

Patient advice and liaison service (PALS)

If you have a compliment, complaint or concern please contact our PALS team on 020 7288 5551 or whh-tr.whitthealthPALS@nhs.net

If you need a large print, audio or translated copy of this leaflet please contact us on 020 7288 3182. We will try our best to meet your needs.

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The Chronic Lower Urinary Tract Service

A patient's guide



Changes to the Service

Professor Malone-Lee has now retired and Ms Rajvinder Khasriya has now taken over the service. There is a new structure to the clinic as outlined in this leaflet. From April 2018 the clinic opened to new patients. We have a large number of referrals and all new cases at present must be discussed in our Multi-disciplinary team meeting (MDT), due to this pressure we ask you to work with us on a number of procedural points outlined in this leaflet.

Clinical Research Programme

You may be asked to participate in our ongoing research studies investigating the cause and treatment of chronic urinary symptoms. This will not affect your treatment if you decline. But we hope you will consent to take part if requested. You will be given detailed information should you wish to participate.

Notes

Notes

Your treatment plan in the clinic

You have been referred to this clinic because treatment for your bladder condition in secondary and in many cases, tertiary care has been unsuccessful using standard protocols and guidelines. We use protracted courses of high dose antibiotics to treat chronic recalcitrant lower urinary tract symptoms. You will have an opportunity to discuss this with a doctor in your consultation.

The treatment regimes in this clinic are outside local and national guidelines, which cover acute urinary infection and recurrent UTI (NICE), but are based on observational study data and a few small randomised controlled studies on urethritis. The treatment with long term antibiotics is not licenced in the UK. For this reason we ask that you adhere to our safety guidance relating to the reporting of side effects and that you follow your treatment plan diligently. You will be monitored very carefully.

You will be given information leaflets related to the medicine you will be prescribed. It is essential that you read this information and ask your doctor about your treatment plan. We request that you confirm you have read and understood this information before your treatment can proceed. We will record your consent to this treatment in your medical notes following our discussion of your treatment plan.

Off Licence Treatment

As you may be aware, the LUTS service offers a unique treatment strategy which may involve a long course of antibiotics. This treatment is off license.

An 'off-license' use refers to the use of a licensed medicine in a way that is not covered by its UK medicine licence. In other words, the use of the medicine has not been assessed by the UK licensing authority and its effects may be less well understood than those of a licensed medicine.

Because of this, your case will be discussed at a multi-disciplinary team meeting which includes Ms. Khasriya, another Urogynaecologist, a Urologist, Microbiologist and Pharmacist amongst others.

Blood Tests

All patients on long term antibiotics are asked to have blood tests checking the function of their liver and kidneys every three months as antibiotics can negatively affect these organs. We ask you to please comply with this and get this done either through the GP or our clinic as advised. You may be asked to stop treatment if these tests indicate.

Contact details

LUTS Clinic telephone number:	020 3074 2251
LUTS Clinic email address:	lutscommunityadmin.whitthealth@nhs.net

We thank you for your support

Finally I would like to take the time to thank you all for your continued support and if you have any queries or questions please do not hesitate to contact the unit.

With best wishes

Ms Rajvinder Khasriya PhD MRCOG
Consultant Gynaecologist with a subspecialty interest in
Urogynaecology,
Senior Research Associate, IfWH, UCL

Compliance to treatment

We ask you to ensure that you take the treatment as prescribed and do not deviate from your plan. Any change of treatment will usually be suggested after the analysis of a fresh urine specimen and you will be asked to come and provide this. Any self-medication is not acceptable. We have a very good email service through which you have access to the clinic doctors. Please report all side effects promptly through our email service: lutscommunityadmin.whitthealth@nhs.net

Side Effects

If side effects are problematic we should be informed. If prescriptions are needed then we should be contacted by email as well. The contact can be arranged by all patients by sending an email to lutscommunityadmin.whitthealth@nhs.net

The email service, which is provided for emergencies, adverse drug reactions, failed efficacy and prescription request are monitored all of the time. Please be brief and succinct.

You are also encouraged to report medication side effects especially those that are severe or not listed in the patient information leaflet to the MHRA using the Yellow Card Scheme via Freephone: 0800 731 6789 (10am to 1pm Monday to Friday) or Online: <https://yellowcard.mhra.gov.uk/> .

Prescriptions

Prescriptions will be provided every 12 weeks in line with your follow up, unless a change of therapy is required.

Urinalysis or 'Pee and Flee'

You may be asked as part of your treatment to provide a urine specimen. This has been termed 'pee and flee'. It involves coming to the department at a pre-arranged time to provide a fresh urine specimen. You will be notified of the results of this sample either via email or a phone consultation. This service facilitates those patients who have had a flare of their symptoms and we will give advice as to any change in therapy.

Open appointments

Open appointments mean if you have not been seen by any clinician within the service for longer than 6 months you become automatically discharged and you have to be referred back to the service by a consultant and not your GP.

Missed appointments

If you do not attend (DNA) an appointment that has been scheduled a letter will be sent to you so that you can make contact. You will be reminded that if you DNA again, the hospital policy is to automatically discharge you from our care. You will then need to be re-referred to our service.

Missed hospital outpatient appointments on average cost the NHS £120 for each patient.

Late Arrivals

If you are running late for your appointment please telephone in advance to make us aware. If you are going to be more than 15 minutes late and you make contact by telephoning, our receptionist will then speak with the clinician to see if they will still see you. It is at the discretion of the clinician whether the appointment will still go ahead or not. All patients should remember that if you are late for an appointment you are compromising someone else's clinical time. We appreciate unforeseen circumstances may arise but communicating with the clinic will help us to administer the best care for our patients.

We must stress how important it is for patients to turn up on time for their appointments. Patients must remember that late patients cause the whole clinic to run late. These rules apply to all clinics within the department i.e. Urine checks, Doctor and Nurse appointments.

Finally, can we kindly ask all patients, due to the nature of our service and the clinicians requiring a urine sample each time you visit, to please arrive no longer than 15 minutes early for their appointments. This ensures the clinic to run smoothly and waiting times to be less.