

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 adult 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 and seamless 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 long term treatment, 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 also feel that you need some advice and support through this transition period. We would like to support you in helping your 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. Young people are seen by their paediatric team and new adult kidney teams at this clinic. Your nurse will be able to tell you when and where these clinics are held.

Who will support my child?

The whole kidney care team will support your young person 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.

Useful sources of information

Guy's and St Thomas' website

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

w: www.guysandstthomas.nhs.uk

Evelina London Children's Hospital website

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

w: www.evelinalondon.nhs.uk/our-services/hospital/kidney-services/transition

MyKidney

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.

w: www.mykidney.org.uk

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

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

Twitter: @gsttkpa

Kidney Care UK

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

t: 014 2054 1424

w: www.kidneycareuk.org

National Kidney Federation

A charity that provides information, support and grants.

t: 0845 601 0209 (helpline)

w: www.kidney.org.uk

Other organisations

To find your local carers centre visit **w:** www.carers.org/search/network-partners

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

Carers Direct

An NHS helpline offering information, advice and support for carers.

t: 0300 123 1053 (Monday to Friday, 9am to 8pm, and weekends, 11am to 4pm)

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

MIND

A mental health charity offering advice and support.

t: 0300 123 3393

w: www.mind.org.uk

YoungMinds

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

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

w: 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, visit their website, or call their national phone service, Adviceline.

t: 03444 111 444

w: 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 the young adult kidney nurse on **t:** 020 7188 7188, ext. 52722, or via hospital bleep 1965 (Monday to Friday, 9am to 5pm).

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit **w:** www.guysandstthomas.nhs.uk/leaflets

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, 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

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

NHS website

Online information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing.

w: 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, please get in touch.

t: 0800 731 0319 **e:** members@gstt.nhs.uk **w:** www.guysandstthomas.nhs.uk/membership

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