

**Patients  
Speak Up**

**Be Your  
Own Best  
Advocate**



**PATIENTS  
RISING**

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# About Us



Patients need and deserve ready access to treatments that are right for them. Patients Rising was formed to stand up for patients and to advocate for their rights.

- We are **fighting for access** to vital treatments, medication and services for patients with life-threatening and chronic diseases.
- We are empowering patients to seek and receive the **care they need when they need it**.

Right now, patients are struggling to have their insurance company pay for the medications they need to survive and live a more productive, better quality life. They are often shut out from deciding what treatment is best for them, and they are denied basic rights of privacy and transparency they deserve from their insurance companies. Every patient should have access to the **right treatment—at the right time**.

- We focus on **giving patients a voice**, advocating for giving them access to new treatments and protecting the pipeline of innovative treatments.
- We also urge insurers to pay for precision and personalized medicines that enhance and extend people's lives.

The ultimate decision about treatment should be **between patients and their doctors**, not between the patient, doctor and insurance company. Only the patient can decide what the goals and value of treatment should be.

This **Patient Advocacy Guide** is designed to give patients, family members and other related caregivers and supporters the tools you need to advocate for the right treatment at the right time.

- We give you useful tips on finding others to help you advocate, and how to advocate for yourself. We tell you how you can learn about clinical trials, which lead to innovations that bring hope and extends patients' lives.
- We also provide information on how to deal with doctors and insurance companies, and how to stay on top of the mountains of paperwork you will inevitably collect. We have linked to valuable information from credible health organizations, government websites and other medical sources that will help you find the best information and get the care you need.



**"Reach out.  
Find these groups.  
Find other people that  
can help you along  
in your journey."  
—Chantelle**

## WHO IS A PATIENT ADVOCATE?



Dealing with an illness is stressful for you (the patient) and your families and loved ones. You must deal with many complex and sometimes difficult decisions at a time when you may be in pain and feeling weak. You may feel ready to be your own advocate, as you know your preferences and what you're feeling the best. Consider, also, that it can be very helpful to have someone—a friend, family member or paid professional—be an advocate, looking out for your best interests and helping you navigate through the health care system.

# Choosing a Patient Advocate



When choosing an advocate, consider the following important points:

- 1** Ask your doctor or the facility where you're getting treated if there is someone you can talk with who can help you.
- 2** Focus on finding someone you trust who is willing to work on your behalf, and who will work well with your doctors, nurses and other members of your health care team.
- 3** Pick an advocate who will be assertive and has good communication skills.



For information on being your own advocate, see page 10.

## Family or Friends

The most common patient advocate is a family member or friend. These loved ones may be willing to help, but often need advice on how to be most useful to you.

## Professional Patient Advocates (Navigators)

One type of patient advocate is a paid professional. Hospitals may have professional patient advocates, who may also be called patient navigators. Some hospitals use social workers, nurses or chaplains to advocate for patients. These professionals know the system and may be able to help you cut through red tape. When patients enter the hospital, the hospital is required to give each patient a copy of the Patient Bill of Rights. This usually provides the contact information for a patient advocate.

Professional patient advocates can provide patients information about their disease, access to care and getting into clinical trials. They work with other members of the care team to coordinate the patient's care.

A professional navigator can help identify challenges to care, identify possible solutions with patients and their families, identify financial assistance and help patients identify important questions to ask their doctors.

Some patient navigators work for community-based organizations, or work independently and are hired on a freelance basis directly by patients. Independent patient advocates may focus on one particular disease area, such as cancer. Others focus on billing and health insurance claims. They may help to coordinate care among several providers, accompany patients to medical appointments or sit with them in the hospital.

Two resources for finding patient advocates are the **National Association of Healthcare Advocacy**, which requires members to sign a code of ethics, and the Alliance of Professional Health Advocates, which requires participants to have professional liability insurance.



Questions you may want to ask a patient advocate you are considering hiring include:

- Have you handled other cases similar to mine?
- Do you specialize in a particular area, such as dealing with insurance or billing, or helping patients understand treatment options?
- What do you charge for your services?
- Do you have references?

### **Nurse Navigators**

Nurse navigators are often employed by hospital systems and cancer clinics. These professional nurses help patients through the care system, from diagnosis through treatment and recovery. A nurse navigator assigned to you by a hospital or clinic may not be able to help coordinate care with doctors outside that system, however.

### **For-profit (Employer-based) Advocates**

For-profit patient advocates are part of a health care company that usually contracts with employers, usually at no

**"The patient voice  
is really important  
when it comes to  
legislation that's going  
to impact us directly."  
—Mariah**



cost to the patient. These advocates may be part of your workplace employee assistance program that can help with health care issues. The services vary and are often provided over the phone. Some organizations have care managers that can meet with patients and their health care providers.



# HOW TO USE AN ADVOCATE



When choosing an advocate, first decide what you want the person to help you with, and what you want to handle yourself. Common ways that an advocate can help you is by:

- Accompanying you to medical appointments and treatments
- Spelling out your options for hospitals, doctors, tests and treatment choices
- Helping you get information
- Asking questions and writing down answers
- Ensuring your wishes are carried out if you are not able to do so yourself

Before you engage an advocate, decide how involved you want this person to be in your treatment decisions, and how much you are willing to let them know about your condition. Talk to your doctor and health care team and let them know this person will be your advocate, and how you want them involved. Also let the rest of your family know the role you have chosen for your advocate.

There are a number of forms that patients and their advocates should have on file, including:

**HIPAA release form.** This allows advocates to speak to providers and receive information about the patient's condition, and to have access to the patient's medical records. ([Here](#) is an example).

**Designation of a personal advocate form.** This confirms and records the patient's intention to name a personal advocate. Some states, such as [Michigan](#), have a required form; your hospital patient advocate should be able to tell you if your state requires such a form.

**Advance directives.** These are written statements of a person's wishes regarding medical treatment, made to ensure those wishes are carried out should the person be unable to communicate them to a doctor. Advance directives can take many forms, and laws about them are different in each state. CaringInfo, a national consumer education and engagement

program of the National Hospice and Palliative Care Organization, allows you to download **state-specific advance directives**.

Advance directives include:

- **Health care proxy (medical power of attorney).** This form names a legal agent who will make your medical decisions if you are unable to do so. The form is signed by the patient. A copy (not the original) should be with the patient when they enter the hospital.
- **Living will.** This document tells the medical power of attorney designee what to do if you become incapacitated. This form needs to be completed and signed before hospitalization.
- **DNR (Do Not Resuscitate) form.** This confirms that you do not want to have heart function or breathing restarted. These forms must be obtained and signed by a physician.

# For Advocates: Helping the Patient



If you are a family member or friend of a patient, here are some ways you can be helpful as an advocate, both in the doctor's office and at the hospital.

## Being a Patient Advocate at a Doctor's Visit

Before you go, work out with the patient what your role will be. Ask the patient if you can ask the doctor questions after the exam.

- Always have a pen and notebook, or a note-taking app such as Evernote to write down information the doctors and nurses give you. Write down as much of the conversation as possible between the patient and doctor so the patient can go back and review it later. Also write down the date and time for the next appointment, and what number to call for test results.
- Ask about anything you don't understand. Find out what medication the patient is taking and why/for what purpose. Make a list including name, dosage, frequency and duration (e.g., two weeks vs. daily for the duration of a patient's condition).
- Find out if and when the patient should return for another visit and clarify any next steps. Schedule a follow-up appointment if necessary.
- Ask for several referral recommendations if another specialist is suggested. Ask the provider which of the referrals might be the best fit for the patient you're supporting, based on experience, the case and temperament.
- Ask if the patient should watch for certain warning signs or reactions for their condition, and when they should call the doctor.
- If the patient received a new prescription, ask about possible side effects and what to do about them. Ask about potential interactions with existing medications (refer to your list if necessary).
- Ask how to reach the doctor directly if you or the patient have questions or concerns. Ask if email communication is available.

## BEFORE HEADING TO THE DOCTOR'S OFFICE OR HOSPITAL

Have a binder or log for:

- Bills, paperwork and receipts
- Important contact names and numbers, including caregivers
- Insurance information
- Living wills and health care directives
- Lists of medications and dosages, including supplements and other over-the-counter products routinely taken
- Medical history (tests, procedures, treatments), including family medical history
- Contact information for patient's health care team
- Running log of dates when symptoms started





## In the Hospital

- You can help the patient by staying with them as much as possible. When you aren't able to be there, call the nurse to get updates several times a day. As shifts change, ask who the best contact will be during your absence. Ensure that your contact information is noted on the patient's information board or chart.
- Always have a pen and notebook, or a note-taking app such as Evernote to write down information the doctors and nurses give you. Write down the questions you and the patient you're supporting want to ask the next time you see the doctor or nurse. Keep a running list of the names and roles of the patient's care team, including doctors, nurses, aides and even housekeeping/food service staff. All are essential eyes and ears and their work has an impact on the patient's care.

**"I just want the care to be delivered by a doctor. Period. With no interference, no one coming in between."  
—Bob**

- Ask about anything you don't understand. Ask for written explanations or further reading; ask for the spellings of tests or medications with which you're not familiar.
- Add any medications being administered in the hospital to the patient's medication list. Be sure to ask about why the medications are prescribed and whether there are any interactions with existing medications.
- When the patient is discharged, make sure you understand the discharge instructions.

- Get prescriptions for any new medications the doctor prescribes. Find out if the patient will have any changes to their existing medication regimen—should they continue taking the same medications as before they came to the hospital, or should they stop any of the medications they were taking before?
- If there are new medications, research if they are covered by the patient's insurance. If coverage or cost issues are identified, you can discuss with the prescribing physician whether an alternative is safe and effective, or start the process before discharge of getting the medication approved based on medical necessity.
- Get contact information so you can schedule follow-up appointments with doctors or testing facilities.

# Being Your Own Advocate



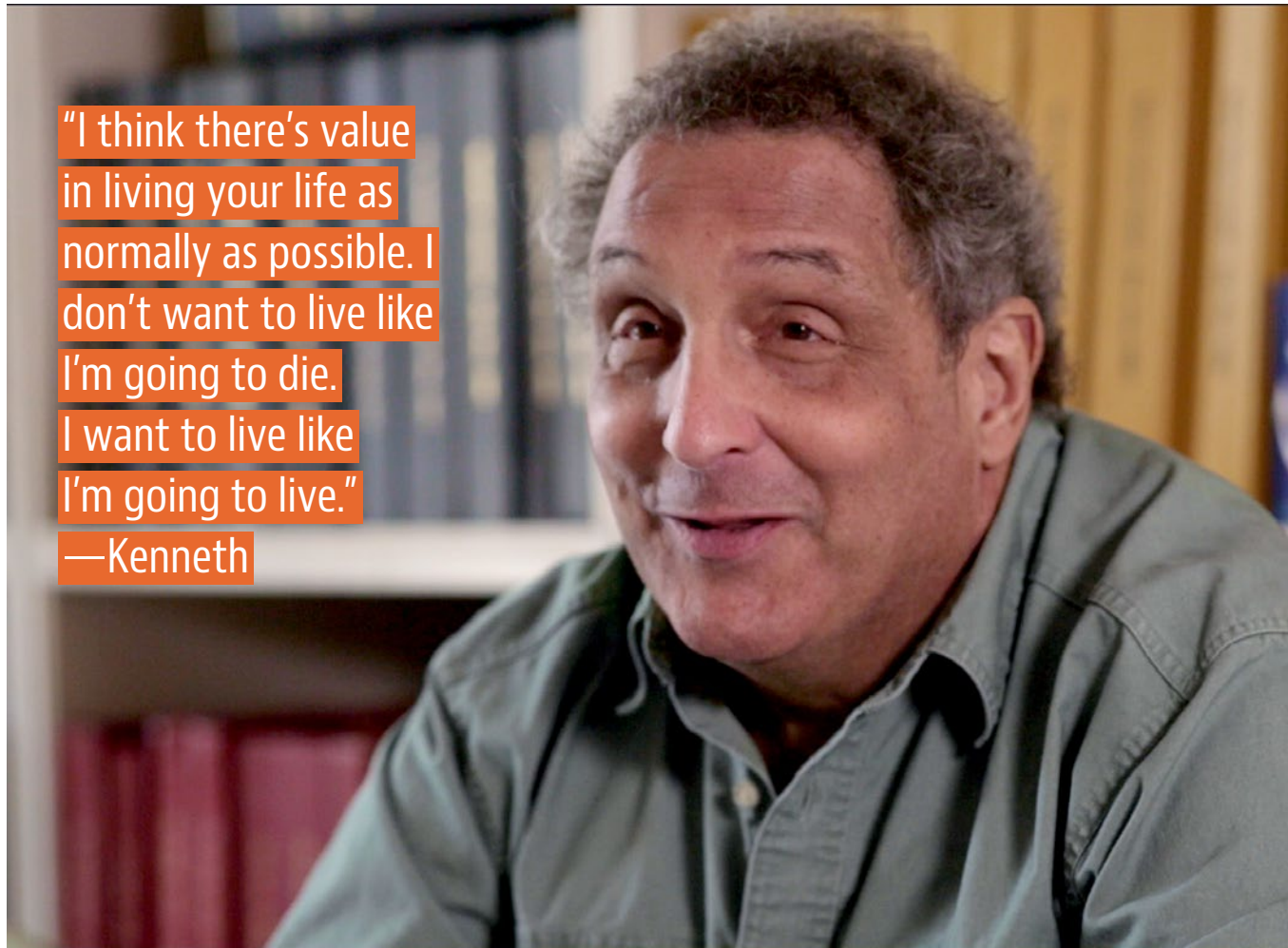
As a patient, you may not have a close family member or friend who is available or able to help you navigate through the health care system, or the resources to hire someone. Whether you're dealing with an initial diagnosis, a recurrence or a chronic condition, there are resources and steps to help you advocate for yourself. Making complex decisions in the midst of trying to recover or heal is a challenge, but you know yourself best and you can get the best from your care team.

## Be Prepared

Stay organized by keeping a binder for bills, paperwork and receipts. Include:

- Important contact names and numbers, including caregivers
- Insurance information
- Living wills and health care directives
- Lists of medications and dosages including supplements or other over-the-counter products you take routinely
- Medical history (tests, procedures, treatments) including family medical history
- Contact information for your health care team
- Diary of dates when you started noticing symptoms that led you to seek care

"I think there's value in living your life as normally as possible. I don't want to live like I'm going to die. I want to live like I'm going to live."  
—Kenneth





## At the Doctor's Office

Make a list of the most important questions you want to cover with your doctor or other care team members. Don't wait until the end of the visit to bring up these questions—you want to have adequate time to discuss your concerns. If you have access to a patient portal, see if you're able to email a list of questions in advance of your next appointment. This may help your care team be better prepared to help you.



## RESOURCES

The **Agency for Healthcare Research and Quality** provides a comprehensive list of questions to ask before, during and after a doctor's appointment, as well as a tool to help patients build their own list of questions.

"Somewhere along the line, there's somebody that's able to diminish my quality of life, and that shouldn't be."  
—David

The [National Institutes of Health](#) has a wealth of information to help you get the most out of your doctor visits. They advise you to:

- Bring someone with you to be an extra set of eyes and ears
- Take notes about what the doctor says, or ask a friend or family member to take notes for you.
- Learn how to access your medical records, so you can keep track of test results, diagnoses, treatments plans, and medications and prepare for your next appointment.

- Ask for the doctor's contact information and their preferred method of communication.
- Remember that nurses and pharmacists are also good sources of information.

Tell your doctor about how your condition is affecting you both physically and emotionally. Be prepared to talk about how your condition is impacting your daily life, and if it is affecting your relationships or preventing you from achieving your goals.

Don't be embarrassed to bring up financial issues related to your care. Some patients may think their doctor can't do anything about costs, or they may not get the best care if they bring up money issues. Your doctor may be able to connect you with a financial assistance program or other resources. He or she may offer to discount their fee, or provide you with free prescription drug samples.

# Communicating With Your Doctor



Medical terms can sound like a foreign language. Each time you talk with your doctor, make sure you understand exactly what they are telling you. If they use medical words and phrases you don't understand, ask them to say it differently until you do understand. It is the doctor's responsibility to explain everything to you in terms you can understand. You need to know what the doctor is telling you in order to make the best choices about your health and treatment.

If you are not sure whether the doctor is listening carefully to you, ask the doctor to repeat back what you just said. This helps to make sure the doctor clearly understood you. If you still have questions at the end of the visit, ask if an additional appointment can be set up, whether the appointment can be extended or if there are other staff members who can answer your questions.

## Do Your Research

Before you visit your doctor, you will want to do some research so you know what to ask. There are an overwhelming number of online resources for medical information, and it's important to know which ones are reliable. Many online health resources are useful, but others may contain inaccurate or misleading information.

- When visiting a health-related website, identify who publishes the website. Is it a government website (with a .gov at the end of the web address) or a nonprofit organization that focuses on your condition (with a .org at the end of the website address)?
- Do the claims on the site seem too good to be true? Was the information posted or reviewed fairly recently?
- Is the information based on scientific research?
- Is the site selling something?



## RESOURCES

A good place to start when you are looking for accurate health information is **MedlinePlus**, sponsored by the National Library of Medicine, which is part of the National Institutes of Health (NIH). The site has information about symptoms, causes, treatment and prevention for over 1000 diseases, illnesses, health conditions and wellness issues. MedlinePlus health topics are regularly reviewed, and links are updated daily.

Another good resource is **healthfinder.gov**, sponsored by the Office of Disease Prevention and Health Promotion in the U.S. Department of Health and Human Services.





## Strive for Shared Decision-Making

Decisions about your medical treatment should be a collaboration between you and your doctor. Your doctor provides you with information about diagnostic or treatment options, and explains the

potential benefits and risks. You explain your preferences about the outcomes you want from these options, what your concerns are and other issues of importance to you, such as convenience and cost. Together, you and your doctor

discuss which treatment plan is best able to meet your needs.

Shared decision-making can be especially important when:

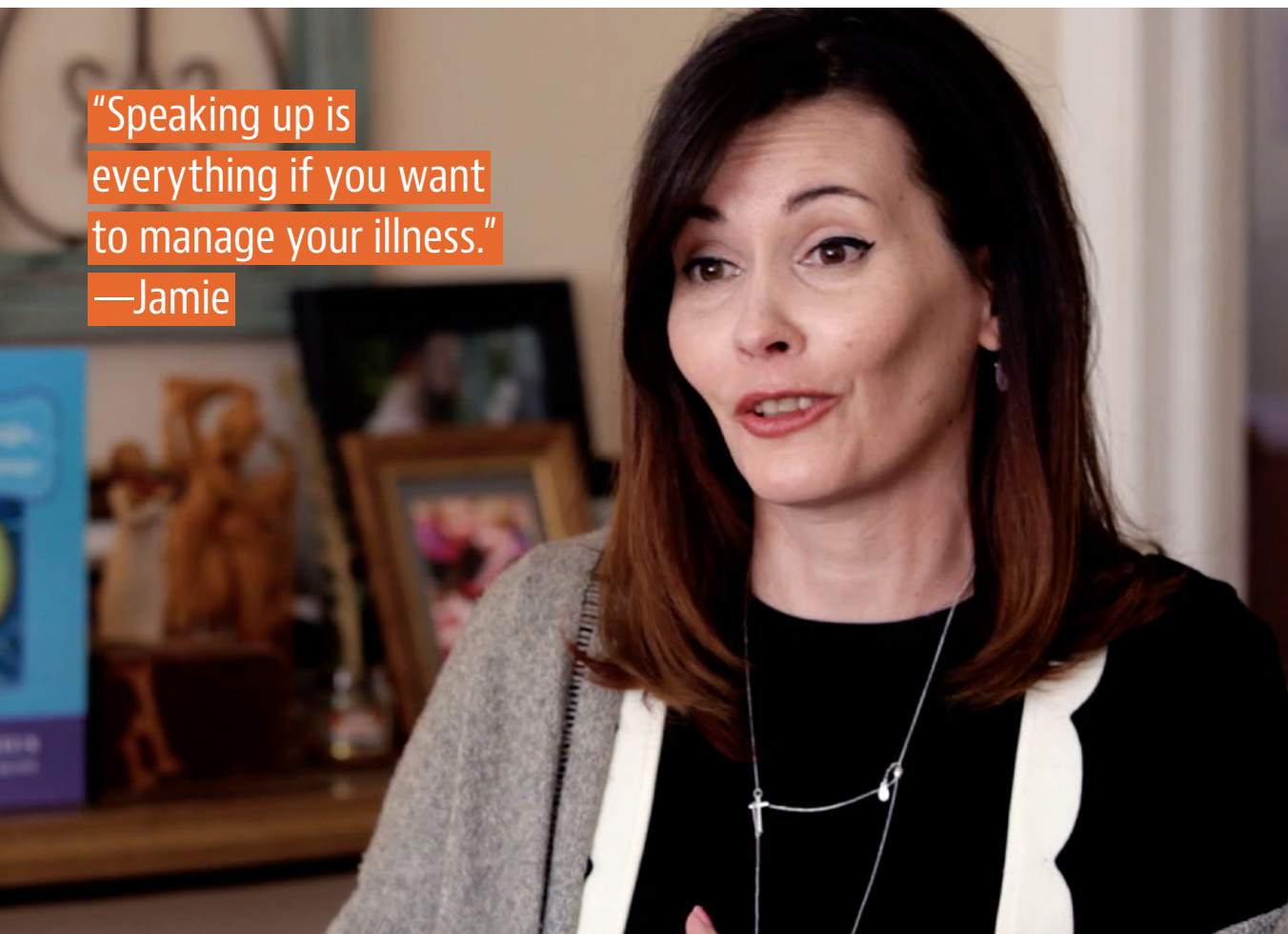
- There is more than one reasonable screening or treatment option
- No one option has a clear advantage
- The possible benefits and harms of each option affect patients differently

Regardless of your specific medical condition, you should ask detailed questions if the doctor suggests a treatment or medical test.

If your doctor suggests a treatment, ask:

- Why are you recommending this treatment?
- What are the expected outcomes?
- What are the pros and cons of this treatment?
- How often will I receive treatment (or how much of the medicine should I take) and for how long?

"Speaking up is everything if you want to manage your illness."  
—Jamie





- How soon do I need to make a decision about treatment?
- Is this treatment covered by insurance? If not, how much will it cost?
- What side effects might you expect? Are any side effects considered severe?
- Are there other treatment options? What are they?

If your doctor suggests a medical test, ask:

- Why you need it, and what the possible outcomes are
- How it is performed
- What the benefits will be
- If it's covered by insurance and if not, how much it costs
- If there are alternatives
- When you can expect to hear results
- If you should phone the office for results, or if the office or testing facility will notify you

## Questions About Your Specific Medical Condition

You will have specific questions and concerns depending on your medical condition. There are a variety of resources available that can help you prepare for your doctor visit and get



## RESOURCES

**Maine Health** has a list of resources to help patients make medical decisions by combining medical information with personal values. Their website includes information that can help you make decisions about many medical tests, medicines, surgeries, and other issues.

The National Learning Consortium also has more information about shared decision-making [here](#).

the information and care you need that is specific to your disease. [Healthfinder.gov](#) is a good place to start to find reliable information about specific diseases. Many health organizations have resources that can help you ask the doctor questions about your specific condition. Here are some examples:

- The Arthritis Foundation has tips for preparing for visiting your arthritis doctor, including a list of words to describe pain, [here](#).
- The Multiple Sclerosis Society has tips for making the most of your visits with your MS doctor [here](#).
- The American Cancer Society has tips for your first visit to the oncologist [here](#).
- For ideas on talking to your doctor about your migraines, [here](#) are tips from the American Migraine Foundation.
- The National Psoriasis Foundation has [ideas](#) for talking to your doctor about psoriasis.





Ask your doctor about good sources of information about your condition— websites, books and other health professionals in the office (nurse, physician assistant, etc.)

### Use Patient Portals

Many health care providers now offer patient portals, which are websites for your personal health care. This online tool can help you keep track of your visits, test results, billing and prescriptions. An important and often overlooked benefit is that you can email your provider questions through the portal. You can let your doctors know ahead of time through the portal what questions you have, to give them time to prepare the answers. You can alert your doctor about side effects you are having from treatment. You can also use the portal to ask any questions you think of once you get home from a visit.

Your provider may get in touch with you through the portal with reminders and alerts. Some portals allow e-visits for minor issues. E-visits, which may have a small cost, allow you to get diagnosis and treatment options online.

**"Decisions affecting patient access to care will be made—whether we speak up or remain silent."  
—Anna**

If you do not already have a patient portal, ask your provider if they offer one, and follow the instructions to register for an account. If you have a child under 18, you may be given access to your child's portal.

The benefit of using a patient portal is that you can communicate with the office when you need to, without having to wait for office hours or return phone calls for basic issues. If you have more than one doctor in a practice, they can all post results and reminders in the portal, and they can see what other treatments and advice you are receiving. If you have an urgent issue, you should still call the doctor's office instead of waiting for an online response.

### Advocating for Yourself in the Hospital

If you are admitted to a hospital for treatment, ask who you can speak to who can help you. This includes language support, a social worker or patient advocate. Ask that the contact information for those individuals be given to you and posted on your patient information board so you can call on them directly.

If you have a concern about how you are being treated in the hospital, speak up immediately, when the problem is occurring. Talk to someone directly involved in your care, such as your doctor or nurse, or the nurse manager or social worker for your floor. Clearly state what you want the hospital to do.

If you feel your needs are not being addressed, you can ask to speak to the hospital's customer service or patient representative, the hospital's Patient Safety/Quality Care officer, or the hospital's patient advocacy office (or customer service office).



If you are contacting the hospital about a problem after you have been discharged, focus on what went wrong, and what can be done now. Clearly describe the problem, the questions you have, and how the hospital can make things better. Keep copies of all correspondence, and keep a log of all phone calls, including dates and the names of people you speak to.

You can also get these thoughts across in a letter. [Click here](#) for information about writing a complaint letter from Health Care for All, a Massachusetts nonprofit advocacy organization.



**"When I reclaimed my hope,  
it was stronger and more  
realistic than before."**

**—Kerrie**

# Getting Help With Access to Treatment



Even with the best preparation and a great care team, you may have difficulty getting access to the right treatment for you. There are many factors involved in determining how easy or hard it is to get access to the right treatment. These can include whether you have insurance, and if so, what type (Medicare, Medicaid or private insurance); who your healthcare provider is, where you live, and which medical condition(s) you have.

Depending on the answers to these questions, there may be resources to help you gain access to the treatment you need. These can include pharmaceutical companies, nonprofit groups and state programs.

Many states have medication assistance programs. Often these programs are designed for the elderly, disabled or people in financial need. Some programs are for people with specific medical conditions such as end-stage kidney disease or HIV/AIDS.

## Support for Medicaid and Medicare Patients

For **Medicaid** patients, the state ombudsman programs can be a resource for claims denials. Find information about [your state's Medicaid program](#) here.

For **Medicare** patients, you can find information on [appeals if you have Medicare prescription drug coverage here](#), and information on appeals if you have a Medicare health plan [here](#).

Beneficiaries are directed to their State Health Insurance Assistance Program (SHIP). You can find the phone number for your state's SHIP by visiting [Medicare.gov/contacts](https://www.Medicare.gov/contacts) or by calling 1-800-MEDICARE (1-800-633-4227). TTY users should call 1-877-486-2048. Or visit this link to search for your state SHIP contact information: <https://www.shiptacenter.org/allstate/va/>

## Support for Uninsured or "Under-insured" Patients

**WebMD** has put together a list of assistance programs run by nonprofit groups including:

- **Partnership for Prescription Assistance:** A program sponsored by drug companies, doctors, patient advocacy organizations, and civic groups. It helps low-income, uninsured patients get free or low-cost, brand-name medications.
- **RxAssist:** An online database of drug company programs that provide free or affordable drugs and co-pay assistance.
- **Center for Benefits Access:** Provided by the National Council on Aging, this shares information about assistance programs for low-income seniors and young people with disabilities.
- **RxHope:** A web-based resource where you can search by medication to locate assistance programs. They also offer help with the application process.



- **RxOutreach**: A mail-order pharmacy for people with little to **no health insurance** coverage.

Other helpful resources include:

- The **Patient Advocate Foundation** has a resource directory for underinsured patients who currently have health insurance but are still struggling to meet the out-of-pocket cost demands.
- **FreeDrugCard.us**, a free national nonprofit prescription access program designed to help Americans lower their prescription drug costs.
- **National Organization for Rare Disorders** (NORD) assists underinsured individuals with co-payments for medications related to the patient's diagnose of a rare disorder. NORD also provides counseling and a comprehensive database of disease-specific information.



### Your Right to a Second Opinion

It is quite common today to seek a second opinion. It is your right as a patient to get a second opinion. You will get more information that will help you decide your choice of treatment.

Most doctors are comfortable with a request to seek a second opinion. Some

insurance companies even require one before they will cover certain treatments.

There are many reasons to seek a second opinion. Some patients want to affirm that what their doctor has recommended is the best course of action. Patients with a more rare disease who are not being treated at a major





teaching hospital may want to consult a specialist who regularly treats the disease. If you can't be seen by the specialist on a regular basis, the specialist may be able to consult with your doctor and make a recommendation about treatment. He or she may know about clinical trials and specialized treatment that you can benefit from.

Other reasons you may want to get a second opinion include:

- You want to be sure you understand all your treatment options
- Your doctor is not sure about your diagnosis
- Your condition is rare
- You are deciding between more than one treatment option
- You are having trouble communicating with your doctor, and you want to discuss your options with another doctor

**"Access to innovative treatments is crucial to living with rheumatoid arthritis."**

**—Mariah**

If you're unsure how to ask your doctor for a second opinion, the [American Cancer Society](#) has suggestions for how to jump-start the conversation:

- "I'm thinking of getting a second opinion. Can you recommend someone?"
- "Before we start treatment, I'd like to get a second opinion. Will you help me with that?"
- "If you had my type of cancer, who would you see for a second opinion?"
- "I think that I'd like to talk with another doctor to be sure I have all my bases covered."

## **Preparing to Get a Second Opinion**

Before you go for a second opinion, call your insurance company to find out what they will cover. Some companies will only pay for a second opinion if you get one from another doctor who is part of your health plan.

Once your appointment is set, gather all of the following information to bring (and keep copies for yourself):

- A copy of the pathology report from any biopsy or surgery
- A copy of any surgical reports
- If you were hospitalized, a copy of the discharge summary
- A summary of your doctor's current treatment plan
- A list of all your drugs, drug doses and when you took them

Your doctor's office will be able to give you a copy of your medical records. The medical records department of the hospital will have records of any treatment you received in the hospital.



## Evaluating the Second Opinion

If the doctor who provides a second opinion has a different approach than your doctor, it can be difficult to decide how to proceed. The American Cancer Society recommends some steps you can take:

- Ask both doctors to explain how they interpreted your test results, what research studies or professional guidelines they consulted, and how they arrived at their treatment plan.
- Ask what they have recommended to other patients in your same situation
- Ask if the two doctors would agree to review your case together
- You may want to get a third opinion from another specialist— such as a pathologist, surgeon, medical oncologist, or radiation oncologist — to talk about the two opinions and give you their view.
- Become informed about your condition, and research the latest treatment guidelines on your condition. For example, if you have cancer, check the National

Comprehensive Cancer Network (NCCN) Treatment Guidelines ([www.nccn.org](http://www.nccn.org)) and the National Cancer Institute's (NCI) PDQ®

Cancer Treatment Summaries ([www.cancer.gov](http://www.cancer.gov)). They have information for both health professionals and patients.

## CHANGING DOCTORS

Your doctor should be your partner through every step of your illness and recovery. If you don't feel comfortable with your doctor for any reason, it's time for a change.

Some patients may decide to find a new doctor if their current physician dismisses their complaints, tells them nothing can be done, spends too little time with them, interrupts them often, writes a prescription with little explanation of why, or recommends treatments without considering the patient's lifestyle.

If you do decide to switch, ask for your medical records right away. You have a right to receive either a paper copy, or an electronic copy (if it's available), and have your doctor send them to another physician on your behalf. It is legal for doctors to charge a "reasonable" fee for sending your medical records.

When picking a new doctor, make sure he or she is accepting new patients and accepts your insurance plan. Ask if they are board-certified, and check whether they are affiliated with hospitals of your choice. Find out about how soon the doctor generally gets back to patients, how after-hours medical problems are dealt with, and whether the office accommodates same-day appointments.



# CLINICAL TRIALS



Clinical trials are at the heart of all advances in medicine. They lead to new innovations in preventing, detecting and treating disease. They allow researchers to test new treatments, and new ways to use existing treatments. Clinical trials determine if new treatments are safe and effective.

There are many reasons to participate in a clinical trial. Some people want the chance to receive new treatments and to have additional care and attention. Participating in a clinical trial also helps researchers find better treatments in the future for other people who have the same disease. By participating in a clinical trial, you could be helping to save lives.

The **National Institutes of Health** has detailed information on clinical trials, including what you need to know if you are thinking about participating,

what questions you should ask if you are offered a clinical trial, how you are protected if you do participate, and what happens after a clinical trial is completed.

The government's **ClinicalTrials.gov** website provides a comprehensive database of clinical trials in the United States and around the world. Their database is searchable by disease, location and study phase.

"One novel therapy leads to another novel therapy, which will lead to another."

—Bob



## RESOURCES

Other resources for clinical trials include:

- **Lighting the Way: A Practical Guide to Clinical Trials** (Patient Advocate Foundation)
- **Clinical Trials** (American Cancer Society)
- **Guide to Understanding Clinical Trials** (American Heart Association)

# Dealing With Health Insurance



So many aspects of health insurance can be confusing—figuring out what type to get, knowing how to use it once you have it, and learning what to do if your claims are denied.

FAIR Health, a national, independent, nonprofit that aims to bring transparency and clarity to healthcare costs and health insurance information, provides a [comprehensive series of guides and videos](#) to explain health insurance. They have information on health plans from employers, an exchange/marketplace or a union, or one that you bought directly from an insurer.

Their website explains many common insurance questions, including:

- What do the terms in my Explanation of Benefits ([EOB](#)) mean?
- How are [in-network](#) and [out-of-network](#) care different? How do they affect my costs?

**"Let the doctor make the decision!"**  
—George

- What are [co-pays](#), [co-insurance](#) and [deductibles](#)?
- What should I think about before I [choose a medical or dental insurance plan](#)?
- I saw an in-network doctor. [Why did I get a bill?](#)
- What do I do if my [claim was denied](#)?
- How can I use my [Flexible Spending Plan](#) to pay for my healthcare costs?

## What to Do When Your Insurance Company Says No

Insurance denials come in many forms. [The Alliance for the Adoption of Innovations in Medicine](#) has identified four of the most common insurance roadblocks:

- **Adverse Tiering:** a method used to discourage patients with certain conditions from enrolling in a health plan by placing newer drugs for diseases like cancer and HIV on the highest copayment tier. A 2015 study in The New England Journal of Medicine found that some insurers participating in the state health exchanges placed all HIV therapies on the highest tier, meaning enrollees in these plans paid more than twice as much for their drugs as those in other plans.
- **Non-medical Switching:** a practice where the health plan switches patients who are stable on a medication to a different treatment for nonmedical reasons by refusing to cover the therapy any longer or significantly increasing the copay.



While insurers use this practice to control costs, patients may experience negative side effects of the new treatment regimen or become less responsive to treatment even if returned to their original medication.

- **Prior Authorization:** a process requiring physicians and other health care providers to obtain advance approval from a health plan before a procedure, service, device, or medication is given to a patient and

qualifies for payment coverage. Prior authorization can lead to delays in treatment. In a 2010 American Medical Association survey of 2,400 physicians, two-thirds reported waiting several days to receive authorization for drugs, while 10 percent waited more than a week.

- **Step Therapy:** a policy sometimes referred to as “fail first” that requires the individual to try one or more less expensive treatments first and “fail” on them before the health plan will cover the one prescribed by the provider. Step therapy not only delays effective treatment, but multiple studies show the practice increases the costs to the health care system, particularly for hospital and emergency-room care.

- **Co-Insurance**
- **High Deductible Plan**
- **Out-of-Network Charges**

If your insurance company denies your claim, you have rights to fight back.



“Never give up hope.  
Don’t give up the fight.  
There’s help out there.”  
—Diane



Aimed Alliance has launched “**Know Your Health Insurance Rights**”—a website that offers specifics steps to take if your insurer improperly delays or denies your coverage. That can include: filing an appeal directly with the insurance company, requesting an outside review by an independent third party, or filing a complaint with the insurance commissioner or attorney general in your state.

Your odds of reversing your insurance company’s decision are better than you think. That goes for internal appeals directly with your insurance company and external appeals with an outside government agency.

According to a **2011 report by the Government Accounting Office**, patients who filed internal appeals directly with their insurance company saw insurance companies reverse their initial denial 39 to 59 percent of the time. In 2009, 54 percent of patients in California succeeded in reversing or revising an insurance denial through the external appeal process.

In other words, it pays to fight your insurance company and file an appeal.

## Health Insurance: How to Request an Internal Appeal

If your insurer denies your claim, you have the right to an internal appeal. This means you can ask your insurer to conduct a full and fair review of its decision. To appeal the denial, you **should do the following**:

- **Review the determination letter.** Your insurer should have sent you a determination letter to tell you that it would not cover your claim. Review this document so you can understand why your insurer denied your claim and how you can appeal the denial.
- **Collect information.** In addition to the determination letter, collect all documents that your insurer sent to you, including your insurance policy and your insurer’s medical necessity criteria. “Medical necessity criteria” refers to your insurer’s policy for determining whether a treatment or service is necessary for your condition.
- **Request documents.** If your insurer did not send you the determination letter, your policy, the medical necessity criteria, or instructions

and forms for filing an appeal, call your insurer and request these documents.

- **Call your health care provider’s office.** Contact your health care provider’s office to ask for help with the appeals process. Someone in his or her office might help you fill out the forms to request an appeal and draft a strong appeal letter.
- **Submit the appeal request.** You or someone in your health care provider’s office should submit the appeal forms along with the letter from your health care provider and any additional information that your insurer requested. Be sure to follow your insurer’s instructions closely and make a copy for your own records of all documents you or your health care provider submitted to the insurer.
- **Request an expedited internal appeal, if applicable.** If your case is urgent, you should contact your insurer and ask for instructions on how to apply for an expedited internal appeal. Your situation is urgent if



waiting 30 days would seriously jeopardize your health, life, or ability to regain function.

- **Follow up.** Follow up with your insurer regularly until you hear back. Be sure to keep a record of the name of any representative you speak with about the appeal, the date and time you spoke with that person, a confirmation number for the call, and a summary of your discussion.

The Patient Advocate Foundation also provides extensive information on appealing insurance denials, including a booklet called “[Navigating the Insurance Appeals Process](#).”

### Keep Track of Your Medical Bills

There’s no one best way to keep track of your medical bills. Some people are more comfortable with paper files, while others prefer keeping electronic records. Once you decide the way you want to keep track of your medical bills, you can find many tools to help you.

“My doctor is willing  
to have a conversation  
with me and try  
any of the options  
that are available...  
and my insurance  
company says no.”  
—Eileen

[Cancer.net](#) has put together an essential list of all the information you should keep track of to help you manage payment of medical bills:

- Records of each appointment, including the date and any lab work, tests, or procedures that took place
- The name and dose of each drug prescribed and the name of the doctor
- Copies of checks and credit card receipts for co-pays and other health care costs

- A current copy of your health insurance coverage
- Bills and invoices from health care providers, such as doctor’s offices, hospitals, or labs
- Insurance claims filed by you, your doctor, or your hospital
- Explanation of benefits statements from your insurance company for processed claims
- Insurance reimbursements you’ve received
- Insurance claim rejections you’ve received and appeal letters you’ve written

You are allowed to deduct from your taxes the amount of your total medical expenses that are more than **10% of your adjusted gross income**. If you think your medical expenses will reach or exceed Internal Revenue Service minimums, keep track of travel, meal and telephone expenses related to your medical care.



## Tools for Tracking Medical Bills

**Calendar:** Using either a paper or electronic calendar, record all your medical appointments, tests, procedures and prescription drug purchases the day they occur so you don't forget. You can refer to the calendar for insurance claims and tax purposes.

**Paper Tracking:** You can use a pad of paper to record the payment status for medical services. Add columns for the date of the appointment, the doctor's name, the amount paid (with the date), the insurance claim status and other notes.

**Electronic Tracking:** You can use spreadsheet software to track this information. There is software available that provides a template to view and manage medical data, as well as templates for writing letters to dispute rejected insurance claims. Or you can create your own spreadsheet. Update the list or spreadsheet every time you receive a bill or insurance statement, or pay a bill.

There are websites that will save your insurance information and help you manage medical bills. Examine them closely—some may charge a fee, and others may not have adequate security to protect your data and privacy.

## Going Over Insurance Statements

You may get several bills for the same care. If you had surgery, you may get bills from the surgeon, the anesthesiologist and the hospital. If you had an X-ray, you may get separate bills from the imaging facility and the radiologist who read the image.

When you get the medical bill, compare it with the insurance statement. Make both have the correct date, provider and type of medical care. Make sure you understand how much of the bill you are expected to pay (the amount your insurer says you owe). If the medical bill is incorrect or unclear, call the provider's billing office. Call your insurer if you have any questions about your health insurance statement. If the insurance company won't cover a service your policy says should be covered, file an appeal (see section above).

## FILING YOUR DOCUMENTS

You can set up a paper filing system with separate files for insurance statements, bills and receipts of payment, or you can scan these documents and save them on your computer. Organize bills by date of service.

An insurance statement can be about more than one medical bill. Make a copy of the statement and match it with each separate bill it mentions. Include any payment receipts and updated statements about those bills.

Medicare has an online tool for storing and accessing personal information: [here](#).



# It's Your Journey: You Are Your Best Advocate



When you are ill, you may feel you don't have the time or energy to take on the role of advocate to fight for the treatment you need—and get those treatments paid for. But that is exactly what patients have to do. We are here to provide the resources to help you. Don't give up—you are your best advocate for getting the right treatment at the right time.

## How Patients Rising Can Support You

Sign up for our weekly email newsletter. We'll send you an engaging and informative summary of the top issues impacting patients and caregivers access to vital therapies and essential services for chronic illnesses.

Patients Rising wants you to [share your story](#) about your treatment successes, failures and ongoing struggles. Whether insurance companies are not responding to your needs, health care is bringing you down, or you want to tell us about your success in solving a patient problem, we want to hear from you. Your personal touch can help and inspire others to act. We will share your stories to build support for reform.

"The biggest thing we need to focus on is that our voices—patients' voices—need to be louder."  
—Jamie



## RESOURCES

Support Patients Rising:

- [Join us](#)
- [Make a donation](#)

Connect with us on social media:

- [Facebook](#)
- [Twitter](#)
- [YouTube](#)

We host events for patients on living with a variety of medical conditions, including psoriasis, migraine, blood diseases, multiple sclerosis, arthritis, atopic dermatitis, osteoporosis, lung cancer and more. Visit our [Upcoming Events](#) page to see what's coming up. Contact us to suggest future events.

[Sign our petition](#) that calls on insurance companies to allow patients to access their right medications, decide what treatment is best for them, and have the basic rights of privacy and transparency they deserve. We need our health care coverage to treat us as individuals, not policy numbers.

Attend an event of [Patients Rising University](#). These events are designed to provide tools and teaching for patients and advocates with the desire to learn new ways to navigate an increasingly complex health care system and ensure that the patient voice isn't muted when regulatory decisions and policy choices are made.

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