Two Boys and Three Kidneys

This is the story of two boys, two families and three kidneys; both boys had at least one blocked kidney; both families had lost trust, sought a second opinion, then gained trust.

On a Friday evening in 2005, days before one of my 15 surgical teaching trips to Mauritius: I took a phone-call while in the home office. I remember looking out the window … hoping to see the solution to yet another problem of a child and a family being "managed", but not cared for.

The second boy's parents spoke to me while I was in Mozambique, 20 years later.

The 2005 boy had a prenatal diagnosis of blockage of both kidneys, which resulted in him being delivered at 34 weeks gestation because of the perceived need for early intervention. The parents were, as you might expect, beside themselves with worry. The father, a big, tall ultra-keen sportsman had already been dreaming his son as a football star. Those dreams had changed to nightmares about the potential problems of prematurity and the possible long-term kidney damage that would end any chance of his boy following in his football-boot steps.

At 90 days of age Liam's kidney blockages had not been resolved, despite having undergone a series of investigations that were as confused in their conduct and interpretation as for Jacob, the second boy, whose saga went for 15 months, up to June 2025. One of the differences between the boys was that both of Liam's kidneys were affected.

Liam had an injection study to assess the function and drainage of his kidneys soon after birth – he screamed, his mother cried, and the study was not done properly. Liam had a catheter put into his penis; his bladder was filled with fluid that showed up on Xray – he screamed, his mother cried, and the unnecessary study was normal. Not long before his inappropriately delayed operations, he had the same study done again – he screamed, his mother cried and that a complication of the placement of a stent into the right kidney (which was obvious on an ultrasound) was confirmed.

Liam had stents placed between the bladder and the kidney on both sides for (inappropriate) treatment, but the obvious had not been recognised. Let me explain … if you have a plastic tube draining between the bladder and the kidney, when the bladder is empty, the kidney should not be dilated; a dilated kidney looks like a black hole on ultrasound – either the tube is not in the correct position, or the tube is blocked – the stents is called a double "J" stent, because it is held in place with a "J" shape at each end; but it is well know that they can slip up into the kidney – if you don't do the procedure properly. Sometimes the truth sounds nasty!

On the right side, Liam's stent ***had*** slipped into the kidney. Therefore, the ultrasound of the kidney showed dilation (consistent with blockage of the urine flow to the bladder). A problem that that had been obvious from the prenatal films, let alone the other studies

done after birth. And, as mentioned, Liam did not need the additional study with the catheter put into his penis. Nor did he need the check cystoscopy (looking into the bladder and urethra with a telescope) to review his urethra, let alone the second cystoscopy to put the double "J" stents in. He should have had the surgery to fix the blockages. Thus, he had two unnecessary anaesthetics in the first year of life – both with the mother crying as he was going to sleep.

The image of the second cystogram showed what was obvious on the ultrasound – the double "J" stent was sitting coiled in the right kidney.

Insanely … yes, strong but appropriately accurate language, the plan was to have a radiologist (while Liam was asleep under yet another anaesthetic), pull the stent out through the skin, under radiological control. Madness! Fortunately, the family came to understand how bizarre that decision was, so were able to agree that nothing would be done (and there was no plan to do anything, anyway), until I had returned from my outreach visit to Mauritius. We kept in touch by phone (pre-WhatsApp), and arranged for an operation on the right kidney, days after I returned to Australia. The tyre-tense kidney had the plumbing repaired, and the Double "J" stent was removed at the same time, through the cut in the blocked renal pelvis, as it was being repaired; and the stent on the left side was taken out via a further (this time necessary) cystoscopy. The following day, the left kidney was reviewed with an ultrasound, showed to have futures that confirmed the previous information that indicated the kidney was blocked without the stent, and a repair was done that day. To go to theatre two days in a row, the father had to have the boy almost forcefully taken from him, such was the dad's fear – the dad was reassured by the fact that the right kidney had been markedly improved within 12 hours of the surgery the night before. Both kidneys have done well, and the boy has become a champion football player.

An appeal to the hospital, and to the national health regulator, led to the involved surgeon being in tears and retiring early, and nothing changed. And, the mother was again in tears again … and angry.

Twenty years later, I noted an email that had gone to my spam folder, which I only discovered because I was on a flight to Africa … flying to Mozambique; possibly while

flying close to Mauritius. The close temporal relationship of trips to the African continent and “meeting” Liam and Jacob is just one of the similarities Liam and Jacob stories.

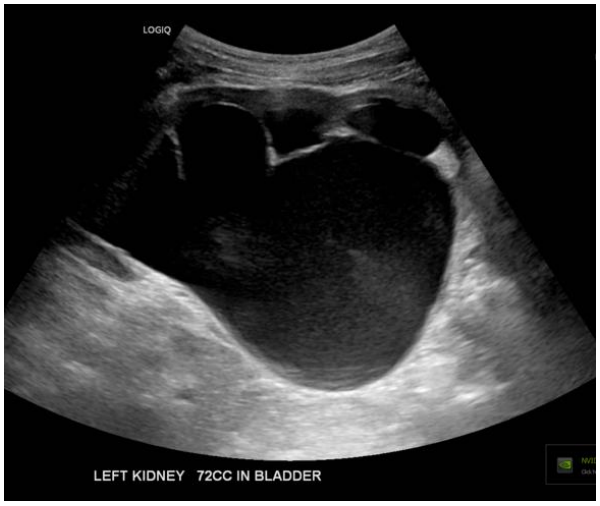
That was my 148th trip to operate in a developing country, which had, fortunately for Jacob (the subject of the spam email) involved several reoperation surgeries, which are usually much more difficult than any first operation. The more experience with that sort of challenging surgery, the more one can deal with the challenges – any difficulty in the operating theatre in Mozambique was at least match by circumstance I would meet in the week of my return to Australia.

Another similarity between the boys … Jacob is also a good football player.

In March 2024, Jacob was taken to the doctor complaining of abdominal pain and vomiting. An ultrasound showed a very dilated kidney, which, with his symptoms, should have resulted in early intervention. Within a week had he been referred to me. Two errors are made in the interpretation of the subsequent kidney function study; one is the failure to recognise that, at the cellular level, you can have significant changes before there is an adverse effect on the radiology function result; the other is that pain during the study should make the situation more urgent, but the lack of pain should not distract from the need for early intervention if the kidney does not drain well. Jacob did not have pain, but his kidney did! That function and drainage study was not performed until June 2024, and the operation to try to fix the problem did not happen until 10th September – six months after the ultrasound had shown the need for the surgery.

When there is a blockage at the junction of the pelvis to the ureter (the tube from the kidney to the bladder), there are a number of considerations about how to deal with the problem; one is to do the repair and leave a catheter (double “J”) stent and take the stent out later, during a second anaesthetic. That is what was chosen for Jacob in September 2024. Having left the stent, a urethral catheter is required for at least a day. In an 11-year-old boy that is not fun … to say the least (in reality - frightening and painful). Also, the lower end of the stent sits in the bladder and irritates the bladder, causing painful spasms – like you feel you are busting to pee, even when the bladder is empty. That abreaction to the stent happened for 8 weeks for Jacob, and he had bleeding, partly due to the inappropriate use of Nurofen, which interferes with the platelets in the blood that help to stop bleeding; and Nurofen is contra-indicated when there are renal function problems.

So …., after the Double J was left in for too long (had the surgery cured the problem it could have been taken out after two weeks), there was no check of the outcome of the operation, after the stent removal, until 20th December. That ultrasound was not reviewed by the surgeon until 29th January, who wrote “likely distended L PD system with overhydration”. The “translation” of which is “the kid drank too much, causing his kidney to look dilated – the term “head in the sand” comes to mind. Looking at the image below – more black means more of a problem – you can see a lot of black!



Remember, Liam had an ultrasound the day after the operation on his right kidney … that looked better than before the operation. My interpretation of the ultrasound images of 20th December … if you heard a cry in agony over the Christmas/New Year period of 2024, it was probably the Jacob's left kidney calling for help; cries that were not reflected in symptoms for the boy, but were echoed in a repeat function study that indicated the left kidney has lost most of its function – it had gone from 36% of overall function to 7.2%: that study was not done until five months after the kidney "screaming" started – the second nuclear medicine study was on 20th May 2025.

The parents and I talked on WhatsApp while I was away, and we arranged for an ultrasound to be undertaken on 17th June. Meanwhile, Jacob played another stellar game of football on the weekend before – and I had a chance to review the radiology. The new scan showed the same old unwelcome news, no surprises there. That Jacob did not rupture his kidney during the football match was surprising.

We operated on Thursday 19th, finding the boy had his own internal football – not a real football, but his kidney, which was so tense you could imagine it could be bounced. Fortunately, the hospital was able to accommodate an additional patient that day, but it meant we started in the mid-afternoon. Usually, an operation for a blocked kidney would take a couple of hours. Not this time; the procedure took five demanding hours. The big kidney squeezed into a small space makes the operation more difficult – and because of the previous operation it is stuck to the surrounding tissue. To make the operation easier, when you dissect down to the kidney, you remove the urine via an appropriate location, with a needle, which takes into consideration the intended postoperative drainage of the kidney. In some cases, you can easily identify where to put a needle into the collection of urine in the kidney to drain the system. Not this time.

Not only was the bowel firmly adherent to the kidney and the huge pelvis, but the lining of the abdominal cavity was directly stuck to the pelvis of the kidney. By the time the kidney was freed up enough to allow a drainage point to be identified there was a large opening in the abdominal cavity (the peritoneum) … which is a "never-event" in my

career, but a reflection of the complexity of Jacob's complication of the previous operation.

Good news (I thought), the meat of the kidney looked half decent once the pressure was let off by draining 400 ml of fluid – yes 400. Opening the blocked pelvis revealed a fibrous connection to the ureter that was virtually completely closed with thick scar tissue; and the ureter was relatively small. That adverse connection was an outcome of the previous surgery. The pelvis was trimmed; the ureter was appropriately shortened and joined – ***very carefully***.

With a kidney in the state it was, you should always expect that it will madly pour out urine after having the obstruction fixed. The most urine produced by a patient I have cared for was in an old man with a prostate problem – he made 24 litres of urine in a day after having a catheter inserted; the most urine coming from a baby was 300 ml per hour. With that sort of "flood", even a very adequate join of the kidney to the ureter will not cope and a "flood" should have been inevitable … so a drain was put directly into the kidney for Jacob, known as a nephrostomy tube.

I hate my job and I love my job; sharing the pain with families is unimaginably hard sometimes. The Liam and Jacob stories are just two of thousands of stories I could tell – too many about things that have gone wrong before I was asked to help, most in developing countries where relatively untrained people had done the best they could, but failed. Far too many have happened in Australia, where the outcome has been problematic and the family have found me on the internet – desperate.

Jacob is a calm, tough, well-mannered very athletic looking young man who cried when he heard he needed another operation, but he soon reverted to the focused self that kicks goals, with an attitude that repeatedly wins him best on ground.

While Jacob was focused on making the process easy, he and his kidney, again, were not on the same page. Before both operations, his kidney was "screaming", Jacob played football as if he had too normal kidneys. After the "Thursday" operation, his recalcitrant left kidney did not drain very much urine through the tube in his side – gluing me to his bed to ensure all was well. It seemed that his kidney was already draining through the new join I had created, even before he was awake in the recovery room.

Over the next three days he stayed in hospital making a great recovery. His blood pressure was fine – mine I did not check; I had enough to keep me thinking already. Through a process of elevating the catheter, checking the pressure in the kidney and the volume of urine retained in the kidney; and what volume of urine was coming out, he was able to go home on Sunday and have the nephrostomy taken from his side on Monday.

Tube free, he had the kidney checked the next day – much improved dilation (despite him having {never} too much fluid to drink before the ultrasound). The function study was disappointing, but one that is virtually never done so early – we needed to double check a problem that was/is much more complex than usual, leading to the early study.

At least the function was 9.5% of overall renal function – and we hope the timing of the study was like assessing a broken leg for its power soon after the plaster has been put on – likely to not be better on future evaluations.

You can see from this second ultrasound image what should have been seen on 20th December (see above), and I am still not happy to wait too long – another ultrasound will happen soon.

Before the second surgery … two days before the surgery, a surgeon involved in the initial treating team rang the parents. For a telehealth appointment. When I do a telehealth check-up for a patient who has had radiological investigations, we talk via a video call that enables me to show the family the images of the studies of the kidneys. And, even more-so when there has been a problem with intervention outcome.

After the function assessment this year, the surgeon who operated in September, spoke to the family after the kidney damage had been identified, in May 2025, insisting that Jacob needed an operation to redo the join between the kidney and the ureter, which was obviously true. “If we don’t operate, he will end up on dialysis” was heard on the phone, sounding both accusing and dispassionate … another mother cried. When I heard what had been said, I too was angry. The loss of one kidney does not result in kidney failure. Jacob’s mother felt the surgeon had been dismissive about the bad outcome. No images of the kidney were shown to the family. That phone conversation led the family to surfing the net: despite my spam folder, we were soon in contact.

As you might guess, it was obvious that the family had gone elsewhere for an opinion because of requests for information about Jacob’s treatment that has gone to the original treating hospital. The treating team had “had a meeting” and another surgeon, not the initial surgeon who operated, spoke with the family, after the family and I had decided a course of action; to redo the previously failed repair of the plumbing.

Jacob’s mum and dad took the call for the telehealth in a state of, shall we say, discontent. Stress makes your stupid; anger causes temporary deafness. But they heard enough to know they did not like what was said, but were calm enough to ask for the advice to be put into writing. The recommendation was to reinsert the Double J stent – the Thursday operation findings showed the Double J stent would not have gone through

the junction of the ureter to the pelvis of the kidney. The “multidisciplinary team plan was “If the stent won’t go through the previous surgical join, we will put a tube in through the skin (which is what I did after fixing the problem), then check if the kidney should be taken out or fixed after a further function study to assess the function”. Both alternatives would mean two further operations. No images of the ultrasound or function study were shown to support the argument. “Everybody agrees”, chanted the message to the family … but where was the opinion of the original treating surgeon who had insisted on the operation that involved repair the post operative blockage. And, why was he not involved in the further communication with the family. These were the “my-son-has-virtually-lost-his-kidney” thoughts the family had leading up to the Thursday operation. You can imagine the reverberation of those thoughts, and how a pre-teenager was feeling.

The beauty of being a surgeon is being able to participate in the artful application of science and the scientific application of art; to share incredible journeys with families and see great outcomes for kids. But not everything smells like roses. Time will tell how good the outcome is for Jacob.

I have only had one real problem with Jacob’s family; not ***really*** a real problem. The family are incredibly grateful, and both his parents very caring. His dad is extraordinarily strong; very muscular. When a caring emotional dad says “thank you” with a hug, I am glad he is happy with me … yes, he is strong … and grateful; having an ***extremely*** firm hug from a happy father is definitely not a real problem.

I hope to never be able to tell another Liam or Jacob story.