Kidney Wales
Aren Cymru

Celebrating 10 years of transplant legislation in Wales!

Croeso! Welcome to the 10th anniversary celebration of transplant legislation in Wales! December 1st 2025 marks a decade since Wales led the way to become the first of the four home nations to introduce new legislation, the Human Transplantation (Wales) Act 2013, which permits an 'opt-out' system of organ donation, known as deemed consent. This means that if you haven't registered an organ donation decision (whether you opt in or opt out), you'll be considered, or 'deemed,' as having no objection to becoming a donor.

Sadly, despite ongoing awareness campaigns, we've seen consent rates drop over recent years, and with almost 7,000 people in the UK currently on the kidney transplant waiting list, the demand for kidney transplants is at an all-time high.

"Kidney Wales campaigned for years for the UK, and primarily Wales, to change its laws on organ donation. Since the legislation was implemented, we acknowledge that some inroads have been made to bridge the gap between people needing a kidney transplant and the availability of suitable organs. But the lower consent rates are a concern. Kidneys are the most sought-after organ for transplant, with people waiting for a kidney transplant making up more than two-thirds of the UK waiting list, so it's important to keep the conversation about consent going.

Last year, transplants from living kidney donors increased by 6% to 964, which is 29% of the total kidney transplant programme – an encouraging step forward. But kidney transplants from deceased donors fell by 5% and research is currently underway to identify the reasons behind the lower consent rates.

We believe that, even with deemed consent, it's important to register your organ donation decision with NHS Organ Donation because it removes all future doubt about your wishes. When you register your decision, you're helping your loved ones to know exactly what you want when you pass away, so it's vital to record your decision now, to avoid uncertainty further down the line."

Ross Evans
CEO, Kidney Wales

Organ donation will only go ahead with the support of your family, and clinicians will never proceed with organ donation if family or loved ones object. So it's important that you **talk to them** and that you **register your organ donation decision** too.

Without recording your end-of-life decision, your loved ones may be unsure what to do.
So, whether you choose to become a donor or not, registering your wishes now will give your loved ones reassurance during a difficult time.

You can also change your recorded decision at any time.

Ways to Donate

As well as registering your wishes on the Organ Donor Register, there are other ways to donate a kidney.

Living donation is where a healthy individual chooses to give one of their kidneys to a person who needs one. Anyone over the age of 18 and in good health can be considered as a living donor. There are several pathways to becoming a living donor. You can donate directly to someone you know (directed donation) or to a complete stranger (altruistic or non-directed donation).

Pooled or paired donation, via the National Living Donor Sharing Scheme, is a great alternative if you're not a direct match for your intended recipient, perhaps because of incompatible blood or tissue types. In this scheme your kidney will be given to someone else who is a good match and their intended donor will give the kidney to your recipient, like a 'kidney swapping' system.

Did you know?
In 2024/25 there were 41 Welsh residents who donated a living kidney.

A living donor kidney lasts on average 20-25 years, sometimes longer, compared to a deceased donor kidney lasting 15-20 years.

More than
2000 organs
have been donated in Wales since the law changed in 2015. Of these, 640 were via deemed consent.

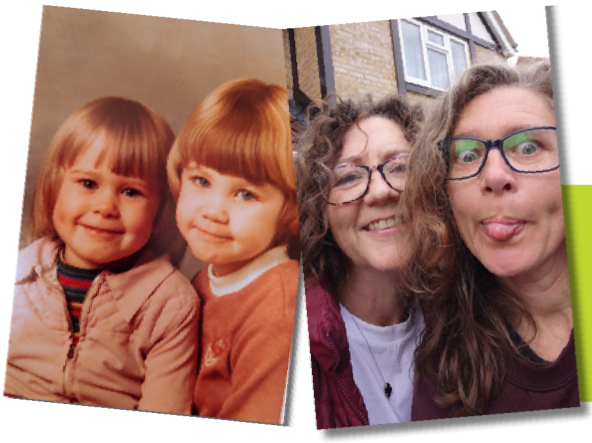
Around
44%
of the population in Wales have registered their decision to opt in to organ donation.

Register your decision now:

www.organdonation.nhs.uk/register-your-decision/

Keep reading to meet Carla and Jude – two kidney patients whose stories of hope and determination are made even more remarkable, thanks to their living donor's selfless decision.

We hope you enjoy reading this special 10th anniversary issue.



Carla & Lynsey

Carla Williams and Lynsey Robinson are sisters with an unbreakable bond. In June 2023, Carla received a kidney from Lynsey, but Carla's journey back to health has not been easy.

In March 2019, Carla started to feel that something wasn't quite right. "I'd been feeling tired and under the weather," she recalls, "and had developed an intolerance to alcohol, so I went to my GP, who took some bloods. They never got back to me, so I didn't think anything of it. But by October 2019, I was absolutely shattered all the time and had bowel issues, so I thought that was the main problem."

Further blood tests showed her kidney function was 14%. Her GP arranged an emergency appointment at Morriston Hospital in Swansea for the next day. "The kidney consultant sat me down and told me that I was in end stage kidney failure," says mum-of-two Carla. "It turns out that in March I was at stage 4 kidney disease, so in those seven months my function had dropped considerably. The consultant told me that I would probably need dialysis or a transplant and the sooner I was on the transplant list the better. It was really overwhelming and I think I went into autopilot mode."

Further tests followed and by April 2020, just as Covid hit, she was diagnosed with MGRS myeloma, which is related to the blood cancer multiple myeloma. As well as being a kidney patient, she was now also a cancer patient and started chemotherapy right away.

Having taken sick leave from her full-time job as a mental health nurse, Carla, 47, from Ammanford, was plunged into a world of tests, treatment and uncertainty.

"Throughout Covid, I went back and forth to Singleton Hospital in Swansea for chemo, and Morriston Hospital for all the kidney issues," she says. "I spent the next year weak from the chemo and the declining kidneys. I also had fistula surgery to allow me to dialyse, but that failed because my veins aren't good. Then I was fitted with an AV loop graft, a different type of access point, and I was able to start dialysis in late 2020. By then I'd finished the chemo.

I was on dialysis for a couple of years and had to wait a year to build myself up after the chemo, to have my stem cell transplant in February 2022, which totally wiped out my immune system. This was to blast the myeloma, because I wasn't eligible to have a kidney transplant unless I'd had the stem cell transplant, and I needed to be in remission for a year, in case the myeloma returned."

During this period, Carla hit rock bottom. Weak from chemotherapy and kidney failure, with serious adverse reactions to her chemotherapy drugs, and with her AV graft failing for the third time, she had almost given up hope.

She remembers: “I was due to go and see my sister in Cornwall and had booked dialysis in a unit nearby, but I was admitted into hospital instead. That’s probably the lowest point I’d experienced and I said, ‘I can’t do this anymore.’ It was too much for any person to take and I felt like giving up and going home.”

It was only the compassion of a vascular nurse that got her through that dark period, making Carla promise that she’d still be in her hospital bed in the morning. Carla’s only option now was further surgery, which she couldn’t face, so she carried on with her plans to visit Lynsey in Cornwall.

“Lynsey had already decided to be my donor,” says Carla, “but, because of the stem cell transplant, we had to wait a year before we could proceed to a kidney transplant.”
I don’t know how I got through that year. Kidney disease is utterly relentless.”

In February 2023 – exactly a year since Carla’s stem cell transplant – Lynsey started the work-up as her living donor.

After months of waiting, Carla and Lynsey’s operations took place at University Hospital Wales in Cardiff on June 21, 2023.

“When I woke up from the operation, still groggy, I just knew it had worked,” Carla continues. “It was like the fog had lifted. I felt like my life was in HD again. The blood results proved that it had worked. I started doing yoga again, and all the other things I loved. These days, my kidney function is a solid 64%. Two and a half years later, I feel amazing. I now work part-time for the Stroke Association in a role I love. I am so grateful for the treatment, compassion and care I received. As for my sister, I don’t even know where to begin with how grateful I am to her.”

Now, Carla has a greater understanding of the important things in life.

“I’ve always been fit and active,” she says. “I was a road cyclist and enjoyed long walks with the family and our dogs, so this illness very much changed my life. Kidney disease hasn’t just affected me, it’s affected my whole family. Although I’ve been through hell and have had some really tough times, I don’t know if I would change anything. As awful as it’s been, it’s taken me on a journey of self-discovery, resilience and helping me prioritise the important things in my life. I’m a different person, a better person from who I was. I’m kinder, more empathic, more compassionate.”

Lynsey

For younger sister Lynsey, 46, seeing a once-fit Carla so unwell was heartbreaking. She remembers the first time she suspected that something was wrong.

“We all went to visit her in October 2019. I knew that she’d been to see the doctor in March. We were both working full time and had young families, so as a busy woman, you’re always tired. We’d gone to walk her dogs in the evening and sat down on a bench, but when we got up to start walking again, she crouched down and needed a minute to recover. I knew this wasn’t right, so I pushed her to go back to the doctor. And it all started from there.”

Lynsey could not have predicted what would happen next.

“Carla had lots of tests, and the diagnosis was pretty bad,” she continues, “but it was more complicated because of the cancer and the kidney disease. I remember when she went to get her diagnosis and thinking that I didn’t want to know the results. There were quite a few moments in the journey where the thought of her not being there was the worst feeling. Thankfully, there was treatment available, and she remained characteristically practical and strong through it all. She had some hard days though, of course. She was able to be honest with me, but she never spiralled or felt sorry for herself.”

Lynsey had no hesitation about becoming a living donor for Carla.

“We’ve always been super close,” says Lynsey, mum to 14-year-old twin boys. “When we found out about the kidney disease, I’d always told her that she could have one of mine. She told me that she could now be considered for a kidney transplant, because her stem cell treatment had ended, and we talked about me being a donor.

“Going through the stem cell transplant was horrendous for her. She had 19 days in isolation, and there was an entry in my diary for that period which read ‘Carla having lethal chemo.’ It’s difficult to watch someone you love so much go through that.

“People ask me how it felt, making the decision. For me, it was never a decision, it was always what I was going to do – I didn’t have to think about it. I took it seriously, talked to my family and had their full support. Carla worried about me putting myself through it, but I reminded her that she would do exactly the same for me.”

Lynsey had to undergo a raft of tests before she could be considered a suitable living donor for Carla. But the outcome was worth it.

“On transplant day,” Lynsey recalls, “I felt very calm and knew it would all go to plan. They wheeled me across to see her after the operation and it was brilliant to see her looking well.”

Lynsey recovered quickly and now, just over two years post-operation, her remaining kidney functions at a very healthy 80%.

“If anybody is considering being a living donor, please go for it,” says Lynsey. “The impact you can have on someone else’s life is unbelievable. Because of living donation, I have my sister back.”

Jude & Tracy

Best friends Jude Stone and Tracy Pritchard have a deep friendship spanning almost 30 years, forged in the memories made from some of life's highs and lows: university, marriage, children and ill health. But their friendship reached a new depth when Tracy donated a kidney to help her best friend.

"We met during our first year at Warwick University where we both did German and Business Studies," says Jude. "After we started talking, we never stopped! We instantly connected and even lived together during our year abroad in Germany. Tracy's always known that I have kidney disease, and she told me that it was never really a huge decision for her to donate to me if I needed a transplant. But she didn't tell me that until last year."

Business owner Jude, 46, has had kidney problems for most of her adult life, and was recently diagnosed with uromodulin nephropathy, following genetic testing among family members.

"My dad is one of three brothers," she says. "His eldest brother died from kidney failure when I was about 10. The family thought that his kidney failure had been caused by some gout medication that he took. But around 10 years ago, my dad's middle brother had a kidney transplant, and I'd been diagnosed with kidney disease by then too. Over the following couple of years, it transpired that the entire side of my dad's family has been affected. What started off as an unfortunate thing that happened to my uncle, has now shown that, after recent genetic tests, we all have the same faulty UMOD gene that causes uromodulin nephropathy."

Aged 23, and with sky-high blood pressure that she'd had since her late teens, Jude was monitored regularly as a kidney outpatient. She was originally diagnosed with FSGS, a disease that causes scarring to the glomeruli, the kidneys' filtration system. But there were no real concerns at the time, until her 30s when she started a family.

"From that point we started to talk about the future, transplantation, and what that might look like," Jude recalls. "But because I was young and relatively fit and healthy, the plan was always to have a living donor transplant."

Then in 2021, Jude faced a huge setback.

"As my kidney function declined to about 30%, I was diagnosed with breast cancer, which needed treatment," she says. "With the specific type of cancer that I had, I had to wait for two years clear before I could have a transplant. I took SGLT2 inhibitors, a drug that helps slow the progression of chronic kidney disease, and that got me through those two years. In November 2022, when my kidney function reached 20%, we started planning for a living donor transplant."

Several family members and friends came forward as a potential living donor, including Tracy and Jude's husband Martyn, but none was a suitable match. To maximise her chances of receiving a matching kidney, Jude entered the kidney sharing scheme, where two or three donor kidneys are 'swapped' in a pool with other pairs across the UK to find compatible matches.

“I entered the sharing scheme when my function was around 14%,” she recalls. “The idea was to have the transplant while I was healthy enough to have the surgery, and it would give me a better recovery outcome.

“Martyn and Tracy put themselves forward for the shared scheme. Tracy was picked as a match for an anonymous recipient. There were three pairs of donors and recipients in our pool. Martyn wasn’t a direct match either, but he’s up for being a potential donor again, if I need another kidney.”

In August 2024, Jude and Tracy were thrilled that a match had been found for them both, as a recipient and donor.

“Tracy wasn’t deterred by the shared scheme, where she knew that her kidney wouldn’t be a direct donation to me,” Jude recalls. “She just knew that I needed a kidney and thought that joining the shared scheme was a complete no-brainer. Although Tracy was matched with an anonymous recipient, I always think of it as Tracy donating to me.”

Jude’s transplant took place at University Hospital Wales in November 2024. She remembers how she felt before and after her life-changing transplant.

“I was lucky and didn’t need to have dialysis because we were able to plan for a pre-emptive transplant. Before the operation, I was much more tired, retaining a lot of fluid and feeling breathless. Fortunately, I didn’t have a lot of the more severe end stage kidney failure symptoms, so I didn’t wake up after the operation with the huge mental clarity that others experience. But when I first looked in the mirror, I saw colour in my cheeks and realised how grey I’d looked before. When I got out of my hospital bed, the biggest difference I noticed was my legs. They felt really light because they weren’t full of toxins anymore.”

One year on, Jude and Tracy’s bond is stronger than ever.

“For a long time, I couldn’t plan for the future, because I didn’t know what the future held, but Tracy’s selfless gift has given me a renewed hope and a new zest for life. We’re both able to plan a lot more now, including doing all the things we missed out on when I was unwell, as well as making many more memories together.”

Tracy

From their initial meeting on campus in 1997, Tracy and Jude had no idea that, nearly three decades later, Tracy’s act of selflessness would start a new chapter in both their lives.

“Jude had tests to find the cause of her high blood pressure when we were at university, so I’ve always known about her kidney disease,” says Tracy, a mum-of-two from Stroud. “Being there right at the beginning of her journey, it seemed inevitable that I’d want to be part of the solution when we found out she’d need a transplant. And supporting her every step of the way has strengthened our relationship even more.”

Civil servant Tracy, 46, has seen her friend endure many health challenges over the years, and the option of stepping forward as a living donor had been at the back of her mind for a long time.

“It never really felt like a decision,” Tracy remembers. “When she had tests while we were at university, I told her that I had two kidneys, but I would be happy to give her my spare if she ever needed it. It may have been a slightly flippant comment at the time, but when her doctors started talking about donation, it felt like the next natural next step in the process was for me to be tested as a potential match. I’d sat with the possibility for over 20 years, and I knew that I could help her by doing something meaningful that could make a big difference to her life. As a friend, you often feel helpless watching them in need or in pain, whether it’s physical or emotional. It felt incredibly fulfilling, and it was a privilege, to be able to do something constructive to help.”

Just after Christmas 2022, Tracy started the matching process, undergoing a series of tests to check her compatibility as Jude’s donor.

She recalls: “As a donor, the work-up process is very thorough. You get a full health MOT, and annual check-ups continue for life, so you’re well looked after. I had phenomenal support from the living donor team at UHW, especially my nurse Lucy. Four people were tested as Jude’s potential donor, including her husband Martyn, but none were a direct match. Jude and I were potentially a match, but it wasn’t an ideal one, so we then talked about joining the shared pool scheme. Jude was concerned that I might feel differently if I wasn’t donating directly to her, but to me, it was no different – I was donating for her.”

Jude and Tracy were fortunate to find their matches on the first ‘run’ of the sharing scheme but for many people, it takes much longer. They were able to have their operations on the same day at University Hospital Wales in Cardiff.

“On the day of the op,” she remembers, “I had some final checks and was wheeled down to theatre really early. I was shaking and had a last-minute wobble on the operating table, which is completely normal! My surgeon was brilliant at calming me down, reminding me that I was actually about to give three people a new kidney, instead of one, thanks to the sharing scheme.

“After my op, I was on the ward recovering and waiting for Jude to come back. It was a tense wait but once I knew she was back safely, I was able to sleep.”

Tracy stayed in hospital for five days and now, 12 months on, is back to full health. She reflects on the change in Jude since having her new kidney. “I didn’t quite realise how much her kidney disease had affected her until she’d had the transplant because the decline was so gradual. Before, her face, fingers and ankles were swollen, caused by a build-up of fluid, but afterwards, I could see the difference and the swelling had gone. She’s also got a lot faster on her feet!

“When she was unwell, she stopped thinking ahead as much, because kidney disease closed her world. It’s been lovely to watch her world open up again.”