bring a book or magazine; if you wish to use a personal music player please bring headphones so that you do not disturb others. Free WiFi access is available using the WiFi SPARK network.

Patients are seen in order of their appointment time so arriving early will not mean you are seen early. To reduce your waiting time please try to arrive no more than ten minutes before your appointment.

Is there any food or drink available?

Water is available and there is a vending machine in the clinic where you can buy hot drinks. The following outlets are also available:

- AMT Coffee – main entrance to Guy's Hospital, selling light refreshments and drinks
- Sakar newsagent – main ground floor corridor, selling newspapers, magazines, light refreshments and cold drinks
- Sainsbury's – Great Maze Pond, just round the corner from the main entrance to Guy's Hospital, convenience store with a Lloyds Pharmacy inside
- Toms@Guy's Café – Bermondsey Wing, Atrium 3, selling light refreshments and drinks.

Please let the receptionist know if you leave the clinic (and leave a mobile number if possible) so that you do not miss your appointment.

What will I need to bring to the clinic?

Please bring a list of current medications (including those prescribed by your GP, medicines you have bought yourself or alternative medicines, such as herbal remedies). If you were asked in the previous appointment to record your fluid intake, urine output or urine PH please bring this information with you.

Do I need to bring anyone with me?

You do not have to bring anyone with you to the clinic, but many people find it useful to bring someone along to the consultation. It would help us if you only bring one person with you as we have limited seating available in the waiting area. However we recognise that some people may need additional assistance. We advise, if possible, not to bring small children as we do not have facilities for them in the clinic.

What can I expect in the clinic?

In order for us to diagnose your problem you may need to undergo a few tests during the clinic visit. Most people that attend the clinic will be asked to provide a urine sample. You do not need to arrive with a full bladder but you may wish to bring a drink if you think that would help you to produce a sample.

You may also need some further tests. We advise women to wear trousers or a skirt rather than a dress to avoid having to take all of your clothes off during an examination or test.

Below is a list of some of the investigations that you may have whilst in the clinic:

- **Blood pressure, temperature, pulse, height, weight** – This information will be recorded and used by the consultant and dietitian.
- **Ultrasound** – An ultrasound scan is a painless test that uses sound waves to create images of organs and structures inside your body.
- **Blood tests** – You will have blood tests to check your kidney function and general well being. If this is your first visit to the cystinuria clinic the consultant may talk to you about having some genetic tests to look for abnormalities in the genes associated with cystinuria.
- **X-ray** – X-rays are a type of high-energy radiation. The rays pass easily through the fluids and soft tissues of the body. X-rays allow us to see your bones and certain other tissues inside the body.

- **CT scan** – A CT (computerised tomography) scanner is a special kind of x-ray machine. Instead of sending out a single x-ray through your body (as with ordinary x-rays), a CT scanner sends several beams at the same time from different angles. CT scans are painless, and allow doctors to inspect the inside of the body without having to operate or perform unpleasant examinations.

If you have formed new stones and need an operation you may need to go to the pre-operative assessment clinic after this clinic appointment where you will have further blood tests and urine tests.

How often will I need to attend the clinic?

You will be offered regular appointments at the clinic. If at any time you want to bring your appointment forward because you have pain you can contact the appointment line or the stone nurse practitioners.

Appointments at King's

We have teamed up with King's College Hospital in a partnership known as King's Health Partners Academic Health Sciences Centre. We are working together to give our patients the best possible care, so you might find we invite you for appointments at King's. To make sure everyone you meet always has the most up-to-date information about your health, we may share information about you between the hospitals.

Contact us

If you have any questions about the cystinuria clinic, please call us on 020 7188 7343 or 020 7188 6788 or email UrologyAppointments@gstt.nhs.uk.

Or you can contact the stone nurse practitioners by calling 020 7188 7188 then requesting to bleep the numbers 0384 or 2380.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Cystinuria UK

Advice and information about cystinuria, written by a group of healthcare professionals and patients.

w: www.cystinuriauk.co.uk **twitter:** @CystinuriaUK

The Renal Association – RareRenal

Information on rare kidney diseases, including cystinuria.

w: <http://rarerenal.org/patient-information/cystinuria-patient-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:

t: 020 7188 8801 at St Thomas'

t: 020 7188 8803 at Guy's

e: pals@gstt.nhs.uk

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 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

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

Become a member of your local hospitals, and help shape our future

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:

t: 0848 143 4017

e: members@gstt.nhs.uk

w: www.guysandstthomas.nhs.uk