

# Support for parents and carers of young adults with kidney disease

Supporting a child making the transition from children's to adult services, or supporting a young person receiving care in adult kidney services, can be an anxious time for parents and carers. This leaflet explains what support is available and how to access it.

## As a parent or carer what should I expect?

As a parent or carer you may have formed strong bonds with the healthcare team who cared for your child when they were young. This may have been a children's kidney service or a community services team. The adult kidney service is much larger and you may not be familiar with all the staff involved in your child's care or the hospital environment. This can be daunting for both you and your child, but the healthcare team are very keen to work in partnership with you and to ensure that the transition from children's care to adult care is as smooth as possible. Please do not hesitate to approach us if you have any queries or concerns.

## What challenges might I be concerned about?

We encourage all our young adults to take greater responsibility for their kidney care, with a view to becoming more independent. We know from experience, however, that young kidney patients can feel very isolated and sometimes this can result in missed medicine doses or missed clinic appointments. We know that the demands of dialysis and clinic appointments can make moving away from home or entering the world of work/college difficult. Many young people also express some level of anxiety about things like finances, body image, exam pressure and forming relationships.

You will no doubt want to help and support your child as much as possible. However, you may feel that you also need some advice and support through this difficult time. We would like to support you to help the young adult to develop skills to become independent in their healthcare.

## Is it possible to talk to other parents/carers who have had similar experiences?

A young adult kidney clinic is held every other month. During this clinic parents/carers have the opportunity to meet and chat with other young adult patients together with their parents/carers, in an informal setting over some light refreshments. Your nurse will be able to tell you when and where these clinics are held.

## Who will support my child?

The kidney care team will support the young adult as they make their journey from children's services to the adult kidney service. We also have a part-time young adult kidney care nurse coordinator, who is responsible for coordinating the transition process and supporting the young adult after they have transferred to the adult service.

## How do I find support locally?

To find out more about local services, talk to your GP or practice nurse. If you feel that you would benefit from some psychological support or counselling, ask your GP to make a referral to IAPT (Improving Access to Psychological Therapies) – a community service for people who may be experiencing depression or anxiety. Some IAPT services accept self-referrals.

## Where can I find more support and information?

### Within Guy's and St Thomas'

**[www.guysandstthomas.nhs.uk](http://www.guysandstthomas.nhs.uk)**

For up-to-date information about all services at Guy's and St Thomas'

**[www.evelinalondon.nhs.uk/our-services/hospital/kidney-services/transition](http://www.evelinalondon.nhs.uk/our-services/hospital/kidney-services/transition)**

More detailed information about the transition/transfer process and who's involved

### Pharmacy Medicines Helpline

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

t: 020 7188 8748 (9am–5pm, Monday – Friday)

**[www.mykidney.org.uk](http://www.mykidney.org.uk)**

A website put together by clinicians in the kidney units at Guy's and St Thomas' NHS Foundation Trust and King's College Hospital NHS Foundation Trust. It is informed by patients' personal experiences of kidney care. The information within it aims to help people understand more about kidney disease and how to live with it.

### Guy's and St Thomas' Kidney Patients Association

The Kidney Patients Association is a registered charity that supports kidney patients of Guy's and St Thomas' Hospitals.

t: 020 7188 7552    w: [www.gsttkpa.org](http://www.gsttkpa.org)

**Facebook:** [facebook.com/groups/gsttkpa](https://facebook.com/groups/gsttkpa)

**Twitter:** @gsttkpa

## **National kidney support organisations**

### **British Kidney Patient Association**

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

t: 014 2054 1424    w: [www.britishkidney-pa.co.uk](http://www.britishkidney-pa.co.uk)

### **National Kidney Federation**

A charity that provides information, support and grants

t: 0845 601 02 09 (helpline)    w: [www.kidney.org.uk](http://www.kidney.org.uk)

## **Other organisations**

To find your local carers centre visit [www.carers.org/what-carers-centre](http://www.carers.org/what-carers-centre)

### **Carers UK**

A charitable organisation, providing information and support on all matters relating to caring in the UK.

t: 0808 808 7777    w: [www.carersuk.org](http://www.carersuk.org)

### **Carers Direct**

An NHS site offering information, advice and support for carers

t: 0808 802 0202    w: [www.nhs.uk/carersdirect/Pages/CarersDirect](http://www.nhs.uk/carersdirect/Pages/CarersDirect)

### **Transition Information Network**

An alliance of organisations and individuals whose aim is to improve the experience of disabled young people's transition to adulthood.

t: 020 7843 6006    w: [www.transitioninfonetwork.org.uk](http://www.transitioninfonetwork.org.uk)

### **MIND**

A mental health charity offering advice and support.

t: 0300 123 3393    w: [www.mind.org.uk](http://www.mind.org.uk)

### **Young Minds**

A parent line for parents concerned about the psychological health of their child.

t: 0808 802 5544 (helpline, 9.30am–4pm, Monday to Friday)

w: [www.youngminds.org.uk/for\\_parents](http://www.youngminds.org.uk/for_parents)

### **Citizens Advice Bureau**

Network of independent charities that give free information and advice to help people with money, legal, consumer and other problems. Look in your phonebook to find your nearest CAB or

w: [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

## Contact us

If you have any questions or concerns about your child's kidney care, or any of the support services available, please do not hesitate to contact Vanda Fairchild (young person's kidney nurse) on **020 7188 7188 ext 52722**, or via **hospital bleep 1965** (Monday to Friday, 9am to 5pm).

### 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](mailto:pals@gstt.nhs.uk)  
**t:** 020 7188 3514 (complaints)      **e:** [complaints2@gstt.nhs.uk](mailto:complaints2@gstt.nhs.uk)

### Knowledge & Information Centre (KIC)

For more information about health conditions, support groups and local services, or to search the internet and send emails, please visit the KIC on the Ground Floor, North Wing, St Thomas' Hospital.

**t:** 020 7188 3416

### Language 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](mailto:languagesupport@gstt.nhs.uk)

### NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

**w:** [www.nhs.uk](http://www.nhs.uk)

### Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, and to become a member:

**t:** 0800 731 0319      **e:** [members@gstt.nhs.uk](mailto:members@gstt.nhs.uk)      **w:** [www.guysandstthomas.nhs.uk/membership](http://www.guysandstthomas.nhs.uk/membership)