

A father's experience of diagnosis and treatment



Our daughter was born prematurely at 27 weeks and developed hydrocephalus after contracting meningitis at two months old at our local hospital. She was diagnosed with hydrocephalus at a district hospital and had her first shunt surgery there at six months old.

When my daughter was three months old, my wife rang me from the district hospital – the doctor had requested a meeting to talk about the results of our daughter's latest MRI scan. After a bungled attempt to put me on speakerphone to hear the news, I stopped working and frantically drove over to the unit, where my wife and I were told that our daughter had developed hydrocephalus.

We had no idea what this meant for our daughter – and neither, it seemed, did her doctors. A parade of increasingly senior paediatricians explained the rudiments of hydrocephalus but couldn't give firm answers on how the condition would affect her brain development. We didn't know how a shunt worked, or if our daughter's head would keep growing and growing. We didn't know if she would grow up with severe disabilities because of this new and unknown condition. All this ambiguity was all the more galling because it seemed so avoidable. Staff on the unit had seen our daughters' head circumference drift upwards and dismissed our concerns. "Babies have large heads," they'd said. "There's nothing to worry about."

Acknowledging their inexperience with hydrocephaly, our neonatal department sent our daughter's MRI scan to a specialist neurology unit in the county and asked for their advice. Their response was positive but vague, stemming from the fact that the unit was busy and the relevant consultant was on annual leave. In the meantime, my daughter's daily routine continued uninterrupted, save for the addition of twice-weekly head circumference measurements.

With that, my wife's resilience finally crumbled. We agreed it was best, after months of living in hospital, that she should stay at her parents' house from now on. By that point she had been thoroughly traumatised not only by the circumstances of our daughters' birth and subsequent infection but a succession of doctors hustling her into side rooms and baldly stating the worst possible news. And so, I elected to stay in the hospital instead.

After about a week we finally sat down with a consultant neurologist. We were both incredibly nervous going in, but we left feeling more confident about our daughter's prognosis. We had gone through uncertainty and we were finally getting straight answers. He told us that a shunt was likely and would almost certainly resolve our daughter's hydrocephaly, but for the moment it was prudent to wait and see if the condition would resolve itself – sometimes, he said, the best shunt is no shunt.

In the meantime, we were told to continue measuring our daughter's head circumference twice-weekly after we'd brought her home and email our findings to a dedicated nurse practitioner. This was hard for us. Our daughter screamed every time we put the tape on her head and, unsurprisingly, we read far too much into whether this millimetre increase or that portended an operation or not – a procedure we ardently hoped we could avoid.

In that period, our nurse practitioner became our rock. She told us that we could call her anytime in the working day and, if we couldn't reach her or needed advice out of hours, to call the ward. We were always able to get an answer. It was reassuring having that consistency in the point of contact. Our daughter had a paediatric consultant at our local hospital, but you weren't dealing with them daily but rather a merry-go-round of registrars and other consultants who happen to be on shift that day.

By the time our daughter had reached six months of age, it became clear that her head circumference was never going to stabilise without a shunt. We agreed to an operation in the summer. Our nurse practitioner did her best to brief us on the practicalities of the procedure and what staying on the ward would be like. My wife and I agreed that it would be best if I were to stay by our daughter's bedside.

Nothing really would have prepared me for those two nights. The doctors and nursing staff were friendly and attentive, but once the lights were put out and the night shift began, the immensity of what was about to happen gradually dawned on me. My daughter would be anaesthetised, placed on a table and a stranger – a superbly-qualified stranger to be sure, but a stranger nonetheless – would drill a hole through her skull and run a thin plastic tube into the centre of her brain. Though her nurse practitioner had assured us that the procedure in of itself was fairly routine as far as the neurologists were concerned, the sight of other patients on the ward in various states of recovery darkened my thoughts. Everything had gone wrong so far – why wouldn't this operation, too?

In the end, it went as well as could be expected. By mid-morning the next day my wife and I had left our daughter in the care of the anaesthetist and were called back about an hour and half later. The operation proceeded swimmingly, we were told. Then we were led to the gurney where our daughter lay asleep, a small bandage above her left eye. She looked ashen. We both wept.

The second night in the hospital was hard. As a father to a premature baby I already felt like a lumbering oaf, paranoid that the normal movements of my fingers, hands or arms as I held her might cause my daughter inadvertent pain and permanent injury – a feeling compounded by her groggy post-operative state, the bandage on her head and the mucky practicalities of changing nappies by torchlight. By dawn, however, glimmers of my daughter's personality began to re-emerge. We took her home in the afternoon and, though her first 24 hours outside the hospital were spent nursing her through the pain of her head and tummy wounds, we gradually observed the positive effects of the operation. She was louder, more alert – ultimately, more herself.

The months since the operation have been largely positive. There was a minor complication – because her skull was still growing, the hole in my daughter's skull let out a tiny amount of CSF into a pocket between the bone and her skin, causing the area above her shunt to inflate – but this disappeared after a couple of months as she spent more and more time upright in her bouncer. Her head circumference also slightly shrank before stabilising. Indeed, her measurements are beginning to even out, with our daughter's head circumference now between the 75th and 50th centile as opposed to being off the chart before her operation.

Our days are now easier. My greatest fear now is, unsurprisingly, shunt failure, and knowing that the neurology unit is best equipped to deal with this scenario I'm minded to disregard the official advice and drive my daughter straight there to deal with the problem instead of wasting time at my local hospital. My wife and I both struggle with PTSD, though its symptoms are beginning to ease – thanks, in large part, to the progress our daughter has made since her shunt operation. At six months corrected her head shape has dramatically improved, she holds her head up perfectly, has taken to weaning like a duck to water and laughs like a drain at whatever weird face I'm pulling at that particular moment. As her paediatrician told us recently, were it not for a small bump above her left ear, you wouldn't know our daughter had hydrocephalus. Long may that continue.