Improving lives every day

Impact report 2018
Right here by your side

“Whether you are living with kidney disease yourself or caring for someone who is, Kidney Care UK are here to support you, every single day.

Over the next few pages you will read how we have spent the last year raising awareness of the many ways we can help people living with kidney disease, improving our services, developing new ones and supporting more patients and families than ever before.

There is no doubt that 2018 has been our most successful year to date and it’s all thanks to the hard work of our wonderful supporters. Whether you raised money through your own endeavours or donated to a friend’s fundraising event, you have helped us make a difference.

It was also the year in which I was awarded an OBE for services to kidney patients. While I carry the letters, I am conscious that any achievements have been a team effort. It has been my privilege and pleasure to work with so many others in this vital field, and I look forward to continuing to build on this alongside my fellow trustees and staff of Kidney Care UK.

We know there is still so much more we need to do to ensure that everyone affected by kidney disease can live their lives to the full. But we continue to be inspired and motivated every single day by the personal stories of people we have helped and the incredible efforts of our fundraisers.”

Professor Donal O’Donoghue OBE, BSc, MBChB, FRCP
Chair of Trustees
Making a difference
Why we’re needed

By working in partnership with patients and health professionals we continue to raise awareness of kidney disease and support more people affected, to help them live their lives to the full.

Life changing
“In the UK there are around three million people currently living with kidney disease. That number will rise as more are diagnosed with obesity, diabetes and high blood pressure – all major causes of chronic kidney disease.

Once someone has kidney disease they need a lifetime of support. It is vital that their mental health is looked after too, but sadly there is not enough tailored psychological or social support available. That’s why Kidney Care UK is so important. Having a trained counsellor on call or someone who can advocate for you in your time of need is life changing.”

Rebecca Suckling, Consultant Nephrologist

Specialised support
“Being a teenager is hard at the best of times. Add kidney disease to the mix and it can all get too much, impacting on education, emotional development, relationships and employment prospects. Young adults need specialised support and that’s exactly what we provide. I have seen first-hand the impact that Kidney Care UK has had on young adults, especially through our Young Adult Weekends. It’s not an overstatement to say that we help to change lives, showing these young adults that they are not alone, there are people out there like them and that we get what they are going through.”

Helen Ritson, Young Adult Worker

Help in the here and now
“The general public still know little about kidney disease. People are shocked when I tell them I can’t wee anymore, and friends struggle to understand that while I may look OK on the outside I am not ‘better’. This is why it is so important that patients work together with kidney charities and patient associations to increase understanding and make improvements for us all. Kidney Care UK is so important because they help in the here and now. When my fridge broke down I could not afford to replace it, yet I knew I had to eat properly to stay well. Kidney Care UK paid for my new fridge. It may not sound much, but that small generosity made a huge difference to me.”

Clement Maynard, Chairman, Heart of England Kidney Patient Association (KPA)

Overview: Why we’re needed

Around 20 people will develop kidney failure every day in the UK

1 in 3 patients with kidney disease will experience depression
Making a difference
Improving lives every day

A diagnosis of kidney disease can have a devastating impact on both patients and their loved ones, affecting health, emotional wellbeing, work, finances, relationships and lifestyle.

As the leading kidney patient support charity in the UK we work hard to improve the lives of kidney patients so that they can live their lives to the full. Over the past year we have:

- Provided personal advice and guidance to more patients, ensuring they have access to high quality information and representation than ever before
- Continued to offer free renal counselling support and reached more patients in areas where the provision is lacking
- Delivered a responsive and flexible grants programme to support individual patients in financial difficulty
- Helped struggling patients and their loved ones to have a much-needed holiday or respite break
- Responded to local needs by funding innovative projects and patient-centred service improvements as well as seed funding critical support roles
- Built strong partnerships and worked in collaboration with others to deliver sustainable improvements in care services
- Engaged with policy and decision makers at local, regional and national level to ensure patient views are represented and reflected in policies that affect them

Supporting more than 100 patients every week

Our website helped
148,645 people

We assisted
1,533 individual patients with support grants

We provided
2,766 patients with counselling advice and advocacy

An amazing
2,044 individuals supported us with acts of giving

We invested
£741,282 on care and service improvements, research and equipment
We spent £1,509,545 delivering support to patients and their families.

We helped 3,699 people through advocacy, counselling and financial grants.

“People often tell me that when they were first diagnosed with kidney disease they didn’t know where to turn. But that’s exactly when they needed support the most, and access to information they could trust. Kidney Care UK’s suite of support services provides the safety net you need from the start, all delivered with the care, passion and dedication you deserve.

Kidney Care UK’s suite of support services provides the safety net you need from the start, all delivered with the care, passion and dedication you deserve.

Our national Advocacy Service continues to play a vital role for people with kidney disease. As the availability of NHS welfare support officers and renal social workers has declined, more and more of you have been turning to Kidney Care UK’s Advocacy Officers, desperate for their vital support and guidance.

We passionately believe that mental wellbeing is just as important as physical health. We therefore take pride in the fact that our free telephone counselling service provides a lifeline for patients and their families in areas where NHS provision for psychological care is now either inadequate or non-existent.”

Paul Bristow, Acting Chief Executive

“Our emotional, financial and practical support services provide a safety net for patients and their families.”
Trained counsellors who really understand

Sometimes just letting someone speak is powerful enough to get them back on their feet.

Jackie Pilcher, Kidney Care UK Counsellor, knows that when people first call her they are usually in a truly dark place.

“I often say to people that it’s as if they are stuck down a dark, damp well and can’t see the light. I can’t lift them out by myself, but by talking things through I can throw them a rope. And when they grab that rope I will be there to help them at every step until they are out and on top again. Sometimes it is simply a matter of helping the caller to feel like they are back in control. It can take many weeks to untangle the complicated feelings that arise after a diagnosis of kidney disease. For others it takes a couple of calls to unlock the issues. I work with lots of people who feel angry about their situation, fed up with dialysis and the impact it has on their life, their relationships and their work. It can all feel overwhelming, so it’s my job to break it down into manageable chunks. And if they are struggling with practical problems I can help there too, by signposting them to other areas of support, such as a Kidney Care UK Advocacy Officer for benefits advice.

When you hear someone say that you’ve saved their life, or that you are the reason the lightbulb has gone off in their head, you begin to realise quite how powerful just letting someone speak is.”

Help is only ever a call away

Our counsellors give people a safe place to talk and a new perspective on their challenges.

Lynne called our helpline soon after her son was suddenly diagnosed with kidney disease.

“It all happened so quickly. We went to hospital because his blood pressure was unusually high, he ended up in intensive care for a week, and it was almost like we didn’t have time to think.

I thought I was coping OK but once he came out of hospital and normal life set in, then the reality became enormous. I am so grateful to Jackie. She really understood what I was going through and her weekly calls were like a safety net. Everything she said made sense. We are a year on now but I know that Jackie will always be there if I need to call again.

She gave me hope when it seemed there was none. The difference she has made to all our lives is huge.”

To thank the charity for the support she received, Lynne has organised a fundraising event with the whole family where they’ll raise awareness of kidney disease because as she says, “People just don’t realise the impact that it has”. Lynne has also signed up for a 10km run to help fundraise for Kidney Care UK.

“Your helped me re-wire my brain!”

Beckie, Counselling Client

We spent £51,590 providing our telephone counselling service

On average our telephone counsellors spend six weeks working with clients who need support.
Advocacy Officers providing peer-to-peer support

Our Advocacy Officers have first-hand experience of kidney disease so they are especially good at supporting others through Kidney Care UK’s sensitive, compassionate and confidential peer-to-peer support service.

“When kidney disease strikes most people are in the dark about what to do next. I like to think I turn up with a torch to shed some light for my fellow patients and direct them safely in the right direction.

For example, Christine recently called me to say that her husband had just had a kidney transplant and they needed help with transport costs as he was no longer working. I met them at the renal unit and organised a grant for their transport costs and a new cooker and advised them about PIP and ESA benefits.

They were very grateful to me for solving their problems and it made me personally very proud. But it also made me proud of Kidney Care UK. Because they are making sure that there are Advocacy Officers like me on the front line. People who really understand the challenges and are willing to listen and give assurances and practical support.”

William Johnston, Advocacy Officer

“Bobby is one of the many people that William was able to help over the last year. Life changed completely for Bobby after his diagnosis. He was forced to retire from work on medical grounds, so money was tight, and his dialysis schedule meant he was spending a lot of time away from his wife.

As he says, “I was lost. I felt like I needed a degree in brain surgery to decipher the benefit forms, but with William’s help we got them filled in and the finances sorted. He has also encouraged me to train for home dialysis. Once I can do that we will have some of our freedom back and be able to head out to our caravan and enjoy some time at the seaside with our dog. We can’t thank William enough for giving us back some relaxation time together.”

Bobby, Advocacy Client
Martin’s Story

How Kidney Care UK took part in a collaborative rescue effort to help Martin back on his feet.

In desperate need of help
When we first spoke to Martin he was living in a caravan with no electricity, cooker or toilet. He was having dialysis three times a week and suffered with a heart condition, so his health was a major concern. His living conditions meant it was difficult for him to prepare the kidney-friendly meals he needed, and he was unable to put his children up when they came to visit. His situation was made even harder by a delay in the benefits system.

A more promising future
Kidney Care UK stepped in to help and, in a collaborative rescue effort, gave Martin the stepping stones he needed to get back on his feet. He is now living in accommodation provided by his local council and equipped with household items donated by ourselves and a number of other charities. This ensures he has somewhere warm and comfortable to recover after each dialysis session and to welcome his children.

Martin says, “I was desperate and felt blocked at every turn. I've worked all my life but the moment I desperately needed help the system seemed to be against me. Thanks to Kidney Care UK’s guidance, practical assistance and signposting, the future is definitely looking more promising.”

“Thanks to Kidney Care UK the future is definitely looking more promising.”

70%
of all advocacy enquiries relate to welfare and benefits
Keeping patients well informed

It is so important to have access to high quality information. We make it easy for patients and their families to access the information they need and trust so they can make informed decisions about their care and treatment.

Working together for better patient information
In 2017 we joined forces with the Renal Association to identify, develop and promote access to the best patient information available, and our partnership has gone from strength to strength. We now use a mixture of channels to ensure information is available however and wherever you want to find it; in printed leaflets, online, at your local renal unit or pushed through your letterbox. And we cover even more subjects than before, from medical matters (such as treatment and drug options) to Dialysis Away from Base (DAFB) to emotional wellbeing.

We added over 150 pages of new content to our website on subjects including accessing benefits, travel insurance and mental health. And the number of site visits has nearly doubled as a result!

Growing online support
We continued to provide funding and support for the InfoKID information portal (for the parents of children with kidney disease) in partnership with the Royal College of Paediatrics and Child Health and the British Association of Paediatric Nephrology. The updated site received 186,553 visits over the year – up 37% on the year before.

Giving kidney patients a voice
We also launched Kidney Matters, a quarterly magazine designed to inform, educate and reassure patients and their families, using real life stories to encourage and inspire others.

Our Facebook support group now has over 8,000 members

“When I get my Kidney Matters magazine it always gives me a real boost.”
Janet, Kidney Matters reader

More than 20,000 patients receive Kidney Matters every quarter

Over 100 kidney units ordered
42,272 patient information leaflets
We know the importance of taking a break
Life can be an endless round of hospital visits and
other demands when you are living with or caring for
someone with kidney disease. So it is important to
have time away from the daily challenges for the sake
of your emotional and psychological wellbeing.
You don’t want the holiday itself to be another
challenge, though. And that’s where Kidney Care UK
can help. If money is tight we can step in with a holiday
grant to give families some much needed downtime.

Working in partnership with Dialysis Freedom
we deliver a UK Dialysis Swap Scheme that helps
dialysis patients to continue with their treatment
while they are away from home. Last year we received
nearly 800 enquiries and confirmed more than
400 bookings, which involved liaising with health
teams around the country to secure dialysis slots.

New experiences for young adults
Over the last year we also organised and funded
activity breaks that enable younger patients to get
away from the rigours of kidney disease and spend
some time with others who truly understand. One of
the highlights was the annual Young Adult Weekend,
which we run in conjunction with young adult and
youth workers from across the UK. This year we sent
75 young adults with kidney disease on the trip. They
were able to mix with other young people of their own
age (all with their own medical challenges) to share
their common experiences, realise they are not alone
and grow in self-esteem and confidence.

Our holiday and respite grants
make all the difference to
people like Jamie and Thomas

Jamie is a loving grandfather who needs regular
dialysis to treat his kidney failure. He had not had a
holiday for 12 years so, in 2018 we gave him a grant
that allowed him to go on a caravan holiday in Devon
with his family and young granddaughter, ‘the apple of
his eye’, while continuing his dialysis at a nearby unit.

A delighted Jamie told us, “You have no idea what
you’ve done for me and my family – to go on our first
family holiday together was amazing. We were over
the moon.”

Thomas was diagnosed with kidney disease when he
was just two. He is now a teenager and his mother
Lucy, was worried that he was struggling with
depression. Kidney Care UK gave the family the money
to send Thomas on the kind of holiday that his friends
were able to enjoy – and he promptly took himself off
to Amsterdam to see his favourite band in concert!

Lucy told us “This couldn’t have come at a better
time. The grant gave Thomas a new lease of life.
You truly have helped us so much.”

Kidney Care UK established the first holiday
dialysis units in the UK and pioneered foreign
holidays for kidney patients.

We spent
£440,398
on respite breaks and holiday grants for
patients and their families

<table>
<thead>
<tr>
<th>Holiday grants</th>
<th>UK Dialysis Swap Scheme</th>
<th>Young adult trips</th>
<th>Paediatric holidays</th>
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<tbody>
<tr>
<td>369</td>
<td>446</td>
<td>75</td>
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</tbody>
</table>

Helping patients take
a break from it all

That's 144
more than
last year!

We helped
927
kidney patients
to have a break

Supporting: Holiday and respite breaks

Supporting: Holiday and respite breaks
Financial assistance that makes all the difference

From home appliances to retraining, our grants provide financial relief and future opportunities

Kidney disease can affect someone’s ability to find or retain a job and so the family income suffers. Our grants are here to plug the gaps, paying for essential items such as beds, washing machines, fridges and freezers – whatever it takes to enable normal life to continue.

Donna is a member of our patient grants team. As she explains, “We answer the phone within a few seconds and sometimes the person calling doesn’t even know what they want, but they do need someone to listen. My aim is to help every caller, either with a grant or by referring them to our website or to my advocacy and counselling colleagues. I have never once had to tell someone ‘No, sorry, I can’t help’.

It means so much to me that I can play a small role in improving people’s lives by helping them out of a crisis.”

Supporting opportunities for a brighter future

When Mark T was diagnosed with renal failure he realised that his 20 year career as a property developer was over because the work was too physically challenging. We provided Mark with a grant to attend college and retrain as a counsellor, studying from home when dialysis left him worn out. Mark says, “I’d advise anyone who is newly diagnosed to pick up the phone and call Kidney Care UK immediately! Being able to study and retrain has changed my life and given me a new focus, a renewed enthusiasm and a brighter future.”

Help with everyday essentials

Sometimes the smallest things can make the biggest difference

Mark N has had to deal with such a lot over the years, including dialysis and chemotherapy. And while he felt tired all of the time, his broken bed was so uncomfortable that he found it impossible to sleep on.

We gave Mark a grant to pay for a new bed and mattress and it quickly turned things around. As he explains, “I used to have such an active life but once I became ill my world got so much smaller. I’d lie awake at night and wonder why it had all happened to me, and the lack of sleep made me really depressed. Now I sleep so much better. It’s these little things that keep you going, keep you striving for the future.”

Expanding our team

In 2019, we handled 7,487 calls for support, a 23% increase on the previous year’s 6,000 calls.

<table>
<thead>
<tr>
<th>Type of grant</th>
<th>Number of individual grants</th>
<th>Total spent (£)</th>
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<tbody>
<tr>
<td>Education and training</td>
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<tr>
<td>Rent &amp; housing costs</td>
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<tr>
<td>Domestic, heating &amp; utility bills</td>
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<tr>
<td>Household goods, furniture and sheds</td>
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<tr>
<td>Travel &amp; motor costs</td>
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<tr>
<td>Holidays &amp; respite breaks</td>
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<td>£369,270</td>
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<tr>
<td>Funeral costs</td>
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<td>Clothing and hardship</td>
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<tr>
<td>Assistance grants</td>
<td>56</td>
<td>£21,185</td>
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<tr>
<td>Total</td>
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<td>£929,305</td>
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We handled 1,400 more calls for support than the previous year a 23% increase

“Thank you for being there when we needed you most.”

“Sometimes the smallest things can make the biggest difference.”

Emma donated a kidney to her husband Stuart in May 2018. A few weeks after their operations, when both were still off work, their oven stopped working and they were left with just a hob. This made it even harder for them to cook the healthy meals they needed to keep their energy up while they recovered from the transplant.

They eventually turned to Kidney Care UK. As Emma recalls, “It was all so simple and within days we had a new cooker installed. The grant has meant so much to us. Without Kidney Care UK I don’t know what we would have done as we just couldn’t afford to replace it. Thank you for being there when we needed you most.”

Here when you need us

Emma donated a kidney to her husband Stuart in May 2018. A few weeks after their operations, when both were still off work, their oven stopped working

We handled 7,487 calls for support
Jake’s Story

We supported Jake as a young adult and now he is supporting us with his fundraising!

A helping hand
“I was born with an inherited disease that causes kidney failure and kidney stones. I have had to give up my career as a cleaner as I’m in so much pain all of the time. But Kidney Care UK has been so generous to me all my life.

They helped me with grants to re-train as a carpenter. They also helped me get my advanced motorbike licence so I can volunteer for Devon Freewheelers and ride a blood donation bike.”

In 2018, Jake attended our annual Young Adult Weekend. The weekend gives young people with a renal condition the chance to meet others in a similar situation and take part in outdoor activities.

Giving something back
Jake made many new friends on the trip and hatched a plan with three of them to raise some much-needed funds for Kidney Care UK.

“We did a sponsored walk from Exmouth to Exeter and raised over £1,000. It was raining on the day and we were soaked through but happy that we had managed to finish our challenge.”

“Kidney Care UK has given me financial help and introduced me to new friends and now I’ve given something back to them.”
Improving quality in health and care services

“‘Our hospital grants enable thousands of patients to live their lives to the full.’

We provided direct support to nearly 50% of the UK’s main renal units to improve patient services.

We spent £194,131 on patient-centred research that makes a practical difference to patients today.

“We may not be the biggest charity but we have a huge heart, we care so much and really understand the people we help. We recognise the issues patients face and work with organisations across the UK to coordinate our approach and achieve more together.

My role involves making sure that Kidney Care UK works as closely as possible with NHS hospitals, patient groups and in partnership with other charities to improve the quality of health care services for people with kidney disease. This also helps us to maximise the number of people we can reach and the support that we are able to deliver ourselves.

Knowing what is going on around the country also helps us to identify where services are stretched or limited. If we spot gaps we do our best to fill them, providing the initial funding needed to get a local support service up and running.

It makes me especially proud when I see roles and services that we have seed funded taken on by the local NHS Trust. It means that our investment has turned into an ongoing legacy.”

Suzan Yianni, Hospital Grants Manager
Innovating at a local and national level

Kidney Care UK plays a very active role in the broader ‘kidney community’, funding innovative projects and service improvement programmes that can’t be met by NHS funds and by working collaboratively to lead change that benefits patients at a local and a national level.

Funding vital local roles
Our hospital grants programme enables us to support innovative local ideas and respond to urgent patient care needs, often working in partnership with local Kidney Patient Associations. For example, in 2018 we identified the need for a young adult worker in Southampton and worked with the Wessex Kidney Patient Association to co-fund the role for three years. This will give the local health team time to evaluate the role and prepare a business case for the Trust to make the role permanent.

Reaching those most in need
We worked with Public Health England (PHE) and NHS England to promote their winter ‘Help Us Help You’ campaign, sharing tailored advice for kidney patients on social media and sending posters and leaflets to every renal unit in England. Masuma Tasnim from PHE thanked us for our support, saying “It’s really important to work with partners like Kidney Care UK to help us reach those most in need.”

Gathering crucial evidence to improve psychosocial services
We want all kidney patients to have access to the best emotional support available. In 2018 we published a report that mapped out the support available across all 84 of the main renal centres in the UK. This report shows that psychosocial support services for kidney patients are variable, inadequate overall and have declined over the last 15 years. The evidence we have provided will help the renal community to improve their future workforce planning.

43 Hospitals received funding from Kidney Care UK for care and service improvements

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<thead>
<tr>
<th>Type</th>
<th>Number</th>
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<tr>
<td>Specialised care</td>
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<tr>
<td>Social workers</td>
<td>1</td>
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<td>Young adult workers</td>
<td>3</td>
</tr>
<tr>
<td>Psychologists</td>
<td>3</td>
</tr>
<tr>
<td>Counsellors</td>
<td>1</td>
</tr>
<tr>
<td>Coordinators</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>16</td>
</tr>
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</table>
Developing bespoke tools
We worked with Great Ormond Street Hospital to develop an interactive diet app to help children and their parents better manage their child’s renal diet.

Putting patient views first
Three years ago Kidney Care UK, together with the Renal Association, researchers and patients, designed the Kidney Patient Reported Experience Measures (PREM) questionnaire. The purpose of the PREM was to ensure patient views are at the heart of driving improvements in kidney care. To our delight, in 2018 the Kidney PREM was adopted by ‘NHS Getting It Right First Time’. This means that our Kidney PREM will be used as an official tool to tackle variations in the way services are delivered across the NHS and ensure best practice is shared.

Championing the issues that matter
We are a founding member of the Kidney Quality Improvement Partnership (KQuIP), a programme that drives quality improvements within renal care services. This programme champions the three national priorities identified by the kidney community. These are: improving vascular access, offering transplant first (so that suitable patients receive a transplant before starting dialysis) and increasing home therapy rates. In 2018 we helped NHS regions in England to hold their own Kidney Quality Improvement Days, encouraging each to adopt one of the three priorities and make a plan to deliver it in their region.

Giving young adults life experiences
Over the last year we continued to fund organised activity breaks that help children and young kidney patients to enjoy some down time with people their own age who are going through similar experiences. In 2018 we increased our investment in this vital area to £37,366 and supported five organised trips.

Fahad, a patient at Nottingham Children’s Hospital, is one of the many children who was able to enjoy a short break in 2018. His mother, Sarine told us “When Fahad got back he was full of stories to tell. He had made new friends and had a great time. I’d like to thank everyone who donates or raises money for the charity. Their support makes a lot of difference to children’s lives because they spend so much time in hospital. Trips like this bring a lot of happiness into their lives again.”

We heard
13,770 patient voices from around the UK through the Kidney PREM

We invested
£73,456 on equipment to improve care services for patients

We have committed
£494,791 to patient-centred research over the next 3 years
Max and Keira’s Law comes into effect in Spring 2020

Did you know

8 out of 10 patients on the UK transplant waiting list are in need of a kidney?

“Kidney Care UK is one of the leading charities working to represent patients and shape national policies around kidney care. We do this by researching the issues and collaborating with other concerned parties to deliver our compelling arguments with a stronger voice.

Over the last year we helped to change the law on organ donation in England. We supported the ‘opt out’ system, under which everyone is presumed to consent to organ donation unless they have actively said otherwise. We went to great lengths to explain to MPs and Lords the difference that having a transplant would make to thousands of people. And to our delight they supported the decision that we had been championing for years.

We are confident that the Organ Donation (Deemed Consent) Act 2019 (colloquially known as Max and Keira’s Law) will make a great difference to the lives of people with kidney disease. Hearing that our hard work had paid off was a truly momentous moment for everyone here at Kidney Care UK and for me personally. Because this is not just my job or my passion, it’s my life too. As a patient, I know the amazing difference a transplant can make.”

Fiona Loud, Policy Director

“We helped to change the law on organ donation.”
It takes years to change a law

The wait for a kidney transplant is years, too.
People with kidney failure spend (on average) 2½ to 3 years on the UK transplant waiting list before a suitable donor kidney becomes available. Until recently the law on organ donation was based on an ‘opt in’ system, so people had to sign up to be organ donors. Yet research showed that while 80% of people in England claimed to support organ donation, only 38% had recorded and shared their decision with family members.

Kidney Care UK has campaigned for many years for an ‘opt out’ system based on presumed consent. When the law came under review in 2017 we worked tirelessly to raise awareness of what this would mean for people waiting for a kidney. We provided briefings to MPs and Lords, raised questions in Parliament and secured significant press coverage. We also held a joint parliamentary event with the NHS Blood and Transplant service, which was hosted by the Health Minister Jackie Doyle-Price, took part in two live debates on Sky News and explained our position on BBC Breakfast – twice!

A positive change for the future

We were delighted that the Organ Donation (Deemed Consent) Act passed through Parliament and will become law in England in 2020. But it is not the end of the story. We will now continue to campaign to ensure that sufficient resources are made available for public education and awareness and that the NHS has the capacity to meet the expected increase in transplantations.

Campaigning to support kidney patients after Brexit

Concerns over ‘no deal’

Removing reciprocal healthcare will reduce the opportunities for people with kidney disease to travel abroad

Over the last year, Kidney Care UK has been campaigning hard to ensure the needs of kidney patients are considered in any Brexit negotiations. If we lose the European Health Insurance Card (EHIC) – and the reciprocal care that goes with it – kidney patients would have to pay privately for their dialysis in the EU. This would put a holiday in the EU out of reach of most patients, and losing that freedom to travel to neighbouring countries would have a negative impact on their quality of life.

We have worked closely with many of our patient supporters to ensure that MPs are aware of the importance of kidney patients having easy access to dialysis while abroad. We have also highlighted the importance of maintaining an uninterrupted supply of drugs and medical equipment for patients across the country.

Travelling after Brexit

We have presented our concerns at the British and EU parliaments to politicians, committees and people at the Department of Health and Social Care. We have also been talking directly to pharmaceutical companies and the Association of British Insurers.

At the time of going to print the negotiations continue and we are still campaigning on this at the highest level.

“I am very grateful for the exceptional support the team at Kidney Care UK have dedicated to the Bill. Your contribution has been hugely significant and I really appreciate everything you have done.”

Dan Jarvis, MP

“There’s no question that Kidney Care UK played an essential role (in helping the Organ Donation Bill become law).”

The Rt. Hon Lord Hunt of Kings Heath

10 people are added to the UK transplant waiting list every day
Driving change in patient transport

Kidney Care UK campaigns at every level, helping to solve local problems and deliver national changes for the benefit of everyone with kidney disease.

Responding to local concerns
In January 2018 we were contacted by a dialysis patient who was having problems with the transport to and from his local dialysis unit that had been arranged by the NHS Clinical Commissioning Group (CCG) for his region. We learned that the CCG had recently awarded their patient transport contract to a company with no previous experience of transporting renal patients. Within one week of the new company taking over the service was in chaos.

The Kidney Care UK team spent weeks working closely with patients, gathering evidence and attending meetings with the CCG. After six months of campaigning the renal transport contract was taken back and put in the safe hands of the local NHS Ambulance Service.

Bringing interested parties together
We were also hearing from others around the country who were concerned about proposed changes (and in some cases cuts) to their local renal transport services. Therefore in 2018, we set up the Dialysis Transport Working Group to investigate the matter, with a coalition of kidney patient organisations, the Renal Association, the British Renal Society and the National Kidney Federation.

The Working Group looked into renal transport services around the country and discovered many variations in the way the service was being organised. For example, only half of the renal units that responded to our questions were using eligibility criteria for patient transport; only 60% of the respondents were monitoring their service using key performance indicators, and in some areas patients were being charged for transport while in other areas it was free.

Drawing up guidelines
We also discovered that there are no specific national guidelines on transport services for renal patients. So in 2018 we decided to write some, putting everything we had learned from our research into a report that was published in June 2019: ‘Dialysis Transport – Finding a way together’. We look forward to seeing the suggestions we have made being implemented around the country.

Kidney patient transport services cost the NHS an estimated £250m a year.
The Rossiter’s Story

How we helped a family coping with kidney disease and they in turn became extended members of the Kidney Care UK family!

With you every step of the way
Martin and Michelle have had more contact with us than most. Their daughter Katie was diagnosed with kidney disease at eight years of age and years later, just three weeks after sitting her last A-level exam, she underwent a transplant operation with one of Michelle’s donated kidneys. Kidney Care UK has been there to support the family with information, advice and guidance every step of the way.

Representing patients and giving back
As a way of thanking Kidney Care UK for all the support they received over the years, Michelle joined our Patient Advisory Group. The group is an opportunity for both patients and their families to provide feedback and help shape the work of the charity. As a passionate speaker Michelle took on the additional role of lay representative on behalf of Kidney Care UK, acting as a patient ambassador on the executive board of the British Association of Paediatric Nephrology; speaking in both Paris and Manchester to raise awareness of kidney disease amongst healthcare professionals and researchers.

Becoming a Kidney Warrior
Meanwhile Martin has undertaken many challenge events to raise awareness and has also raised thousands for Kidney Care UK. He even ran the 2018 London Marathon dressed as a ‘Kidney Warrior’ in a Viking costume. As he says, “Running while carrying a sword and shield took some practice, but the cheers from the crowd kept me going for the whole distance. Running for Kidney Care UK, a cause so dear to us as a family, was just one small way that I could give something back.”

Determined to live life to the full
As for Katie, kidney disease certainly hasn’t slowed her down – if anything it seems to be driving her on! Only nine months after her transplant surgery, with the consent of her renal team, she went interrailing around Europe with two friends, fulfilling a long held dream. Katie says, “Kidney Care UK have been on hand to support my family over the years whenever we have needed them.” Having just recently completed her first year at University, Katie’s message to anyone with kidney disease is: “Don’t give up on your dreams, if anything it is a reason to dream bigger.”

“Don’t give up on your dreams, if anything it is a reason to dream bigger.”
Thanks to the 2,044 Kidney Care UK supporters who raised almost £1.5m over the year.

“Every single donation makes a real and lasting difference.”

“Our heartfelt thanks goes to every one of you for the support you have given and continue to give. Every challenge you take on, every legacy you leave and every single donation, makes a real and lasting difference.

In 2018 we introduced a number of new ways for you to get involved, and that is exactly what you did. In April, our first team of Kidney Warriors took on the London Marathon and raised £22,402. In May, we started using Facebook Donate and an amazing £18,120 was donated this way to celebrate birthdays and kidneyversaries. In November, the ‘I Can’ appeal raised an incredible £22,163, which will enable more than 80 young adults to take part in an activity break in 2019.

We continued to grow and develop our support services and help more patients than ever before. This is only possible because of the incredible generosity of our amazing supporters, many of whom choose to support us time and again.”

Rob Hope, Head of Fundraising
Danielle’s story

How motherhood made Danielle even more determined to thank the charity that helped her so much as a child

Danielle was born with kidney disease and received a kidney transplant when she was seven years old. Kidney Care UK supported her with several financial grants during her teenage years. We also encouraged her to take part in the UK Transplant Games, little realising what impact this would have on Danielle’s later life.

“Being at the Transplant Games helped me to see that I could do anything I wanted,” Danielle explains. “Having been poorly for most of my childhood it was incredible to have a sense of normality again. Then Kidney Care UK gave me an award for Courage and Endurance, and I decided that I was going to do something to help them.”

That ‘something’ turned out to be running six half marathons and five 10km runs – raising £1,500 to support kidney patients along the way. “My health is the best it can be and I’ve managed to raise loads of money for Kidney Care UK in the process!”

Going the extra mile

Now 30 years old, Danielle is married to Steffan, mother of two-year-old Gethin and still running to raise money for Kidney Care UK. As she says, “Becoming a mother made me even more determined to thank the charity that helped me so much when I was a child. I find running really tough but it means I’m active, my health is the best it can be and I’ve managed to raise loads of money for Kidney Care UK in the process.”

Helping us to always be there for kidney patients

Bob’s story

How our one-off grant turned into a regular gift

Dialysis wore Bob out so much when he was first diagnosed that he felt “like somebody had pulled the plug!” As a result he used to fall asleep on the sofa when he came home and his wife would leave him there to rest and recover. Over time the sofa became worn and misshapen, making it harder for Bob to get comfortable and have the rest he needed. So we stepped in and gave the family a grant to replace this much needed household item.

Bob was so grateful, saying “Thanks to Kidney Care UK for a grant for a new sofa. I still fall asleep on it after dialysis, but now it doesn’t sag so badly! It was such a godsend to us at the time. Now that things are going better for us we wanted to say thank you by giving something back to the charity. I have set up a regular gift through the bank, so we donate £5 a month by direct debit. Kidney Care UK helped me in my time of need, and I know that by making this contribution I am helping to support others.”

“We wanted to say thank you by giving something back.”

Kidney Care UK helped
19 teams
to attend the 2018 Transplant Games in Birmingham

Danielle’s story: I could do anything!

Bob’s story: Helping to support others
Thanks to every one of you for supporting us

129 Kidney Warriors took part in a challenge event

23 Supporters arranged a fundraising collection

209 people donated goods or stamps

163 individuals gave us a regular monthly donation

27 people left us a lasting gift in their wills, totalling £1.15m

We received 157 donations in memory of a loved one

1,007 of you purchased Kidney Care UK Christmas cards

129 Facebook Donate pages were created... receiving 1,079 donations from friends and family

23 companies (and their lovely employees!) chose us as one of their charity partners

31 people organised a World Cup sweepstake

282 people helped young adults say "I can!" in response to our first fundraising appeal

1,079 donations from friends and family

Kidney Care UK would like to say thank you to everyone that supported the charity and got involved with fundraising in 2018.

42
“You donated the money to enable me to buy a laptop, a piece of equipment that was much more than just a means of research. It allowed me to prove to myself and everyone else that having a serious health condition, and even being on dialysis, need not be an obstacle. With the right combination of ambition and support you can still achieve anything you set out to do. Once again, I cannot thank you all enough - your donations really do make a huge difference to people’s lives.”

Miles, graduated from Lancaster University with a First Class Master’s Degree in December 2018