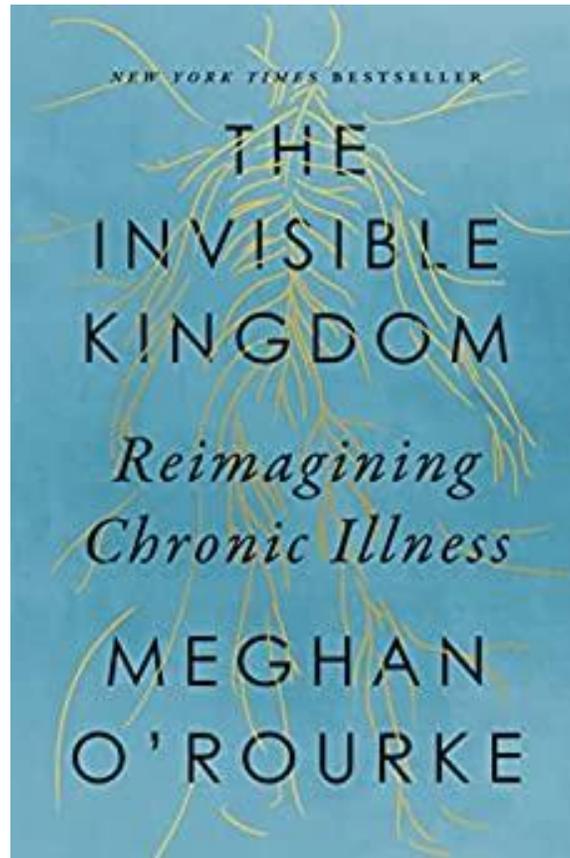


**Review of The Invisible Kingdom:
Reimagining Chronic Illness,
by Meghan O'Rourke**



This book is about people who have an illness that mainstream medicine does not understand, and how poorly they are treated. This includes being brushed off, disbelieved, gaslighted, and psychologized by American physicians who can't admit they have no cure to offer.

Keywords: chronic illness, gaslighting, disbelieved, medical controversy, psychologized, Meghan O'Rourke

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Meghan O'Rourke was a freelance journalist, poet, and sometime lecturer at universities. In her late twenties she lived the hectic life in New York, when she started getting strange symptoms. It started with a rash, then various pains that moved around her body, flu-like symptoms, brain fog, food sensitivities, and crushing fatigue.

She loved her work, and also needed the money to pay the medical bills, so she continued working. But it was hard:

... And so I sat at my desk every day even though I nodded off in my chair, waking myself up when my head hit the computer screen

She has weeks where she doesn't produce anything, as her illness waxes and wanes. But she doggedly continues working as best she can, even taking on more ambitious projects such as travel and lectures.

Many days she simply escapes into distractions, such as film, television, and shallow web cruising.

Meanwhile, her friends keep telling her she looks great. She can't make them understand they only see her on her good days, that she doesn't go out on her bad days, so what they see is always her at her best.

She candidly discusses her fears, self-doubt, anxieties, and hopes. It is hard to live with a disease that for many years she had no name for, no treatment and a very uncertain future. The situation produced what she called a "metallic tang of terror."

As anyone with a chronic illness can relate to, she says:

I want to go for a day without thinking about my body.

Her big fear was that what if her illness really was just some sort of flaw in her character, as pop psychology for years promoted the idea that positive thinking was all that was needed for health. She seriously considered this several times, but each time rejected it.

She uses the term "brain fog" throughout the book. It is such a pleasure that it has become mainstream, thanks to the Covid-19 epidemic. For decades it was only used inside the MCS community, while journalists usually insisted on putting it in quotes, as if it were something suspect.

Friends and family

O'Rourke was fortunate to have a good circle of friends and family, especially her live-in boyfriend who stuck with her.

Her friends didn't run away either, even though she could no longer go out for drinks in bars, and she had to mandate they go to certain restaurants that served food she could tolerate – sometimes rather strange foods.

But it was still not easy in a culture where youth and health is celebrated, and the sick rather not seen. As she quips:

But wasn't it dire to slide slowly into quicksand as those around you look away?

From doctor to doctor

She spends ten years going from doctor to doctor. Luckily, she lives in a big city with many specialists, and she is able to do it financially, though sometimes she has to shuffle the debt around on credit cards.

She goes to top specialists, and sometimes uses her journalist credentials to get interviews with leading scientists, who give her some personal advice on the side.

She went to top-tier doctors who did not accept any insurance plans. This allowed them to think outside of the box of cookbook medicine required by insurance companies and avoid hiring the staff needed to hassle with their bureaucrats. These doctors were so good there was no shortage of patients, despite the extra cost and hassle imposed on them.

She found the medical system to be very byzantine:

At the hospital, I always felt like Alice at the Mad Hatter's tea party: I had woken up in a world that seemed utterly logical to its inhabitants but quite mad to me.

Finding a diagnosis was very difficult. She carried around a giant stack of lab tests. Some were a little off here and there, but no test could produce the hoped-for "aha moment."

She discovers many of the failings of the American medical system, such as the hyper-specialized doctors who can't see the larger picture, and who refuse to discuss her case with other specialists or even share their lab results. It's a system

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where a patient who tries to participate in solving the problem is frowned upon, especially when bringing along a stack of lab reports.

She clearly expresses the need to get some sort of diagnosis – to get to “a form of understanding” and validation. A need healthy people rarely understand.

She tries to find out why doctors are so bad at handling chronically ill patients. She found they like patients they can fix, and not those they can't help – or worse, those who they suspect are really mentally ill and try to fool them. Doctors are a competitive tribe and don't like to lose a game.

She quotes the surgeon Atul Gawande, who candidly admits:

Nothing is more threatening to who you think you are than a patient with a problem you cannot solve.

One patient she interviewed stated:

I wish doctors had just looked me in the eye and said, I don't know what's wrong with you. But I believe you. And one day we'll figure it out.

When they can't help a patient, doctors tend to blame the victim. That is even built into their lingo. They say that “the patient failed the treatment” not “the treatment failed the patient.”

She was determined to get better and tried a great many treatments, some of which had bad side effects. This prompted a colleague to advise:

I know you think you're doing the right thing, but aren't you just making yourself sicker?

Eventually, after years of effort, she arrives at a cluster of four diagnoses. Only one was fully treatable, but what a difference that made. Unfortunately, she had to travel to England for one of the treatments, which in America was blocked by the Food and Drug Administration (FDA). (The FDA is always looking out for the interests of Big Pharma).

She doesn't say how much this all cost, except that she spent \$22,000 one year, beyond what her insurance covered – and she says she had “good” insurance.

If she had not had the resources, support and persistence she had, she would never have gotten any real help. Few people are able to do this. The vast majority of

people in this situation are destined to live out a life of pain, disability, and possibly poverty, with a cloud of “psychosomatic” hanging over their heads.

All in your head

Along the way she had to contend with a lot of doctors trying to convince her it was all in her head. Most couldn't see anything wrong, so they thought she just made things up or made a big deal out of very little. They frequently downplayed her symptoms by saying everybody had them, even though there was a big difference in severity.

A central theme of this book is how doctors dismiss, disbelieve, and mistreat chronically ill patients. How some doctors falsely believe some illnesses are all psychosomatic, such as post-Lyme, and long Covid, and nothing can convince them otherwise.

She hopes that long Covid may help on these attitudes. That seems quite naïve, given how many times doctors have been proven wrong before and not learned from it. And how medical schools teach their students to psychologize patients with many and diffuse symptoms.

These attitudes often show up rather subtly. One example was that some doctors refused to give her copies of her own lab reports and told her they would just make her “worried” or “confused.”

As someone she interviews states:

I don't really understand how so many doctors could think that I was making up my symptoms – did I really have nothing better to do in my life than make things up?

O'Rourke summarizes the consequences of this widespread failure:

This is the real tragedy of our cultural psychologization of diseases we don't understand: the ways such dismissals leave patients to suffer alone, their condition turned into a character flaw.

(There are actually many more consequences, O'Rourke just hasn't been subjected to them herself).

Surprisingly, the book barely mentions the politics of medicine, which is a huge problem. She doesn't at all mention how corporate interests can keep diseases controversial and influence which diseases receive research funding, and for what

types of research. How that can make what seems to be a consensus in the medical journals really be one-sided.

The only politics she describes is how two medical societies fight against each other over whether post-Lyme is psychosomatic or not.

Not a sob story

This could easily have been a sob story, which nobody would want to read. It is not. It is also not a stoic story that tells us how great a teacher chronic illness is. She freely tells us there is really no upside to being sick, no matter how much healthy people want to hear that. Thank you, O'Rourke!

The ending is positive in many ways, but it is not Hollywood. Such is real life with chronic illness. She feels bitterness and grief about the whole ordeal:

I feel a black hole for what I lost: nearly the entire decade of my life. So many possibilities and freedoms.

(This reviewer has lost twenty-five years and counting. Others have lost much more).

People with any sort of chronic and misunderstood illness should recognize much in this story. Those with even less-accepted illnesses might find it interesting that even "the other half," the "luckier ones," do not have it so easy either.

O'Rourke never got so sick that she had to apply for disability and doesn't talk about the absurd process, the automatic refusals and the indignities bestowed upon people with controversial illnesses.

The story is not a breezy read. There are too many details and too many quotes from what various writers philosophize about illness. It gets tedious in the middle of the book, but the persistent reader is rewarded with more interesting fare later on.

Healthy people would probably never finish this book, even though it should be required reading for med students.

The tribe of Meghan O'Rourke

O'Rourke appears to be a champion of people with invisible, chronic and psychologized illnesses. This reviewer kept hoping she would be inclusive of all people in that situation, but remained disappointed.

The title of the book appears all-inclusive, but throughout the book she just keeps listing the types of illnesses she herself has, with the occasional nod to fibromyalgia. This is also the case in her magazine articles on this topic.

She never mentions repetitive stress injury (RSI), whiplash, multiple chemical sensitivity (MCS), electrical hypersensitivity (EHS), hyperacusis, or severe light sensitivity. Irritable bowel syndrome (IBS) is only mentioned indirectly.

These are even more invisible and psychologized than O'Rourke's list of favorites. Perhaps that is why she doesn't mention them, being afraid of acknowledging people even lower on the ladder of "medical respectability" than she herself is?

Three of these diseases (RSI, MCS, EHS) are direct threats to corporate interests and actively psychologized and discredited by their shills. Perhaps O'Rourke got fooled by their efforts, and the echo chambers they created? That is an easy mistake for diseases you don't have yourself.

The closest she gets to acknowledging MCS is in a single sentence, where she indirectly mentions Todd Haynes' film *Safe*. She calls MCS an "environmental allergy," which is a term commonly used by journalists to downplay a disease that in severe cases can have an impact far beyond anything she ever experienced.

People with severe MCS or EHS are routinely denied access to hospitals and clinics, and may be forced out of their homes. Those are two dimensions O'Rourke never had to face.

She expresses compassion for the transgendered and Black Lives Matter activists, but remains utterly silent about the sick people who are routinely psychologized and mistreated worse than she was. So, is she really any better than the doctors her whole book rails against?

More reviews

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