



Supporting kidney patients
through adversity

Impact Report 2021

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Why we are needed:

Currently

3.5million
people



in the UK are diagnosed with chronic kidney disease (CKD)



68,000
have kidney failure

30,000
receiving dialysis treatment



By 2036, it is expected that **4.2m people** will be living with CKD

Kidney Care UK's patient support services are needed more than ever at a time when they are more important than ever

Supporting kidney patients through adversity: now and in the future

In 2021, we reached and supported a record number of kidney patients and those affected by kidney disease. The ongoing challenges of Covid-19 meant it was more important than ever for us to stand with, and give stronger support and voice to, our extraordinarily resilient kidney community. While the pandemic continued to dominate the year and impacted every aspect of the charity's work, we were determined to advance our patient support services and this was only possible due to your relentless support.



Having learned how to adapt to remote working, we listened and shaped our services and support to better reflect the immediate and longer-term challenges faced by everyone in our community. At a time when 6% of outpatient dialysis patients died as a result of Covid-19, we redoubled our advice, information, and practical support to ensure we were always at hand.

“Staying relevant in perpetuity requires stable financial reserves, which in turn requires generous donors. Everything we achieve is made possible by your support.”

Because Kidney Care UK is fortunate to have a stable financial position, certainly by the prevailing standards in the UK, there is some understandable ambiguity about whether the charity really needs to raise more money. With an endowment of over £100 million, Macmillan doesn't suffer from any such nervousness, which is particularly sobering when you consider that more people live with CKD in the UK than the 3 million people living with cancer.

It is then not so much a question of whether Kidney Care UK needs to raise more money, but a case of whether we can afford not to. Reading the many letters and emails we receive from kidney patients and their friends and family as well as healthcare professionals we supported

in 2021, it is clear why our financial stability is so important and why your fundraising generosity has such a clear impact. The investment income our reserves generate allows the charity to cover its operational costs, so that our fundraising income goes directly to advance our patient support services. It is this very position that means we can continue to invest in our free renal counselling service that supports hundreds of patients every year, give over £549,000 in grants to kidney patients in immediate need of our support, and provide community advocacy support to thousands of people with kidney disease throughout the UK.

I hope this Impact Report explains and clarifies our financial position. I want to thank those of you who supported us throughout 2021 and celebrate the incredible impact you have made. I also want to encourage more people to join in sustaining and advancing our support of the kidney community now and long into the future.



Handwritten signature of Paul Bristow in black ink.

Paul Bristow,
Chief Executive



2,890

people supported by
our counsellors and
advocacy officers



1,191

patients and their
families received
financial support



£1.3million

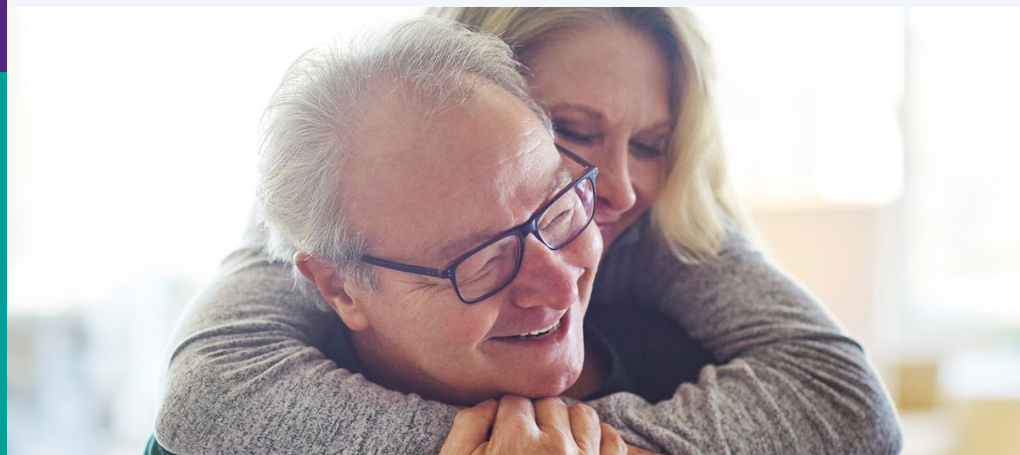
raised via 11,315
donations from
3,472 donors



2021

£3.2million

invested to improve
the quality of life for
everyone affected
by kidney disease



3,472

fundraisers and
donors making it
all possible

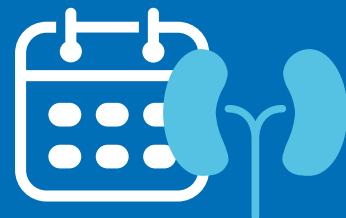
More than

£650,000

invested in our grant-funded hospital initiatives, which in turn supported

12,000

people with kidney disease



More than

500

people with kidney disease and their families helped every month

The amazing impact we made thanks to your support

Through our welfare and benefits advice service, we have realised more than **£2m** in financial benefits for more than **450 patients**



£549,000

given through our individual patient grants

We work every day to support kidney patients wherever they are in the UK

A diagnosis of chronic kidney disease can be devastating, taking a considerable toll on patients and their loved ones, affecting their physical health, emotional wellbeing, financial situation, relationships as well as employment and lifestyle. As the UK's leading kidney patient support charity, we work every day to improve the quality of life for patients, whatever their age, wherever they are in the UK and at whatever stage of the disease they might be.

Northern Ireland

Following many years of work by our Northern Ireland Ambassador and former MLA Jo-Anne Dobson, the final stage of the organ donation opt-out bill in Northern Ireland was passed in 2021, meaning that all four nations now have an opt-out organ donation system.

“Organ Donation is an issue which has and will always remain close to my heart and I am delighted that the law has changed in Northern Ireland” Jo-Anne Dobson.

75

people supported by William, our Advocacy Officer in Northern Ireland

£16,000+

provided in financial support to patients and their families in Northern Ireland

240

people supported by Linzi, our Advocacy Officer in Wales

£35,000+

provided in financial support to patients and their families in Wales

Wales

“Kidney Care UK have been genuinely instrumental in supporting the patients I work with as a renal youth worker over the last six years. They have without doubt positively changed the lives of so many patients here in Wales and across the UK.”

Shaun Thomas, Senior Renal Youth Worker, Cardiff and Vale UHB & Swansea Bay UHB.

Scotland

We delivered four webinars in partnership with Living Donation Scotland. Subjects included 'updates on vaccines and treatments', 'living donation', and 'support on emotional wellbeing and dealing with anxiety'. All were well-received, becoming a valued way for people living with kidney disease in Scotland to hear and discuss the many queries people with kidney disease continue to have.

150

people supported by our
Advocacy Officers in Scotland

£35,000+

provided in financial
support to patients
and their families in
Scotland

2,200+

people supported
through our Advocacy
Officers in England

£460,000+

provided in financial
support to patients and
their families in England

England

In 2021, after our three year-long campaign, the NHS in England made a commitment to free transport for all journeys to and from dialysis. Kidney Care UK sat on the Expert Advisory Group and worked extensively with NHS England to ensure they were aware of the need for improvements to quality and access to dialysis in hospitals and kidney units via non-emergency patient transport or improved processes to support personal transport. This has the potential to help 21,000 people in England and the charity continues to work with NHS England to ensure this commitment is established across the NHS and rolled out in 2022 and beyond.

Helping kidney patients to manage everyday life with chronic kidney disease

Advocacy is about taking action on behalf of people living with chronic kidney disease. Every week, we receive hundreds of enquires about benefits, housing, transport, dialysis choices, employment and simply managing everyday life with chronic kidney disease. Our national advocacy service helps people living with chronic kidney disease to gain access to the right people, services and support, and to ensure every patient is properly represented. The team supported a record 2,645 people during 2021; people like Amanda, Martyn and their son Michael.

“For the last twelve years we have been literally watching our poor son circle the drain.” Michael Stephens’ loving mum Amanda describes the health challenges they have faced as a family and the positive impacts of involving Kidney Care UK in her son’s care. Michael, who is 30, has undergone heart surgery and endured a series of health complications which make everyday ordinary activities either impossible or extremely complicated.

His health conditions include pulmonary oedema and constant pain due to calcification of his joints, and the breakdown of skin areas on his legs means he needs additional support from his family. He is a long-term kidney dialysis patient who, due to his medical complications, is currently unable to go onto the kidney transplant list. Until recently Michael was undertaking haemodialysis three times a week at Nottingham Renal Unit which is over 100 miles away from his family in Norfolk.



Amanda explains the challenges the family faced: “My husband Martyn and I have been banging our heads off a brick wall for three years to get a dialysis place for Michael close to us in Norfolk.

“During that time we’ve been travelling backwards and forwards, over three hours each way, to get our son to dialysis in Nottingham - a frankly dangerous journey for Michael because of his medication and frailty. That was the only choice we had and while dialysis is draining anyway this totally shattered Michael - he was just worn out with it.

“It really is sad that at the age of just 30 he needs all this help and support but this is the situation he, and we, face on a daily basis. He’s taken a few falls and is so frail that we’ve recently purchased him a wheelchair, so that we can take him out more.

Rachael, a renal youth worker, suggested that Amanda give Sandy Lines a call - describing her as ‘a person who gets things done!’

Amanda continues: “Rachael wasn’t wrong and Sandy, who is our local Kidney Care UK Advocacy Officer, has achieved successes and solutions, not only for Michael but for our whole family, where we were being passed from pillar to post.



Sandy Lines MBE - aka ‘Super Sandy’

“Through her interventions, Sandy initially secured a dialysis place firstly in Norwich, which we had been trying to get for three years, and then she goes one better and does the impossible by getting him a place in Cromer which is the closest renal unit to us and is just seven miles down the road. This really was beyond our expectations but Sandy worked at both ends getting his notes transferred and doing all the things that should happen but despite our efforts simply weren’t.

“She’s now working away on Michael’s accommodation needs so that he can move closer to us and can get all the help and support he so desperately needs.

“She just gets it - she understands exactly what we are going through as a family and the challenges we face with Michael’s healthcare - she’s our Guardian Angel!”

Amanda

Amanda, an ex-healthcare professional who is now a Special Educational Needs teacher in a small private school, continues: “The last three years have been a nightmare for Michael both physically and mentally. When I look at him today and look at pictures of him just three years ago, he’s a totally different lad.

“His health problems have affected him so much that he’s lost 7 inches in height due to hyperparathyroidism which caused hypercalcemia and osteoporosis, meaning that calcium has leached out of his bones causing shrinking and curvature of his spine – he has changed so much. Some of his nurses who put him onto his dialysis machine ten years ago didn’t even recognise him recently.

“It’s really tough as a family for us to experience this and having support from Kidney Care UK has really transformed things for us. Sandy has lifted a weight from our shoulders and we will forever be indebted to the kind, caring, compassionate and professional way in which the charity have helped us and helped Michael when he needed it the most.”

In 2021, the Advocacy team supported 2,645 patients, helping them with a huge range of challenges.

Ensuring people living with kidney disease are getting the full care and support they need



Our free, specialist renal counselling service provides a lifeline to those kidney patients who have nowhere else to turn. In 2021, our renal counselling service continued to deliver specialist support to 245 patients and their families. Growing numbers of patients contacted the charity, needing psychological and emotional support where there was either nothing timely or suitable available through their local NHS services.

During 2021, many clients our renal counselling team were supporting felt like the rest of the world was moving on while they were being left behind. It was very hard for them to handle the anxiety and anger they felt as guidance changed; one day they were classed as being vulnerable and the next day they were not. Here Sarah, one of our counsellors, talks about the work of the team:

“We found ourselves supporting people who felt like they were not in control of the world around them. This left people feeling anxious, isolated and depressed and we spent a lot of time helping people to understand that their feelings were valid responses to the situation, but highlighting that there were still things that they could control. We worked with people to help them to build the confidence to open up their world again, in a way that felt safe and manageable. Whether that was gradually moving from shielding to having a coffee outdoors at a café wearing a mask, or spending time with family outdoors at a safe distance. We encouraged people not to feel ashamed that they were wearing a mask when others had stopped, but to applaud themselves for moving forward with their lives.

“Everyone handled the pandemic in different ways, so we would often encourage people to think about what

helps them to manage their anxiety; for some watching the daily news conferences was reassuring as they had access to the data and information, for others it was a terrifying and constant reminder of the virus. Our work focussed on helping people to recognise what made them feel happier and less anxious and cutting out things that had a negative impact, allowing them recognise the benefits that opening up our worlds again would have to our mental health.

“I found myself regularly reminding the patients I spoke to that **they are survivors; they are warriors** to go through kidney failure, dialysis and transplants. What they accomplish on an ‘average day’ would be a mountain for so many people. They take on battles every day and they can take this on too.”

Sarah

“We don’t just offer support to kidney patients, but also to their families and partners. In many cases, partners felt extremely anxious and wanted to keep their loved one safe. This often meant closing down completely and shutting out the world, so they were in their own bubble together. We had to break down those walls and help people to understand what was driving that response. For many it was the fear of losing their husband or wife that was motivating that behaviour, but their way of responding to ‘keeping them alive’ translated into ‘not letting them live their life’ due to fear. Being there and being able to reassure people that they are not alone, and that there are things they can control in safe ways, was the cornerstone of our work and still remains in many cases.”

245 people supported through our counselling service in 2021

Psychosocial care

Psychosocial care saves lives, yet too many people living with chronic kidney disease (CKD) are not getting the support they need. A CKD diagnosis can have a significant impact on all aspects of a person’s life, particularly their emotional wellbeing and mental health.

There is still a big difference between physical and mental health services for kidney patients, and we believe that mental wellbeing is just as important as physical wellbeing. Which is why, with experts from the National Psychosocial Working Group, we have developed a Psychosocial Manifesto. It is crucial that the UK Government and devolved Governments work together to achieve an integrated, whole-system approach to the care available to everyone living with kidney disease. We demand equal access to the highest quality, timely and renal specialist psychosocial care. Too many people living with kidney disease are not getting the support they need. Please join us and help us make the change together.

Thousands of patients responded to our psychosocial surveys in 2021



40% said they are concerned about emotional wellbeing

33%



respondents reported feeling lonely or isolated



68% would like peer or professional mental health support to manage their worries

To find out more about our Psychosocial Manifesto scan the QR code or go to www.kidneycareuk.org/manifesto



Providing invaluable support in unprecedented times

The Covid-19 pandemic continued to dominate 2021. It remained our priority to ensure that we were able to be there for every single individual and family that needed our support. We continued to strengthen and adapt the organisation to ensure we could respond quickly and meet the increased demand for support. We expanded our reach and engagement with patient communities to make them aware of the help available and reduce the feelings of isolation. We redoubled our efforts to represent patients' views and campaigned to ensure their voices were heard and not forgotten or ignored.

We received 2,400 separate responses as a result of our Covid-19 patient experience reports about how the pandemic affected people with CKD and their families. This was a unique resource that we used to demonstrate to policymakers and parliamentarians the depth and breadth of the direct impact that the pandemic continued to have on people in our community. This highlighted the continuing need for support for people with CKD to move back into society, to restart surgery and transplants, and to support their mental health.

Kidney Care UK led a group of 25 charities representing clinically extremely vulnerable people, calling on the government to do more to support those who are at most risk from Covid-19 as they returned to the workplace. We commissioned a survey, which found that 68% of people (including

employers) were not aware that people with suppressed immune systems were not adequately protected by their vaccines. Half a million people in the UK are immunosuppressed and may have low/or no protection, even after two doses of the vaccine. Many vulnerable people told us that they felt forced to choose between protecting their livelihoods and protecting their lives.

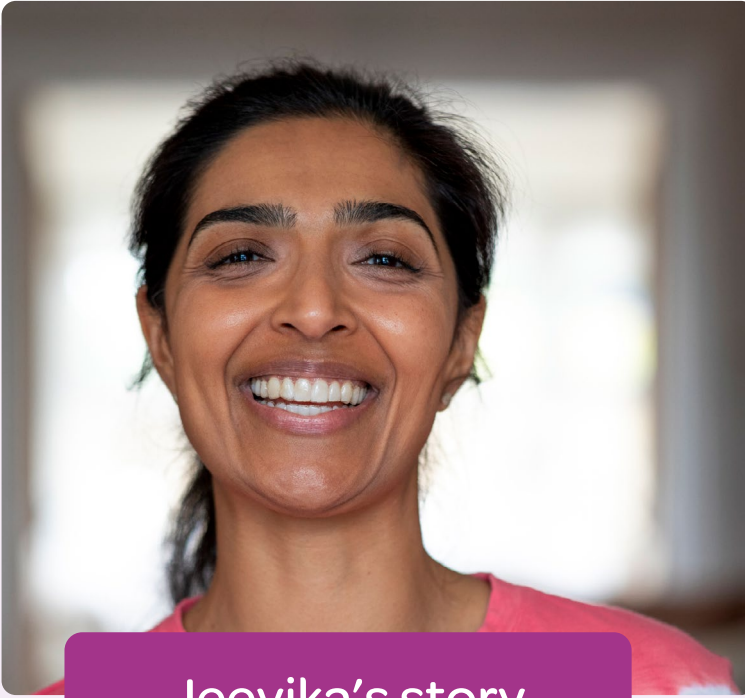
In response, we created a letter that individuals could download from our website and share with their employers as restrictions eased. Throughout 2021, our Advocacy Officers used this letter frequently to support patients in discussions with their employers, and it has been widely disseminated to policy makers, employer groups and the Health and Safety Executive.



Hal's story

Hal Cohen, 41, a kidney transplant recipient from London, told us about the impact that seeing our campaigning work had on him and his family: "Seeing the work that Kidney Care UK did in terms of raising the profile of the issues facing kidney patients like me in the media and on social media was incredibly reassuring. I know a lot of us felt forgotten, so knowing that Kidney Care UK was campaigning for us and particularly the work they did to highlight the fact so many of us were struggling to book our third dose of the vaccine was something that will stay with me.

"Kidney Care UK gave me and my family the reassurance we needed that there were people out there championing our needs and that we were not alone."



Jeevika's story

Jeevika told us how vital our regular Covid-19 guidance updates were when she was looking for advice.

"I have been hugely fortunate that I haven't ever needed any additional support with my health and the transplants have meant that I've been able to simply get on with my life. In many ways I pride myself on being somewhat invincible. But of course, the pandemic hit everyone, and all of a sudden - and for the first time in my life - my immunosuppressed status made me 'different'.

"Like all of us immunocompromised people, I shielded for most of 2020 and parts of 2021 not knowing whether Covid-19 would pass me by or kill me. The Kidney Care UK website was really helpful during the pandemic, and I lapped up the information provided by the charity. I joined every webinar and really felt I could trust the information Kidney Care UK was giving me; it was reputable and it helped answer questions I had.

"I still appreciate the information and resources provided by Kidney Care UK and check back to make sure I have the most up to date and reliable information. Knowing that I can turn to the Kidney Care UK resources and their advice and support if I have any concerns or questions about Covid-19 has been invaluable during such an unsettling time."

More than

635,000



people came to our website looking for information and advice at a time when clarity and reassurance was needed most by those in our community

More than

1,160



people attended our Covid-19 Question Time webinars in 2021

2,400



responses received about how the Covid-19 pandemic affected people with CKD and their families

Kidney Care UK led a group of



25 charities

representing clinically extremely vulnerable (CEV) people

Our Hospital Grants programme: reducing variation and improving patient care

Investing in innovations, staff and projects to drive sustainable improvements in patient care

For more than 40 years, Kidney Care UK has been supporting improvements and innovation in healthcare, investing in better facilities, funding new roles or service improvement projects, and working with key decision-makers to drive sustainable improvements in patient care. These service improvement projects help to improve the way kidney patients are cared for across the UK with access to the highest quality holistic care.

Over time, our investments into the sector through our Hospital Grants Programme have done incredible things.

75% of all of the staff posts the charity has funded in the last 10 years have since been picked up full-time by the NHS.

The investments we make to support projects, staff posts and service improvements and innovation usually run for a number of years, which means that the amount we invested in total in 2021 was more than £650,000. The financial support we gave in the form of six new grants in 2021, accounted for almost half of this amount, at nearly £300,000. This included a Paediatric Psychologist and Paediatric Renal Social Worker in Cardiff; the funding of a compassionate mindful resilience pilot programme with Queen's University in Belfast; and investment in a Renal App to be trialled in Walsall, designed to raise awareness of healthy lifestyle choices for ethnic minority communities.

Not only does this enhance our reputation as the UK's leading kidney patient support charity, it also improves outcomes for our community, reduces the burden on the NHS, and enhances the quality of life for patients and their loved ones. And since our reserves are fully committed to our operational overheads, your donations really do make a tangible impact on our ability to not just sustain our current patient support services, but to advance them.



In the last 10 years we have invested more than **£9.5million** to improve care and services across the UK

In 2021, we invested more than **£650,000** our grant-funded hospital initiatives

Supporting over **12,000** people with kidney disease

We awarded 6 new grants totalling nearly **£300,000**

“

Having worked in healthcare for many years now, I can honestly say that the whole renal community would be a very different place were it not for the long-term and ongoing financial support and investment from Kidney Care UK through their hospital grants programme. ”

Gráinne Walsh, Advanced Nurse Practitioner at Evelina Children’s Hospital and trustee of Kidney Care UK.

Case study - The ERAS project

The ERAS project (Enhanced Recovery After Surgery) is making huge improvements to the transplant recovery pathway in Newcastle-upon-Tyne Hospitals NHS Trust. The preliminary results of this pilot, funded by Kidney Care UK, have shown that the length of stay in hospital post-transplant has now been reduced from 12 days down to 5 days and feedback from patients has been hugely positive.

Alison Brown, a transplant recipient, told us: “The ERAS patient booklet contained information on what to expect from day zero onwards, monitoring my fluid balance and meeting daily targets for walking and sitting. It also included a plan of what the team were aiming for. My mind was at ease and I felt like part of the team. The ERAS process is by far the best advance in hospital care I have seen. It is patient focused, and as a patient, it gave me back some control over my mind and my body.”



“

The ERAS process is by far the best advance in hospital care I have seen. ”

Carrie Scuffell, Lead Nurse at the Freeman Hospital, added: “It has been a privilege to witness the positive difference ERAS has made to both the experience and recovery of our transplant patients. We have also seen a culture shift on the transplant unit, positively affecting the care of other non-renal transplant patients. This would not have been possible without the generous funding and support from Kidney Care UK, and we are now sharing our results with other units, hoping to use what we have learnt to ultimately improve the recovery and experience of other transplant patients across the UK and beyond.”

Thank you for your amazing generosity



At a time when central and local healthcare provision is being cut across the board, with the cost-of-living crisis becoming increasingly worrying at the time of writing, staying relevant in perpetuity requires financial stability more than ever. **It is also why we are so grateful to you, our supporters and community, for your continued donations.** These gifts allow us to support and reach more patients across the UK and sustain our investment in critical support wherever it is most needed for you.

THANK YOU!

There is a huge amount to do and your support makes it possible for us to continue to initiate, promote and advance the leading patient support services, patient information, hardship grants and sector investment for which the charity is famous.

In 2021, we were able to raise an incredible £1.3million via 11,315 donations from 3,472 donors. This is over £500,000 more than 2020, representing a huge achievement in the face of the challenges presented by the pandemic. By the end of 2025, we set ourselves the ambitious target of growing our voluntary income to £3.5 million.

£1.3million
raised via

11,315
donations from

3,472
donors

By 2025 we want to grow our voluntary income to **£3.5million** to enable us to help many more kidney patients across the UK. We need your support to reach this target.



Find out why our fundraisers and donors support Kidney Care UK

Meet Emma

Emma is eleven years old and despite lockdown restrictions at the start of 2021 she found ways to keep herself busy. Thanks to the wonders of technology, she was able to continue her hobbies - gymnastics, dancing, and Guides online during the pandemic.

She was inspired by family and friends who were raising money for various charities, so Emma decided to do some fundraising of her own by signing up to our My #KidneyWarrior Challenge and decided to cycle 10 miles per week throughout the month of February. Emma's grandad has kidney disease, and this prompted her to support Kidney Care UK.

Emma started her 'sponsored super spin' on 1 February 2021 with indoor cycling, aiming to cycle 10 miles per week throughout February. The initial fundraising target was £100, but by the end Emma raised more than £4,000! Emma told us how much everyone's support meant to her: "Thank you to everyone for all your generous donations, they have kept me motivated to keep on going!"



Emma raised more than **£4,000!**

"Thank you to everyone for all your generous donations, they have kept me motivated to keep on going!"





Meet Stacie

In December 2021, Stacie along with her family and friends dined and danced the night away to remember the life of her sister and mother of two, Carly Jackson. In total, she raised an incredible £12,517 for Kidney Care UK and Kidney Research Yorkshire.

Carly had a transplant in 2019 after being unexpectedly diagnosed with kidney failure two years earlier. However, in March 2021, she contracted pneumonia and due to a severely compromised immune system was unable to fight it. As Carly's passing was during the Covid-19 pandemic there was no opportunity for friends and family to come together to celebrate her life.

Stacie told us, "We think that Carly will have been really proud of what we achieved together in her honour. Her two children, Maddie and Jorgie, were able to be present at the dinner which made it extra special. There was so much love in the room for their Mummy – hopefully this will be a treasured memory for them as they grow up. She was warm and mothering, a real livewire and hilarious. She loved her family and her children fiercely and is so missed every single day by so many people."



In memory of Carly Jackson



Stacie and her friends and family raised an incredible

£12,517

Meet Amy

To celebrate World Kidney Day, Amy sold a variety of her colourful kidney keyring creations, raising over £300.

Amy comments: "I have been living with chronic kidney disease for over 21 years. I've had so many ups and downs but Kidney Care UK has supported me and my family in so many ways as well as lots of other families across the UK."

Later in the year, she bravely took to the skies – for her very first time – to complete a sponsored skydive, raising a further £1,000 to support her fellow kidney community.



£300

raised from selling
colourful kidney
keyrings

£1,000

raised from a
sponsored skydive

Thanks to your support, we
gave **£549,000** to people
affected by kidney disease in 2021

Meet Lesley

A large part of Kidney Care UK's work is made possible by generous supporters who have left us a gift in their Will, passing on something wonderful and helping a cause they care for to live on for future generations. In 2021, we received £689,000 in gifts in Wills.



Lesley has left a gift to Kidney Care UK in her Will. She told us, "I see writing my Will as a very positive experience. I don't think of it in terms of end of life, but more as a way of defining my legacy. Through my wishes, I'm ensuring that

my values will live on. It's a way of helping other people and having a lasting impact on a cause I care about. It makes me feel good that I'm able to help people in this way, and it costs me nothing now.

"For me, the decision to include Kidney Care UK in my Will is a mix of the emotional and the rational. I was rewriting my Will and decided I wanted to spread money further than just to my relations. My ex-partner has CKD and has received help from Kidney Care UK in the past. I got in touch to find out more and spoke to a very nice gentleman who explained about the impact my gift could have on patients' lives.

"Writing a Will is actually a very simple process, you decide on your wishes, make yourself clear, get it all written down and you can pretty much forget about it. If you change your mind, you can simply change your Will. I like knowing that I can have a long-term impact on the causes I care about."

£689,000

from 21 people who
made 'A Promise to
Care' by leaving a gift
in their Will





“Today, I am sitting on the bench where in September I felt like my world was just about at an end. I feel a sense of peace and well-being that I have not felt in a long time. I can without question thank you for guiding me on this journey. Words cannot express my gratitude for your help and sincerity.”

Alesha who received support from our Counselling service*



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*quote shared under an anonymised name from a real kidney patient to protect their identity.