
FACT SHEET

Second Opinions

Even though second opinions are a common and accepted practice in medicine, many people feel uncomfortable asking for them. To some, it feels like a betrayal of their current doctor, or an expression of lack of confidence. To others, the difficulty is determining when and how to seek a second opinion. And, once you have one, how do you assess it? While there are no definitive answers or solutions as every situation is unique, we hope the following information will empower you to do what is best for you, or your family member with hydrocephalus.

The Need for a Second Opinion

First and foremost, we must recognize that the desire for a second opinion is legitimate. After all, we do this all the time in many aspects of our lives: We get multiple bids from contractors and auto repair shops; we switch insurance companies and banks without agonizing over the decision or feeling stupid or traitorous to the original provider. Obviously, the process of making decisions about medical care is a lot more complicated. But it is important to understand that you, as the patient or patient's family, are the ultimate decision maker about who provides health care, and it is imperative that you feel comfortable and respected in this relationship.

Fortunately, most of us are able to build mutually trusting relationships with the professionals involved in our care or the care of our loved ones. The hard question is when to break that pattern—when to trust our own instincts or observations over the judgment of a medical professional. Certainly, there are many valid reasons to seek a second opinion, including the desire for reassurance before making a serious decision. It should never be construed as a reflection on the professional's competence or the patient's trust in him or her. Just because the second, or even the third, opinion agrees with the first does not mean you should not have sought that opinion.

Why a Second Opinion?

One of the first questions to ask yourself is, Why the need for a second opinion? Is it to validate a new diagnosis and/or treatment plan, or for reassurance that the information you have been given is current and up-to-date? Is it because you're frustrated and upset that there have been a series of shunt problems or other medical problems associated with hydrocephalus, like multiple shunt revisions, shunt infections or persistent symptoms, that can't be identified? Perhaps you feel the doctor is not listening to you, not paying attention to what you are saying or not respecting the experience you have as the parent, caregiver or patient.

It's important that you distinguish between needing a second opinion with regard to an identifiable issue and "shopping around"—that is, visiting a number of medical professionals one after another, without resolution. The latter can be a symptom of denial, anger, insecurity or lack of confidence. It is imperative that you take the time to establish clearly in your own mind why you want a second opinion so that you can go forward with confidence.

Communication: A Two-Way Street

The most common reason for seeking a second opinion has to do with the level of communication between the patient (or patient's family) and the medical professional. Neither one of you can make valid decisions without establishing a level of trust and communication. If the communication between the parties is unsatisfactory, the

quality of care is likely to suffer. Sometimes professionals do not present information clearly or don't take the time to answer patient's questions. In some cases, they don't respect the knowledge that you have about your or your family member's condition. As the recipient of care, you have the right to have your questions answered—even if the answer is that there isn't a concrete answer—in a non-intimidating and timely manner. You have the right to be treated with respect.

But remember, this is a two-way street. Sometimes patients hold back details that they think are irrelevant or don't feel comfortable discussing. Sometimes they don't do adequate homework before the medical visit, or take time to be clear in their own minds exactly what they hope will be accomplished. If you're feeling angry, it's important to try to identify where that anger is coming from: Is it rooted in general sadness about your or your child's condition? Are you still trying to cope with the reality of the medical situation—perhaps hoping that it will just magically go away, or that by finding the right physician everything will be better?

There are a number of things to keep in mind as you work through the decision to seek a second opinion:

- You, or your child, may have more than one health-care provider and they may or may not function as a team. Make sure you understand their individual roles as well as the disciplines they represent. What does each specialist know and do? It may be possible that a specialist necessary for your particular situation is missing and needs to be brought onto the medical team. It's also possible that you're addressing your questions and concerns to the wrong member of the team. Try not to be intimidated by physicians; ask for suggestions or recommendations if it appears that your questions fall outside their level of expertise. The desire for a second opinion may actually indicate a need for further discussion or a third-party interpreter, possibly another medical professional involved in the case.
- As in any field, medical professionals vary in degree of competence, experience, sensitivity and the extent to which they keep current with developments in their own field and in other disciplines. They can also have their own biases and personal philosophies that can influence their judgments. It is ultimately up to you to judge whether or not there is a good or right fit between you and the physician.
- And finally, but of great importance, is recognition and acceptance of the fact that there are situations in which there are no concrete solutions or quick fixes for a problem. For example, chronic headaches are a reality for many people with hydrocephalus. In some cases they are indicative of a shunt-related problem; in some cases they are a by-product of a particular situation (such as slit ventricle syndrome), and in others they may be related to other medical problems, work or school related stress. It is important to decide on achievable goals, and then accept that creating a game plan with the current medical team that includes both short and long-term objectives, a timeline, or a difference plan of management may be the realistic and achievable goal.

Finding a Doctor

- Start with your current physician, unless your relationship has completely deteriorated. A caring professional will rarely object to a request for a second opinion. They may even offer suggestions of qualified doctors and possibly even help you arrange an appointment in a timely fashion. It's important that you make it clear to your current physician what you hope to gain from this action. Discuss your objectives and what has led up to your request. Sometimes when you explain just what you are looking for from a second opinion, the existing physician or the health-care team involved in your care may be able to provide it. If that's not the case, then you should ask for a referral to a doctor who your physician knows and respects.

Your physician should be willing to talk with whomever he or she recommends—two smart people considering a problem together will often have a better answer than one alone. Additionally, the field of neurosurgery is small in comparison to other medical specialties, and doctors interested in and experienced with a particular condition such as hydrocephalus will no doubt know one another.

- If your physician refuses to discuss your request for a second opinion, or acts rudely or attempts to intimidate you, your lack of confidence is probably justified and it's time to turn to other sources for assistance. If you do not feel comfortable asking your present physician about a second opinion, then go to another doctor you trust and ask for a referral.
- Your general practitioner (or pediatrician, if this is for your child) or any other doctor that knows your medical history and situation may be able to help. You can also get a list of doctors in a particular specialty from your insurance plan.
- If this is for your child, it's important that you seek out a doctor who either specializes in pediatrics or has a practice that includes lots of children with hydrocephalus. For a teen, young adult or middle-aged adult, your best bet may be a referral to a pediatric neurosurgeon either for direct care or for suggestions for a colleague who has experience with hydrocephalus in your age group.
- In the case of NPH, the quest for a second opinion may be more cumbersome. It's possible that your care has been provided by a neurologist, a general practitioner or an internist who is not well versed or experienced in updated protocols for the diagnosis and treatment for NPH. You may have been misdiagnosed, your symptoms dismissed as part of the aging process, or you may have been initially scared away either by the thought of major surgery or the variable rate of success for surgery for NPH. While there are no guarantees, we strongly suggest that you look for a doctor who is comfortable and experienced with current diagnosis protocols—you may want to get a copy of our resource "Questions for Your Doctor for Adults with Normal Pressure Hydrocephalus." We suspect that, as with children, there is a positive connection between doctors who treat a sizeable number of adult patients and positive outcome.
- Whatever your age or situation, be as diligent as possible in your search for a second opinion. Ask friends and colleagues, co-workers and relatives; networking is a powerful tool. Search the Internet, go to a medical library, call hospitals in your area—many have a doctor referral service. Contact medical schools, university teaching hospitals, local and state medical societies and advocacy groups. The Hydrocephalus Association, for example, publishes both a Directory of Pediatric Neurosurgeons and a Directory of Neurosurgeons for Adults. There are no doubt experienced physicians not listed in our directories, but it's a good place to start.
- While it is obviously more convenient to have your care provided locally, it's possible that you may have to travel to find an expert to consult about your case. If you decide to seek treatment away from home, your doctor should be able to recommend someone locally to provide continuing or emergency care.
- And lastly, contact your insurance company to find out what your policy covers. You may need pre-approval from your provider, or be required to get a second opinion from a doctor who is associated with your plan. Your insurance provider may employ a case manager who can help you. HMOs may deny your request to see someone outside of their plan unless it is authorized in advance. In that case, you should inquire about their appeal process and be prepared to pay the costs involved out of your own pocket. PPOs are usually less restrictive; however, they pay less if you see a physician who is not a participating provider.

Preparing for the Second Opinion

Once you've decided to seek a second opinion, it's important to gather background information so that the physician can evaluate your situation and offer an informed opinion.

- Bring actual films (CT, MRI, x-rays) along with the radiologist's report of the films. If you do not routinely get a personal copy of your films, you will need to contact the facility where they were performed. Most facilities will require the full name and date of birth of the patient, and a signature when you come to pick up the films; some will make you a copy and keep the original. If you take the original, you will be responsible for getting it back to the facility. There may or may not be a charge to get copies of films; it's a good idea to ask in advance. We strongly suggest that when you pick up the films, you look inside the packet to make sure that they are your films, that they are the most current films and that the radiologist's report is included.
- If you have had surgery, a copy of the operating notes can be very helpful, particularly in the case of shunt revision. The notes should contain specific information about the type of shunt you have. If not, get this information from the neurosurgeon or someone in his or her office. You have the right to request a copy of these notes from your physician. Usually he or she will need the request in writing with a date and your signature.
- Write down a detailed description of symptoms: when they began, how long they last and anything that seems to make them better or worse. Keeping a daily or weekly log or diary can be invaluable, for the patient as well as the physician.
- Write down detailed questions that you want to ask and bring them to the appointment. Often, in stressful situations, it is hard to remember all the things we wanted to ask the physician. If your questions are thought out ahead of time and written down, you can give your full attention to listening to the answer the physician gives you and then move on to the next question.

Your preparation might include outlining your questions: what I want to tell the physician; what I want to ask the physician; and, finally, what I want the meeting to accomplish. Whatever the situation, preparation is the key to your search. The Hydrocephalus Association has put together a list of questions to ask a new doctor, and we suggest you review them and take them with you to your appointment. This resource is available in four versions: for parents of infants and children; for teens and young adults; for young and middle-age adult-onset hydrocephalus; and for NPH. Contact our office for a copy.

- Bring a family member or friend with you to the appointment. Having a second set of ears is invaluable, and also a source of personal support.

The better prepared you are, the better the physician will be able to advise you as to all available health-care options.

Assessing a Second Opinion

Congratulations—you've made it through the difficult process of assessing the situation, asserting your needs and getting a second opinion. Now comes another difficult issue: how to assess the second opinion.

- If you've ever been in a room with more than three specialists in the same discipline, then you know there's more than one way to approach a problem. Highly respected and competent physicians often have legitimate disagreements on an appropriate course of treatment or action. Patients, however, are entitled to know the reasons for a particular recommendation so that they can compare probable risks and benefits.

We all know that sometimes there is no right or wrong answer and that smart and talented people often disagree.

- Medical professionals may have available to them, or choose to employ, different diagnostic tools, which may influence their opinions. You have the right to ask questions about a physician's approach and to share conflicting information that you received from another source. But doing your homework and assertively (but not aggressively) sharing what you've learned from another source will do a lot to establish a respectful atmosphere of communication and trust. In the end, of course, the patient or the patient's family must review all the facts and information gathered and make the best possible decision for their situation.
- The Internet is a wonderful resource and certainly there are lots of good reasons to use it for background information. Gathering information about your particular medical problem, participating in a chat room or posting your questions on a bulletin board can expand your knowledge base. However, there is no substitute for hands-on, direct personalized care by a physician. We caution you to use any information gathered from the Internet as just one piece in completing the puzzle.

Making the Decision

There are many benefits to getting a second opinion including gathering more knowledge: understanding both old, new and different treatment options, strengthening your medical care team, putting into place realistic and achievable goals and of course, reassurance and peace of mind that you are making the right decision. The bottom line is that at some point you must make a decision and go with it. Don't use seeking additional opinions as a delaying tactic. Gather your information, review the facts and make the best decision possible. Then don't look back. You did the very best you could.

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For additional resources about hydrocephalus and information about the services of the Hydrocephalus Association, please contact:

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