

Your transition from children's to adult services

Information from the Department
of inherited metabolic diseases

What is the transition process?

We use the word 'transition' to describe the process for someone preparing, planning and moving from children's to adult services. Transition is about making plans **with** you for your future care.

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

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'll feel more confident and happier about it.

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

Why you need to transition

As you get older, you'll find that some of the things you want to discuss, or some of the care you might need, is not covered 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 might 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 to transition as everyone is different, but we begin the process when you're about 13 years old.

This leaflet is to get you thinking about, and preparing for the transition. Your doctors and nurses might have an idea about when they think that you might be ready, but it's important that you're involved in that decision and feel confident with the transfer of care.

Helping you get ready

Your healthcare team can 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 they'll be able to give you lots of helpful advice. While you're 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 us about how you feel about moving on to adult care, and ask any questions you might have.

When does the transition happen?

You will continue to come to your usual follow-up appointments with the paediatric team. When you and your team agree that it's the right time for you to move to adult services, a multidisciplinary team (MDT) meeting will be held with the adult metabolic service.

At this meeting, your medical history and current treatment plan will be shared. This is so that the adult team is fully informed before your first appointment with them. We'll write to you after the meeting to confirm that it's taken place. From this point onward, the adult metabolic team will take over your care.

We strongly encourage you to go to your first appointment with the adult metabolic team. This allows them to get to know you and provide the best possible support for you as you move into adulthood. They'll support you with the treatment, and ongoing management of your condition.

Possible questions you might ask us

- 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 own health care?
- How will my condition affect my future, such as my education and employment prospects?

Prescriptions

There are different ways you can receive your medicines, but it will probably remain the same after you move to the adult service.

If you're in full-time education or receive certain benefits, you might be exempt from paying for NHS prescriptions. If you're not in full-time education or do not receive benefits, you will need to pay for your prescriptions.

If you expect to need multiple NHS prescriptions, it might be more cost-effective to buy a Prescription Prepayment Certificate (PPC). You can search 'PPC' on www.nhs.uk

Travel costs

If you're receiving a particular type of benefit you might be entitled to claim some or all costs of travelling to and from your hospital appointments. We'll help you to find out if you can claim these.

Contact details

If you have any questions, please contact the inherited metabolic diseases team on any of these numbers, Monday to Friday, 9am to 5pm.

Phone 020 7188 0855, 020 7188 0850, 020 7188 4008 or 020 7188 9611

Out of hours, leave a message with your name and phone number and we'll get back to you as soon as possible. This is not an emergency service.

Paediatric inherited metabolic diseases team

Dietitian **phone** 020 7188 4008

Nurse specialist **phone** 020 7188 0855

Secretary **phone** 020 7188 0848

Adult inherited metabolic diseases team

Dietitian **phone** 020 7188 9611

Nurse specialist **phone** 020 7188 0850

Secretary **phone** 020 7188 4004

Guy's and St Thomas' hospitals switchboard

phone 020 7188 7188

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

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