

The Role of the Patient/Healthcare Advocate

Imagine your doctor has just given you a serious diagnosis or told you she was concerned about the results of your medical test. You might understandably be frightened. Getting a diagnosis of a serious illness can be an overwhelming experience. Listening carefully to your doctor and asking questions about a diagnosis or test results can help you get better care.

But here's the problem:

Just when you should be paying close attention to what your doctor is saying, you may be stunned by the news you've received. You're likely to be distracted and miss hearing important information. **An advocate can gather that information for you and ask the questions that need to be asked.**

Research shows that quality health care requires taking an active role in decisions about your care. If you're facing a difficult medical decision, **it's a good idea to bring someone with you who can help focus on your care when you're not fully up to it.** It is in these instances when we realize how valuable it is to have "another set of ears and eyes" in the exam room. Having an advocate at medical appointments or during a hospital stay can ensure that you get the information you need to manage your health.

Of course, many encounters with the medical system are routine and don't require the use of a patient advocate. But there are instances when an advocate can be valuable. For example, if you've had a series of tests and you're concerned the results may reveal a diagnosis such as cancer, you might want to bring an advocate with you to hear and discuss the results.

That's when having a health or patient advocate can help. It's likely that you or a loved one will one day need a health advocate. **For many patients, the benefits of having an advocate are priceless because this person can help you understand your options and give you peace of mind so you can focus on your recovery.**

Health advocates can provide a helping hand by:

- Attending doctor visits, lab or radiology appointments, or admissions to hospitals with you.
- Asking questions or voicing concerns to your doctor for you.
- Helping you to communicate to your healthcare provider what kind of help you need and what worries you.
- Assisting you in communication with family members about your condition (with release of information permission).
- Compiling and/ or updating your medicine list.
- Remembering your medication regimen and helping you follow treatment.
- Remembering doctor's instructions, including asking questions about your follow-up care.
- Helping to arrange for transportation.
- Researching treatment options, procedures, doctors, and hospitals.
- Filing paperwork or assisting with insurance matters.
- Asking the "what's next" questions, such as, "If this test is negative what does it mean? If it's positive, will more tests be needed?"

Hiring a Health Advocate

Enlisting a doctor or nurse to be your health advocate can be costly, but there are options. You can hire someone from a home health aide company or organization. These advocates work by the hour. Fees range considerably – from as low as \$15 an hour (often with a minimum number of hours) to much higher – depending on your needs, where you live and other factors. Some health insurance plans cover these services. And some employers provide benefits for this through membership in a patient advocacy company.

It's helpful to give your advocate details of your medical history. For example, you may want to discuss the tests you've had, list medicines you take, and provide any treatment preferences as well as contact information for other family members and your durable power of attorney.

If your advocate doesn't know you well, be certain to let him or her know if your hearing or vision is limited. He or she can alert your medical team to speak clearly and to read instructions aloud if they are not available in large type.

If you can't locate an advocate before an important medical or hospital visit, you can often find a nurse or doctor to serve in this role. Some professional advocates specialize in researching the best available treatments and can assist you at home or in the hospital. Check to see if your health insurance covers these services.

You can also ask your local hospital staff to recommend a patient advocate. In fact, some hospitals and nursing homes employ advocates who work on patients' behalf at no charge.

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Protect Yourself From Hospital Errors

Advocates agree that patients can minimize their risks by keeping a close eye on their care. Hospitals are busy places with lots of moving parts. "You cannot assume that people in the hospital have a really clear idea of who you are or why you're there," says Jean Rexford, director of the Connecticut Center for Patient Safety.

Here are some tips on how to protect yourself:

- Bring an advocate — a friend or family member — especially for check-in and discharge. Many hospitals have a patient advocate or staff person you can consult. Or you can hire your own advocate, but be aware that the profession lacks licensing requirements, so get referrals and check credentials.
- Bring a notebook. Write down all your medications, why you take them and who prescribed them. Include phone numbers of key personal and medical contacts (and don't forget your cellphone and charger). In the hospital, when questions arise, write them down.
- Bring a big bottle of hand sanitizer. Put it by your bed to remind you and the staff to keep hands clean.