

Parental Feedback - Dysfunctional Kidney - Printable version

We discovered our eldest son had one undeveloped kidney during my pregnancy. Once he was born further tests showed that his left kidney had not developed, it had grade 4 reflux to this kidney and had a function of only a couple of percent. The concern in this situation was that we had to keep him clear of any infections which could damage or scar his other healthy and fully functioning kidney. There was an increased risk of this happening due to the severity of the reflux he had. He was put on a low dose of trimethiprim and monitored every 6 months at the hospital. Throughout the first four years of our son's life, we saw a consultant who at each appointment said it was really our choice to have an operation to remove this dysfunctional kidney.

We felt we were left with a huge dilemma. We felt it was a huge responsibility to make a decision when we could think only emotionally about our child and of course did not have any expertise in this area. If, at any stage, our son developed an infection and was ill with it – the left kidney would need to be removed. The operation suggested was an open surgical procedure which would involve a great recovery time and would be painful for our son for some time and most certainly a distressing experience for him. Did we have this operation when he did not have an infection and was healthy and therefore would possibly have a better recovery from the operation. Or did we wait to see if he ever got an infection – which could damage his good kidney – and then have an operation when he would be quite ill? This was in addition to the natural concerns about general anaesthetics.

I was conscious that he would be starting school shortly and should he ever need this operation it could involve taking quite some time off school. It was at this point I asked for a second opinion from a different consultant, preferably if there was a consultant who performed a less invasive technique. I did not know if such a thing was possible. We were introduced to Mr Subramaniam and we discussed the situation with him and asked for his opinion. It was a great relief to have a surgeon take the responsibility away from us, and we felt reassured by Mr Subramaniam's openness, communication and expertise. When our son went into hospital, we had spoken a couple of days prior about what was happening and he was very relaxed about the whole thing. We had various tests the night before to check his health and a physiotherapist came and gave him a couple of exercises for him to keep his chest clear before and after the operation.

On the morning of the operation I was allowed in the room where my son was given the anaesthetic and we counted beads on a bracelet he had made me before he went to sleep.

We waited in the parent room for four and a half hours before we were called to the recovery room. We were told that he may not be able to have this new procedure and Mr Subramaniam would not know until our son was under anaesthetic, the only indication was that the time for the more intricate procedure would be longer than the open surgical option.. I had anticipated the going to sleep bit would be one of the hardest parts but actually seeing him after the operation was quite a shock. He had obviously been under anaesthetic for a long time and was incredibly pale, clammy and groggy. Mr Subramaniam came and told us the operation had gone very well. Once we were back on the ward, he was in bed and regular checks were being made to check his recovery. It still makes us smile now to think about it but his recovery was miraculous. Within a couple of hours he was sitting up in bed asking for more toast and weetabix. He was smiling, in no pain, chatty and intrigued by his various tubes. He slept that night and we stayed in one more night after that before going home.

After our son's operation, he was more tired than usual for a couple of weeks, which he had off Kindergarten. It was then the summer before he started in Reception class and I could not believe how well and quickly he recovered. He has only four small scars, he has far more energy that he had before and you would not even know he had had such surgery.

When we think of the alternative we could have had we are so appreciative and grateful to Mr Subramaniam and his staff. It has been a positive experience and our son has no emotional scars either

from this operation. We are delighted we took this option and feel very fortunate to have had the skills and expertise of Mr Subramaniam. It has given us great pleasure to be able write this and we hope it helps any parents in their decision should they have the same dilemmas we had. Our son has now been discharged from the hospital and is a very normal, boisterous seven and a half year old boy!