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## QUESTIONS FOR YOUR DOCTOR: Adults with Normal Pressure Hydrocephalus

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Creating and maintaining a good relationship with your doctor is one of the most important elements of your overall health care 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" 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 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.

We strongly recommend that you take someone with you to your 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.

*Note:* The first specialist you see during the diagnostic phase may be a neurologist, rather than a neurosurgeon. Some of the questions suggested below are appropriate to ask the neurologist.

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### **What can you tell me about the kind of hydrocephalus I have?**

#### **In your experience, is this a common condition?**

- Do you see a lot of this?
- Is it easily treatable?
- Is there another patient with NPH I could speak with?

#### **What makes you believe a shunt will be helpful for me?**

#### **OR Why do you think that I am a good candidate for a shunt?**

- How have you attributed my symptoms to NPH instead of other cause(s)?
- My symptoms are \_\_\_\_\_. Is it reasonable to think that they will *all* improve with surgery?
- Can you tell me about the different diagnostic/prognostic tests involved with NPH before surgery (i.e. external lumbar drainage)?
- If I decide not to have a shunt, what would be the expected course of my hydrocephalus?

#### **Will you perform the surgery?**

- How many shunt surgeries have you done (in the last year? during your entire practice?) specifically for NPH or other types of hydrocephalus?
- In general, what were the outcomes?
- What were the common complications, if any?
- What kind of shunt(s) do you use? Does it have the magnetic/programmable valve?
- Can you tell me about the endoscopic third ventriculostomy (ETV)?
- Would I be a candidate for an ETV?

### **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 a little afraid of 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”?
- Do you prescribe rehabilitation after surgery? Will I start a program of physical therapy (PT), or what kind of therapy will you suggest to increase my chances of recovery?
- Do you recommend some regular interval of follow-up visits?
- Who can I call when I have a question or if I suspect there is a problem?

*If the potential complications of **infection** and **subdural hematoma** 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
  - What can I do to proactively strengthen my body before 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 watch out for this after I leave the hospital?
- Subdural hematoma (bleeding in the brain)
  - How often does this occur in your personal experience?
  - What steps do you take to prevent this?
  - How do you watch out for it? Is there anything I can watch out for?
  - What happens if I have one?
  - Is there a period of time after which it is no longer a risk?

### **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?
- 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?