

Going to the Doctor

Getting the most out of health care services requires you to be an active and vocal consumer. If you feel intimidated, uncomfortable, or forget to ask questions when you visit a doctor, you are not alone.

Visiting a doctor can be highly stressful. Being prepared and having faith in your life experience and common sense will help you avoid feeling intimidated by places and doctors who may appear cold and distant.

Expect that doctors will not know everything they need to about your condition or disability. The information explosion in health care makes it difficult to keep current. Doctors cannot be experts on everything. Plus, the fact that your condition or disability often represents a small percentage of a doctor's practice means it is important that you educate yourself and then your doctors.

Be informed about the health conditions that are of most concern to you. This helps you participate as a partner in your health care. It will also improve the quality of your decision-making.

Anticipate that some health care doctors may not be free of the common negative stereotypes of disability. Unfortunately, people working in medical settings may reinforce these stereotypes because they are exposed to only people with disabilities who are indeed sick. Medical students report that little is taught about disability during their years in medical school.

Consider taking an advocate, family member or friend who can listen, take notes and help ask questions. This is especially important if you tend to forget your questions, freeze, or become less effective as a self-advocate when dealing with health issues. If you take an advocate, family member or friend:

Choose a support person who has the skill to think objectively, is able to listen and remember accurately, and who can offer you emotional support.

Ask them to be there for you and assist you but not take over.

During an appointment, take notes on important information. At the end of a visit, always check your understanding by briefly repeating what you heard the doctor say.

Ask open-ended questions. Avoid leading questions. Leading questions can force doctors to give the answer you want even if it's not true.

Leading question:

"I'm going to be OK, aren't I?"

Open-ended questions:

"What are the chances of my recovery?"

"What is the outlook?"

"What are the implications of the treatment?"

Never be afraid to say, “I’m having trouble understanding. Could you describe the problem in plain terms?” Don’t pretend you understand if you don’t.

Sometimes what you hear may surprise, shock, or upset you. **Don’t hesitate to ask for more time to make a decision that could affect your life.** Ask if delaying your decision will affect the outcome of your treatment. Speaking up is the most powerful tool you have for protecting yourself, and protecting how you want to live your life.

People often hesitate to get a second opinion. It’s your health; get one if you think you need one, particularly if:

- You feel uncomfortable with your doctor or the treatment recommendations.
- You feel what you are being told doesn’t make sense or isn’t right for you.
- You are concerned about a procedure (especially a surgical one). Your provider isn’t sure or doesn’t seem to know what the appropriate course of action should be.
- You are dealing with a life-threatening condition or risk of increased disability.

When the second opinion differs from the first, you may feel confused and decide you want a third opinion. Get one or use a trusted doctor to review the differing recommendations.

When you visit any specialist, **make sure the doctor goes over all your options and answers all your questions to your satisfaction.** Since it may be difficult for you to sort these issues out alone, having a primary care doctor can be beneficial.

If your care is not coordinated through a primary care provider, it may be more difficult to sort out recommendations that are given to you by specialists about complex medical problems.

An additional consideration is that the advice and opinions people with disabilities get for everyday conditions are often not put through a disability filter. For example, at times the doctor may attribute a symptom to your disability when the two are unrelated. Sometimes, a symptom that may in fact be an early warning sign for another condition could be a typical characteristic of your disability.

Selecting a doctor

You can increase your chances for quality care by establishing a long-term relationship. In fact, research confirms that people who are more active in their relationships with their doctor have more positive results. As doctors get to know you, they’re able to see you as an individual.

Talk to your friends, especially those who have disabilities similar to your own, to see if they are familiar with any of the doctors that participate in your health plan. Call the offices of different doctors about the types of patients they see. This will help you pick a primary care doctor that will have at least some familiarity with disability-related issues.

Providers practicing in rehabilitation settings tend to have a stronger knowledge base related to health needs of people with disabilities and often know doctors who offer primary health care for people with disabilities. Primary care providers can coordinate the referrals to sub-specialists who may be able to address your more complex problems.

Experienced primary care doctors are usually familiar with specialists from many different disciplines and they have knowledge regarding the competence and expertise of such doctors. This awareness comes from having referred patients to these specialists on previous occasions and from having evaluated the quality of their consultations.

The experience and familiarity of the primary care doctor with various experts will help to lessen concerns you might have about biased or inappropriate recommendations. Recommendations are usually sent to the primary care provider for review. If the recommendations do not seem appropriate to you and your primary care doctor, get further advice and consultation.

Being an informed health consumer does take time and planning. Follow some of these visit strategies and remember – you have the right and responsibility to ask: Why? Why not? How? When?