

Questions for Your Doctor

Parents of Children with Hydrocephalus

Creating and maintaining a good relationship with your child's doctor is one of the most important elements of overall health care planning. Some people feel nervous when speaking with a doctor, especially a neurosurgeon. It is important, however, to find out about the doctor's experience and whether there is a good "fit" between the doctor and your family before entrusting him or her with the care of your child.

We have compiled a list of questions that we believe are integral to establishing a good relationship with your child's doctor. These questions are worded in a conversational way that is respectful of the neurosurgeon's experience and expertise, and we hope, empowering for you and your family.

We strongly recommend that you take someone with you to the doctor's appointment for comfort, support, advocacy, an impartial opinion, and a second set of ears to review the information with afterward. Try not to go to your doctor alone. Some people like to audiotape their doctor appointments for later referral and clarification.

What caused the hydrocephalus?

What can you tell me about the kind of hydrocephalus that my child has?

In your experience, is this a common condition?

- Do you see a lot of this?
- Is it easily treatable?
- Are there other parents that I could speak to?

(If there is a need for surgery) Will you personally be doing the surgery?

- How many shunt surgeries have you done on children in the last year?
- In general, what were the outcomes?
- What were the common complications, if any?
- Is my child a candidate for the Endoscopic Third Ventriculostomy procedure?
- If so, how many ETV surgeries have you done?
- What is the success rate in children of my child's age?

What kind of shunt(s) do you use?

- Can you tell me a little bit about it (them)?
- Do they have the magnetic/programmable valve?
- Why do you use this one (these)?

What can you tell me about my child's surgery and hospital stay?

- How long will he/she have to stay in the hospital?
- How much of his/her head will you shave?

- I am afraid of brain surgery for my child. Is there anything you can tell me about your personal experience with this surgery that will help allay my fears?

What can you tell me about my child's recovery and follow-up care?

- Who will be in charge of my child's follow-up care?
- How long is the recovery time and what can we expect?
- Will there be any restrictions for my child in terms of activity?
- Do you recommend that my child receive interventional services such as physical therapy (PT) or occupational therapy (OT) after surgery? How do I get connected to these services?
- Do you recommend some regular interval of follow-up visits, including regularly scheduled scans?
- Do I call you when I have a question or if I suspect there is a problem, or do you have a nurse practitioner or clinical nurse specialist?
- Can we go over the signs and symptoms of a shunt malfunction/failure so I am clear on what to watch for?

If the potential complications have not been addressed in the answers above, you may want to ask specifically about them.

I have heard about a couple of complications that I'd like to know more about.

Infection

- Is there anything we can do to proactively strengthen my child's body before the surgery?
- Do you prescribe prophylactic antibiotics?
- How can I recognize the signs of infection?
- What do you do if there is an infection?
- Does infection happen often in your experience?
- How long do I need to continue to watch out for this after my child leaves the hospital?

General questions

- I would like to keep copies of my child's medical records including test results and copies of CTs and MRIs. Who do I speak to in your office about this?
- Are you able to connect me with other families who have a child with hydrocephalus?
- You are a busy person and I appreciate the time you have taken to answer my questions. After I get home and have time to digest all this information I will probably have more questions. Is there a medically knowledgeable person I could call, like a physician's assistant (PA) or nurse practitioner (NP), as these questions arise? Or should I contact you directly?

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