



What Patients With Chronic Illness Want Providers To Know

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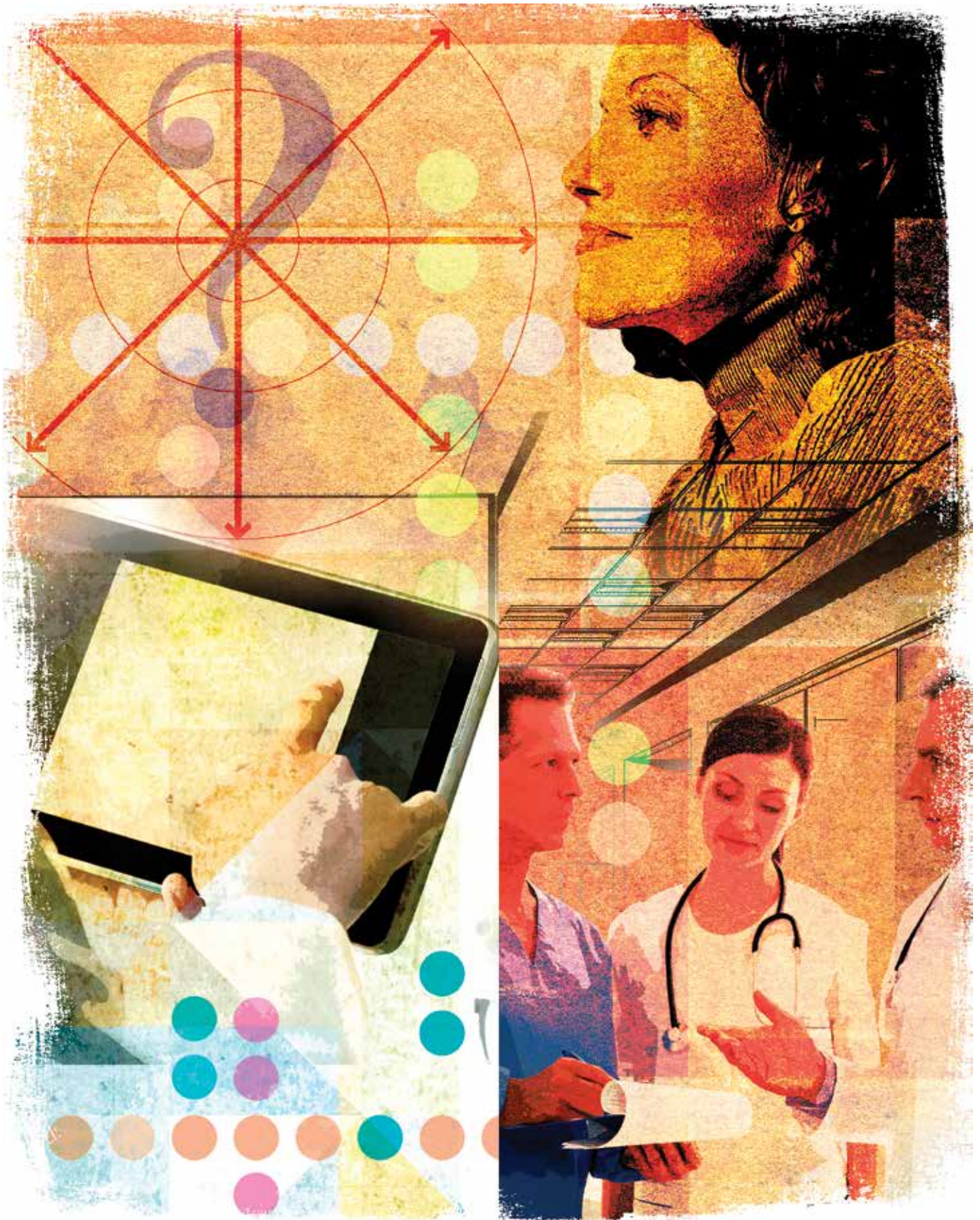
When Julie Rehmeyer recently had a sudden flare-up of her complex, chronic conditions, she sought care at her local hospital, a place she goes only for the most urgent emergencies. “I had a pretty horrendous experience just due to a lack of familiarity with my condition and misinterpretation of what was happening,” she shared. “Because of that experience, I feel a certain kind of ongoing peril.”

Rehmeyer explained she often convulses and even becomes unconscious, so she wears a bracelet with important medical information and care instructions, and it’s also quickly accessible on her phone. Hospital staff and other emergency personnel have, in the past, treated her “in a way that makes things worse,” she said, “just because of their lack of familiarity with my conditions.” Following this recent emergency visit, she said she personally coordinated directly with insurance for medical transportation to her specialist neurosurgeon, who then stabilized her condition. While this event was one of the most extreme of her experiences, she has regularly encountered medical personnel who misinterpret the symptoms and flare-ups that result from her chronic conditions.

As a person with multiple chronic conditions myself, I understand Rehmeyer’s advocacy, and I sympathize with her fears. While my conditions are different, they have sent me to emergency rooms and surgery tables where I had to educate my providers in some way. After 10 years as a technology provider to health care clients,

I now administer and contribute to multiple large patient support groups — including one for women with endometriosis and another for women with a rare lung condition. Members seek vetted information from scientific resources and support from one another, including discussions on how to navigate their care. For those of us with chronic conditions, accessing care is often beset with barriers both inside and outside the health care system.

More than half of the U.S. population has at least one chronic disease, and more than a third has multiple chronic conditions.¹ As of 2020, the data showed that 7 to 8 million people in the U.S. are newly diagnosed every five years.² All in, non-communicable chronic disease is considered an epidemic by the World Health Organization that accounts for more than 85% of total U.S. health care spending and nearly 75% of global deaths, statistics that existed before COVID’s arrival and its subset of post-acute Long COVID patients.^{3,4} The conclusion of Stanford University Professor of Medicine Halsted Holman in a 2020 *ACR Open Rheumatology* article is the same as most patients





I know: Chronic disease requires a fundamentally different kind of medical practice than acute care.⁵

Chronic disease encompasses a wide array of conditions for which there is not yet a cure, from diabetes and heart disease to a broad spectrum of autoimmune diseases and post-infection syndromes. While some conditions are highly manageable with regular medication, the nature of ongoing disease means that there is a life cycle to our responsibilities, treatment changes and emergency needs. Further, many people are chronically sick without having the diagnoses that could unlock the proper treatment options; they are more likely to experience emergencies because of their unknown and unmanaged conditions.

From both observation and research, I know that as patients with chronic disease, we often accept limits to “energy, vitality, ability to carry out activities of daily living, and relationships with family and friends.”

While the particulars vary based on where a patient is on the chronic continuum, I hear similar refrains echoed across research, patient support groups and even casual conversation. Through published studies and my discussions with thousands of patients managing chronic conditions, it seems clear that improving both care and health outcomes is possible. By changing the approach, beliefs and support system, patients with chronic illness and providers can both benefit.

NAVIGATING CARE WITHOUT A GUIDE

Chronic illness often involves complex symptoms caused by several factors (and perhaps affecting multiple organ systems) with little or no guarantee of linear progress or recovery. Because of this, chronically ill patients carry burdens — and even new disabilities due to their condition — which affect us and those around us. While an injury or acute disease may impact life substantially for a time, there is usually a recovery arc supported by traditional medical models and societal expectations.

Yet, due to the nature of these diseases, those of us with chronic illness do not face just a diag-

nosis with a code and clear trajectory — this is something we must live with, adapt to and mediate daily for the rest of our lives.⁶ Work or school attendance may become unpredictable, but financial burdens related to treatment do not stop. Our bodies may increasingly or intermittently interfere with life, including friendships, hobbies, responsibilities and sometimes even basic self-care. From both observation and research, I know that as patients with chronic disease, we often accept limits to “energy, vitality, ability to carry out activities of daily living, and relationships with family and friends.”⁷ We are processing grief (whether known at the time or not) as functional levels change or fluctuate, all while others may have to accommodate us in some way.

Amidst the realities of personal burden, we remain the experts on our own lives. “Especially with complex chronic illness, patients develop a level of expertise that is unparalleled,” said Rehmeyer. “The patient’s view of their own illness is so much deeper and broader because they’re living with it 24/7.” Of course, patients don’t have medical degrees or training, which are essential for proper treatment. As patients, we don’t have the same resources of knowledge, technique or process, but we are the ones implementing what any health care provider recommends outside of the hospital or exam room. We are the ones facing all the consequences when something works or doesn’t. In many ways, we are the “primary” care provider, doing the day-to-day work of care. And to be most effective, health care providers need the knowledge that only patients can provide.⁸ This means that we need to be supported in a way that allows us to better serve in this role.

Patients want to get better, to not need extensive care. But getting what we need involves many basics that could easily become obstacles. For example, providers go to the same places each day and generally know all of their colleagues, but patients put in lots of extra labor: researching, selecting and making appointments with physicians, managing medical records and possibly tolerating long waits, all while accommodating our own work and other responsibilities. For women, the chances are high we will need to consider someone else’s care when planning our own. Like

all people (but perhaps enhanced by our changing physical state) we may have good days and bad, and we may even worry that our appearance or mood might affect how we are perceived in a health care setting and, ultimately, treated.

While the physical, social and financial barriers can start well before the appointment, they also continue long after: handling records, prescriptions, side effects, treatment requirements and test results. Managing these issues is an ongoing reality that holds no guarantee of future relief. For some, even getting to a provider's office or facility is impossible. "There are extended stretches when I just simply cannot physically get to a doctor's office," Rehmeyer explained. "Also, I've needed specialized care that just isn't available locally."

For Rehmeyer, telehealth is the number one avenue to access care, and she fears that providers and systems may be reverting back to a time when virtual visits were much less available, instead of continuing to consider telehealth a vital tool for chronic care. While Medicare-related telehealth reimbursement remains in effect until the end of 2024, many state emergency waivers — which allowed providers to prescribe and deliver services across state lines — have expired at different times. With patchwork state license requirements and removal of other protections established during the public health emergency, many hospitals and systems may choose to limit telehealth to avoid additional risks. On the ground, patients continue to report that some providers are gradually opting out or removing this option.⁹

Lastly, despite any internal preparation, as patients we may still struggle to communicate to our providers the very concerns that motivated us to face barriers (especially in emergencies). Even as a "veteran" patient, I still doubt that my own suffering is worth a provider's precious time, and wonder if I am instead seen as a burden.

Several years ago, I began surveying patients with chronic illness about the ways providers spoke to them to understand how these interactions harmed or helped them. The responses were shocking: While a small percent of the responses were positive, the vast majority were not. Patients recounted personal encounters that included

receiving nonmedical advice, dismissals of self-perceived danger and even downright disrespectful remarks. When our expressed concerns are met with dismissiveness, we experience harm, as mistrust can lead to mistakes in treatment, reluctance to share relevant details or delays in seeking out new care team members who will listen to us.

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These struggles do not even include the notorious challenges experienced by patients who require multiple providers across different systems, including managing medical records or health insurance. Who still keeps a fax machine or CD drive at home? As a patient, I've often been told by providers and their staff to use outdated technology to track and manage my own conditions, further compounding any frustration. And as a caregiver to others with chronic conditions, I've had to retrieve image discs from family members and physically deliver them hundreds of miles to specialists so that loved ones could get required surgeries in a timely fashion. Chronically ill patients often joke that their condition is a costly part-time job, one that comes with colleagues who consider them highly unqualified.

OVERCOMING BARRIERS TO ACCESS CARE

I presume (and a physician even confided to me once) that patients like me can be frustrating or discouraging. After all, most clinicians get into this profession to help others and to heal people. A study published in *BMJ* confirms what many of us who live with chronic illnesses already sense: Care providers often equate the absence of disease or signs of clear progress as personal success, so chronic cases can make a doctor feel like a failure.¹⁰

Jamie Seltzer, the director of Scientific and Medical Outreach at MEAction,¹¹ Stanford Medicine researcher and chronic illness patient, believes that medical providers need to think dif-



ferently, even when working in an acute care environment. “The reality of chronic illness is that it’s not the doctor’s job to cure the patient,” she said, “it’s the doctor’s job to improve the patient’s quality of life, and that’s an imminently achievable goal.”

To many, the unspoken role of the patient is to get better. However, as chronic illness patients, we need slow, methodical care from a range of providers often for the rest of our lives. And even then, better is a relative term. The mismatch between expectations and realities can cause disillusion, resentment and even physician burnout.¹² If providers don’t accept or consider the chronic nature of patients’ conditions, then patients may be harmed by inappropriate or unsustainable treatment.

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— JAMIE SELTZER

“You must assume that whatever you’re prescribing, the patient will need it for the rest of their life,” said Seltzer, when asked the number one thing that providers should know when treating chronic illness. She wants physicians and other care providers to believe patients, to maintain curiosity while diagnosing and to prioritize quality of life in treatment. “Low and slow is the key in chronic illness patients, because you don’t know yet what their sensitivity is.” She also recommends against downplaying remedies or therapies that can provide some relief or improve quality of life. “It’s not less important because it doesn’t require a white coat to administer,” Seltzer said, “and patients need to know that.” Health professionals can advise appropriate diet changes, which can significantly alter certain disease progression, and auxiliary treatments, like physical, occupational and other therapies.

Underneath the practical ways to increase access to care for those living with chronic illness lies the fundamental need to shift the traditional provider-patient role. We must be considered

an equal member of the care team, surrounded by medical professionals who act as our expert guides and coaches. “We have different kinds of expertise,” Rehmeyer said. “We’re bringing that expertise together to try to make things better.” What happens when a provider brings that attitude to care? “It is huge,” she sighed. “It makes all the difference.”

EQUAL PARTNERS TO ENSURE A BETTER QUALITY OF LIFE

If we can both accept new roles and shared work — and build systems that support those roles — then real change is possible. When “the physician becomes a partner with the patient,” when the patient with chronic illness “becomes an equal, functioning member of the health care team” and when the health service takes responsibility for “support of these new roles, a task distinct from generating profit,” then results can transpire.¹³ There is ample evidence that when this occurs, quality of care goes up and costs go down. Patients take better care of themselves and may even face fewer complications from disease or treatment as a result.

Through my findings and experiences, I believe that when we are more trusted partners and supported with the education, infrastructure and tools we need, our health progress can become more steady.

TRICIA STEELE is the author of the Sick Person Guide e-book series, which helps chronically ill patients better navigate health care. She previously worked as a technology entrepreneur for 15 years and is currently in the Johns Hopkins University graduate program for science writing.

NOTES

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QUESTIONS FOR DISCUSSION

This article points out that more than half of the U.S. population has at least one chronic disease, and more than a third has multiple chronic conditions. Chronic diseases account for roughly more than three quarters of the country's health care spending. Author Tricia Steele, who has written about and worked extensively with others with chronic conditions, describes ways that health care systems and providers can rethink care for those with chronic illness.

1. Does your health care system have any care approaches, pathways or educational offerings specific to patients handling a chronic illness or illnesses? What kind of assessment is done to gauge how effective these offerings might be?
2. What does it mean to be part of a care team? Are there true opportunities to gather together to share information, adjust care over time and make joint decisions?
3. Do you feel like patients should be considered part of their own care team? What sort of adjustments are needed in health care frameworks — such as refraining from calling a struggling patient noncompliant — that might shift the approach to providing care to patients with chronic illness?
4. How often do you talk with others in health care about what is helpful, or not, when you can't cure a condition? Do you focus on the patient's goals, that is, what they view as success? Do you incorporate measures that may bring the patient some comfort or relief, whether physically, spiritually or mentally?
5. The *Ethical and Religious Directives for Catholic Health Care* tell us that "A person in need of health care and the professional health care provider who accepts that person as a patient enter into a relationship that requires, among other things, mutual respect, trust, honesty, and appropriate confidentiality." What implications does this have on the care that the Catholic health care ministry provides to patients with chronic conditions? Do our providers fully understand and appreciate the nature of the professional-patient relationship?

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