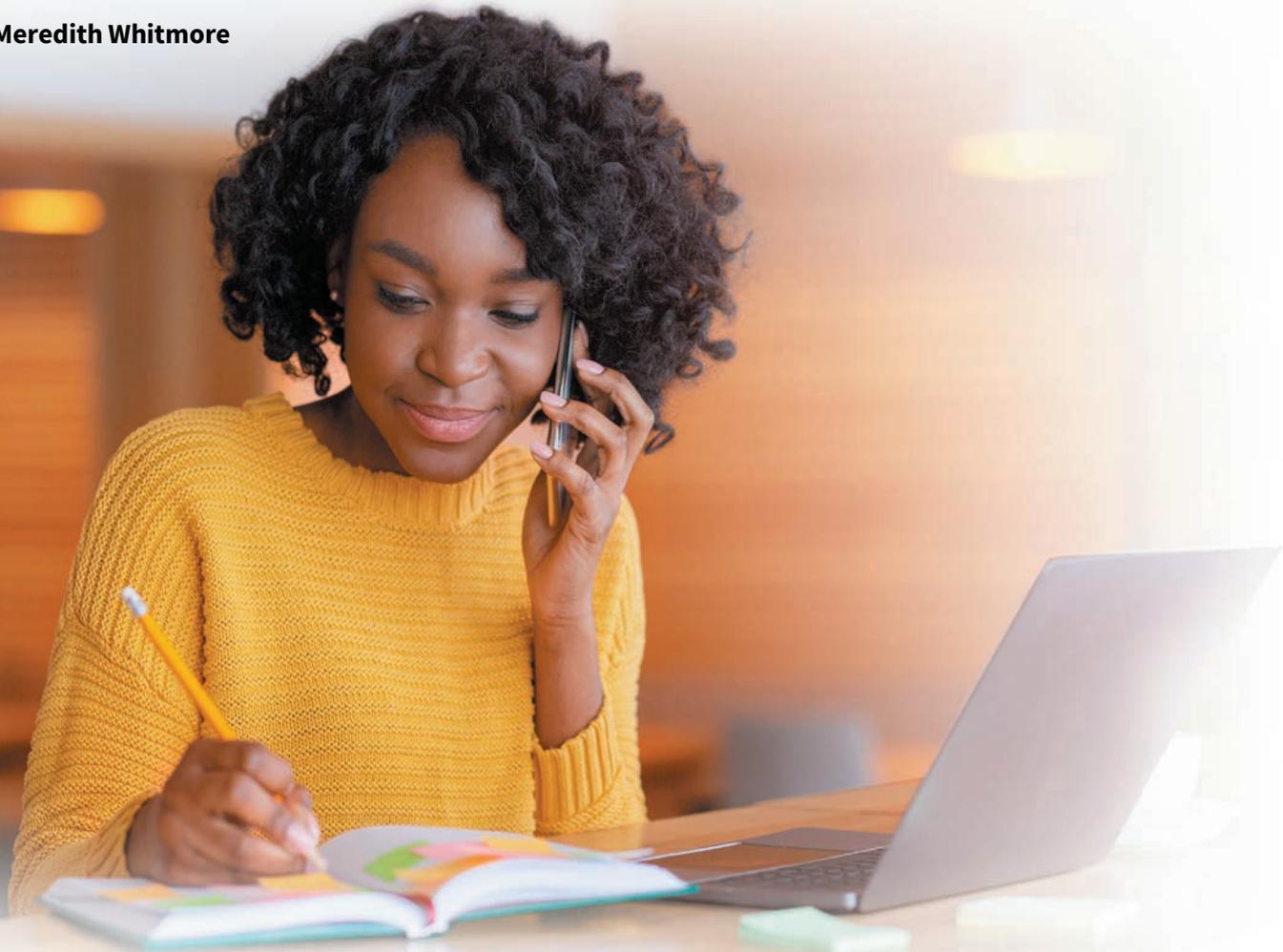


How to Be Your Own Best Advocate

Using these practical strategies suggested by patients will help you take charge of your health.

By Meredith Whitmore



LIVING WITH CHRONIC illness is tough on many levels, from struggling to find the energy to get dressed, let alone meet the day's demands, to trying to understand a cryptic explanation of benefits from the insurance company. Factor in the number of care providers who could be involved in your treatment, and the sense of emotional inundation can feel crippling at times. Chronic illness might sometimes seem as if you've lost control over your life — especially as you navigate the labyrinth the healthcare system has become, fighting for your rights and your ability to find treatment on your terms.

But learning how to advocate for yourself is possible. With practice and some insight from others, you can begin to regain hope and independence you might feel you've lost.

Why advocate for yourself? Because there might not be anyone else who can or will. The sooner you take responsibility for your own path in the healthcare maze, the sooner you will have greater opportunity to receive the services and help you need to feel better.

Following is tried-and-true advice from those who have experience.

1) Have a Plan Before Your Appointment

Before anything else when looking for a provider, first know what qualities you are seeking. Do you want someone who can make accommodations for specific needs such as a translator or a learning disability? Someone who is body positive? Someone who is an especially good listener? Healthgrades, WebMD, RateMDs.com, Zocdoc, Vitals, Angie's List and CareDash are sites that reveal what other patients have said about physicians you might be considering. Even Facebook and Yelp provide similar information. Each site can offer a glimpse into what people have personally experienced, showing what a provider is like in person and not merely content from his or her corporate webpage.

Next, figure out what you want to accomplish during the appointment. Are you looking for more information? Do you need a specific treatment for a chronic illness? Are you interested in exploring a possible new diagnosis? Such questions might seem silly and simplistic, but it's surprising how many simple thoughts can fly out of one's head under stress. You've likely heard of white coat syndrome, which results in higher blood pressure readings in a doctor's office than a patient would normally experience at home. In the same vein, feeling flustered and pressured at a doctor's office is common, so plan for it in case your mind goes blank in an exam room. Make a list of questions you want to ask, topics you want a provider to research, possible treatments you've researched, specific things you want the provider to examine, etc. You are the expert regarding what you want, so don't lose sight of this when meeting with a provider. Keep the list with you so you have a prompt to keep you on track. Organize your thoughts, and even practice/role play with someone beforehand if you're experiencing anxiety. Such preparation can calm you because practice makes better. A common appointment plan might look like this: goals you have for the time, symptoms you're experiencing, questions and concerns you have, stats for the doctor (medication dosages, glucose readings and anything else you anticipate the physician might request).

Shannon, a veteran hospice nurse on the East Coast, has this advice for those who want to self-advocate: "Have an agenda. It ensures your questions are answered, and it shows the doctor you value his or her time. If you don't understand the language the doctor/medical staff uses, ask them to stop using medical terms. If possible, ask to have a medical friend go with you to explain things. If you do not feel you can openly talk to your provider, get a new provider. Go to the

right person. If you don't know who the right person is, ask. If you don't like the answer you get from one person, go to their superior."

2) Know Your Stuff

It helps to conduct research yourself. S.D., a two-time breast cancer survivor who lives with fibromyalgia, has found when she goes into an appointment prepared with a deeper understanding of her condition, she is calmer and better equipped to ask for her needs to be met. "I think in my case, part of learning how to advocate for myself meant learning how to gain information that's respected by the medical community," she explains. "Know what your sources are, and make sure it's not just some person who's writing about something they don't know about. Investigate the illness to gain not only an understanding of it, but also of what the future course of treatment could be."

Good sources include PubMed and Google Scholar, as well as medical journals such as *The Lancet* and *The New England Journal of Medicine*. For students, many high schools and universities provide online resources.

"I researched treatments and medications, and took that with me into appointments — anything I thought the medical community either wasn't overtly stating well enough or was confusing to me," S.D. adds. "Or perhaps finding something they hadn't mentioned yet — it's just literally finding a way to bring that up that, hopefully, doesn't offend any of the egos of the people in the room." In her own experience, she has learned "finding a way to say what I need to say clearly, concisely and respectfully is good, but then also coming at it from the one-down position by saying something like, 'I know I'm not an expert, but I found some information on this. Is this something you could help me understand?' This approach is less likely to cause a professional to feel frustrated or dismissive."

3) Get Backup

Sometimes, two heads are better than one. Especially if your head is tired, foggy or otherwise less than its best on appointment day or in any other crucial healthcare circumstance.

"If it's possible, find someone in your world who is willing to walk with you on this journey," S.D. says. "Keep them up to date on what's going on with your treatment. If you're ever in the position of being in the emergency room [or even a doctor's appointment] and unable to communicate as clearly or as well as you want and need, then you have



someone you can invite to come in and do it for you if necessary. That person knows your thoughts and preferences regarding your condition and is not afraid to speak up for you about it. Sometimes a care provider might try to shut you down if you're unable to communicate well, because they're trying to save time and figure out what they would do, not necessarily what you want. If you stand up or have someone who can stand up for you and really push, it's amazing what you actually can do to help yourself."

Another form of backup is emotional support outside the care facility. "In order for me to have some of the energy and drive to keep advocating for myself," S.D. adds, "I started to meet with other people who have similar conditions or similar experiences to draw understanding and support. They can recommend care providers, they can recommend treatments and medications, or they may have found some of the newer research you haven't come across yet. They can point you in that direction, at least. To locate such a group, sometimes it's just as simple as finding a local support group that deals with your particular illness. From there, you get to know people a bit. Often for me, it was people I met in treatment rooms who I got to know, and that led to a friendship or other support. Or, if I was wearing something like a T-shirt or ribbon that was associated with cancer or another illness, that sometimes led to conversation with those who approached me because of it."

4) Get a Second Opinion if Necessary

"I think there is a common misconception among patients that doctors are all-knowing, and anything they say has to be taken at face value," says Andrea, a Lyme disease survivor who struggled to find an accurate diagnosis for seven years (via 14 doctors). "In reality," she continues, "medicine is a practice. That means a good doctor is constantly learning and evolving their practice not only from professional education and resources but also from their patients. If you encounter a doctor who is dismissive of or downplays your symptoms, that is a red flag this doctor may not be the best fit for you. You are essentially hiring a doctor for a service: providing medical care for improving health. In the same way you would not put up with a handyman who does not pay attention to detail or offers half-hearted solutions that may cosmetically patch up a flooring issue but does not address the wood rot underneath, you do not need to feel compelled to continue working with a physician who throws Band-Aids at your symptoms without seeking to address a root cause. You are in charge."

And that means if you have reason not to trust a doctor's assessment of your situation and health, you have the right to vote with your feet and find another provider.

5) Understand Your Health Insurance, and Keep Copies of Your Records

Be sure you understand your co-pays and deductibles, as well as whether providers are in-network. If you receive any insurance paperwork that is confusing or seemingly in error, it is your right to call and ask for an explanation from a human, not merely a confusing piece of paper.

Tammie, a 30-year veteran of medical billing, provides this advice: "For health insurance, document everything. Who you talked to, including date and time. Calls are often recorded, and if there's a question, the date and time helps with getting back to the recording. Know your insurance. It's your responsibility to know/find out what your plan does and doesn't cover, including who's in-network. Again, ask questions and be persistent. Keep calling or writing letters until you get what you need. If all else fails, file a claim with the Division of Insurance. Our healthcare system has become so difficult to navigate that you really do have to do your homework, which is incredibly disheartening when you or a loved one are ill."

Kim, who did understand her insurance-related paperwork, paid a price nonetheless. "I spent a whole year of my life fighting an unfair \$39,000 medical bill due to an insurance filing error," she explains. "They finally wrote it off after I filed a complaint with my state attorney general's office. I love my state attorney general's office. I need to send them cookies."



And Kim's nightmarish situation illustrates another point: Do not be afraid to seek legal advice or governmental intervention when a serious mistake has been made. Equifax conducted a 2015 audit revealing hospital bills totaling more than \$10,000 contained an average error of \$1,300. Make sure you review the itemized bill for errors, or hire a professional or a savvy friend to do so for you if that is not your strength.¹

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Beyond this, transferring records from doctor to doctor can be frustrating and complicated. If you obtain copies of your own records, you can be assured they won't get lost between offices, and you'll know exactly what your providers are seeing, which helps you to communicate with them more effectively. Apple's Health app, among other apps and tools, enables you to store your records on your phone, offering you the ability to help physicians avoid making errors in your chart and with your treatment.

6) Believe in Yourself

You are worth quality treatment — emotionally, physically and spiritually — and that means finding a compassionate, knowledgeable provider who listens to your needs and responds accordingly. Period. This point is not debatable.

7) Be Kind, Respectful, Patient — and Avoid Aggression

Even if you feel frustrated or find yourself in a difficult situation with a provider, remain respectful and kind. Be firm if you are not being heard, but know the difference between being assertive and aggressive. There's a fine line that's not always well-interpreted by the other party. Not only will remaining respectful and avoiding belligerence help you to regulate powerful emotions you might feel in the moment, it will help your points to be made and received

much more effectively.

Any human being, physician or not, will find another person's anger, accusations and other fruitless forms of communication off-putting. Should you resort to using such means, you risk being blackballed and labeled by an entire healthcare system if the provider you're poorly dealing with is connected to others in the region. Hostile behavior does not bode well for you. Respect, even in the face of disagreement, does.

8) Be Persistent

Anne, who faces multiple immune disorders and who advocated for her husband's health some years ago, explains, "I did a lot of my own research when he was waiting for his liver transplant. It took me three tries and many phone calls before they even considered voting on exception points that he eventually got. I guess I would

say persistence and educating yourself is the key. Don't just go with what they say. Be kind, but don't let your foot off the gas."

Keep calling, whether it's the insurance agency or a doctor's office that is not getting back to you. Do take into consideration their restrictions regarding test results timing and such. But if you're not getting information regarding your condition or questions after the time frame promised, call until you can speak to someone who will listen and communicate with you clearly.

Finally

Always remember self-advocacy will take practice. If you're unused to advocating for yourself in a stressful and complex environment — or even advocating for yourself to begin with — be kind to yourself if you don't knock it out of the ballpark the first (or second or third) time. Doctor's offices, among other healthcare sites, can be nerve-racking. You will grow with each experience. Practice, keep these tips in mind and go in more confidently to your next appointment. 

Reference

1. Brenoff, A. There's a Strong Chance You Are Paying for Expensive Medical Billing Mistakes. *Huffington Post*, May 17, 2017. Accessed at www.huffpost.com/entry/nearly-90-percent-of-medical-bills-contain-mistakes_n_5902146be4b0af6d718c6e80.

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