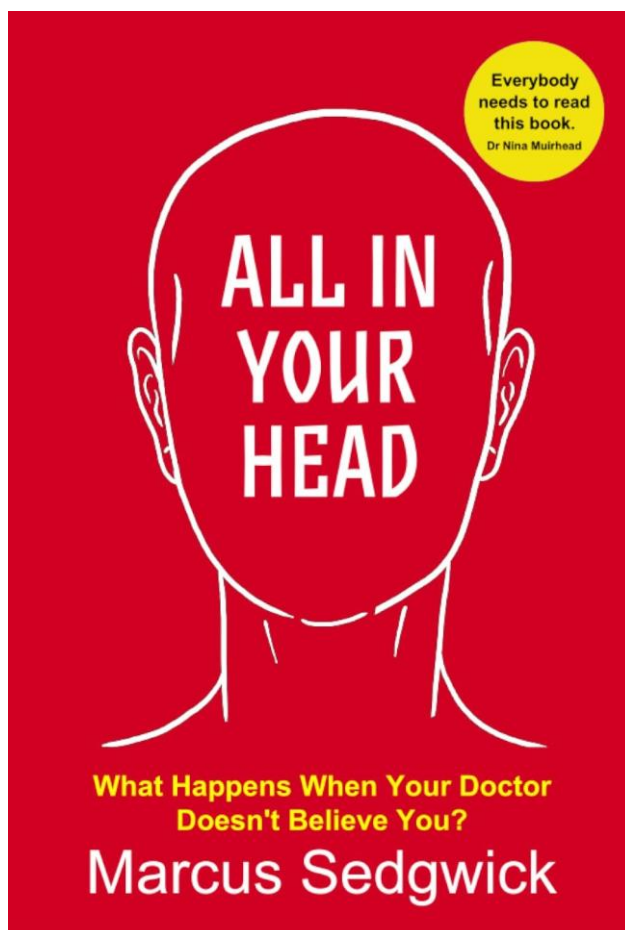


All In Your Head: what happens when your doctor doesn't believe you? By Marcus Sedgwick

Book review



A famous British author gets sick with a hard-to-diagnose illness. The doctors tell him it is “all in your head.” Welcome to the world of medical controversy.

Keywords: Marcus Sedgwick, All in your head, chronic fatigue syndrome, CFS, MCS, EHS, controversy, hostile doctors, chronic illness

Marcus Sedgwick is a successful British writer with more than fifty books to his name. He travels a lot to give workshops about writing. On a tour to Asia he suddenly becomes very fatigued and it never lets up.

From running 5K every week, he becomes barely able to walk for five minutes. When he receives a prestigious literary award on a stage in Las Vegas, he is so brain fogged he loses his track in the middle of his acceptance speech.

The first doctor he asks for help is a substitute who is barely out of medical school. She tells him with great authority that it is “all in your head.” Thus starts his descent into the underworld of controversial illnesses.

Over the next five years he sees more than fifty doctors in a wide range of specialties, from tropical diseases to reiki. He visits doctors in four different European countries. He is deeply skeptical of alternative medicine and New Age philosophies, but when the mainstream system has nothing to offer he is willing to try anything.

He apparently has Chronic Fatigue Syndrome, also called Myalgic Encephalomyelitis (CFS/ME), but his story is also relevant to the MCS and EHS community. CFS/ME is just one rung higher on the ladder of understanding and acceptance, and his experiences are similar in many ways.

CFS has a terrible stigma. One reason is that they don't look sick. And on the days they can't get out of bed, other people don't see them – they only see them on their good days, and think that is how they always are.

He gets lots of dumb comments, such as:

So you can't walk, then enjoy being at home.

Sounds like you've got the perfect excuse to stay in and watch lots of movies every afternoon.

Maybe this is the universe sending you what you need.

Part of that may simply be that people don't know what to say. But it shows that healthy people simply cannot comprehend the impact of chronic illness.

Even though he was offended by the “all in your head” label that was so callously slapped on him, he wonders if it is actually true. Perhaps he is “too sensitive” a personality? Maybe he is a hypochondriac? Psychosomatic?

Those questions are a central focus of this book, together with a very personal description of how his mindset develops over time as he tries to come to terms

with his new role as a disabled person and with the stigma attached to a controversial illness.

He describes about a dozen of the doctors he went to, including a sort of sanatorium in Germany and the French doctors who treat him with much more respect than the British.

He also travels to the MCS/EHS community in Snowflake, Arizona, to see if the people there have some answers and meet people with a different sort of illness that is also disbelieved (this takes up all of chapter 12).

As so many people with illnesses the doctors do not understand, he becomes disillusioned with the magic of the medical system:

I now know the unspoken truth about orthodox medicine: that it doesn't know as much as it pretends to; that it's often convinced about one thing only to change its mind a few years later; that even major advances can take years to get peer approval and become accepted new method.

He learns that what is considered established science in one country is officially discounted in another. Even lab results are interpreted differently in each country.

On the social media site Reddit, he finds multiple threads where doctors ridicule patients with CFS/ME.

A physician prescribes him a dangerous drug that is totally unnecessary. It is only because the pharmacist warns him that he gets a second opinion by someone more qualified.

He talks to a bioethicist and other scientists about what it does to people when they get labeled with the huge stigma of “psychosomatic.” It turns out that nobody studies that. He also learns that the scientists who push the label “psychosomatic” for anything currently not understood is a small clique who peer-reviews each other’s papers (the same people also bestow their opinions on MCS, EHS, etc).

He quotes one of the most prominent psychiatrists in this group, Dr. Simon Wessely, as stating in a speech to hundreds of doctors that:

There is no reason why they all cannot return to work tomorrow.

To his horror, he discovers that these scientists live in a castle of sand, with little science to support their views, and hardly any replications. Yet they get to stigmatize millions of people worldwide.

And they push a treatment of “graded exercises,” which turns out to be ineffective and actually permanently harms some people with CFS/ME. All based on a single highly flawed study.

He briefly looks at reasons why doctors are so disdainful of the CFS/ME sufferers. That includes dogmatism and insurance companies saving money. (Perhaps these few reasons is why CFS/ME is more accepted than MCS and EHS, which also threaten enormous corporate interests, as well as people loving the chemical and wireless lifestyles.)

He continues to ponder:

Was I ill because I was depressed, as my doctors wanted to suggest, or was I depressed because I was ill, as had seemed much more logical to me. Or, as I had started to think was possible, were both the result of a third, unknown cause?

Throughout, he struggles with whether to accept the illness, and thus gain more peace of mind, or battle on with all that entails of stress, effort, and cost. He early on learns the disdain some doctors have for those people who give up and “settle into the sick role,” as they call it.

This book is probably not of interest to healthy people other than sociologists and psychologists. It is simply too scary to think this may happen to you. Healthy people simply cannot relate to these issues, and prefer to let the doctors sit on their pedestals.

For anyone with chronic illness it can be helpful to read such a deeply personal inner struggle with doubt, disillusion, anger, and acceptance. Those are universal themes for anyone in that situation.

Afterthought

This reviewer met Marcus Sedgwick when he visited the Snowflake MCS/EHS community in 2017. The visit inspired him to write the fictionalized novel *Snowflake, AZ*.

People with CFS/ME tend to live much shorter lives than healthy people. Sadly, that includes Sedgwick, who died November 17, 2022, at the age of 54. The cause of death is not disclosed. It happened shortly after *All In Your Head* was published.

More information

More reviews of books about environmental illnesses on www.eiwellspring.org/booksandreviews.html

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