



Great Ormond Street Hospital for Children NHS Foundation Trust: Information for young people and families

# Moving on to adult kidney transplant services

When you reach 13 or 14 years of age, it will be time to start thinking about getting ready to move on to an adult kidney transplant service. At Great Ormond Street Hospital (GOSH), we see this transition as a process rather than a one-off step. We will work with you to help you become more independent in dealing with your health. We will also make sure you understand why you needed your transplant and what this might mean for your life as an adult. If you have any questions at any time during the transition process, please ask us – our contact details are at the end of this information sheet.

## What is transition?

In healthcare, we use the word 'transition' to mean the process of planning, preparing and moving from children's healthcare services to adult healthcare services. Transition is a gradual process – how long it lasts depends on your needs and your families' needs. We like to start the process around three to four years before you are transitioned from GOSH. The timing of your move to an adult healthcare service varies, but most young people do it between the ages of 16 and 18 years.

## Who will help me through transition?

You will have a key member of staff who will support you through the process. We aim that this person – your 'transition coordinator' – will be the same person throughout the process, although we can't guarantee this.

In addition, you'll be able to talk to any member of the transplant team about worries, concerns, information and questions. If you want to talk to someone of the same gender, we will usually be able to arrange this. You will also get to know our adolescent clinical nurse specialist, who will play a role in your transition. They will be available to talk to you about any teenage issues or answer questions about transition.

## How does the transition process work?

We will give you a transition plan which will tell you more about what's involved in transition. It also gives a rough idea about the timing of different phases of transition, although this can vary from person to person.

We will also talk to you about the adult kidney transplant services available. Depending on how your kidney is working, you may be able to choose. Currently, we hold joint clinics at GOSH with four transplant centres in the South East of England – Guy's and St Thomas' Hospital, the

Royal Free Hospital, the Royal London Hospital and the Churchill Hospital at Oxford. If you live elsewhere in the UK, we can work with them to arrange your transition to a hospital with an adult kidney transplant service nearer to your home address.

The transition process involves attending joint clinics (where appropriate) to see the clinical nurse specialist and nephrologist from the adult centre alongside the team from GOSH. We will also arrange informal visits to the adult centre of your choice. You will have alternate clinic appointments at GOSH and your adult centre – it is important that you attend both – while you prepare for transition. After a series of appointments at GOSH and the adult centre, we will formally hand over your care to the adult centre at a time that is agreed with you and your family.

## How will you help me get ready?

As you get older, you will start to take more responsibility for your health, with support from your family and hospital team. This could include arranging appointments, taking your medicines and talking to doctors on your own. You'll probably be taking more responsibility for other areas of your life too, such as education or employment. We will work with you to feel comfortable about this new independence – talking to you about what it will involve and giving you chances to practise new skills.

There's a lot to think about when it comes to transition – you might want to talk to your parents and members of the transplant team at GOSH about some or all of the following:

- Do you understand why you had a kidney transplant?
- Could you give a breakdown of your medical/surgical history?
- Do you know what you need to do each day to look after your kidney?
- Do you know what to do or who to contact if you're ill?
- Do you know what medicines you are taking and why?
- How organised are you about taking your medicines?
- Do you know how to order your medications?
- Do you know how to arrange follow up appointments?
- How comfortable are you about talking to doctors and nurses on your own?
- Are you clear about lifestyle issues, such as alcohol and contraception, and how they could affect your kidney?

There are probably lots of other questions you need to ask or topics to think about – why not keep a special transition notebook where you can write down the questions when you think of them and make notes at appointments.





## My parents are still taking charge of everything - how can I become more independent?

Transition is a hard time for your parents as well as for you. For all of your life up to now, their main focus has been on you and keeping you well. When you had your kidney transplant, they will have had to spend lots of time in hospital looking after you and probably made changes to your home life too. It's understandable that they find it hard to 'let go' and let you become independent.

The most important thing is to keep talking – they are probably as worried as you are about leaving GOSH and going to a new hospital. There are things you can practise together, such as how to describe your medical history and ask questions. As your parents see you coping with the transition process, they will feel more confident for the future and will be able to let go a bit more.

## Can I keep in touch with the team at GOSH?

Of course you can let us know how you're getting on at your adult hospital but it's important that you turn to your adult team with any questions or concerns. They should be your first point of contact for everything to do with your health.

## Useful websites

The Direct.gov website at [www.direct.gov.uk/en/YoungPeople/index.htm](http://www.direct.gov.uk/en/YoungPeople/index.htm) contains lots of information about public services for young people. They have a section about starting work at [www.direct.gov.uk/en/YoungPeople/Workandcareers/index.htm](http://www.direct.gov.uk/en/YoungPeople/Workandcareers/index.htm) and one about staying on in education at [www.direct.gov.uk/en/YoungPeople/DG\\_10016099](http://www.direct.gov.uk/en/YoungPeople/DG_10016099). There is also a section for young people with disabilities at [www.direct.gov.uk/en/YoungPeople/Youngdisabledpeople/index.htm](http://www.direct.gov.uk/en/YoungPeople/Youngdisabledpeople/index.htm)

The Connexions website ([www.connexions-direct.com](http://www.connexions-direct.com) or telephone 080 800 13219) also contains lots of information for young people aged 13 to 19 years old, on health, relationships, education and employment. They also have a separate section for young people with disabilities. There are Connexions centres in most major towns and cities if you would prefer to talk face to face with an advisor.

### useful numbers

**Clinical Nurse Specialist**  
– Renal Unit: 020 7813 8172  
**Adolescent Nurse Specialist:**  
020 7813 8541

### Notes

Compiled by the Renal and Adolescent Medicine teams in collaboration with the Child and Family Information Group

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