

Patient Rights and Responsibilities

Increasingly, patients want to be involved in their own medical care, to learn about their choices, and to participate in decision making. They want a partnership. Creating such an alliance requires commitment from both doctor and patient. Both parties must assume responsibility for communicating effectively, clarifying expectations, and sharing control.

Navigating the healthcare system and becoming a full partner in treatment decisions requires time, effort, and commitment. Understanding both your rights and responsibilities helps you to maximize your chances for a rewarding relationship with your doctor.

Patient rights

Receive considerate and respectful care. Patients have a right to be treated with respect, fairness, and without discrimination. Descriptions by patients of disrespect in medical settings include: poor communication with the doctor, feeling rushed or ignored, lack of dignity during examinations, lengthy waiting room delays, inadequate explanations or advice, inadequate time with doctors during routine visits, feeling that complaints were not taken seriously, and feeling that providers are more concerned with holding down medical costs than giving the best medical care.

Obtain complete information on illness and treatment. In the past, many patients passively sat back and let the doctors make all decisions for them. Times have changed. You now have a well-defined legal, as well as ethical, right to full disclosure of all information related to your health. This includes accurate, easily understood explanations of diagnosis, prognosis, test results, and treatment options (including no treatment).

Disclosure also includes obtaining accurate information about your health plan. You should be fully informed about benefits, costs, and procedures to resolve complaints or appeal decisions. Health professionals are also required to disclose, if asked, their education and board certification, their years of practice, and experience performing specific procedures. They must also tell you if they have a financial interest in any facilities to which they refer you, for example, radiation or laboratory services. If you ask about any financial incentives

or punishments, they need to give you an honest answer. Similarly, healthcare facilities such as hospitals or outpatient facilities need to disclose experience performing surgeries or other procedures, accreditation status, any known measures of quality or consumer satisfaction, and their methods for handling consumer complaints.

Participate in treatment decisions. You have the legal and ethical right to fully participate in all decisions about your medical care. If you are unable to make these decisions, then you have the right to be represented by parents, guardians, or family members. Full participation includes a thorough discussion of all treatment options (including no treatment) in language that you understand, as well as the risks, benefits, and consequences of treatment. Your doctor should answer all of your questions and ask about your preferences concerning the treatment options.

If you choose a treatment that your doctor cannot medically or ethically support, he may explain the possible consequences of your decision or, in serious cases, ask you to find another physician.

Refuse any treatment. If you are an adult of sound mind, you have the right to refuse medical treatment or spurn the services of specific medical caregivers. Refusing treatment at the end of life can be legally accomplished by preparing a living will (also called an advance directive). By statute, health plans and hospitals have an obligation to educate the public about advance directives, and most require patients to fill out living wills upon admission to the hospital. But patients near the end of life sometimes encounter difficulties when they refuse life-extending treatment. These end-of-life misunderstandings (or even disagreements) can be avoided by filling out an advance directive and giving a copy to all of your doctors. You need to discuss your feelings and thoughts on end-of-life care with your primary doctor and, if in the hospital, with all of the caregivers. In case you cannot make these wishes known, legally appoint a healthcare power-of-attorney to make decisions for you. Your loved ones can then ensure that you get all of the care you want and no more.

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Not be kept waiting. Just as you show respect for your doctor's time by arriving for appointments promptly, you should expect the same degree of respect for your time from the doctor. Doctors should do their best to avoid long delays in seeing their patients. If you do have to wait, the doctor should explain the reason and if appropriate, apologize. If lengthy waits are commonplace, you can call before leaving home to ask whether or not the doctor is running on time and whether you will be able to see him at the appointed time. If not, ask how late he is running. In some cases, patients don't mind occasional waits because they appreciate the time the doctor spends with them.

Maintain confidentiality of records. The legal right to confidentiality of healthcare information has been upheld by judicial bodies up to and including the US Supreme Court. Clearly, your doctor has the obligation to protect the confidentiality of your health information. The only staff authorized to see your chart are those who are directly involved in your care. At the same time, current healthcare systems require the sharing of information. For instance, insurance companies and doctors communicate regularly concerning payment for services. Rapid advances in information technology and changes in healthcare delivery can jeopardize your healthcare privacy. Large groups such as provider networks, information management companies, utilization review committees, and quality review committees now request records. If possible, stay aware of the contents of your records through frequent reviews, and give written permission for disclosure only when absolutely necessary. The permission should be very specific as to what can be released and to whom. You should indicate exactly which sections are authorized for release.

The few reasons for disclosure of healthcare information without written consent are: public health reporting, investigation of healthcare fraud, and medical or healthcare research that an institutional review board has determined cannot use anonymous records. In these cases, nonidentifiable information should be used as much as feasible, and no more information than is necessary to fulfill the specific purpose of the disclosure should be allowed.

Get copies of requested records. Medical records are the property of the hospital or the doctor, not the patient. However, most states have laws giving you the right to review, copy, and request amendments to your medical records. One way to get the particulars of your state law is to contact your state legislator's office and ask her to provide the medical record access law for your state. If you run into problems getting copies of your records, it sometimes helps to phone or write to the medical records administrator of the hospital or medical group and ask for help. In addition, copies of medical records are usually provided directly to a new healthcare provider without fee upon receipt of a written authorization. If you are having trouble getting access to your records, you might authorize an MD, dentist, naturopath, or chiropractor to receive the records and turn them over to you.

Right to an advocate. You have the right to bring an advocate to doctor's appointments, procedures, or hospitalizations. Your support person can be a spouse, family member, friend, or anyone you choose. A companion can help you feel at ease, remind you about questions you forgot, and help you remember later what the doctor said. If you've recently learned that you have a serious disease or illness, it helps to have an advocate along to take notes or ensure that all questions are both asked and answered. If you are hospitalized, your support person will make sure you get the correct treatments and medicines.

Patient responsibilities

An excellent relationship requires that both parties shoulder some responsibility for the outcome. The following are but a few of the responsibilities that patients must accept to have a satisfying and smoothly functioning relationship with their doctor.

Treat doctors with courtesy and respect. Doctors have a right to courtesy and kindness just as much as patients do. An environment of mutual respect sets the stage for long-term, satisfying medical relationships. Respectful treatment of physicians includes recognizing that they have values, preferences, and needs, too. Some simple courtesies that should be practiced with doctors are:

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- Arrive on time for appointments.
- Use polite language. “Please” and “Thank you” are always appropriate words to use in any interaction. Abusive language or threats should never occur.
- Use a pleasant tone of voice. A demanding or demeaning tone of voice will not improve your relationship.
- Don’t interrupt. Listen closely to what she says, without interrupting, then share your views.
- Apologize if you have said or done something inconsiderate.
- Clearly state your needs or concerns.
- Use the telephone appropriately. Give the doctor a reasonable amount of time to return your call—don’t repeatedly call unless something urgent happens. You should call your doctor after hours only for true emergencies.

Clarify expectations. Part of your responsibility as an informed patient is to have a realistic view of what doctors can and can’t do. There are illnesses that are difficult to diagnose and some for which no effective treatment exists. It’s reasonable to expect your doctor to make an informed effort to determine the problem, and when he reaches the end of his knowledge, to send you to a specialist for further input. It is not reasonable, however, to expect doctors to be able to successfully treat all illnesses or never make a mistake. Patients sometimes unrealistically expect that doctors know it all or that doctors can instantaneously fix something that has taken weeks, months, or years to develop. Sometimes they want a pill or a treatment that doesn’t include personal involvement such as behavior changes.

Tell the whole story. When you go for an appointment, be prepared. Make a list of concerns or symptoms that you wish to discuss and tell the doctor how many issues you have to discuss. Your doctor also needs to know what prescription drugs and over-the-counter medications you are taking. If you are also using any complementary or alternative therapies (vitamins, herbs, teas),

tell your doctor about those, too. The majority of diagnoses depend solely on what you tell your doctor. In an emergency room visit, chronic or non-acute problems should not be brought up: such complaints only waste time and confuse the issue.

Speak up. Passive patients get plenty of medical advice but not always the best health outcomes. Part of effective communication with your doctor is speaking up about your concerns, thoughts, and values, and asking questions until you understand exactly what you have and what the proposed treatment is. Your doctor cannot factor into the treatment equation your perspective if you do not share it.

Learn about condition and treatment. Partnerships with medical professionals are based on patients taking an active role in learning about their illness and the options for its treatment. Ways to learn about your illness are:

- Ask your doctor questions and make sure you understand the answers.
- Get a second opinion if necessary.
- Research your illness and treatment options.
- Express wishes and concerns clearly.

Share responsibility for decisions. You do not need to blindly follow what your doctor recommends. In the best of all worlds, your doctor would ask how you felt about his proposal and if there are any potential problems with his recommendation. But even if he doesn’t ask, speak up and say what you would like to do and why. For instance, you may have a problem with the pill schedule, or you may not be able to have elective surgery next week due to family problems. The doctor will not know your feelings or life situation unless you tell him. This allows the doctor to explain more fully the proposed treatment or to make an alternate proposal based on your input. Your doctor may simply view the risks and benefits of a course of action differently than you do. After you have shared the full story with your doctor and spoken up about your own feelings and concerns, it’s time to jointly decide on your treatment. One treatment option worth discussing is to do nothing.

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Watchful waiting has fallen out of vogue since technology has boomed and malpractice suits have increased. However, many maladies are self-correcting.

Comply with a mutually acceptable treatment plan. You have the ethical and legal right to fully participate in all treatment decisions. Once the decisions are made, you then have a responsibility to make a good faith effort to comply with the treatment. It is frustrating to doctors when patients do not follow the agreed-upon plan, or even worse, say they did when they didn't. Once you've agreed, follow the plan or call the doctor to tell him why you can't.

Help keep costs down. Healthcare costs have dramatically increased over the last two decades. Patients have a responsibility not only to their individual insurance company or managed care plan to help keep costs down, but also to society as a whole. Healthcare is a limited resource, and the dollars you use for your care are dollars not available to another patient. In addition, profligate use of resources increases the cost for everyone. Healthcare consumers have a responsibility to use only the resources they truly need.

Discuss money and pay all bills. Patients are obligated to pay for the service their doctor provides in a reasonable amount of time. Timely payment allows the doctor to pay employees, benefits, rent, utilities, and other costs. Patients who are tardy cause an accounts receivable problem for doctors, causing the doctor's practice to owe more money than is coming in. If you have a problem paying for your medical care, talk to your doctor and the bookkeeper about it. Often, a payment schedule can be set up to allow you to pay a smaller amount for a longer period of time. Many physicians donate a portion of their services to patients who don't have insurance and cannot afford their care. Rather than just not paying the bill, try to work out a mutually satisfying solution.

Complain constructively. You have a responsibility to complain constructively to your doctor. A laundry list of grievances or an argumentative tone undermines your partnership. Try to focus on just one problem, present it in a positive manner, and conclude with a suggestion

on how to fix it. And remember, doctors deal with ill or injured patients all day long, every working day. They deal with people at their worst who may not be so easy to get along with at their best. It is an emotionally and physically draining job. Unless you speak up, your doctor won't know that something she said or did offended you. It also helps to keep in mind that it's hard to know what one person might find offensive. Each patient is different.

Understand that patient and doctor have different perspectives. Satisfying relationships require recognition that each person has a unique perspective. Differences between patients and doctors can be vast. Just recognizing that the other person has a valuable and crucial viewpoint can build bridges and forge bonds. Recognition that the other view has value allows you to listen quietly without anger or judgment. And from the quiet listening sometimes comes understanding.

Maintain a healthy lifestyle. If doctors could wave a magic wand and get a wish about their patients granted, it most likely would be that they eat well, exercise, and avoid stress, alcohol, and cigarettes. More than 875,000 deaths in the U.S. in 1990 were caused by behaviors that undermine health—totaling over 40 percent of all deaths. The costs to society are staggering—\$179 million from cigarette and alcohol use alone. The old adage “an ounce of prevention is worth a pound of cure” is simple common sense.

This fact sheet was adapted from *Working with Your Doctor: Getting the Healthcare You Deserve*, by Nancy Keene, © 1998 by Patient-Centered Guides. For more information, call **(800) 998-9938** or see www.patient-centers.com.