



Patient support
services

A guide to the services and support provided by Kidney Care UK for kidney patients, their families and carers.

Improving life for
kidney patients



Kidney Care UK are dedicated to helping kidney patients. Every year we help thousands of patients and their families to tackle everyday life with kidney failure; providing kidney patients with the practical, emotional and financial help they need, when they need it.

As well as providing the direct patient help and support you will read about in this guide, Kidney Care UK also helps kidney patients by working hard to improve health and care services and campaigning for change. Our work funds better equipment, specialist staff and quality improvement projects. Our focus is on adding value by only investing in initiatives that fall outside of NHS funding and which make a practical difference to patients today.

Our direct patient services

We are committed to improving life for kidney patients and their families. We are here for everyone affected by kidney disease. Whether you have only recently discovered you have a kidney condition or you have been dealing with kidney disease for many years, we're here to give our total support and to make life easier for patients like you.

No one facing kidney disease alone



Advice



Financial support



Modern equipment



Lifestyle

How we help kidney patients and their families

Kidney Care UK has been helping patients and their families for over 40 years. Our direct patient services are free of charge and provide support to around 3,000 patients and their families every year. They include:

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Family life



Flexible treatment



Professional care



Psychological support

Advice, guidance and advocacy

Understanding exactly where you stand and what options you have is important for patients and their families.

Our services are designed to help answer the myriad of questions kidney disease throws up. Some people just need someone to talk to, others need to know more about their dialysis and transplant options, to understand their situation and entitlements and to find out about the services they can access, whilst others need help and proactive support to resolve issues they are facing. Whatever your needs, we're here for you.

Advocacy service

Our advocacy service is all about taking action on behalf of patients. We advise people on the many issues surrounding kidney disease and actively direct and help you. We deal with hundreds of enquiries about benefits, Dialysis Away From Base, housing, transport, dialysis choices, dialysis holidays, work, treatments and simply managing day-to-day life. We can help patients and their families gain access to the right people, services and support, and we ensure every patient is properly represented.

Our advocacy team, most of them with many years experience as a patient or carer themselves, are trained not only to listen and advise patients but also to fight their corner to the best affect. We often act as a bridge between the patient and renal units, local authorities, the Department for Work & Pensions and local MPs.



To find out more call us on **01420 541424** or visit **www.kidneycareuk.org**



It's hard to put into words what a huge difference Mark has made to my life. Since I was diagnosed with kidney cancer in 2005, no one ever took the time to ask how I was coping with life beyond the hospital, and in truth, I wasn't coping. It was a real struggle with the loss of my job, young children to care for, no income, complex benefits and little hope in sight.

When I met Mark at the transplant meeting, he listened to what I was saying. He could see the challenges I was facing and pro-actively set about finding ways to help me.

Nadir, who has been supported by our Advocacy Officer Mark for more than three years

Information leaflets, fact sheets and application forms

We have an extensive resource of patient information sheets and leaflets. Our information resources cover a wide range of topics around treatments, decision making, side effects, related conditions, expectations and many other issues that might affect kidney patients and their families.



These can be downloaded from our website, visit **www.kidneycareuk.org**, or call **01420 541424** to request free copies.



Often I talk to patients who have just been diagnosed with a serious condition and are struggling to comprehend what it really means. We chat about the effect their condition may have on their lives, families, work and plans, and I help them to come to terms with the implications. Giving people back their sense of worth is so important.

Jacquie Fraser,
Kidney Care UK Counsellor

Telephone counselling

Counselling is a talking therapy provided by our specialist counsellors who are registered and accredited by the British Association for Counselling & Psychotherapy (BACP).

Our Telephone Counselling Service provides professional and confidential counselling, information, advice and support to patients and their families. The service is a great resource for people who are worried about dialysis options, transplantation or simply managing everyday life. Our counsellors are able to listen and offer help and support to those who are unable to access counselling services in their local kidney unit.

At a time when you may be experiencing a range of difficulties or distress related to kidney disease, you may want to talk to a trained counsellor about things you might not feel comfortable discussing with anyone else. Even if you don't want to talk about your personal feelings in depth, we may be able to support you.

Kidney disease can affect work, finances, relationships and self-confidence. Our counselling service helps to equip people for the challenges they face. We can direct them to the right information resources, listen to their concerns and offer advice.

Our Counselling Support Service is available Monday to Thursday. Telephone counselling support sessions can be arranged at times to suit you. Telephone counselling sessions are usually between 30 and 40 minutes, and you can discuss this with your counsellor if this is a problem.

To make an appointment please call 01420 541424, or find more information by visiting www.kidneycareuk.org



Join our Kidney Care UK Facebook group and connect with almost 5,000 members to share your experiences, concerns and ideas.



Personal grants, holidays and respite

Kidney disease can have a massive impact on people's ability to earn a living. The impact can have a significant effect on the standard of living for the whole family.

When you're struggling to deal with kidney disease, the pressure of trying to make ends meet can make life very difficult. Kidney Care UK provide funding for kidney patients who are struggling to make ends meet. Our grants are intended to avert a crisis, make a purchase possible that improves your quality of life or help with a short break or holiday.

Individual grants

Our individual grants help kidney patients to meet costs that they would otherwise struggle to afford. Examples of some of the grants we have made include the replacement of domestic appliances or furniture, mobility aids, help with bills or a purchase that improve the quality of life.

Individual grants are available to:

- Dialysis patients and families on low income.
- Transplant patients and those receiving conservative care, if health and quality of life is being seriously affected by your renal condition.

To apply for an individual grant please contact your kidney unit social worker, a member of your kidney healthcare team, or a Kidney Care UK Advocacy Officer. Alternatively, you can download an application form from our website or call us on 01420 541424.



Holidays and respite breaks

Our holiday and respite grants help patients and their families enjoy some time out from the demands of life with kidney disease. We understand the financial pressures of relying on benefits or only being able to work limited hours. Our holiday grants provide patients with the chance to enjoy a break.

We give grants to individuals and families towards the cost of a basic holiday in the UK or overseas. The grant can be used to cover the total cost or can be used as a contribution towards the final cost.

To apply for an individual grant please contact your kidney unit social worker, a member of your kidney healthcare team, or a Kidney Care UK Advocacy Officer. Alternatively, you can download an application form from our website or call us on 01420 541424.

Dialysis Swap Scheme

The UK Dialysis Swap Scheme is a Kidney Care UK funded partnership with Dialysis Freedom that helps patients to receive dialysis at renal units in the UK away from their home unit.

So, whether it is that important family occasion, a chance to meet up with family and friends or just a chance for a few days away,

visit the website

www.kidneycareuk.org

or call 01420 541424 to

speak with one of the team.



Their first holiday in 20 years

Leigh has been a dialysis patient for over 20 years. Since his diagnosis he has spent 1,040 days on dialysis at his local hospital. Leigh is married and has a beautiful six year old daughter.

He has never taken a holiday with his family, in part because of his kidney failure but also because of his lack of income with no work. Finally, thanks to Kidney Care UK funding, Leigh and his family have enjoyed their first holiday together, on a family break to Legoland.



I've been on dialysis for over 20 years and in all this time we've never taken a holiday, in part because of my kidney failure but also because of my lack of income. Finally, thanks to a Kidney Care UK holiday grant, I've been able to take my family on our first holiday together, to Legoland. It wasn't just the days away that meant so much but the excitement and build up too. Thank you Kidney Care UK.

Leigh, dialysis patient

Supporting children and young adults

Kidney disease presents young people with a huge challenge in life. The disruption to school routines can have a detrimental impact on academic achievements. The need for dialysis, check-ups, medication and related treatments makes it hard to fit in with the social activities of peers. The emotional impact on the whole family can make life very difficult.

As well as investing in specialist staff, units and equipment to help children and young people, we also fund direct initiatives to help young people come to terms with their situation, share their experiences with other young people and grow their self-confidence and sense of self-worth.



Ravenstor weekend

The Ravenstor weekend is a free three-day event, sponsored and organised by Kidney Care UK, in the beautiful surroundings of the Peak District. It is the highlight of the year for many young kidney patients between 18 and 30 and gives them a chance to relax, laugh and unwind among old and new friends, who understand and share the trials of living with kidney disease.

There are lots of activities including canoeing, archery, climbing and cycling. The weekend is a great opportunity for young people to enjoy time away from parents and routines, to try out new activities and build self-confidence.



I'm an emotional wreck right now, thinking about this weekend just gone. I literally couldn't ask to spend it with a nicer bunch of people, both the young adults and the staff. I did shed a tear on my train back I admit it. I'll be replaying this weekend over and over again in my head for ages, probably until September of next year knowing me! Thanks to everyone... you were all amazing!

James, who attended Ravenstor in 2015



To find out more about Ravenstor call us on 01420 541424.

InfoKID website

An extensive online information resource for parents of children with kidney disease.

Finding out that your child has kidney disease is a distressing and worrying time. Parents need to understand more about the illness and what it means for their child and their family. The InfoKID website provides parents with comprehensive information and advice.

The website was funded by Kidney Care UK in a collaboration with the Royal College of Paediatrics and Child Health and the British Association of Paediatric Nephrology. It provides 46 online, downloadable fact sheets that cover different kidney conditions, tests and diagnosis, treatments, kidney information and useful contacts.



InfoKID can be found at www.infokid.org.uk.



Understanding kidney disease and the impact it will have on your child's life is such an important part of trying to come to terms with the situation.

Jan Dudley, Consultant Paediatric Nephrologist and co-founder of InfoKID



Kidney Care UK has been an enormous asset in helping us to put on such a brilliant Games this year and we're so grateful for their commitment and continued support.

Andy Eddy, Chair of Transplant Sport

The Transplant Games

For anyone who hasn't experienced the Transplant Games, it's a bit like a mini Olympics, only much more emotional!

There's a whole range of sports including cycling, tennis, swimming, track and field. The competitors range from toddlers to those in their seventies. Some come to win, others are just delighted to take part, but they all come to show the world how donating an organ changes lives.

Kidney Care UK is one of the main sponsors of the Transplant Games. We also help fund kidney transplant teams to enable patients and their families to take part.

You can enter a team by visiting the website at www.britishtransplantgames.co.uk and if you would like to apply for a grant for your team please call us on 01420 541424 or visit our website.

Investing in better patient care

In addition to our direct patient support, Kidney Care UK invests millions of pounds, and works tirelessly to improve professional care and support for patients.

We fund staff posts, innovative new projects that improve patient care, renal equipment, and invest in some major renal projects where NHS funding won't meet the requirement. Our strategy is only to provide funding where projects or posts fall outside the NHS provision, which means our grants are always delivering added value.

Funding key facilities

Kidney Care UK has invested millions in renal equipment and facilities. In the face of limited health service budgets, our investment provides essential support for the efficient treatment of kidney patients. Our funding includes hospital building projects for renal units, as well as new dialysis equipment and complex kidney preservation machinery. We provide support across the full spectrum of patient dialysis, transplantation and critical care.

Funding research

Over the last five years we have worked closely with the British Renal Society (BRS) to fund practical, patient centred research that improves the lives of kidney patients. Our focus is to improve the level of research in both the practice of kidney disease treatment and the support of patients. Our work is critical in an area that has been highlighted as being under-resourced in the National Renal Research Strategy.

Funding key staff

We are constantly in discussions with renal units across the country as well as patients and families to identify areas of greatest need. Very often it is the psychosocial aspects of patient care that need extra support, as professional medical staff find themselves unable to meet the needs of patients and their families outside essential treatment. We fund dieticians, social workers, psychologists, counsellors and youth workers as well as medical specialists.



My role is to recruit and train volunteers so that they can work on the five renal units with patients. These volunteers will deliver therapies to the patients, including aromatherapy, reflexology, indian head massage and reiki. Complementary therapies can really help dialysis patients – by reducing stress, easing muscular or bone pain, reducing the symptoms of restless legs, improving dry skin, helping reduce itching and cramps and helping to make a repetitive dialysis treatment more engaging. We have had great feedback from patients who really value the service.

Janet Cairnie, who runs the Kidney Care UK funded Complementary Therapy Service at Salford Royal Hospital Trust

Campaigning for better services, policies and NHS practice

We work tirelessly to help shape and improve government policies in the interests of patients. We talk with politicians to gain support and introduce them to kidney patients who can explain some of the challenges they face; we lobby for change, involve focus groups in dialogue, hold receptions for decision makers, fund research to support our campaigning and constantly seek to improve policy and practice for kidney patients and their families.

Help raise funds for Kidney Care UK

Kidney Care UK relies on donations from our wonderful supporters to fund all our work supporting kidney patients and their families. With no statutory funding, it is only with your support that we are able to provide kidney patients with the help and support we do.

Mark Smith needed a pancreas and kidney transplant, after 25 years of living with Type 1 diabetes. Thanks to a wonderful young man who donated his organs in the event of his death, Mark received a transplant that saved his life. After his transplant, Mark took on the Three Peaks Challenge, an incredible feat, raising £1,300 for Kidney Care UK.

Nine year-old Eva's Grandad was on dialysis three times a week. Eva wanted to raise funds for Kidney Care UK to help her Grandad. Teaming up with her 11 year-old brother, Alex, the siblings ran, swam and rode their way to raise an amazing £260.

How to get involved

There are lots of different ways to help support Kidney Care UK. You can raise sponsorship for an activity, hold an event and invite friends and family to come along, sign up for payroll giving, provide a one-off or regular contribution or leave a legacy in your will. The more funds we raise, the greater the impact of our work.



However you choose to support us, our fundraising team are here to support you. To find out more about how you can get involved visit www.kidneycareuk.org, email fundraising@kidneycareuk.org or call 01420 541424.

Leaving a legacy

Legacies form an important source of income to help support our work. Whilst it's not always at the top of people's list of priorities to think about legacies, a simple addition to your Will can make such a big difference to kidney patients and their families. Legacies to a charity are free from inheritance tax, so can reduce the tax burden too.

If you'd like more information about leaving a legacy, we would be very pleased to chat with you. You can reach us on 01420 541424 or email info@kidneycareuk.org.



After his transplant, Mark took on the Three Peaks Challenge, and raised an incredible **£1,300 for Kidney Care UK**

**Kidney Care UK is the leading
kidney patient support charity**



**Kidney Care UK provides support, advice,
counselling and financial help for kidney
patients and their families.**

We fund the improvement of renal equipment, services and specialist staff. We also invest in research and help to influence government and NHS policy. To access our full range of services, please use the contact details below.

Visit our website at **www.kidneycareuk.org**
Call us on **01420 541424**

How you can support our work

It is only through the generosity of our supporters that we are able to raise the vital funds that enable us to make such a difference to patients lives. To find out how you could get involved and help, please visit the website or call us. Thank you.

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