

# The importance of communication during a shunt complication



***Our daughter was born prematurely at our local hospital. She was transferred to our local neurocentre and then on to a national specialist hospital at two weeks old. She was diagnosed with a fused skull and had surgery to try to expand it. Our daughter developed hydrocephalus and had a shunt fitted at ten months old.***

It was during COVID lockdown that our daughter suffered her second shunt failure at two years of age. We were at home alone when she started vomiting and became lethargic. I knew it was a shunt blockage.

***I knew the signs and symptoms to look out for, because of a previous blockage.***

I called 999 and an ambulance arrived swiftly to take our daughter to our local hospital for triage. I told the ambulance team that she urgently needed to go to our neurocentre, a 40 minute drive away, but they would not agree to this. They needed permission from the neurocentre to do this, which was refused when they contacted them.

***We wouldn't call an ambulance again. We would take her straight to our neurocentre, even if meant getting a taxi.***

I contacted our national specialist hospital team and they agreed that our daughter needed to go directly to the neurocentre, due to the complexity of her diagnoses. Our neurosurgeon phoned the neurocentre paediatric team to demand that she be taken directly there, but they refused again.

***It was traumatic for us watching her go through so much.***

The shunt blockage was confirmed by CT scan at our local hospital and our daughter was finally blue-lighted to the neurocentre in the middle of the night over 12 hours later. She was in agony, vomiting, and the local hospital didn't know what to do. I was telling them that she needed iv fluids and paracetamol.

***Do doctors in local hospitals even know about hydrocephalus? Do they understand the emergency? I remember feeling relieved arriving at the neurocentre. We knew she was going to get the treatment she needed.***

Another time, while on a family day out, our daughter fell. She knocked herself out and came round vomiting. She was blue-lighted to the nearest hospital, from where she was discharged home. The vomiting continued and we ended up in our neurocentre where the surgeons were all ready to (consent signed) take her to theatre. Thankfully, the CT scans had gone to the national specialist centre. She had severe concussion and needed surgery to expand her skull, which was done at the national specialist centre some weeks later.

***They phoned me directly and said don't let them take her to theatre.***

This experience was worse as, because of COVID lockdown, we were only allowed one visitor at a time. Our daughter has a strong trauma attachment to me and wouldn't be put down. I felt 'naughty' when husband came in briefly to help.

***Even going to toilet and having a shower was impossible.***

Communication between our nearest neuro centre and our daughter's neuroteam at the national specialist centre is important and the hospitals are now good at liaising. I keep all the medical and shunt information on my phone and our neuroteam at the national specialist centre trust me. This relationship has evolved because our daughter is such a complex case and I feel lucky to have their backing.

***Communication is key. I am involved, and I will phone anybody to get answers. I must hear it for myself.***

We were lucky that the national specialist centre provided training before our daughter was discharged. We were shown a shunt device and taught about signs and symptoms to look out for. I am a very well-informed parent.

***If you have parent who does not/cannot understand hydrocephalus and a doctor who is not aware of it, then that is a scary thought.***

My advice for other parents would be to learn to recognise the signs of a shunt blockage for your child so you can act on it quickly. I used to trust medical professional judgement, but they don't know your child. You know your child best. It is your mother's instinct.

***Go with your gut.***

Don't be afraid to challenge, to call an ambulance, to do what you need to do to get the right support, to ask for second opinion, to ask the radiographer to send scans to your neuroteam at another hospital.

***Everything is heightened in an emergency. Those hours waiting for surgery. A minute feels like an hour.***