

Your experiences of hydrocephalus awareness at your local hospital in a suspected shunt blockage emergency.

1. Background

The standard protocol in the event of a suspected shunt blockage is to take your child to your local hospital for assessment, where the local hospital will arrange onward transfer to the specialist neurological hospital for treatment. We wanted to learn about your experience of this triage procedure and hear your thoughts about the level of support and understanding of hydrocephalus in your local hospital.

2. Insight gathering

We initially posted on Facebook asking you to comment on your experiences (16 comments) and inviting you to get in touch if you were happy to talk to us in more depth (5 remote video interviews).

3. Summary of key themes

Of the responses we received, most of you reported negative experiences at your local hospitals following a suspected shunt blockage. The key themes which emerged were:

- As new parents with no knowledge of hydrocephalus, your local hospital did not provide you with sufficient information about the warning signs of your child's condition'.
- Lack of awareness and understanding of hydrocephalus in local hospitals.
- Lack of knowledge of the signs and symptoms of a shunt blockage.
- Lack of medical professionals trained in neurological emergencies.
- Because of the above, many of you drive past your local hospital directly to your neurosurgery centre in an emergency.
- Poor record sharing and communication between your local hospital and your neurosurgery centre.
- Failure to listen to your concerns, including dismissing your intuitive knowledge of shunt blockage warning signs for your child.
- Improved communication with health professionals reduced anxiety about your child's health.
- Having a trusted, named contact in your neurosurgery department improved your child's care experience and the communication with the family.
- On occasion, you reported long delays for ambulance transfer from your local hospital to your neurosurgery centre.

4. Recommendations

Based on your experiences, we have used your insights and collated your suggestions for improving your acute shunt blockage emergency experience:

- Raise awareness of hydrocephalus amongst all parents to be/new parents including understanding the warning signs.
- Improve awareness and provide training about hydrocephalus and the signs of a shunt blockage for medical professionals in paediatric A&E units in local hospitals.
- Consider including the symptoms of hydrocephalus/shunt blockage in the general 'Paediatric Early Warning Signs' checklist protocol (*as is already the case for suspected meningococcal disease*): 'think hydrocephalus'.
- Review the current protocols for paediatric neurological emergency triage and consider introducing a national standard as for the general 'Paediatric Early Warning Signs' emergency assessment.
- Encourage medical teams to listen to their parents and carers – they know their child best.
- Encourage medical teams to communicate with their patient and their family as much as possible, throughout a shunt blockage emergency.
- Encourage neurological teams to provide families with a named contact, to foster a trusted relationship with the family and to provide greater consistency of care.
- Invest in improving the onward transfer of emergency shunt blockage patients from local hospitals to their neurosurgery centres.

admitted adult advice ambulance away believe breakdown child
decision delays doubt effectively feel felt fight forums frustrating
future help hospital hydrocephalus inform
instinct learn list normal parents transfer trust voice

5. Your words, your experiences

Shared on social media

"I have congenital hydrocephalus and I am registered as a nurse. Unless you specialise in brains, you only know the absolute basics. So, those of us who have shunts really need to be seen at a hospital which has a neurosurgery department. A couple of years ago I landed up in my local A&E and I spent a whole day listening to doctors and nurses handing me over. They didn't know what to do with me. They did bloods, an ECG, an x-ray. Everything came back as normal, and I was discharged and was told to tell my neurosurgeon I had been in A&E."

"My local hospital didn't seem to understand hydrocephalus, or any symptoms of shunt blockage and I was made to feel like an over-anxious parent. My son's treatment hospital was not even consulted by my local hospital on his shunt when he displayed signs of malfunction."

"I pop my son in the car and drive two hours, going straight past my local hospital less than 10 mins away."

"Our local A&E knew nothing about hydrocephalus and didn't even interpret the X-ray right. We would prefer to drive the 40 minutes to our neuro centre than go to our local hospital!"

"It seems so many parents have been told different things for different children. It's interesting to see about local [hospitals] not always being the first ... I think a lot of local hospitals don't have neuro departments and nurses which is a big issue, and some are lucky to live near one or be able to reach them quicker."

"Last month we had to attend our local A&E twice and both times we had to explain and tell them what hydrocephalus/ VP shunt /ETV [were] when my son was poorly. A group of doctors even came in to look at what his shunt was. I feel hydrocephalus awareness is not widely spread."

"Our neurosurgeon told us to just go straight to A&E at the hospital he works at and not bother going to our local one."

"My local hospital has little to no knowledge of hydrocephalus. I feel at times that I knew more than the hospital. I refuse to be seen there now after numerous times being sent home told he was fine and being undiagnosed throughout pregnancy until [my son was] nine months old. My son is now seen at a different hospital further away."

"Our local hospital has been rubbish on both occasions of a malfunction. Almost a week in high dependency for low heart rate and being non-rousable, I pushed them to check her head etc. It took me calling her neuro team and telling them what was happening for them to transfer her on blue lights."

"I've had a mixed experience over the years but generally my local hospital has always been great at getting me straight from there over to Oxford, where they have specialists. But in more recent years I've actually skipped going to the local hospital and gone straight to specialist. Mainly because I've been so poorly that it's been pointless going local, when they can't treat the problem."

"We took our son twice with shunt issues straight to the specialist. We didn't see the point in going to local to wait to be transferred as we were told shunt issues need dealing with asap."

"Our local hospital has said: 'he has what, sorry? A what cyst?'. They also misdiagnosed him from seven weeks till 13 weeks! I was, to them, the ultimate over-anxious first-time mum. A Dr got nurses to stand and watch how I made his bottles to make sure I was doing it properly... in case it was that making him sick."

"Our local hospital has always been incredible."

"We are very lucky our local hospital has a great neuro department. If we go in, I usually phone our neuro nurse (who is based at the hospital) and, if it's during the week, I usually see her that day. She knows my daughter's case, which really helps. The only negative is that, if we go in on Friday or at the weekend, I know that we're going to be in all weekends as the consultants on-call never make a decision and will wait for our consultant to come and see her on Monday. I know if things deteriorate quickly they'll do something about it, but it's just frustrating that we just get monitored for two to three days before a decision is made."

"Our local hospital is incredible and very knowledgeable. Our daughter has had 10 shunt operations in four years. We have had eight emergency admissions: one via A&E and seven via Paediatric Assessment Unit. Each time, they are straight on the phone to our neuro hospital which is over an hour away they are also so aware of our daughter and how fast she goes downhill, especially as her ventricles do not enlarge so can't be picked up on imaging. Most of our delay is waiting for an ambulance for transfer and she is now often transferred with an anaesthetist so they can do a shunt tap on transfer if required."

Detailed interviews

We asked you why you responded to our Facebook post

You felt that it is important to talk openly and educate people, to enable your children to enjoy a normal life. ***“Some people are embarrassed or ashamed of their child having a disability”*** and you want to provide a message of hope to other parents. You also told us that you wanted to change things for new parents and carers and that you were ***“heartbroken to read their experiences on HHAT FB so If I can help anyone, then I will”***. You wanted to share your experiences of great local hospital as ***“they get a bad rep”, “wanted to champion local hospitals”*** to increase awareness of hydrocephalus. You also told us that you ***“wanted give my story to Harry’s Hat so that hopefully my experience can help others or let them know that we share similar experiences. ”***

We asked you what worked well?

You felt that your local hospital experience worked well because the team:

- ***Had a consistent approach***
- ***Followed the same steps each time***
- ***Everything was clearly explained***
- ***They were well-informed, including being fully aware of the hydrocephalus and your child’s shunt details.***

You also told us that communication between hospitals has improved dramatically now that the family have a named neurosurgeon and nurses at the tertiary centre. You contacted SHINE straight away and they helped you access physiotherapy immediately.

Your experiences with your neuro nurses were a positive one: ***“There is an expectation that you know what they’re talking about – but it’s difficult when you’re in shock as a parent”***. The neuro nurses had a bit more time and bridged the gap in communication. They returned to you after doing their ward rounds and answered questions. You have been able to build a trusted relationship with your named neuro nurse and you have also had the same ***“brilliant”*** consultant since your daughter’s birth.

You told us that when the shunt was first fitted that ***“it was as if our son became filled with life”*** and it has ***“greatly improved quality of his life.”*** You have welcomed face to face appointments with specialised nurses.

You told us that when you first arrived at A&E that ***“we were lucky that a doctor was in the reception (which sped up the process) as it did not seem the reception staff understood the severity of hydrocephalus. We then were looked after by an amazing paediatric nurse who was persistent and proactive and genuinely supported us throughout the situation and procedures.”*** This type of experience with staff such as that paediatric nurse, can make a huge difference and improve the experience. It can impact whether we go to certain hospital or not.”

We asked you what could be improved and how?

You would have like **“more explanations of the options”** (i.e., shunt vs other treatments/ management) and There was a huge financial impact on the family’s life as you had to give up work to care for your son. His dad couldn’t be there for the surgeries as he couldn’t afford to take time off work.

You told us that weekend cover did not work well, and your impression was that registrars etc. who cover on the weekend were frightened of the consultants and were consequently wary of making decisions. You were often asked for your opinion but **“sometimes they don’t follow through with it”**.

You told us that you would like to see improved communication and access to patient notes (e.g., NHS app), and that you believe that this would help you manage your child’s care and your anxiety regarding their health. You also told us that **a “peer-to-peer buddy system would have been helpful”** at the beginning of the journey. You also felt that better access to a local neuro centre would improve your care experiences.

You shared that **“initially we felt the treatment was poor with a delay/ misdiagnosis”** and that you **“felt let down by the staff involved- if only they had measured his head sooner, the diagnosis and treatment could have been sooner too.”**



We asked you how these experiences made you feel?

You told us that these experiences were **“frightening,”** that you were fighting to be believed and that you **“felt helpless as parents”, “nothing I can say or do makes them believe me”, “professionals are making decision about your child without listening to you.”** You told us that you **“were afraid that he was going to die”** and that you found it **“so difficult to get support”**. You **“accepted what they said and didn’t question”**.

Regarding the delays for the ambulance transfer you **“felt we were always having to fight and convince the medic at the neurosurgery hospital”** and **“the parents’ instinct was dismissed.”**

When your child was admitted over the weekend, it was **“frustrating being held for the whole weekend”** because care decisions were not made. You have another child at home so feel **“guilty”** spending so much time away at the hospital.

You shared that your initial diagnosis experiences at A&E **“made me feel less hopeful/ have little faith and so I drive to another hospital I have more trust in.”**

Finally, you shared your advice to parents/carers

- **“Trust your instincts: I knew something was wrong”**
- **“You know your child. If in doubt, then take her to the hospital”**
- **“Be firm”**
- **“My voice is her voice”**
- **“Ask questions; make a list every time she is admitted”**
- **“Ask for a breakdown of what happened medically”** (will help inform best practise for future emergencies)
- **“Don’t be afraid to challenge”**

- *"The only way my child this is going to have a normal life is if people are aware of it and can talk about it"*
- *"Be persistent and get seen"*
- *"Be assertive and prepared- make sure to always take snacks to the hospital!"*
- *"Manage healthcare effectively as there is always something to do"*
- *"Don't think too much about the future, especially with multiple diagnoses"*
- *"Educate yourself"*
- *"Learn what is normal and what is not for your child"*
- *"Adult hydrocephalus forums can be useful, I learned that air pressure can affect hydrocephalus"* (This is especially useful as son is non-verbal which can help to understand how he is feeling better).

admitted affect afraid aware best breakdown challenge **child** educate effectively firm
 forums **future** healthcare hospital **hydrocephalus** inform
 instincts **learn** list manage **normal** talk trust **voice**