
QUESTIONS FOR YOUR DOCTOR: Young and Middle-Aged Adults

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 lists 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. Do not 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.

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

Do you have any reading materials I can take home with me?

Do you know of any groups that I could join for support and resources?

Do you think I have had this condition since birth?

Can you explain why I have become symptomatic now?

In your experience, is this a common condition?

- Do you see a lot of this?
- Is it easily treatable?
- Do you have other young/middle aged adults with the same diagnosis I could speak with?

Do you recommend a shunt or an ETV?

- What makes you believe this treatment will be helpful for me?
- Why do you think that I am a good candidate for a shunt or an ETV?
- My symptoms are _____. Is it reasonable to think that they will *all* improve with surgery?
- How have you attributed my symptoms to hydrocephalus instead of other cause(s)?
- If I decide not to have a shunt or an endoscopic third ventriculostomy, what would be the expected course of my hydrocephalus?

Will you perform the surgery?

- How many shunt surgeries or ETVs have you done (in the last year and during your practice) specifically for young and middle-aged adults?
- In general, what were the outcomes?
- What were the common complications, if any?

What kind of shunt(s) do you use?

- Can you tell me a little bit about it (them)?
- Why do you use this one (these)?

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?
- When will I be able to return to work?
- Do you have any recommendations for what I should tell my co-workers?
- Would you write a letter for my employer explaining my condition and the effect it may have had on my work performance?
- Who can I call when I have a question or if I suspect there is a problem?

I have heard about a complication that I would like to know more about.

- Infection
 - Is there anything I can do to proactively strengthen my 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 I leave the hospital?

General questions

- Who do I call in the case of an emergency? Which emergency room should I go to?
- I have heard about shunt cards, would you help me obtain one?
- 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?