Moving Forward After a Diagnosis

Engaging With Your Medical Team

When faced with a new diagnosis or if you have been managing a chronic illness for quite some time, there is a lot of information to take in, such as available treatment options or strategies to reduce insurance barriers. As a patient, you will hear medical and clinical terms, which can certainly be overwhelming. To help make sense of your situation, consider these tips when discussing your treatment:

- Bring someone with you to your appointment. They can ask questions you may not think of and help you take notes. Or with your provider’s permission, record the conversation to review later.

- Write down your questions before your doctor’s visit. List the most important ones first to ensure they are answered and leave space to write down the answers for future reference.

- Ask your provider to show you diagrams or drawings that may help increase your understanding. It’s important for you to fully comprehend your treatment plan. If you don’t, ask to spend time with a nurse to discuss your concerns.

- Get to know your treatment team. Your treatment team may consist of any number of specialists. Remember that your primary care doctor is also an important part of your team, so be sure to keep them in the loop.

- It’s okay to take your time deciding on the best course of treatment for you. Allow yourself time to ask questions, conduct your own research, speak with family and friends, or seek a second opinion, without feeling rushed by your doctor. Remember that it’s also okay to ask your doctors questions about the cost of your care and treatment.

Becoming an Empowered Patient

It’s important to realize that you can improve your medical outcomes by taking responsibility for your own healthcare decisions. Start to form a partnership with your providers and participate fully in the process so you can make the most out of your care. Being engaged from the beginning will help both you and your providers. Here are some tips that might help you get started:

- Research to become an expert on your own diagnosis

- Make the most out of every appointment with your specialist

- Ensure you understand your health insurance benefits and limitations

- Speak up if something doesn’t feel right. You know your body better than anyone else
Emotional Support is Crucial

Emotional support is a component of treatment and recovery that is often overlooked. Caring for your emotional well-being is an integral part of your care. A chronic disease diagnosis can be life-altering and may cause a lot of emotional unrest for you and your family or caregivers. Also, research and patient experience shows that focusing on your emotional health can be beneficial to your overall wellness.

Consider seeking these types of resources to help you find the support that works best for you:

- Peer connections of others with your diagnosis
- Support groups (both in-person and online)
- Professional-led therapy (in-person, via phone, and online)
- Faith-based emotional support sessions are regularly hosted by local churches and are often open to the community
- Provider-sponsored or endorsed support groups. Ask your doctor for a list
- And over one hundred support organizations which can be found in Patient Advocate Foundation's Resource Directory online at www.patientadvocate.org/financial
Questions to Ask

Making informed choices about the care that is best for you involves having the right information available to you. It can be difficult to know where to start or what questions to ask when faced with such a big decision. Take it one step at a time, beginning with asking questions about your diagnosis, your treatment plan, and other impacts on your life. Below is a list of topics that are easily missed in conversations with doctors, that can help guide your decision-making process.

Understanding your treatment options and choosing your plan

What is my recommended treatment plan? Why was this plan chosen for me?

Are other treatment options not available or recommended for me?

What risks and benefits are associated with the treatment?

Am I able to participate in clinical trials?

What is the goal of my treatment? What does success mean?

Where will I receive treatment (in the hospital, in the doctor’s office, or at home)?

Will you or another specialist oversee my care and treatment?

Will I need someone to drive me to and from treatment?

What are the possible side effects of my treatment? How can these be managed?

Clinical trials are often thought of as a last option after other treatments have failed. Actually, some clinical trials are more effective in the early stages of treatment.

Ask yourself whether your doctor’s goals align with your goals for treatment. If not, this is important to discuss.

If you have other pre-existing medical conditions like diabetes or heart disease, it is crucial to keep your other doctors briefed on your diagnosis and treatment.

You can call your insurance company using the member services number on your insurance card and discuss coverage for your treatment plan. Always double check that the medical team is within your coverage network.
Seeking Financial Assistance

Planning for the cost of care begins with asking about the cost of care. A chronic illness can influence all parts of your life, and can certainly impact your finances, even if you’re insured with comprehensive coverage. For the majority of patients, the cost of treatment and care will strain your monthly budgets and savings account. While you are in treatment, chronic illness may also impact your ability to work and bring income to your household.

Within many medical offices today, there are patient advocates or financial counselors that can assist you with filing for government financial assistance programs and ensure you’re receiving employment protections. Your doctor and other providers may also be able to offer you payment options if you alert them to any financial challenges you may be experiencing. Additionally, there are non-profit organizations and programs that may be able to offer patients help paying for medical bills, insurance co-pays, and/or prescription costs.

Be honest with your medical team about how you are dealing with care costs. It will not reduce the options available to you, but your doctors want to lessen the impact and stress of worrying about the finances and will offer help when they can. A chronic disease diagnosis doesn’t have to ruin your financial health.

The good news is there are resources available to you to assist in planning and managing the financial aspect of your care, both within your doctor’s office and from outside programs.


Brought to you by the professional case management team at Patient Advocate Foundation, this self-help tool assists insured and uninsured patients to quickly locate programs and resources for a broad range of needs including housing, utilities, food, clinical trial assistance, medical devices, pharmaceutical agents, and transportation to medical treatment. Learn more at www.patientadvocate.org/financial

Certified Resources
Each resource has been thoroughly researched to ensure that it is immediately useful to patients.

Direct Help
The directory focuses only on the resources that can directly impact and help those in need.

Powerful Search
Fully customize your search and filter results based on age, location, insurance status, and illness or disease. Search for resources based on over 35 unique assistance categories.

Emailed Results
Results containing a resource list with contact information can be directly emailed for future reference.

Custom Description
A custom description tells you exactly what you need to know in order to quickly assess a resource’s usefulness to your unique situation.

Understanding how your diagnosis affects your life

How will this care impact my work? Can I work at the same level? Will I need to take time off of work for my treatments and recovery?

Who else should I inform to help and coordinate my care?

What does my caregiver or family need to know about my care?

How much of my treatment and care is covered by my insurance? What are the costs I will be required to pay?

Who can I talk to about concerns over cost? Is there someone in your office available to discuss this?
Informed Choices Let You Take the Lead

In the same way that we have many options when we purchase an item from a retail store, every patient has a variety of treatment options available. Treatment plans may include standard therapies which are successful for most patients, or cutting-edge and promising therapies new to the market. Your doctor may want to utilize a personalized treatment based on your disease type, complimentary or holistic approaches, or a combination approach.

The decision is ultimately yours to make based on the information you have available. There are a number of factors to consider – genetics, characteristics of your illness, fertility, age, side effects, other medical conditions you may have, your doctor’s past successful outcomes and more. It is your right, and your responsibility, to ask questions before and during your treatment.

Resist the idea that you are a passive participant of the process. Instead, be the leader in your treatment plan!

Ask why your medical team has designed the specific treatment plan for you and why other options are not recommended in your case. Do not be afraid to seek a second opinion, even if you have no reason to disagree with your doctor. Sometimes another medical professional can give a fresh perspective or can confirm what your original medical team has suggested. In any case, more information will only help you feel confident in your choices.

Second Opinions Are Always an Option

A second opinion is when another doctor reviews your medical records to give you advice based on their training and expertise, most frequently to provide diagnosis or treatment recommendations. In fact, doctors often encourage you to seek a second opinion, and should not take it personally. Most insurance providers will cover the visit and it is so common that many doctors assume you will get one. You can even ask your doctor for suggestions on whom to visit for a second opinion. Otherwise, you can contact your health insurance for a list of providers within your network.

Below is a scenario illustrating why second opinions are important:

Jason used an in-network doctor to review some symptoms he was experiencing. He was given a diagnosis and told he would need to have surgery. He was concerned about his diagnosis and worried about the upcoming surgery, so he scheduled a second opinion. When he had the second consultation and more blood testing was completed, it turned out that he actually had an infection that was easily treated with antibiotics. It was Jason’s intuition and instincts that ensured he had a much easier (and cheaper!) path to wellness.

Antibiotics! Surgery!
You purchased a health insurance policy and hoped you would never have to use it. But now that you have a diagnosis that requires treatment, you may be worried about how much you will have to pay out of pocket for your care. The design of the insurance plan (HMO, PPO, HDHP) you chose during your open enrollment period determines what you’ll be required to pay. Depending on the type of plan you picked, the cost-sharing amounts defined below should help make sense of what your health insurance will pay, and what you will be responsible for when it comes to the cost of your care.

**Cost-Sharing Basics**

**Deductible**  
The amount you pay out-of-pocket before your plan pays anything for the healthcare services you received.

**Co-Payment**  
The amount you pay when you receive care. The co-payment amount is set by the insurance company not the doctor’s office.

**Co-Insurance**  
The percentage of costs you pay after you meet the plan’s deductible.

**Out-of-Pocket Maximum**  
A cap on the amount of money you have to pay for covered health care services in a plan year. If you reach that limit, your health plan will pay 100% of all covered health care costs for the rest of the plan year.

Here are some **tips** to help you stretch your dollar where healthcare is concerned:

- **Make sure you are staying in your plan's network of providers.** Utilizing in-network facilities, doctors, and labs will help lower costs. And sometimes the language you use makes a difference. For example, when asking if a provider is in-network with your insurance plan, make sure you ask if the provider is contracted with your plan, not just if they accept it.

- **If your provider prescribes a brand-name medication, ask if the generic would be just as effective.** Most often, generic medications are significantly cheaper than brand-name medications, and are required to have the same dosage, safety, strength, route of administration, quality, and performance. If your doctor has no problem swapping out brand for generic, it could mean more money in your pocket.

- **If you have a procedure or treatment planned, it is well within your patient rights to ask for a cost estimate upfront.** Getting a cost estimate of your procedure can ensure that you have time to plan for the costs or find another in-network provider that may offer a cheaper rate for the same treatment.