

Your transition from children's to adult services

Information from the Department
of Inherited Metabolic Diseases

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Information adapted from 'Ready Steady Go' transition programme

What is the transition process?

We use the word 'transition' to describe the process of preparing, planning and moving from children's to adult services.

Transition is a gradual process that gives you, and everyone involved in your care, time to get you ready to move to adult services, and discuss what healthcare needs you will need as an adult. This includes deciding which services are best for you, and where you will receive that care.

Transition is about making plans **with** you - and not **about** you.

We know that moving away from a team of doctors and nurses that you have been with for many years can be scary. Hopefully, by getting involved in the transition process, you will feel more confident and happier about it.

If you are seen by the metabolic team in an outreach clinic, your transition will be tailored to your local hospital services.

Why do I have to move?

As you get older, you will find that some of the things you want to discuss, or some of the care you might need, is not properly provided by our children's services. Adult services are used to dealing with all sorts of issues that may arise, such as higher education, travelling, careers and sex.

You may also find that you would prefer to be seen in a more grown-up environment, rather than the children's departments or wards.

When does the transition process start?

There is no exact time that is right for everyone, but we begin the process from about 13 years old.

This leaflet is to get you thinking about moving on and preparing for the transition.

Your doctors and nurses may have an idea about when they feel that you might be ready, but it is important that you are involved in that decision.

Who can help me get ready?

Your healthcare team will be able to give you information and support about moving on. They can help you get ready for adult services by:

- teaching you about your condition or illness, its treatment and any possible side effects
- seeing you on your own, when you're ready, for part of the clinic appointment, and working towards seeing you on your own for the whole clinic appointment
- making sure you know when to get help and who to contact in an emergency
- helping you understand how your condition or illness might affect your future education and career plans
- making sure you understand the importance of a healthy lifestyle, including exercise, diet and sex.

Your parents or carers have been really important in looking after your health and will be able to give you lots of helpful advice. While you are in the process of transitioning, your parents will still be very involved in your care and their role is still important. Try to talk to them and your health care team about how you feel about moving on to adult care, and about any questions or concerns you might have.

What happens at the transition clinic?

You will be seen for your normal follow-up appointments with the paediatric team and, when a time for transition to the adult service has been agreed with you, an appointment will be made to see the paediatric and adult teams together. Transition clinics will take place in the hospital premises.

Questions you may like to discuss with your healthcare team

- What is the plan for my transition?
- When am I moving to adult services?
- Can I choose which adult service I move to?
- What is different about the adult service?
- Can I meet the adult staff before I leave children's services?
- Are there any young people I can talk to about moving to adult services?
- What do I need to know before I move to the adult service?
- When can I start getting more involved in my health care?
- How will my condition affect my future, such as my education and employment prospects?

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 tell 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 all costs of travelling to and from your hospital appointments. We will help you to find out if you can claim these.

Important contacts

Paediatric inherited metabolic diseases team

Dietitian **t:** 020 7188 4008

Nurse specialist **t:** 020 7188 0855

Secretary **t:** 020 7188 0848

Adult inherited metabolic diseases team

Dietitian **t:** 020 7188 9611

Nurse specialist **t:** 020 7188 0850

Secretary **t:** 020 7188 4004

Guy's and St Thomas' Hospitals switchboard

t: 020 7188 7188

Notes

Contact details

If you have any questions or concerns please contact the inherited metabolic diseases team, **t:** 020 7188 0855 / 0850 / 4008 / 9611, Monday to Friday, 9am-5pm. Out of hours, 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 **w:** 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, Monday to Friday, 10am-5pm

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

Leaflet number: 2751/VER4

Date published: March 2020

Review date: March 2023

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A list of sources is available on request