



Patient Advocacy: How Patients Can Gain Control

Patients will feel more in control over their healthcare situation if they are informed, understand their rights and advocate for themselves.

By Annaben Kazemi

Millions of patients and caregivers across the U.S. are faced with illnesses and difficulties accessing healthcare. These individuals find themselves trapped in a maze of access issues, financial worries and emotional strain. No matter what the diagnosis, the process of getting the best healthcare is often rife with red tape and confusion.

For individuals with primary immunodeficiency diseases (PIDDs), one of the greatest challenges is finding the right information and resources when they need them. But, the more information they can obtain, the more capable they will be to make decisions that can ultimately impact their healthcare, long-term insurability and financial stability. Here are some tips to help these individuals advocate for a better personal healthcare experience.

Be Informed

Knowledge is power. Patients need to get educated about their particular health concerns before entering their doctor's office. They should think preemptively about the treatment desired and whether it will work, rather than just appearing at their doctor's office and asking for advice about a particular health condition. They can also conduct their own research and become educated about the various screenings, tests and treatments available. Antoinette Dziejczak, the nursing campus chair at the University of Phoenix Detroit Campus and former president of the Michigan Public Health Association, suggests preparing for medical appointments "by checking reliable online health resources to review the latest research or brush up on fundamentals." She also recommends patients ask practitioners questions. The more patients learn about their diagnoses, the more in control they will ultimately feel.

All patients have the right to seek and receive all the information necessary to understand their medical situation. The same is true concerning insurance. Patients should take the initiative to manage their healthcare before a crisis arises. Most patients receive healthcare through some form of managed care plan: a health maintenance organization, preferred provider organization or point-of-service option. These plans provide an evidence of coverage (EOC) booklet that should be reviewed. The EOC booklet will list detailed information about what is covered and what is not. In addition, before receiving treatment, the insurance provider should be called to ensure that treatment will be covered. An insurance customer service representative can also explain the plan's policies and

procedures. And, because health plans often change, patients should stay updated on the latest information.

For patients with multiple health insurance coverage, each type of coverage is called a "payer." When there is more than one payer, coordination of benefits rules decide which one pays first. The primary payer pays what it owes on your bills first, and then sends the remaining balance to the secondary payer. In some cases, there may also be a third payer. This can be confusing, so questions should be asked and advice should be sought if it's unclear which payer covers what.

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Patients on Medicare or Medicaid can review the benefits to find out if tests, items or services are covered. Understanding Medicare coverage, including Parts A, B, C and D, MediGap and Medicare Supplemental Plans, is a challenge for most patients. However, there are resources to help. One is *A Clear View to Medicare* published by the Patient Advocate Foundation. This clear and easy-to-understand booklet helps Medicare-enrolled patients and those eligible for Medicare make the most of their benefits. Another resource is the Medicare Coordination of Benefits Contractor, which can answer questions about who pays first.

More and more, patients find themselves struggling to meet out-of-pocket expenses associated with their medical and pharmaceutical needs and are seeking assistance. "Most hospitals have generous financial-assistance programs to help trim large bills even if your household income is above the poverty line," states Tony Dale, founder and chairman of The Karis Group, an Austin-based patient advocacy and bill-mediation service. If patients are unable to pay the full amount of a bill, doctors' offices often will offer an income-based sliding scale program. And, many pharmaceutical manufacturers have

patient assistance programs that serve as resource centers for patients. These pharmaceutical companies can help direct patients to internal and independent resources that help reduce the cost of medication for insured and uninsured patients, assist with insurance and pharmacy documentation, or generate the paperwork needed for appeals.

Patient Rights

Patients have certain rights. Some are guaranteed by federal law such as the right to get a copy of their medical

records and the right to keep them private. Many states have additional laws protecting patients. And, healthcare facilities often have a patient bill of rights.

An important patient right is informed consent. This means that when patients need treatment, the healthcare provider must give all information needed to make a decision. Patients have the right to engage in conversation with the healthcare provider regarding options for therapies and services, regardless of health insurance policies. And, they have the right to refuse treatment or stop a procedure.

Advocacy Resources

Sometimes, patients need an advocate to help with the challenges of living with a diagnosis or illness. An advocate can be anyone who is willing to be an active liaison between patients and their insurers, employers and creditors. While a friend, family member, healthcare professional, social worker or educator can act as an advocate, there also are many organizations that offer free advocacy services to chronically ill patients.

Below is a list of organizations providing information and online resources and referrals. Many offer free advocacy services.

Patient Advocate Foundation (PAF) is a national 501(c)(3) non-profit organization that provides professional case management services to Americans with chronic, life-threatening and debilitating illnesses. PAF case managers serve as active liaisons between the patient and their insurer, employer and/or creditors to resolve insurance, job retention and/or debt crisis matters as they relate to their diagnosis. These liaisons are assisted by doctors and healthcare attorneys. www.patientadvocate.org/resources.php

The Immune Deficiency Foundation (IDF) Advocacy Center was created to help solve some of the problems that the primary immunodeficiency disease community faces. IDF's full-scale program at both national and state healthcare levels focuses on one main concern: access to quality care. This includes access to all treatments, all sites of care and specialists. primaryimmune.org/idf-advocacy-center

Patient Services Inc. evaluates individuals' financial, medical and insurance situations to determine if they are eligible for premium or co-payment assistance. The organi-

zation provides help for many illnesses and offers many types of financial assistance. www.patientservicesinc.org

At healthcare.gov, individuals can learn about, compare and apply for insurance plans. A simple tool allows them to preview marketplace health plans and view price estimates without filling out an application. Also included are important details such as deductibles, co-payments and out-of-pocket maximums, as well as links to a summary of benefits, the provider network, drug coverage rules and customer service contacts. www.healthcare.gov

InsureUSToday provides information on the Affordable Care Act and insurance marketplaces to inform individuals how the law benefits them. Included is a contact form where individuals can ask specific questions of a professional case manager. www.insureustoday.org

Co-Pay Relief is a patient assistance program to help those who meet certain qualifications pay for out-of-pocket expenses for prescriptions and/or treatments. www.copays.org

www.medicare.gov provides information on Medicare, resolving disputes and help with costs and benefits. www.medicare.gov

At the National Health Council Resource Directory, patients with chronic diseases and disabilities and their family caregivers can find links to various patient advocacy groups, government services and useful resources. www.nationalhealthcouncil.org

IG Living's Ask the Experts is a question-and-answer resource for patients with issues related to immune-mediated diseases. Patients' information is kept confidential. www.igliving.com/asktheexperts.aspx

Patients also have the right to choose medical personnel who can deliver quality healthcare for their disease state. If they so choose, patients have the right to request second opinions or consultations without consequence. Should there be concerns, problems or complaints about the quality of care or service received, a formal grievance may be filed.

Any decision rendered by the health plan can be appealed (most plans provide information in the EOC booklet on the appeal process). Kevin Lembo, the first healthcare advocate for the state of Connecticut, tells patients and their caregivers: "Any time you're on the phone with your insurer, take notes: the date, what you asked, what they answered. If you need to appeal a claim denial, it helps to have a paper trail."

Health plans are required to follow state and federal rules for handling their enrollees' complaints and appeals inside the health plan, known as an "internal review." And, many states have additional legislative procedures outside of the health plan, called "external reviews" or "independent reviews," to provide an unbiased way to resolve disputes between patients and their health plans. An external review is a reconsideration of a health plan's denial of service, with the review conducted by a person or panel of individuals who are not part of the plan.

Be an Advocate

Frequently, patients find themselves acting as their own advocates. Being proactive puts patients in control of healthcare outcomes. Here are some key points for those advocating for themselves:

- **Study before the appointment.** Trisha Torrey, a patient advocacy expert, says that showing up with a stack of computer printouts can imply that patients think their research equals another person's years of experience. Instead, patients should study information online, and then say, "I've seen articles about a new type of treatment; what do you know about it?"

- **Ask any and all questions.** Patients should ask pharmacists, nurses and physicians questions concerning treatments or any prescribed medication's purpose, proper dose, side effects and drug interactions. Also, they shouldn't hesitate to inquire if any alternative treatment options exist.

- **Track down a receptive healthcare provider.** Patients should find a provider with whom they are comfortable confiding their health prognoses and concerns,

even if this means seeking second and third opinions. Dr. Paul Haidet, staff physician at the DeBakey VA Medical Center in Houston, emphasizes that "the ideal doctor-patient relationship is like a meeting of two 'experts.' The doctor comes to the meeting with medical expertise. The patient is entering with contextual knowledge."

- **Know insurance benefits and coverage, and review bills monthly.** Caryn Isaacs, a nationally recognized health policy analyst, regulatory expert and professional patient advocate, recommends patients ask for itemization of bills and clarification. In addition, patients should check to see if that doctor's office offers different fees. A lot of times, they can get a negotiated rate if they can't pay the full amount of a medical bill.

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- **Keep proper documentation.** A detailed log of all appointments, conversations and medications should be kept. When on the phone or at appointments, patients should take notes. And, they should keep an organized file (either electronically or physically) of medical conditions, treatments and financial statements.

- **Keep a health journal.** A journal can help patients organize and keep track of symptoms, changes in health and general wellness habits, as well as help keep them abreast of any changes, responses to treatment or other medical details that, in turn, they can share with their healthcare providers. Patients can jot down questions in the journal as they come to mind.

- **Find a support group.** Dealing with the complex aspects of an ongoing illness can cause anxiety and stress, so it is important for patients to have psychological and emotional support. H. Kenneth Schueler, the director of HKS Patient Advocates in New York City, advises that "disease advocacy groups can offer educational seminars, summaries of clinical trial results, emotional support and more." To find one, patients can Google "advocacy" and the name of their disease. ■

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