

Adult kidney service - a young person's guide

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Introduction

This booklet provides information about the kidney services available at Guy's and St Thomas' for young adults aged 15 to 25 with a kidney condition.

What is 'transition'?

Some time between the ages of 16 and 18, young people will transfer from children's kidney services to adult kidney services. This move to adult services is a planned and gradual process often referred to as 'transition'.

This gradual process gives everyone time to talk about what health care you will need as an adult, choose which adult hospital or services are best for you and make sure you are ready to make the move.

During transition we aim to provide coordinated care, in which you and your parents or carers are fully involved and share in decision making.

When should I start talking about transition with my doctor or nurse?

The process of transition starts at around 15 to 16 years of age but your doctors and nurses in the children's service may start talking to you about transition before this. If you feel ready to discuss it and it has not been brought up, ask your doctor or nurse to explain the process to you.

You and your parent or carer should have the opportunity to ask questions and be given plenty of time to think things over and talk about how you feel about moving.

When should I transfer?

This depends on many factors, including how independent and confident you feel, and what is going on at school, college, university, home or work. For example, you may not wish to transfer in the middle of exams or while moving away from home.

Transferring to adult care is always planned with you and your kidney care in mind. You may not want to make the move too soon; likewise, if you wait too long you may find it more difficult. Most young people transfer around their 18th birthday or within six months of turning 18 years old.

As you develop into a young adult, an adult service will be the best place for you to get the care that is right for your needs.

Can I choose where I transfer to?

Sometimes you can choose a hospital near where you live. Alternatively you might need to go to a specialist hospital. Your consultant, clinical nurse specialist or family doctor (GP) will be able to recommend which hospital or services are right for you. You will be fully involved in making a shared decision about where is best for you.

During transition we will involve and support your parents or carers, as their role in your kidney care will be changing. Young people and their families can sometimes find that transition from children's to adult services causes anxiety. We recognise this and all of our doctors and nurses are happy to talk to you if you have any queries or need additional information or support.

How should I prepare for the transfer?

Guy's adult kidney unit has a dedicated young adult service to help with transition. You will be able to attend a 'joint transition clinic' where your doctors from both the children's and the adult units are present. The purpose of this is to discuss your clinical care and for you to feel confident about how this will be managed by the adult team.

You will gradually be encouraged to do more for yourself, becoming more responsible for managing your medicines and appointments.

Your doctors and nurses will start talking to you, rather than your parents or carers, about your care. You will also be given the opportunity to talk to them on your own as there may be matters you would like to discuss privately. Letters from the adult kidney service will be addressed to you personally.

You will get to know members of the adult kidney team and become familiar with the adult centre before transferring. You will also be able to take a tour of the adult outpatients and inpatient kidney ward areas.

What is the young adult kidney service at Guy's?

The young adult kidney service supports young people aged 15 to 25 living with kidney disease to take greater control of their condition and provides a welcoming and understanding adult service.

Young adult specialist nurse/kidney care coordinator

You will be able to meet the young adult specialist nurse to talk through your transition plan and assess your readiness for transition. You can also discuss any other important issues, such as managing your studies or work, financial implications of having a long-term condition, managing relationships, taking your medicines and moving away from home, and getting the most out of clinic appointments.

The young adult nurse will be your named link nurse between the adult and children's team whilst you move to adult services and can also be a resource for your parents or carer too.

Young adult clinic

You will have the opportunity to attend the young adult clinic, which is held every other month in the kidney clinic at Guy's Hospital. Young adults have sole use of the clinic that afternoon. Information and education sessions often take place during that time and many young people enjoy socialising with their peers.

You will also be able to meet other members of your kidney team for advice about your medicines, diet, exercise, benefits or for any additional support.

How will the adult service differ from the children's service?

One of the main differences is the amount of independence you will be given. This means that you will need to learn about your condition so that you can be involved in your care and make decisions for yourself. You will need to be able to give information about your condition and know how to keep yourself well. Although this can be worrying, it is good to have control over your health and the care you are given.

When you are asked to make decisions about your health, you will be given all the information you need to make the right choice. You can always ask questions and let staff know if you are not sure about anything. Although you, rather than your parents, will be asked to make decisions in adult care areas, you can still ask their advice before making a choice.

In adult kidney services during appointments or admissions, doctors, nurses and other staff will spend more time talking to you than your parents. You will get used to this and so will your parents. You can still take your parents into clinic appointments, but you will be the one who needs to talk about your health and ask questions.

If you are admitted to an adult hospital, your parents will not be able to stay overnight with you. Although the visiting times might be shorter, your family and friends will still be able to visit and phone you. Most hospitals, including Guy's and St Thomas', have free wifi.

You may also notice:

- The adult kidney care team is much larger as the patient group is larger.
- You may not always see the same doctor or nurse at your appointments.
- The appointment time is shorter.
- Your GP is more involved in your kidney care and becomes your first point of contact.
- You may have to pay for your prescriptions.

Is the process different if I am coming directly into the adult service rather than moving from a children's service?

You may have been directly referred to Guy's kidney service by your GP. If you are aged 16 years or over, there is often no need for you to go to a children's unit first. Instead you will have your first appointment in the adult kidney clinic at Guy's hospital.

Coming directly into adult services can be just as daunting as transferring from a children's area but you will be given every opportunity to meet all of the staff caring for you and you will settle in gradually. You will also be able to access all kidney services at Guy's available to young people.

Questions you might like to ask:

- What is the plan for my transition?
- When am I moving to adult services?
- Who is responsible for organising my transition?
- Can I choose which adult service I move to?
- Can I meet the staff from the adult service, before I leave the children's service?
- Can I visit the adult service to look around?
- Are there other young people who I can talk to who have already moved to my adult service?
- How can my family help me to get ready?
- When can I start getting more involved in my health care?
- What is it like to be an adult with my health condition?
- Will my kidney condition affect my education or career choices?

Peer support

Many of our young people are keen to offer support to other young people who are coming into the adult kidney service. If you feel isolated or anxious and would like to talk to someone who has had a similar experience, the young adult service can put you in touch with other young kidney patients. We can also let you know about other useful organisations that offer support or information.

Every year events take place across the country offering the opportunity for young people with a kidney condition to meet up and have fun. These events are open to

everyone and range from day trips to taking part in local social events or national residential activity weekends.

The cost of these events is often heavily subsidised by funding from national kidney patient charities. Guy's adult service actively supports these events and many of our young people attend. Please ask the young adult specialist nurse for details.

How will my care be organised in the Guy's adult kidney service?

Dialysis

Your dialysis care will be transferred to one of Guy's seven haemodialysis units, or the home dialysis unit which includes haemodialysis or peritoneal dialysis.

The Astley Cooper dialysis unit is located on the 5th floor of Borough Wing at Guy's Hospital. It is primarily for inpatient dialysis or for those with complex care needs.

We also have community haemodialysis centres offering haemodialysis as close to home as possible. Dialysis units away from the main hospital are called satellite dialysis units and are located in the following areas:

Borough Kidney Treatment Centre
46 Long Lane, London SE1 4AU

Camberwell Dialysis Unit
Chartwell Business Centre, 61–65 Paulet Road,
London SE5 9HW

Forest Hill Dialysis Unit
107-113 Stanstead Road, Forest Hill, SE23 1HH
(this unit is expected to move into the University
Hospital Lewisham in 2017)

New Cross Gate Dialysis Unit:
Unit A Ewen Henderson Court, 40 Goodwood Road.
New Cross Gate SE14 6BL

Sidcup Kidney Treatment Centre:
Queen Mary's Hospital, Frognal Avenue,
Sidcup, DA14 6LT

Tunbridge Wells Kidney Treatment Centre:
Abbey Court, 7-15 St. Johns Road, Tunbridge Wells,
Kent, TN4 9TF

Some of the units offer evening appointments.

The dialysis team at Guy's supports young adults who wish to self-care in satellite units and have an active home haemodialysis and peritoneal dialysis programme. The home dialysis team are located at Borough Kidney Treatment Centre.

Your doctors in the children's unit will discuss the options you have available for your dialysis care at Guy's. You will also meet the young adult specialist nurse and members of the adult dialysis team. They will help you move across to adult dialysis as smoothly as possible, providing support in managing your own condition and fitting dialysis around your needs, such as college and work commitments.

There is more information about dialysis at home and self-care in the film **Living life to the full on dialysis** which can be viewed on our kidney website www.mykidney.org.uk

You can find out more about our dialysis services at: www.guysandstthomas.nhs.uk/ourservices/kidney/patients/patients

If you do not have access to the internet, you can find detailed information about dialysis at Guy's in the **Welcome to our dialysis units** leaflet. Please ask a member of staff for a copy.

Transplant care

Guy's kidney unit has a team of nurses and doctors who care for young adults with kidney transplants. You will be invited to attend the young adult clinic early in your transition journey, and will meet the young adult specialist nurse as well as the doctors and nurses who are taking over your care at Guy's. It will give you an opportunity to become familiar with Guy's adult service before you transfer your care and ensure that you are involved in your transition planning.

You can find out more about our transplant services at: www.guysandstthomas.nhs.uk/our-services/transplant/overview.aspx

If you do not have access to the internet, you can find detailed information about transplant services at Guy's in the **Your guide to kidney transplantation** booklet. Please ask a member of staff for a copy.

Long term (Chronic) kidney care

Guy's kidney unit has a team of nurses and doctors who care for young adults with chronic kidney conditions. You will be invited to attend the young adult clinic early in your transition journey, and will meet the young adult specialist nurse as well as the doctors and nurses who are taking over your care at Guy's. It will give you an opportunity to become familiar with Guy's adult service before you transfer your care and ensure that you are involved in your transition planning

For further information please see the **Your kidneys, your choice** booklet. Please ask a member of staff for a copy. You can also find out more about our services at: www.guysandstthomas.nhs.uk/our-services/kidney/patients/patients.aspx

Inpatient care

If you need a hospital admission related to your kidney condition, you will stay on Richard Bright or Patience wards, located in Borough Wing of Guy's Hospital. The wards are organised into separate male and female bays for beds and toilet facilities.

You may find the wards larger, busier and noisier than you are used to. Some young adults find this daunting but it is important to remember that the staff are there to help you manage any anxieties or concerns you have about staying in hospital, and will respect your privacy at all times.

The nurses are there to discuss anything you do not understand about your condition or treatment, particularly if you are uncertain about consenting for (giving permission to) any treatment. The young adult specialist nurse can also help you and provide additional advice.

Parents or carers do not stay overnight on the wards and for some young adults and their parents this is a big change.

As a young adult it is important that when your parents are not with you, you feel confident asking for help from your nurses. You can talk to them **at any time**, no matter how silly or small your questions or concerns may appear.

Your parents or carers may wish to find overnight accommodation near the hospital, particularly if you do not live locally to Guy's Hospital. If you would like more information on accommodation nearby, please speak with your nurse or the young adult specialist nurse.

When coming into hospital for an overnight stay, it is always helpful to bring activities to keep you occupied. Adult wards do not always cater for young adults' entertainment needs and do not have the same resources or staff as children's wards.

Please note that we cannot take responsibility for the security of smartphones, laptops, tablets, or any other valuables.

What else should I do to get ready?

It will be helpful for you to practise doing the following things (if you aren't doing them already) to help you prepare for adult care:

- Learn about your conditions and treatments.
- Practise asking and answering questions during ward rounds and clinic appointments.
- Try and take some responsibility for remembering what your medicines are called, what they are for, how much to take and when to take them.
- Learn how to get more supplies of your medicines or dressings.
- Practise arranging appointments with your consultant, family doctor (GP), and other health care team members.
- Keep important phone numbers and appointments in your mobile phone, calendar or diary.
- When you agree to treatment plans, make sure you follow them properly.
- Try spending time without your parents for part of your clinic appointments, then when you feel ready try spending the whole appointment on your own.
- Find out what the changes are in your condition that mean you should get urgent help.
- Find out who to contact in an emergency.

The adult kidney team are here to help you and will respect your privacy and confidentiality. Always try to talk openly about your condition, symptoms and concerns.

Come to the adult kidney care areas prepared; bring with you a list of your symptoms, questions and concerns. Try not to feel embarrassed and if you do not understand medical terms, just ask.

Nurses and doctors in adult services often get asked about:

- mood changes
- feeling low
- feeling tired
- itching
- diet and fluids
- weight loss or gain
- relationships
- sexual problems or loss of interest in sex
- safe sex, contraception and planning a pregnancy
- managing work, study, sport and holidays
- tattoos and piercings
- drugs, smoking and alcohol.

Getting to know your GP

When you transfer to adult services you will find that your GP is more involved in your kidney care. Your GP will prescribe most of your medicines and will be responsible for looking after any health needs not related to your kidney disease.

We strongly advise that as part of your transition plan, you take the opportunity to meet your GP and discuss with them your transition to Guy's adult kidney unit.

Where can I find more information and support?

Support organisations

Guy's and St Thomas' Kidney Patients' Association

w: www.gsttkpa.org

K2K Young Person's Kidney Care Arena,

A Facebook group for young adults with kidney disease.

Kidney Care UK (British Kidney Patients' Association)

A charitable association providing advice, information and grants to kidney patients and their carers in the UK.

t: 01420 541424 **w:** www.britishkidney-pa.co.uk

Young@NKF

A charitable organisation that provides support and advice for young people living with kidney disease.

t: 0845 601 0209

Useful websites

MyKidney website provides more information about living with kidney disease. **w:** www.mykidney.org.uk

NHS Choices – Live well, live healthy

Information sections for teenagers and young adults:

w: www.nhs.uk/livewell

Youth Health Talk

A website about young people's real life experiences of health and lifestyle. It is not just a website about the medical facts; it is about real people and real lives.

There is a section that focuses on young adults living with long-term health conditions:
www.youthhealthtalk.org/Young_people_with_long_term_health_conditions/Topic/1872

Youth Health Talk also includes information about sexual health, alcohol, depression, health and weight:
w: www.youthhealthtalk.org

Teenage Health Freak

General health information aimed at teenagers:
w: www.teenagehealthfreak.org

Brook advisory centres

Providing free, confidential advice on sex and contraception to the under 25s:
w: www.brook.org.uk

Frank

Friendly confidential drugs advice
w: www.talktofrank.com

Young Minds

Information for young people and children about mental health and emotional well-being:
w: www.youngminds.org.uk

Connexions

Connexions is the careers information, advice, guidance and personal support service for young people aged 13 to 19 years, helping them to prepare for their future:
w: www.connexionslive.com

Gov.UK

The best place to find government services and information – working, driving, housing, benefits, and money and tax:

w: www.gov.uk

Citizens Advice Bureau

An organisation, with local branches throughout the UK, providing information and support on a wide range of topics, including finance, legal, housing and employment:

w: www.citizensadvice.org.uk

Notes

Contact details

If you have any questions or concerns about your transition process or clinical care, or any questions about information provided in this booklet, please contact the young adult kidney nurse specialist on **020 7188 7188** ext. **52722** or mobile: **07851 621 930** or bleep **1965**.

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

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 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

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