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## **QUESTIONS FOR YOUR DOCTOR: For Teens and Young Adults**

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Creating and maintaining a good relationship with your neurosurgeon is one of the most important elements of your overall healthcare planning. Some people feel nervous when first 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 you before entrusting them with your care.

We have compiled a list of questions that we believe are integral to establishing a good relationship with your child’s doctor. You might want to “try out” these questions with your current neurosurgeon for practice, before you go to a new neurosurgeon for the first time. 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. It’s possible that not all the questions will pertain to you, and there may be other issues that are not listed that are important to you. Remember, this is your chance to take charge, so use our suggestions as a starting point.

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. Do not go to your doctor alone. Some people like to audiotape their doctor appointments for later referral and clarification.

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### **What can you tell me about your experience with hydrocephalus and shunts?**

#### **In your practice, do you have a lot of patients with hydrocephalus?**

- Do you have other teens and young adults you treat?
- Is there a way I may be able to connect with them?

#### **If I need to have surgery will you personally be doing the surgery?**

- How many shunt surgeries have you done (in the last year, ever?) specifically for teenagers and young adults?
- In general, what were the outcomes?
- What were the common complications, if any?
- If you personally cannot perform my surgeries, who would be? May I meet with them?
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#### **What kind of shunt(s) do you use?**

- I have a \_\_\_\_\_ shunt. Do you use these kinds?

#### **In the case of an emergency, who do I call first?**

If I have to go to a hospital emergency room, which one should I go to? Is there anything I should take with me – previous scans, etc?

**What can you tell me about my surgery and hospital stay?**

- How long will I have to stay in the hospital?
- How much of my head will you shave?
- I am little afraid of having to have more brain surgery. 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 recovery and follow-up care?**

- Who will be in charge of my follow-up care?
- How long is the recovery time – when can I expect to get “back on my feet”?
- Who can I call when I have a question or if I suspect there is a problem?

**I have had a few complications (list them). How do you handle problems like this?**

- Insidious shunt failure (shunt failure with very subtle symptoms)
- Infection – I have/nave not had a shunt infection in the past.
  - 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 I leave the hospital?
- Slit Ventricle Syndrome
  - How often does this occur in your personal experience?
  - What steps do you take to prevent this?

**General questions**

- I would like to keep copies of my medical records including test results and copies of CTs and MRIs. Who do I speak to in your office about this?
- Where should I go to get more information about my type of hydrocephalus – or hydrocephalus in general?
- I would like to have medical identification on me like a shunt card or medic alert card. Could you help me go about getting this?
- 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?