After a healthy pregnancy, our son, Arthur, was born at term by emergency Caesarean, following unexplained HIE (severe oxygen deprivation). He was given a blood transfusion, resuscitated and transferred to NICU where he was given hypothermic cooling for 72 hours to try to limit the damage to his brain and other organs. He was given a 50% chance of surviving his first 24 hours, and we were told to expect him to have a severe disability.

Our time in NICU, like the year that pursued it, was fragmented and splintered. I remember being led to Arthur’s side to meet him, to where his tiny chest rose and fell, fed air by an intubator, as he lay in a plastic box, kept alive by machines and the immeasurable genius of an Indian doctor and the team who flowed around him. I remember spending the first three days of his life reading him nursery stories and singing to him, in-between desperate attempts to interpret an improvement in his EEG. I remember feeling like a broken-hearted porter, pushing Sophie in a wheelchair propped up with thin hospital pillows, from gynaecology to NICU. I learnt to avoid every single rise and bump in the linoleum that would hurt her caesarean wound. I remember looking out over Bristol, alien and wintry, from the hospital and wondering whether Arthur would know this city and its hills. Despite the exceptionally bleak prognosis we initially received, we were discharged when Arthur was 17 days old.

Over the next few months, against all the odds, Arthur was assessed as “developing normally” by many medical professionals. In many ways this was both miraculous and true, and yet failed to acknowledge the full reality of life with a small baby who had suffered a traumatic brain injury. While Arthur was indeed reaching his motor milestones, his sleep was poor and his behaviour and mood were characterised by an exceptional sensitivity and irritability that was overwhelming. Doctors reassured us that irritability at this age was common and would likely fade and that we should “enjoy our child”. There is of course, no way to refute this and yet we felt, as parents, that something was not right.

This irritability worsened steadily, and his babbling fell away, replaced by a near constant growling. It was the end of June and incredibly hot. Quite desperate, we saw a GP who suggested in a very frank and human fashion, that his irritability could be addressed by continuing to try to improve his sleeping habits. We returned home, feeling somewhat buoyed by another “normal” assessment, married to a prosaic, typical treatment.

Arthur woke an hour after he was settled that night. His head was incredibly hot. While I was fetching a thermometer, Sophie saw Arthur make a series of involuntary arm raises, accompanied by eye bulges. I returned to see the last of these. Sophie knew instantly that they were seizures of some kind. An ambulance was called, which arrived very quickly. By this point Arthur was downstairs and was calm. The paramedics did obs and told us they suspected that he had had a febrile convulsion. Based on Arthur’s history, they agreed that taking him to A&E was a sensible precaution. Once there, hours later, the senior consultant confirmed the paramedic’s hypothesis, and said febrile convulsions were common and harmless.

Five days later, after waking from an afternoon nap, Arthur repeated the same movements in a longer cluster. I returned from work to find the house empty, multiple missed calls and a text from Sophie, saying “Arthur did the movements again, we’ve gone to A&E. I think they’re infantile spasms”. And so a horrible prophecy came true.

One of the many things that having a severely ill child denies you, is a relaxed parenthood. With oxygen deprivation, there are a vast number of outcomes and complications. All of your baby’s behaviour is viewed through this prism. And probably the greatest fear that we had was Infantile Spasms. Sophie had discovered IS shortly after Arthur was born while reading about complications associated with HIE.

Now, back in A&E, 5 days after the first cluster, the consultant ceded that in the absence of a temperature, his latest movements could no longer be a febrile convulsion. Arthur was assessed again (“normal”, “lovely”) and we were sent home, and told to return if the movements reoccurred and to video them if possible. Arthur fell asleep in the car on the way home from A&E and awoke as we were parking the car. He immediately had a cluster. This time we filmed it and returned straight to hospital. The consultant reviewed the video and remained convinced it was “normal movements”, but because of Arthur’s history we were admitted for observation on a sideward, to await an EEG the following afternoon.

The process leading to diagnosis was not linear. His EEG didn’t show hypsarthymia, but neither was considered in any way normal. A doctor who witnessed a cluster that evening said it looked like reflux. Despite having about 5 clusters in 24 hours, the following afternoon, the senior neurologist was in fact confirming that it wasn’t IS, when he excused himself to take a call and returned two minutes later to say he had just spoken to a colleague who had advised him, that on the basis of the periodicity of the spasms we had filmed, it was IS.

We pushed for combination treatment (both vigabatrin and prednisolone) immediately. Incredibly, Arthur’s spasms stopped after the first dose of treatment and while we remained in hospital for monitoring for a week, he had no further spasms.

The weeks and months that followed are something of a blur. I remember feeling further banished from the world, stood above Bristol again watching the normal lives of people below and realising there is no word in the English language for the pain a parent feels at not being able to prevent their child’s suffering. The days trammelled to rawest survival, as we watched Arthur disappear, all semblance of routine shredded by the steroid’s side effects.

At night Arthur would alternate between feeding ravenously, or being rocked either in our arms or in a swinging crib, all the while screaming inconsolably. The melatonin we were prescribed to aid his sleep often did nothing and after a certain point in the early morning, I gave in and placed him in his car seat and swung him back and forth him for 20 minutes at a time. Sometimes, I would put him in the car and drive out of Bristol at 5.30am, hoping to get him to sleep.

On the final day of the prednisolone wean, Arthur relapsed. His follow-up EEG, 2 weeks after starting treatment, had been “completely free” of epileptic activity and we had dared dream that we might have crept away from IS without further difficulty. Although his relapse EEG returned clear again, the neurologists believed our videos showed spasms so his vigabatrin dose was increased and he went back up on the prednisolone again. Arthur was on prednisolone for 12 weeks in total.

People ask how you did it, and there is no real answer other than you have no choice. A work colleague, attempting to be supportive, told me in full seriousness that at least I had been denied the trappings of a boring routine. Others simply assume the sleep is a bit off and that “modern medicine” will sort it. And how do you explain what it means when you return home and look at your son and he smiles at you for the first time in 2 months, that his stoic fortitude in the face of HIE, the spasms, and the endless invasions of his being still cannot defeat his spirit?

The second, slower wean of the prednisolone was successful and Arthur came off it at the beginning of October 2019. Following which, weight fell off him. In mid-November he began commando crawling, 2 weeks shy of his first birthday. Every acquired milestone is beyond joyful. Following the beginning of the vigabatrin wean in mid-December he began pulling himself to standing and on Boxing Day, began cruising along the sofa, which was a present that even a week before, we could not have imagined. He is a truly extraordinary boy and everyday he does things that are so beautiful, that I want to cry.

It has been the hardest year of our lives, with very little rest. That said, to arrive at the end of 2019 four months seizure free feels like a blessing. Because of his birth injury and infantile spasms, Arthur is at risk of relapse and further types of epilepsy, but we cling onto hope that when he is off all meds by the end of February 2020 that he remains seizure free.

We are immensely grateful for the ongoing support and insight provided by fellow parents and the UKIST team, who have helped steer our little skiff through the choppiest of waters. And I am beyond happy to say, we have learned to enjoy our son.