


Transition to the adult liver service: a young person's guide



Information for patients

This leaflet explains what happens when you move from the children's liver service to the adult service. This process is called transition.

Transition is a gradual process. We will spend time talking with you about what sort of care and support you will need when you move to the adult service. For example, how ready you feel to make the move and when you will make it.

Confirming your identity

Before you have a treatment or procedure, our staff will ask you your **name** and **date of birth** and check your **ID band**. If you don't have an ID band we will also ask you to confirm your address.

If we don't ask these questions, then please ask us to check.

Ensuring your safety is our primary concern.

What will happen?

We help you to understand your condition, your treatment and talk to you about topics and issues that affect you as a young person. We will also discuss with you the transfer of your care to the adult teams either at King's or closer to where you live, if this is possible or if you want to.

Key stages

From 12-16 years: you are seen in the paediatric outpatient department.

At your first visit we introduce you to the doctor (paediatric hepatologist) who runs the adolescent and young adult liver service, the clinical nurse specialist (CNS) and our clinical psychologist. This may mean your visit takes a bit longer than usual. You will have blood tests and an ultrasound scan as usual.

From 16-18 years: we will see you in the adult liver outpatient department (Suite 9, third floor, Golden Jubilee Wing). The clinics run on a Tuesday and Wednesday afternoon.

On your first visit you will meet with the doctors: either one of the paediatric or adult hepatologists who are running the young adult liver service. The other members of our team such as clinical nurse specialist, clinical psychologist and specialist social worker will also be able to see you in the same clinic. You will have blood tests in the liver outpatient clinic after you have seen the doctor.

In the young adult liver clinic, the receptionist will arrange your next appointment and an ultrasound before you leave the clinic. You will be sent a text message reminder a few days before your appointment date. If you would like to change your appointment



date, you will need to contact the young people's liver clinic and also the ultrasound department, to rearrange your scan.

From 18 years: during your visits to the young adult liver clinic we will discuss the different options with you and your family and set up a transition plan. This will include your medical details and other important information, for example how you cope with procedures like blood tests and who will look after you in the future.

If you have any questions or would like some more information about your first appointment, do not hesitate to contact the liver transition team.

Who can I bring with me to clinic?

You can come in on your own but your parents, carers, or relatives are welcome to join you. It depends what you feel most comfortable with. If you prefer, we can see you on your own for part of the clinic appointment.

We will discuss topics such as smoking, alcohol and sexual health in relation to your liver condition but we will be guided by what you would like to know.

Confidentiality

Up until the age of 16, we will send a copy of your clinic letter to your parents or carers. After you are 16, we will address the letters to you. You can then decide if you want to share the letter with your parents or carers. However, we will also send a copy to your GP and other doctors or services that may be looking after you.

We value patient confidentiality and will only breach this if we are concerned about your health is at risk. When you are over the age



of 18, we are not allowed to communicate with your parents or carers about your health without your permission.

What happens about shared care?

Shared care arrangements will stay the same until you leave the young people's liver service. The clinical nurse specialist or the liver transition doctor will explain to you any changes about your treatment and how to find out your blood test results.

If you are a young person and have had a liver transplant, we will introduce you to the liver transplant co-ordinator who will take over the role of the paediatric liver clinical nurse specialist once you turn 18 or move on to the adult services.

What happens if I need to be admitted to hospital after I turn 16?

When you turn 16, you can continue to be admitted onto the paediatric wards, or if you prefer, you can be admitted to the adult wards. Either way we will continue to visit and support you while you are in hospital.

After 18 you will be admitted onto an adult ward. We will talk to you about this in clinic.

What if I have special needs or difficulties?

We work very closely with the adult safeguarding team who support patients over the age of 16 with special needs. When you come to hospital we will refer you to this team.

We appreciate that you might need your parents/carers to be with you during the clinic appointments or need extra support when you are admitted to hospital. We will make up a special passport with



you and your parents/carers to ensure everyone involved in your care will be aware of your needs.

Young people's liver service team

The team includes:

- doctors
- clinical psychologists
- clinical nurse specialists
- specialist social workers
- transplant coordinators,
- support from a liver pharmacist and transplant surgeon.

How can I find out more about the transition service?

To find out more about our transition service, please contact one of our administrators on **020 3299 1162** or **020 3299 3774**.

For queries about your appointment or for outpatients, please contact the outpatients clerk.

Tel: **020 3299 4504** (paediatrics)

Tel: **020 3299 4979** (adults).

Sharing your information

We have teamed up with Guy's and St Thomas' Hospitals 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 Guy's or St Thomas'. 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.



Care provided by students

We provide clinical training where our students get practical experience by treating patients. Please tell your doctor or nurse if you do not want students to be involved in your care. Your treatment will not be affected by your decision.

PALS

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. The PALS office is located on the ground floor of the Hambleden Wing, near the main entrance on Bessemer Road - staff will be happy to direct you.

PALS at King's College Hospital, Denmark Hill, London SE5 9RS:

Tel: **020 3299 3601**

Email: **kch-tr.pals@nhs.net**

You can also contact us by using our online form at

www.kch.nhs.uk/contact/pals

If you would like the information in this leaflet in a different language or format, please contact PALS on 020 3299 1844.



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