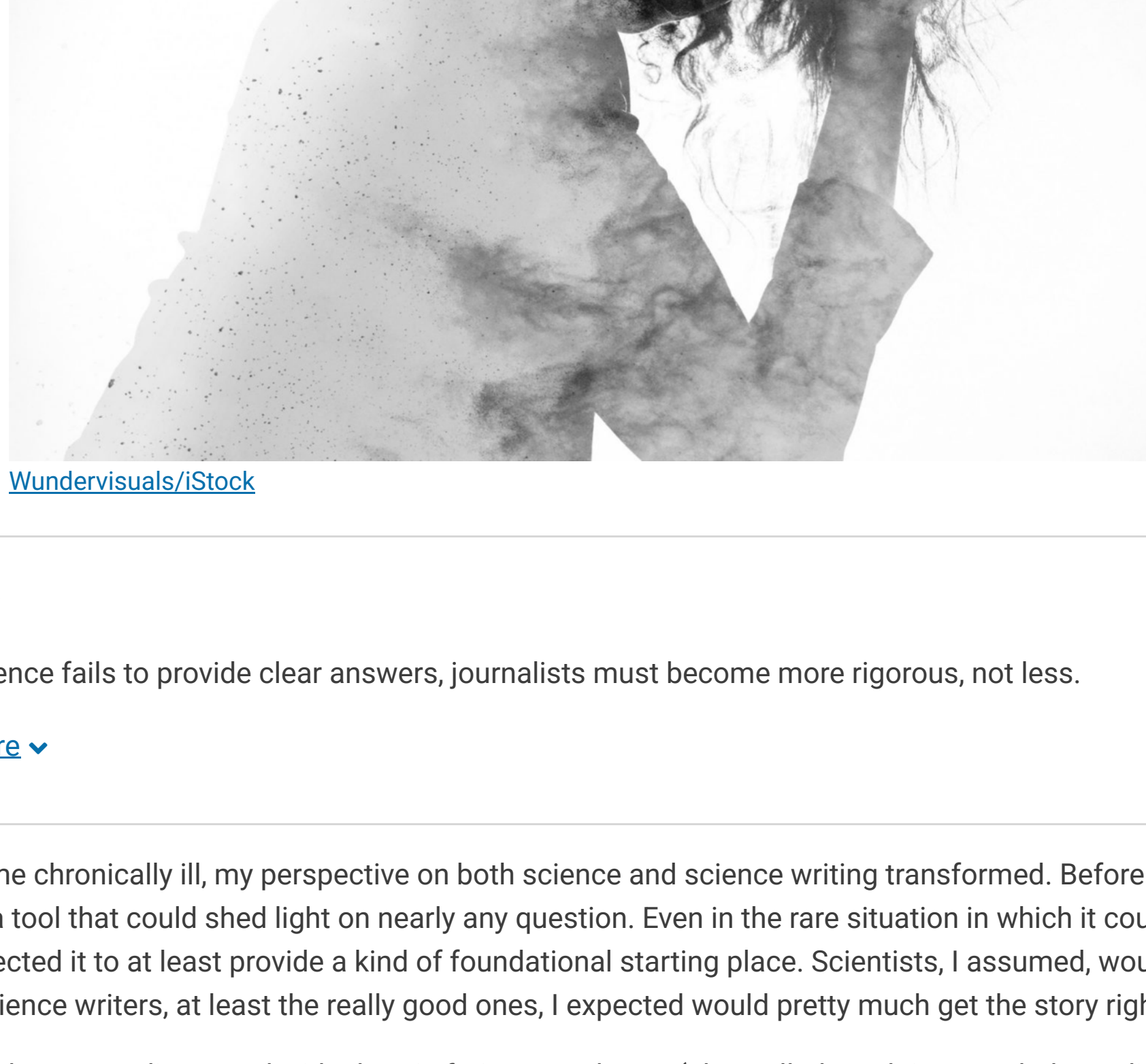


REPORTED FEATURES

How to Report with Accuracy and Sensitivity on Contested Illnesses

Julie Rehmeyer · January 26, 2021



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Summary

When science fails to provide clear answers, journalists must become more rigorous, not less.

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When I became chronically ill, my perspective on both science and science writing transformed. Before that, science seemed like a tool that could shed light on nearly any question. Even in the rare situation in which it couldn't, I certainly expected it to at least provide a kind of foundational starting place. Scientists, I assumed, would always be allies. And science writers, at least the really good ones, I expected would pretty much get the story right.

But in 2006, when I was diagnosed with chronic fatigue syndrome (also called myalgic encephalomyelitis or ME/CFS), this scientific grounding fell away beneath me. I discovered not only that there were no FDA-approved treatments for ME/CFS, but that scientists couldn't even agree on what this diagnosis meant; that most doctors didn't know the basic facts about the illness; that the great majority of the available science on ME/CFS was of poor quality, and the science that appeared the most solid was actually flawed to a point that [approached fraud](#); that government agencies frequently spread false information about ME/CFS; and that merely mentioning my illness raised doubts, in the minds of many, about my reliability and even sanity. I felt as though I had fallen through the looking glass and found that up and down and right and wrong and science and bullshit had scrambled into a nauseating mess.

Reading journalism about my illness only increased my sense of alienation. Too often, journalists guilelessly repeated damaging falsehoods—but almost worse, it often seemed that the journalist was peering down into my looking-glass world from solid ground, demanding that it behave according to the ordinary rules and sneering when it didn't.

I'm pleased to say that over the time I've been sick, journalists' handling of ME/CFS has improved hugely, and some have written truly excellent stories that have improved public understanding. But coverage remains uneven.

Journalism on contested illnesses has become newly critical as millions of people worldwide are now struggling with long COVID—an illness with [strong similarities](#) to ME/CFS, which we also don't yet understand well, and which is frequently regarded skeptically by doctors. Journalists will play a major role in determining whether these new chronically ill patients face the same ignorance and disregard experienced by patients with other contested illnesses—not just ME/CFS, but also treatment-resistant Lyme disease, multiple chemical sensitivity, functional neurological disorder, mold illness, fibromyalgia, irritable bowel syndrome, Morgellons disease, PANS/PANDAS, and others.

Although the skills required for covering contested illnesses are no different from any other subject, there are so many possible pitfalls that journalists have to bring their top game to get the story right. Tension and uncertainty surround almost every question about them. All of the parties involved—health care providers, researchers, patients, advocates, caregivers, government officials—disagree, not just with one another but among themselves. History and politics inextricably complicate every issue around them. Rule-of-thumb guides that ordinarily work just fine can lead to devastatingly bad journalism on these illnesses—journalism that damages lives.

Here are some guidelines I've found that may help.

This story is part of the [Diverse Voices series](#), which aims to examine the experiences, expertise, and perspectives of science journalists from communities that are underrepresented in science journalism. The series is a partnership between *The Open Notebook* and the [National Association of Science Writers](#); Diversity Committee, and is supported by [Science Sandbox](#), an initiative of the Simons Foundation. Read other stories in the [Diverse Voices series here](#).

Find All the Perspectives

Good science journalists ordinarily aim to present the scientific consensus—the conclusions drawn by the great majority of respected scientists, even if a few fringe scientists disagree. But with contested illnesses, there is no scientific consensus on many or even most questions; that is the essence of their contested nature.

It is easy to be fooled, though, because powerful scientists often express strong opinions that they present as representing a consensus when in fact, many other highly respected researchers disagree. This dynamic is common because the scientific, medical, and governmental gatekeepers shaping mainstream opinion may have an interest in maintaining the status quo.

Acquiring that level of influence takes a long time, so these key people can easily become deeply invested in old paradigms, resisting change as evidence accumulates for alternative views. Always remember that credentials aren't the same as correctness, and evaluate the claims of powerful scientists as carefully as those of anyone else.

Keep going beyond the most prominent researchers to discover the full range of perspectives. To find that range, ask your interviewees not just for their views, but also for the alternative ones—and then talk directly to people who hold those perspectives. Be wary of how one side describes those who disagree, as they may caricature one another.

Note that studying a contested illness is rarely a savvy career move for an accolade-driven scientist. So while some researchers who are at the pinnacle of their careers do take these illnesses on in innovative ways, the researchers who are pushing understanding forward the most are sometimes younger or at less-impressive institutions. Evaluate their work with equal open-mindedness and equal skepticism.

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Keep Science as Your Guide

Whenever things get confusing, orient yourself by returning to the nitty-gritty details of the science.

Since you can't rely on credentials to guide you to the truth or take anyone else's word on the quality of the science, ask everyone you interview for the evidence that led to their conclusions and evaluate it for yourself. [Read](#) and carefully [analyze](#) the studies, find the government documents, track down the sources of oft-repeated claims.

Remember, though, that research funding for most contested illnesses is extremely limited. For example, the National Institutes of Health spent only [\\$15 million](#) on ME/CFS research in 2019; by comparison, it spent \$111 million that year on multiple sclerosis, a disease that affects a similar number of patients and that [studies](#) have shown to be significantly less devastating. This paucity of research funding makes it difficult to accumulate a large body of evidence to back any theory. Small, well-designed studies may provide key clues, even though they can't produce definitive answers. And don't dismiss patient-funded or patient-generated research—evaluate its quality like any other.

Digging into the science this deeply is difficult and time-consuming. It also takes courage, since it can feel like hubris to rely on your own scientific judgment rather than that of the scientists themselves. But when the scientists disagree, your job is to make sense of the contending views for your readers. The only way to do that is to evaluate the science for yourself.

Regard Patients as Experts

Patients are the only people who can observe an illness from the inside, so they offer critical expertise. And just as one scientist isn't the same as any other scientist, one patient isn't the same as any other. Patients disagree, so to understand the patient perspective, you're going to have to talk to many patients with many different perspectives. If you find yourself saying, or even thinking, "Patients say," or "Patients believe," you've lost your way.

Also recognize that some patients simply have more expertise in particular areas than others. You have to find the right patients, just like you have to find the right researchers. Many patients acquire deep knowledge of the science or politics or history of their disease. Bloggers, leaders of patient advocacy and social media groups, and patients with relevant professional experience (healthcare providers, researchers, social workers, lawyers, and so on) can all be good possibilities. But those with the loudest megaphones may not be the most reliable. Evaluate patients' work as carefully as you do that of scientists: Do they reason carefully, cite evidence, refer to the literature, acknowledge uncertainty where it exists, and give credence to alternative viewpoints?

Patients may have theories, based on their lived experience, that have no objective data to back them because those theories have never received scientific attention. Dismissing these theories as pseudoscientific woo is inappropriate, since absence of evidence is not evidence of absence, particularly when no effort has been made to find the evidence. Furthermore, lived experience is a type of evidence, one that can become substantial when repeated or shared by many.

It's no gift to merely say you don't believe someone is out-and-out lying. To be truly empathetic, you need to treat patients as you would wish to be treated.

Bring Empathy, Not Pity

Too often, empathy is interpreted as a kind of condescending softheartedness. For example, journalists sometimes write something like, "I believe their suffering is real... even if it might be mostly in their heads." It's no gift to merely say you don't believe someone is out-and-out lying. To be truly empathetic, you need to treat patients as you would wish to be treated: You would want your arguments to be evaluated carefully. You would want to be treated respectfully. You would want your expertise to be recognized.

So if you find genuine evidence that points at a psychological explanation, present the evidence directly to the patients you interview, give them a chance to respond, and consider whether you'd find the evidence compelling if you'd had their experiences. Don't act sympathetic to their perspective during the interview while concealing your true opinion, allowing them to find out only when they read your piece.

Another aspect of empathy lies in respecting patients' physical limits. Their illness may fluctuate unpredictably, so be understanding if they need to reschedule. Ask how long their bodies can sustain talking and respect that carefully. End the interview immediately if you notice them flagging. Let them know how much you appreciate them allocating energy that may be terribly limited and precious to your project.

Be Protective of Patient Sources

Be aware that patients with contested illnesses are among the most vulnerable populations there are. They've lost power in so many ways: On top of being sick, they frequently can't work; are often impoverished; usually have poor access to skilled healthcare (because so little of it exists for them); encounter widespread prejudice; often experience an active denial of their most basic bodily reality from health care providers, friends, and family; and are part of a culture that most healthy people have no idea even exists.

All this means that you'll need to use the same skills you use in covering any vulnerable group. Patients may not be used to talking to the media and may be unfamiliar with journalistic mores. Be explicit about what talking "off the record," for example, means. Patients also may not realize the implications of revealing personal details publicly. Warn them of possible repercussions, and make sure they are comfortable with them. Don't use quotes that may embarrass them.

Think Hard about Psychological Explanations

Avoid the temptation to use psychology as a magic wand to fill in gaps in scientific understanding of how poorly understood ailments work, and be watchful for sources who do so. Like any other theory, psychological explanations of disease require evidence. History shows that until the pathophysiology of an illness is understood, it tends to be dismissed as psychological, with enormous harm to patients in the meantime. Examples include multiple sclerosis, ulcers, endometriosis, narcolepsy, syphilis, epilepsy, autoimmune encephalitis, lupus, and many others.

Healthcare providers are [explicitly trained](#) that a patient with multiple unexplained symptoms is likely suffering from psychosomatic illness, but many contested illnesses are known for causing widespread and varying symptoms. For some of them, there are clear scientific reasons—when mold illness is caused by mast cell activation syndrome, for example, since mast cells (a type of immune cell) are overly sensitive, pouring out alarm signals at the slightest provocation. Mast cells occur throughout the body, this can cause symptoms as varying as hives, confusion, diarrhea, and wheezing.

Because patients frequently respond negatively to being told that their illness is psychological, proponents of psychological theories often use obfuscating language. For example, the researchers behind the enormously influential PACE trial, which falsely claimed that cognitive behavioral therapy or gradually increasing exercise could treat or even cure chronic fatigue syndrome, insisted that they were not asserting that ME/CFS is psychosomatic, while simultaneously arguing that it could be cured by ridding patients of the belief that they suffer from a physiological illness. Given how critical clear hypotheses are for sound science, you should give the research a particularly hard look when you encounter a confusing web of language like this. In the case of the PACE trial, there were [shocking problems](#) that journalists overlooked for years, even though patients worked assiduously to bring them to light. (Even now that the PACE trial has been thoroughly debunked and the [CDC](#) no longer recommends its treatments, the problems have received so little journalistic coverage that few healthcare providers know its advice is unsound and even dangerous.)

A similar confusion surrounds functional neurological disorder (FND), the current name for what was once called hysteria or conversion disorder. This rebranding was done explicitly to increase acceptance of the diagnosis among patients. Experts disagree about whether FND is "psychological" or not, and again, the disagreement hinges around differing definitions of the word.

Note that while it's easy to conclude that psychology may play a role in any illness, highlighting the possible role of psychology without clear evidence when the pathophysiology of a disorder is poorly understood can cause harm, leading to the illness being taken less seriously.

Guard against Prejudice

Watch for prejudices—in yourself and in your sources—that could affect your reporting.

Ableism—personal or institutional prejudice or discrimination against disabled people—is widespread and little recognized. Ableism plays out through the expectation that everyone has similarly functional minds and bodies, leaving those who don't unseen and marginalized. It also plays out through the assumption that disability somehow represents a personal failing. Remember that you could become ill too, that individual virtue doesn't suffice to fend off illness, and that every single one of us faces physical decline eventually. Don't let the idea creep into your mind that patients are crazy. Of course, as in any population, some are mentally ill, but that doesn't imply that they are nonsensical or irrational or unthinking, notions that are wrapped into the derogatory "crazy" label.

Sexism is also pernicious in the context of contested illnesses, contributing enormously to certain illnesses becoming contested in the first place. The mere fact that an illness affects women more frequently has been repeatedly used as evidence that the illness is psychological, a problem Maya Dusenbery, author of *Doing Harm: The Truth about How Bad Medicine and Lazy Science Leaves Women Dismissed, Misdiagnosed and Sick*, calls the "trust gap." Once an illness is considered psychological, there seems little point in spending money to research it, creating a second problem Dusenbery dubs the "knowledge gap." The worst thing is that the two reinforce one another.

Racism and classism have led to these diseases being caricatured as affecting only wealthy, striving, white women, when the reality is far more nuanced. For example, studies that randomly screen people for ME/CFS have shown that although the disease is more often diagnosed in white people, it affects poor, Black and brown people at higher rates than whites. Lyme disease is also more commonly diagnosed in whites, perhaps because it first became endemic in wealthy, predominantly white areas. But the true prevalence in non-whites is less clear: A [study](#) of the Upper Eastern Shore of Maryland, where Lyme is endemic, showed that Blacks had higher rates of complications from Lyme when they were diagnosed, suggesting that doctors were missing the diagnosis early on in these patients, when Lyme is far more treatable.

Such stereotypes are perpetuated by unfortunate choices of art. Stories about ME/CFS, for example, are often accompanied by a picture of a skinny, young white woman sitting at a desk, head in hand, with a giant cup of coffee next to her computer—a far cry from the reality of people of all genders, races, ages, and sizes lying motionless in bed, sometimes unable to tolerate light or sound or touch. Writers usually aren't responsible for art, of course, but it's worth warning your editor to avoid misleading, damaging clichés.

Avoiding bias and being empathetic aren't just necessary for being a nice person—they're essential for getting the story and the science right. Prejudice and condescension cloud our view and allow us to be misled. And if we fail to recognize bias or ignorance from our sources and then report these perspectives as reasonable positions to take, we legitimize bigotry.

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Watch for Language Traps

Surprisingly often with poorly understood illnesses, words themselves—even seemingly innocuous terms used to label or characterize the illness—become contested or are misleading. As discussed above, the word "psychological" is one of them.

The term "chronic Lyme" can also mean different things. When someone argues, "There's no such thing as chronic Lyme," they commonly mean that no one continues to be infected with the Lyme bacterium for years after treatment. (Evaluating this claim requires a deep dive into the science.) But when patients say they have chronic Lyme, they typically mean they got a Lyme infection and never recovered from it, whatever the reason for that might be.

The language trap is especially pernicious in the ME/CFS world, where the name "chronic fatigue syndrome" has done vast harm. The biggest issue is that the hallmark symptom of ME/CFS isn't fatigue at all—it's a phenomenon known as *post-exertional malaise*, or the dramatic increase in many symptoms, not just fatigue, after exertion. For example, for some patients, merely brushing their teeth is enough exertion to trigger hours of vertigo, convulsions, or near paralysis. Many patients have declined permanently after pushing themselves.

Another problem is that the name "chronic fatigue syndrome" invites the abbreviation "chronic fatigue." Chronic fatigue, however, is a symptom common to many illnesses, while chronic fatigue syndrome is a distinct illness of its own, with characteristic symptoms beyond fatigue, including post-exertional malaise, crashing blood pressure, racing heartbeat, cognitive problems, unrefreshing sleep, and more. Furthermore, studies have shown that chronic fatigue is a symptom doctors don't take seriously, thinking of it as ordinary tiredness—but ME/CFS can be nightmarishly disabling, more so than [every single disease](#) studies have compared it to. Journalists and editors should thus resist the temptation to abbreviate the name, either in story copy or in headlines.

A third problem with the term "chronic fatigue syndrome" is that researchers disagree about who has it. Some [research definitions](#) require only six months of fatigue, while others require an array of neurological, endocrine, and autonomic problems. This has made a mess of the research, with different studies scrutinizing different types of patients. As a journalist, the first question to ask about an ME/CFS study is which research definition was used.

For these reasons, many patients push for rigorous definitions and the use of the name myalgic encephalomyelitis (ME), a term used more commonly outside the U.S. that means "muscle pain and inflammation of the brain and spinal cord." In recent years, evidence for neuroinflammation in the illness has grown, and U.S. health agencies now call the disease ME/CFS. (But note that some patients consider ME to be distinct from CFS and deeply resent this conflation—another example of the diversity of patient perspectives.) As for myself, when I'm speaking primarily as a patient, I call it ME, and when I'm speaking primarily as a journalist, I call it ME/CFS.

Editors: Hire Journalists with Contested Illnesses

Some editors have expressed concern that as a patient, I may be biased in writing about ME/CFS. But this is a little like considering Black reporters biased on stories about race. The fact is that there's no neutral position: We all have a race, and we all have bodies with varying capacities. All of those experiences affect the assumptions we bring to our stories, and ignorance of a subject does not equate to lack of bias. Nor does having an illness automatically turn someone from a journalist into an activist, even if they assert the opinion that that illness should be taken seriously. The experience disabled journalists have with their subjects should be considered an asset rather than a liability.

Of course, being sick does make it more difficult to do one's job, so chronically ill journalists may require particular types of support from their editors. Even a highly conscientious journalist who is chronically ill may not be able to meet a deadline if they have a flare-up of symptoms, so if possible, plan ahead to allow for flexibility. (This story is an extreme example of that—I started it two and a half years ago and then was delayed by a serious decline requiring two neurosurgeries.) Actively counter ableist ideas that may incline both your and your writers' minds, reassuring them, for example, that a need for accommodations doesn't make them less valuable as journalists. Let them know that you consider their personal experience a source of expertise.

Don't require a journalist to disclose their own diagnosis in their story, especially since this can have significant [personal, journalistic, and financial consequences](#). If your writer does choose to disclose their diagnosis, help them prepare for possible consequences from doing so.

I'd like to end this by speaking to you as a patient rather than a colleague: Please, please, cover these illnesses, and invest the effort and care required to do so well. Patients and patients-to-be—and, hopefully, people who might have gotten sick but won't because of the research that will protect them—need you.

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