



Harry's HAT was created to improve the lives of children and their families who are affected by hydrocephalus.

We know that, to achieve this goal, we need to understand the challenges families face and see things from their perspective. We do this through family/carers engagement work which includes gathering insights through social media, online questionnaires, group workshops and 1:1 interviews.

Hydrocephalus requires timely diagnosis and management: Measuring babies' heads can help to identify hydrocephalus.

Very rapid head growth can be a sign of hydrocephalus and head circumference measurement is an important but simple method of identifying children who should be referred for specialist investigation. Current clinical guidelines recommend routine head measurement at birth, at 6-8 weeks old, and at any time where there are concerns about growth or development. However, a consortium of international experts now recommend that the head circumference should be recorded at every encounter with a healthcare professional for the first six-twelve months of life.

Raising awareness of the importance of head circumference measurement: survey of 750 new parents with babies aged 0-12 months

<b>45%</b> did not know that their baby's head should be measured at birth and only 18% were told why their baby's head was being measured.	"My baby hasn't been seen by anyone since he was 2 weeks old, so he has not been measured since then. They left the measuring tape with us, so we are doing our best to do it ourselves."
<b>only 33%</b> had heard of hydrocephalus and 20% knew that measuring a baby's head can help identify hydrocephalus.	"It would be useful to have more information about such conditions, and reasons for measurements, during the antenatal period as well as during the baby checks"
<b>94%</b> would support an initiative encouraging health care professionals to measure babies' heads until their first birthday	"We were in and out of hospital every week until diagnosis. Health visitors didn't visit, so many potential opportunities to diagnose were missed."

Hydrocephalus is the most common condition treated by paediatric neurosurgeons.

Hydrocephalus is most commonly managed by surgical placement of a device called a shunt, which drains excess fluid from the brain to another part of the body. However, shunt complications are frequent. If a shunt fails, the current guidance recommends going into triage at the nearest hospital. Then, onward transfer to a specialist neurosurgical unit for treatment is recommended if required.

Many children will have had more shunt revisions than birthdays.

Experiences of accessing care during a suspected shunt failure: Engagement with 49 families

<b>69%</b> were first seen at local/district A&E departments during a suspected shunt failure.	"My local hospital didn't seem to understand hydrocephalus, nor any symptoms of shunt blockage, and they made me feel like an over-anxious parent."
<b>40%</b> reported increased carer anxiety due to a delay in receiving specialist advice and/or treatment. Further, 28% believed a delay led to a longer in-patient hospital stay.	"Our local A&E knew nothing about hydrocephalus and didn't even interpret the X-ray correctly. We would prefer to drive the 40 minutes to our neuro-centre than go to our local hospital."
<b>65%</b> of families carry copies of their child's medical history with them.	"[I carry] a list on my phone of surgery dates. I also carry with me the whole medical history (discharge notes) and have a back-up version stored on my computer."



Pregnancy and postnatal experiences of hydrocephalus diagnosis and support.

An online survey of 20 parents with children diagnosed with hydrocephalus:

<p><b>64%</b></p> <p>were given no information about a third trimester scan and 42% were not offered one.</p>	<p>"My child was not diagnosed until 8 months old; the news came as a big shock and was very traumatic as surgery was needed immediately."</p>
<p><b>36%</b></p> <p>reported that hydrocephalus was detected during a routine pregnancy scan and 22% during a routine early health check.</p>	<p>"I think it helped that they found out before it started that there was something wrong so she was continuously monitored and everything was done quickly."</p>
<p><b>22%</b></p> <p>reported that hydrocephalus was diagnosed quickly once symptoms appeared. 22% also reported that hydrocephalus was diagnosed after many tests due to unexplained symptoms.</p>	<p>"I feel earlier intervention should have been carried out. I knew he was developmentally delayed, and I believe he began developing when he had his shunt... I am very angry with the system for letting us down. I had regular scans due to his head size, he was in NICU for a week postnatally, we were in and out of hospital every week till diagnosis, health visitors didn't visit. So, so many potential times to diagnose."</p>
<p><b>36%</b></p> <p>would have liked access to parent/carer peer support at the time of diagnosis.</p>	<p>"Feel that there is little support for parents from other parents with similar lived experience which would have been useful to have at diagnosis and afterwards as it's hard to explain the process of shunt revision when it happens to friends and family as although they can empathise, they don't really understand and often have their own feelings towards it as it also impacts them."</p>

Summary of insights and recommendations

Lack of awareness and knowledge of acute hydrocephalus and/or shunt failure amongst healthcare professionals:

Improve awareness and provide training on the detection of hydrocephalus and the signs of a shunt failure for healthcare professionals.

Failure to listen to concerned families in an emergency:

Encourage medical teams to listen to the concerns of parents/carers. They know their child best.

Poor record sharing and communication between local hospitals and specialist neurosurgical centres:

Review the current protocols for paediatric neurological emergency triage and consider including the hydrocephalus/shunt blockage symptoms in the general 'Paediatric Early Warning Signs' checklist.

Improved communication with health professionals reduced parental anxiety about their child's health:

Encourage medical teams to build relationships with patients and families through timely communication and sharing a named contact.

Find out more

You can find out more by visiting us via: [www.harrys-hat.org/get-help/our-research](http://www.harrys-hat.org/get-help/our-research)