

Your transition from children's to adult inherited metabolic disease services

What you need to know

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This leaflet provides information about your move from children's to adult inherited metabolic disease services.

What is the transition process?

Your move from children's to adult hospital services is an important time in your life. If you have inherited metabolic disease, it is important to make sure that you are involved, prepared and that you understand the changes which are likely to happen as you approach the age of 16. During this time, your care will be moved from the paediatric (children's) inherited metabolic disease services to the adult inherited metabolic disease services. This move will happen gradually, which is why we call it a 'transition process'.

Please note: If you are an outreach patient (seen by the paediatric inherited metabolic disease team from London), your transition will be tailored according to your local hospital services.

When does the transition process start?

From 14 years of age, you will slowly be introduced to the adult inherited metabolic disease services. At each transition clinic appointment, the paediatric inherited metabolic disease team will prepare you for your move by working with you and or your carer(s) to talk about your existing goals and/or set new goals by the time you reach 16 years of age. This will help you to gain more independence and to understand your condition/needs better.

During this two year period, you will meet the adult inherited metabolic disease team and become familiar with the adult settings and services to help prepare you for your move.

Where is the transition clinic held?

The transition clinic will take place at the Evelina London Children's Hospital. You will have around four clinic appointments over the two-year period when you are between 14 to 16 years old. At your last appointment before moving to adult services, the paediatric inherited metabolic disease team will offer to show you where your next appointment will be in adult services at St Thomas' Hospital. The adult inherited metabolic disease clinic will take place at Gassiot House in St Thomas' Hospital. This building is next to the Evelina London Children's Hospital.

Who will I see at the transition clinic?

At your first two clinic appointments, you will see the consultant, specialist nurses and the paediatric inherited metabolic disease dieticians. At your third and fourth appointment, you will see both the paediatric and adult inherited metabolic disease team. During these sessions, we aim to talk about your goals and you will be able to tell us what you expect from the adult inherited metabolic disease team. This is also a useful

time to talk about any concerns/anxieties or questions you may have about your move to adult services.

What happens at the transition clinic?

The aim of the transition process is to set goals and help you begin to manage your condition independently. It is also a good opportunity for you to let us know how we can help you to achieve your goals and become more independent.

Before attending the transition clinic, it is useful to set some goals and write a list of any questions that you would like to ask us. During your first two clinic appointments, your parent(s)/guardian will be invited to come along to the appointment with you, but you will also be given the opportunity to see us on your own. During your last two appointments, we will ask you if you prefer to be seen alone without your parent(s)/guardian. This is to help you to become more autonomous (independent). We will also reassure you that what you tell us remains confidential.

Prescriptions

If you normally get your prescriptions from your GP, this will continue. If you are in full-time education, you do not have to pay for prescriptions. If you are not in full-time education, you **will** have to pay for your prescriptions. We will advise you on the cheapest way to do this.

Travel costs

If you are receiving a particular type of benefit you may be entitled to claim some or full costs of travelling to and from your hospital appointments. We will assist you to find out if you are eligible to claim travel costs.

Important contacts

Paediatric inherited metabolic diseases team

Dietician **t:** 020 7188 4008
Nurse specialist **t:** 020 7188 0855
Secretary **t:** 0207 188 0848

Adult inherited metabolic diseases team

Dietician **t:** 0207 188 9611
Nurse specialist **t:** 0207 188 0850
Secretary **t:** 0207 188 4004

Guy's and St Thomas' Hospital switchboard

t: 020 7188 7188

Contact details

If you have any questions or concerns please contact the inherited metabolic diseases team on 020 7188 0855 / 0850 / 4008 / 9611 (Monday to Friday, 9am to 5pm). Out of hours, please leave a message with your name and phone number and we will get back to you as soon as possible.

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

Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline. **t:** 020 7188 3003 10am to 5pm, Monday to Friday. **e:** letstalkmedicines@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS)

e: pals@gstt.nhs.uk

t: 020 7188 3514 (complaints)

e: complaints2@gstt.nhs.uk

Language and Accessible Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch:

t: 020 7188 8815

e: languagesupport@gstt.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

Leaflet number: 2751/VER3

Date published: September 2016

Review date: September 2019

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