



Chronic Kidney Disease in Children

A parent's perspective

Lucy Wray, Parent

I wrote a version of this article when my son was around 7 months old. He is now almost 6 years old. Returning to this article and documenting our journey has been very difficult. I do hope that reading it gives you an insight into the parental experience of chronic kidney disease (CKD), including the difficulties associated with managing a child's nutrition and the impact that CKD has on the child and the family.

CKD is incredibly complex. The balance between fluid input and output, medications, growth, development, nutrition and everyday life is all-consuming. My son was two-and-a-half years old before he reached his target weight of 10 kg (the weight to be eligible for a kidney transplant). Pre and post-transplant we think in millilitres of fluid consumed each day. The routine of the day is dictated by medications, water and personal care interventions. This is a constant alongside trying to support our child to be a child, to enjoy life and to give him the skills to become independent and manage his health alongside all of the things he wants to, and will, achieve in life. Nutrition is a key part of everything.

This article will largely focus on our experience and journey with managing our son's nutrition. However, if you wish to read an article with a wider reflection on the area, I have published another article (2022) in *Pediatric Research*.*

Pre-CKD & the initial post-natal journey

When I was pregnant with my son, like many new parents, our antenatal journey had been equally exciting, terrifying and filled with the unknown. Our antenatal journey was accompanied by dietary questions, such as: "Are you planning on breastfeeding or bottle feeding?" After what was described by professionals as a "boring pregnancy", my son was born unable to breathe, requiring resuscitation and immediate transfer to the special care baby unit. It was in the special care baby unit that I first felt judgment and pressure around the feeding choices for my son. I was laughed at for bringing in an organic formula milk, told I wasn't allowed to give my baby this formula and then told I needed to work harder to express colostrum; a task

which I had spent hours trying to do, all whilst being separated from my baby, feeling exhausted and terrified.

On his second day of life, my son was diagnosed with posterior urethral valves, which had caused extensive damage to his bladder and kidneys. This is where things changed. He was transferred to a different hospital to their neonatal intensive care unit, I was given support with feeding and with expressing breastmilk and I was given time to spend with my baby to try and promote feeding. After a few days, he was then transferred to the Paediatric Renal Ward at the Evelina London Children's Hospital where specialist support was given with regards to managing his CKD through appropriate milk and feeding.

* Wray L (2022). Family Reflections: Living with, but not defined by: Posterior urethral valves, chronic kidney disease and kidney transplant. *Pediatr Res.*; 92: 899-901.

The jump between the neonatal unit and paediatric ward was massive, and I suspect underappreciated. We went from requiring permission to hold our baby or to do anything with him, to being completely left to it. Looking back, we weren't given advice on how to go from feeding our son in an incubator to feeding him whilst holding him and, as we were in such a scary stage, we didn't ask. In the early days he was fed both orally and through a nasogastric (NG) tube. At various times he required an NG tube, but we were very persistent and eventually he was happy to drink from a bottle.

Early feeding experiences

Once at the Evelina London Children's Hospital, our son was prescribed a milk recipe which incorporated breast milk and a specialist low potassium formula. I could also breastfeed on demand, however due to his high creatinine and blood potassium levels, breastmilk alone was not possible. We have learned that each patient with CKD may have different fluid restrictions. My son required huge amounts of fluid, but his condition meant he did not want to drink. During his hospital admission and post-discharge, to make the milk recipe I would express breastmilk, add this to the milk recipe prescription and try to give this to my son. Initially, I was trying to feed him every 2 hours, which included waking him to feed throughout the night. In addition, every 2 hours I would spend 40 minutes expressing 20-30 ml breastmilk. I lasted around three months with this process before switching from breastmilk to solely formula, as this took a huge toll. The following is an extract of what I wrote at the time:

"I have an unbelievable guilt that I can't fix this, that I can't give him what he needs. I am devastated that the milk I was producing could harm him further and that the safe haven I was meant to provide for him was not safe and that I didn't sense that. At times I can't get past this and the hours of sleepless nights and days feeding him, ever hopeful willing him to drink just a few millilitres, gave me too much time to reflect, panic and question everything that has happened, everything that is happening and what could happen in the future. Feeding isn't just the physical process of getting the correct nutrition into your child, its anguish interwoven with fear that he won't drink it, that he will become hospitalised and become really unwell. Feeding your baby is really, really hard."

Reflecting on this now I would say that drinking has become a core fear for our family and that fear of not meeting the fluid target and its impact on our son's health is never far below the surface. To me it also further demonstrates the impact of nutritional support and advice for those within the postpartum period and why perhaps more support is needed for those learning to be parents, as well as learning to be carers, for complex medical needs.

When we first met our son's paediatric renal dietitian at the Evelina London Children's Hospital, we were told: *"She is your new best friend, and you will speak to her a lot."* I think we spoke every few days for the first 2.5 years of my son's life, with constant adjustments and input to make sure his CKD was managed. Each clinic visit involved close work with the paediatric renal consultants and paediatric renal dietitians. This close work and collaborative approach, I think, was the key factor in keeping my son growing and having his CKD managed until his kidney transplant without the need for dialysis.

Weaning experience

My son's milk recipe smelled and tasted awful and at 4 months he went for food. I thought great, baby-led weaning all the way, but sadly that was not possible as he was not getting enough calories. We were unable to offer him several higher potassium foods such as avocado, banana and potatoes. Certain foods had to be cooked in a specific way, boiled for a long time and served without the water it was boiled in. To help improve his weight, foods also had to be high calorie, so everything was mixed with cream, cream cheese, crème fraiche, olive oil and mayonnaise.

Pre-transplant he did not have a sweet tooth, so although we tried hugely to encourage higher calorie foods, some days it just did not work. In solidarity with our son, we tried to prepare foods for us to eat as a family to encourage social eating, and I suspect that has had a lasting impact today. Our saving grace and go to became a very watery soup we referred to as the 'elixir', which was several veggies boiled then combined with fresh water and a stock cube. As he got older, porridge, the 'elixir' and a sandwich with vegan cheese, savoury biscuits and a quarter of a pot of fromage frais became routine; with a high energy, low electrolyte, neutral tasting powder supplement added to his water for additional calories. The way we needed to wean meant that it wasn't possible to pop out for lunch, go to a friends house for tea or buy something off the shelf, everything needed close, careful, management, which impacts way beyond the food consumed.

Post kidney transplant

Post kidney transplant there are many things we still need to think about in terms of a kidney friendly balanced diet. Combine this with a 5-year-old's preference for beans on toast and cheesy pasta and we now have a different set of concerns. Iron remains an issue for us and supporting our son to make good food choices is now essential in maintaining his kidney health and good habits. However, raising the awareness that everything is fundamental to their health feels like a responsibility that could impact their enjoyment of food and asks too much of them. Achieving fluid targets, both pre and post kidney transplant has been, and continues to be, hard work and high levels of encouragement around drinking water needs to be routine at home. For schools and nursery, we highlight that fluid is medication as it does not take much for our son to dehydrate and require hospital treatment. This is a constant concern for us, and we regularly monitor and review his fluid intake. Illnesses can offset the balance and so we are always on high alert.

In summary

The support we received from Triona, our paediatric renal dietitian, and the renal team to get the right nutrition at the right moment was phenomenal. It has set the foundation for how we navigate and support our son to take ownership of his lifelong condition. We are in a fortunate position where we can collaborate with my son's healthcare team; not all parents are.

Learning to be a parent, a carer and a new way of life alongside celebrating your child, navigating the trauma and recovering from pregnancy and childbirth is hard, collaboration and mutual respect in these circumstances is essential.

Nutrition was and is fundamental for our little boy long-term. We are privileged to see him grow into an amazing, energetic, funny and kind little boy. We get to do this because his care is collaborative, evidence-based and tailored to his needs. This early care, we hope will allow him to take ownership and have a full, long and incredibly happy life.