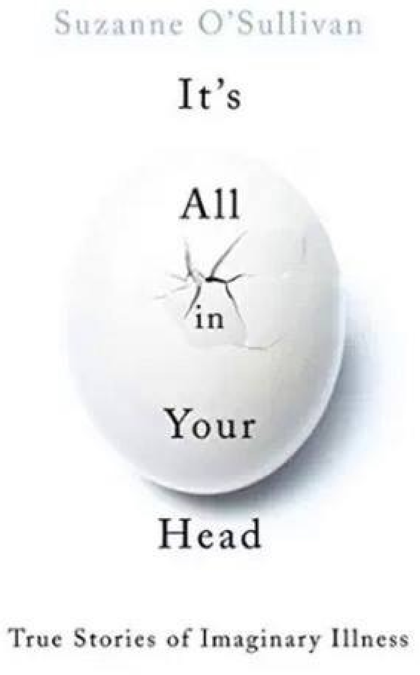

It's All in Your Head: True Stories of Imaginary Illness

Suzanne O'Sullivan

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It's All in Your Head: True Stories of Imaginary Illness Suzanne O'Sullivan
'Even if medical tests cannot explain your pain or tiredness or disability, it does not lessen your suffering. The pain of medically unexplained illness is every bit as real as any other and, if anything, is multiplied by the lack of understanding.

Most of us accept the way our heart flutters when we set eyes on the one we secretly admire, or the sweat on our brow as we start the presentation we do not want to give. But few of us are fully aware of how dramatic our body's reactions to emotions can sometimes be.

Take Pauline, who first became ill when she was fifteen. What seemed at first to be a urinary infection became joint pain, then food intolerances, then life-threatening appendicitis. And then one day, after a routine operation, Pauline lost all the strength in her legs. Shortly after that her convulsions started. But Pauline's tests are normal; her symptoms seem to have no physical cause whatsoever.

Pauline may be an extreme case, but she is by no means alone. As many as a third of men and women visiting their GP have symptoms that are medically unexplained. In most, an emotional root is suspected and yet, when it comes to a diagnosis, this is the very last thing we want to hear, and the last thing doctors want to say.

In *It's All in Your Head* consultant neurologist Dr Suzanne O'Sullivan takes us on a journey through the very real world of psychosomatic illness. She takes us from the extreme -- from paralysis, seizures and blindness -- to more everyday problems such as tiredness and pain. Meeting her patients, she encourages us to look deep inside the human condition. There we find the secrets we are all capable of keeping from ourselves, and our age-old failure to credit the intimate and extraordinary connection between mind and body.

It's All in Your Head: True Stories of Imaginary Illness Details

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From Reader Review It's All in Your Head: True Stories of Imaginary Illness for online ebook

Monica Willyard says

The chances are good that someone you know has a somatic illness and doesn't know it. This empowering, intriguing book explains how the mind can control parts of the body to create genuine symptoms such as pain, blindness, and paralysis, even when all test results are normal. The author doesn't excellent and compassionate job of explaining that while the symptoms are caused by the mind, they are still just as real as if something were physically wrong with the body. Now, scientists are performing studies in an effort to solve this issue and figure out how to help patients find full relief from there symptoms. This book may be of particular interest to those people who have diseases such as chronic back or neck pain, chronic fatigue syndrome, fibromyalgia, Crohn's disease, and lupus. I read the book because I was looking for answers with my own health issues. So if you're reading this review, please don't think I'm dismissing your pain or symptoms. I do think there is a psychological component to some illnesses, and that could be a good thing, because we might be able to control that and find some lasting relief.

Emily says

2.5 stars. I found a lot of things frustrating in this book. First of all, the doctor seemed very reluctant to believe anything her patients were saying and seemed determined to prove them wrong.

Also, many of the case studies ended abruptly and we weren't told whether or not the patient recovered. What's the point in only giving us half the story?!

Ian Kirkpatrick says

I was tempted to purchase this book having read the extracts in the weekend Guardian magazine a few weeks ago. This accessible and insightful book provides a brief glimpse into some of the complexities of the human condition through the real-life stories of patients with a variety of psychogenic disorders.

Perceptive, engaging and really well-written, this gives a fascinating insight into the working practice of a neurophysiologist. O'Sullivan balances true stories of some of the many patients she has treated with an insightful and self-deprecating commentary on her own preconceptions and limitations of understanding.

Her writing style reminds me of Patrick Casement whose "On Learning From the Patient" remains one of my favourite psychotherapy texts. As with Casement my overriding feeling having read O'Sullivan's excellent book is that there's a whole raft of potential novels contained in this rich seam. Part of me hopes that O'Sullivan might be tempted down this path in the future, as I think her voice as an engaging narrator shines through. I would thoroughly recommend this book to anyone with even a passing interest in this intriguing field.

Nasim says

I imagine the publisher was excited by Dr O'Sullivan's 'ideas' - I saw the words 'groundbreaking' and 'controversial' in one of the blurbs. Imaginary illness carries notions of madness across the centuries, as readers we are intrigued - and seduced. However, having read in detail the chapter 'Rachel', which deals with a young woman with 'ME/CFS', I can say that the book is certainly not groundbreaking, but rather, in the case of ME, an irresponsible recycling of a dying - very dangerous - narrative which has been perpetuated by psychiatrists since the nineties. And having dipped into the other chapters, I'm afraid I find her style to be rather unengaging and toneless, though I wonder also if that is a kind of clinical constraint.

So her *ideas* must be sparkling and new if I am to be pulled in.

While vigorously suggesting that patients with myalgic encephalomyelitis (ME) have false illness beliefs, she then bases the entire chapter on her *own* beliefs. There is no evidence whatsoever to prove that ME is psychosomatic. There is however growing robust evidence that ME is a complex, multi-systemic neuroimmune illness, and the key to unlocking the puzzle is ever nearer - biomedical researchers worldwide are excited and hopeful about finding a unique biomarker. Dr O'Sullivan acknowledges that there is evidence of immune abnormalities but then chooses to ignore them completely and goes off on her wild somatisation spree. She seems not to *want* the science to progress, so zealous is she in her beliefs.

The whole chapter on 'Rachel' is manipulative and incoherent, illuminating only in what it omits. I know what the gaps are, so I can see the huge holes. She wrongly says that graded exercise (GET) is the most effective treatment, even although this treatment has been thoroughly discredited, it makes patients worse. This psychologising of ME is extremely harmful to patients, as patients and true specialists have been pointing out for years.

I have had virally-triggered ME since 1983 - I was nineteen years old, an undergraduate, unlucky to get a nasty enterovirus - and was diagnosed by a consultant neurologist, after EMG and muscle biopsy and many blood tests, which confirmed abnormalities. I had been ill for eighteen months at the time of diagnosis, steadily getting worse, and, of course, had never heard of ME then, few people had (I didn't go upstairs to my room and google). My initial treatments included a plasma exchange with immunosupression, and anti-viral drugs. And yet Dr O'Sullivan denies hotly in her book that immunotherapy is used for ME, anywhere. She also seems unaware of the anti-cancer drug trial going on in Norway just now. The scientists have recently been in London discussing their trial at an annual ME conference, which attracts scientists from all over world.

She also fails to mention the huge confusion caused by the different criteria for ME - the CFS (chronic fatigue syndrome) label was introduced in late eighties in UK and the criteria for ME were widened and diluted, with the result that anyone with unexplained 'chronic fatigue' was being diagnosed with ME. This conflation of 'classic ME' and CFS has caused a major headache for patients (no pun intended). Patients who *do* have psychiatric-based fatiguing illness are sometimes being misdiagnosed with ME. The conflation has, naturally, caused immense problems with research; moreover, severely ill/bedridden patients with actual ME are not being included in trials.

O'Sullivan also makes no reference to post-exertional malaise (PEM), which is unique to ME - exhaustion (physical and mental) after trivial exertion - she talks only generally of 'fatigue'. She ignores the disabling cognitive dysfunction - Rachel has some concentration problems but O'Sullivan does not describe the classic ME 'brain fog', which all of us w ME experience as a kind of 'dementia'. We routinely forget everyday words, we mix words up, we forget people's names, we cannot remember simple facts, we leave taps on. Neither does she mention orthostatic intolerance, the inability to be upright, stand for long, another cardinal feature. Indeed, many people with ME have full-blown POTS (postural tachycardia syndrome). She basically excludes all the symptoms of ME in her discussion, bar 'fatigue'. She seems to think managing ME is managing fatigue, and Rachel 'fails' in her management. Naughty Rachel.

I honestly wonder if Dr O'Sullivan truly believes what she has written or if she needed to pad out her book as she didn't have enough real psychosomatic illnesses for the pot. And she knows writing about ME as a psychiatric illness will be immediately controversial - even when she is wrong. Whatever her motive, she has failed spectacularly to keep up with the research and she has insulted not only ME patients but the whole scientific community engaged in ME research.

*I just want to add that this may be one of the most revealing passages in the ME/CFS chapter:

'In my early years training in neurology I encountered many patients with CFS, but more recently neurologists have distanced themselves from this disorder and patients are more likely to seek help from immunologists or endocrinologists. I do not currently see patients for the purpose of diagnosing or treating ME/CFS, but many of my patients with dissociative seizures have a history of ME/CFS, and there is something very interesting in that fact alone.'

There is something very interesting in the fact that Suzanne does not seem to have actually met (m)any patients with classic Ramsay-ME (in 1990s when she was training, the Wessely/CFS/psychiatry school was just taking root, so it's hard to know what was actually wrong with the 'CFS' patients she was seeing).

I reiterate: Rachel, the case study with ME/CFS is, to my mind, an artificial construct, a composite character with the 'behaviours' of ME patients - internet diagnosis, increasingly helpless, 'over-helpful' parents - that the Wessely school adores. Rachel rejects the psychiatric treatment offered her. We never find out what happens to her, though Suzanne says: 'The impact of our emotional well-being on our health is not a trifling problem. I only wish I could convince Rachel of this'.

O'Sullivan also fails spectacularly to describe the experience of probably all of us with ME, of pushing ourselves to 'recover' only to relapse catastrophically. Her apparent lack of contact with patients who actually have ME - coupled with not following the science - would perhaps explain why she felt that including ME in a book of imaginary illnesses was acceptable.

Michelle Keill says

Three years ago, I got really sick - like, really sick. I got all these random symptoms that confused me and the doctors and then, for the grand finale, my lung collapsed and filled up with fluid. Excellent. I had life-saving surgery, but they couldn't quite work out what had caused this meltdown. They could only say it was someone kind of autoimmune problem, and my surgeon said he had seen it before in his native France after people had gone through 'a big bereavement'. He didn't know, at that point, that I had gone through a huge trauma with my mum's illness and subsequent death. I was lucky; not just to have him be the one to poke around inside my lung (he cheerfully told me it was one of the most necrotic he's ever seen - about the only award I am likely to win), but to have a whole medical team who were acutely aware that what we do in life echoes in our physical health (I am sure it's not a coincidence that it was my lungs that went haywire - the same organ that let my mum down; even on the same side of the body). This book expands on this theme, and I found it fascinating. O'Sullivan sounds like a good doctor - one who asks questions, who is interested in her patients' stories (but, of course, she's writing her dialogue here). The case studies are fascinating, and I would recommend this book to anyone interested in this topic.

Sergio Mori says

It has some interesting bits but all in all it has two massive flaws:
1) the title. She doesn't consider them to be imaginary. It's just an annoying marketing ploy.
2) the biggie for me: she doesn't follow up the cases so we don't know if they are success stories or not. For all we know, patients could have been leading a more functional and happier life with the alleged misdiagnosis.

Also, the chapter on ME/CFS feels undocumented and even preposterous, almost as if she had a bone to pick.

But I liked other bits, so it's not a complete fail.

Chris Steeden says

‘Psychosomatic disorders are conditions in which a person suffers from significant physical symptoms – causing real distress and disability – out of proportion to that which can be explained by medical tests or physical examination’.

I am guessing that this book is controversial in some people’s eyes even though O’Sullivan states **‘I hope to communicate to others what my patients have taught me. Perhaps then, future patients – people like you and me, our friends, families and colleagues – will not find themselves so bewildered and alone’.** Right now, **‘Society is judgemental about psychological illness and patients know that.’** Before she gets into the patients’ cases, which are set as different chapters, she says **‘some of the common preconceptions and judgements levelled at those with psychosomatic illness need to change’.**

Dr Suzanne O’Sullivan has been a consultant in neurology since 2004 although she qualified as a doctor in 1991. She had always wanted to be a neurologist (Neurology is the branch of medicine concerned with the study and treatment of disorders of the nervous system). In this, her first book, she is looking at those people who **‘unconsciously think themselves ill’.** How many of us are **‘aware of the frequency with which our emotions can produce serious disability where no physical disease of any sort exists to explain it?’.** She tells us that **‘Psychosomatic disorders are not neurological disorders. They belong to the fields of psychology and psychiatry’.** Through her work she has seen many patients who suffer in this way though. It is because the patient has a physical symptom that they seek help from a medical doctor. The physical symptom is masking emotional distress Sullivan states.

Is this book readable? Will I be able to keep up with the doctor writing this? Thankfully the answer is yes, to both. This is not an academic book in the way it is delivered. I found it absolutely fascinating. Some of the patient stories are incredible. These are not symptoms that are put on by the patient. There is something real going on. Well, the brain says there is. The doctors would say, ‘Your tests are normal. There is nothing we can do.’ What can be done though? As stated, each chapter is set out with a specific case and other cases that are like it. You will see the commonalities. The reviews on Goodreads are so insightful especially those that give the book one star. Read the book then read the reviews on Goodreads. It makes for interesting reading. I make no judgement either way.

Jon Morris smith says

Now I like a good surgical memoire - my top recommendation is "when he air hits your brain" which is both a memoire, an insight into neurosurgery and an historical journey through the evolution of the discipline... ditto for "Do No Harm"

... however, while enjoyable, I felt that the patient accounts were somewhat incomplete - the conclusion of the cases and the patient's journey to recovery (or not) was often omitted. So these were more 'case studies' if you wish, to serve as illustrations of conditions.

This places the focus on the conditions and a degree of medical insight which comes with that. I did find some of the detail somewhat repetative, and there were some blind avenues which were included for apparently no purpose...

... however there is a recurring topic of "phantom seizures" which present as epileptic seizures but are in fact a manifestation of a response to life event (stress, trauma etc). Brains of patients with these seizures don't exhibit the same electrical 'storms' of epilepsy, which is the key differentiator.

Highly interesting.

Also interesting is that treatment can only start when patients start to see psychiatrists - the stigma attached to that and the question of "are you saying I've got a mental illness" is most telling.

So overall a recommendation - a partial recommendation perhaps, but perhaps more so if you have an interest in how mental illness can affect anyone and how accepting that, and addressing the stigma, is as much a part of the treatment as the help which comes after

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Maik Speedy says

It saddens me to see that a so badly researched chapter about ME/CFS, a disease which has been classified as a neurological disease by the WHO since 1969, was published in this book.

In February 2015 the IOM, the Institute of Medicine, a prestigious American Institute, came out with a report about ME/CFS concluding that ME/CFS "is a medical—not a psychiatric or psychological—illness" http://www.ncbi.nlm.nih.gov/pubmed/25...

On the 2nd of April 2015 prof Newton published an article in which she let muscle biopsies from ME patients and healthy controls exercise in the laboratory and found 4 metabolic abnormalities in ME/CFS.

Which clearly proves that ME/CFS is a physical disease and that this disease has got nothing to do with false illness beliefs, being psychosomatic etc.
http://journals.plos.org/plosone/arti...

In January 2015 exercise physiologist professor Betsy Keller from New York wrote:
"Given what we have learned in the past eight years about this illness, it is intellectually embarrassing to suggest that ME is a psychological illness."
http://niceguidelines.blogspot.com/20...

And exercise physiologists measure things like VO2 max, contrary to psychiatrists who don't measure anything.

In October 2011 two Norwegian oncologists published their Rituximab study which suggest that ME/CFS is an autoimmune disease.
http://www.plosone.org/article/info:d...

And these are only a number of the thousands of articles showing physical abnormalities in this disease.

It's very sad to see doctors like Dr O'Sullivan ignore evidence which doctors shouldn't do and as Professor Hooper wrote a few years ago, when does ignoring evidence by doctors become serious professional misconduct ?
http://www.meactionuk.org.uk/Hooper-s...

It's very clear that Dr Suzanne O'Sullivan ignored all the evidence that what she says is wrong and therefore crossed that line as mentioned by professor Hooper, by a mile.

So what should happen is that this neurologist faces disciplinary action from the GMC, the General Medical Council in the UK. Furthermore, Dr O'Sullivan and her publisher should issue a public apology, the book should be recalled and the chapter she wrote about ME/CFS should be removed from the book.

Flapper72 says

Spoiler alert (well, kind of!) - I'm a doctor and this book has been recommended to me by a colleague - having said that I think that this book should and could be read and appreciated by anyone, just as long as they're a human being! It continues to astound me that (especially the medical profession) think that our metal health and physical health are discrete entities. When we have a physical injury it's going to affect our minds so, similarly, when we're mentally unwell it makes sense that our bodies try and protect us in that too. That's what this book is about. The physical symptoms that aren't pathological but are real, genuine; 'somatisation'. The author, who is a neurologist, tells of a number of patients whom she has treated with (for example) non epileptogenic seizures and how these can be managed. It's multi disciplinary. It's trying to explain, with sensitivity, to patients that their symptoms are real, that it is the brain that's interpreting the messages but it's not, 'all in the head' (i.e. it's not real). The people are, genuinely, suffering, they need help and support in order to help them get better or manage their symptoms. Just because there's no label or abnormal investigations it doesn't mean that people suffer. We need to see people as complete entities - physical and mental - one has to affect and impact on the other. The sooner that society accepts that (and, especially, the medical profession) the better. This is a really interesting book, written from first hand experience, with sensitivity but also accepting that it's extremely difficult to deal with and to explain to our patients and there's no easy way of getting people to engage.

Bonnie says

I was sadly, deeply disappointed by this book.

Her writing is fine, she's an obviously experienced doctor with many tales of interest and but if you know anything about psychiatry, psychology or modern neurology, you will find her stories a bit less than fulfilling. She tries really hard to seem compassionate and empathetic but it just appears like a long excuse for having horrible bedside manner and being really poorly versed in anything but her own specialty of seizures. In which case, I'd ask her not to comment on other illnesses, psychogenic or not since she seems to have a bad habit of disbelieving her patients.

Note that her references are from far far back in history - as in deeply irrelevant; also note that whatever she said about chronic pain disorder is completely bollocks - please do a itty bitty research on pain and neuroplasticity. The book left me with a rather horrific sense that we really need better doctors - at least once who understand people better - enough to know if you are a neurologist, don't try pretend to be a psychiatrist.

Damaskcat says

I thought this book was a truly fascinating read. I have always accepted that there is a strong link between the brain and the body and that the brain can produce symptoms in the body which are wholly unrelated to any physical cause. When I was a child I always used to get a stomach upset on the first day of the school term. Once I was at school the upset disappeared completely. My mother sat me down and explained to me that sometimes the brain plays tricks on the body and that I would feel all right once I got to school. She did of course make sure there wasn't anything I was worrying about at school - and there wasn't because I actually enjoyed school. I did gradually grow out of it as I got older.

I suppose because of my own experiences I didn't find this book hard to accept at all. The author is at pains to distinguish between those patients who are real malingerers and who are making up their symptoms for reasons of their own but are consciously doing it and are in control of their symptoms and those who really do experience their symptoms but have no identifiable physical cause for them. So there is a huge difference between those two cases.

I think many of us have come across those people who can faint at will or who can produce tears on demand but these abilities are a long way away from those who faint for no apparent physical cause but are as distressed by the experience as are the onlookers. How can mental and emotional distress produce symptoms in the body? No one really knows but once the underlying distress is dealt with then the physical symptoms usually disappear.

Unfortunately many people confuse the idea of imaginary symptoms with the idea that an emotional trauma can cause perfectly genuine physical symptoms and see it as an insult if it is suggested to them that a psychiatrist might be able to help them.

The author describes the extreme reactions many people have to any suggestion that psychology might be able to help them. In any illness psychology might be able to help since the brain and the body are so closely linked that one is going to have an effect on the other. People who believe they have epileptic seizures are often very upset to be told that they do not have epilepsy and their seizures are caused by stress or trauma. They frequently do not believe this to be the case even when EEG readings and video footage show they are not having an epileptic seizure.

I think the best way to approach the book is at the very least with an open mind. I found it compelling reading. The author writes well and in an approachable style. I would have liked to see a bibliography included though there is an index. I recommend this book to anyone who is interested in the mind/body link and the way it can affect us.

Rebecca says

O’Sullivan is a UK-based neurology consultant. I picked this up from the bestsellers shelf of the library on a whim because I knew it had won the Wellcome Book Prize, awarded to a fiction or nonfiction book on a medical subject. The kinds of conditions she writes about go by many names: psychosomatic illnesses, conversion disorders, or functional conditions. In every case the patients have normal neurological test results – they do not have epilepsy or nerve damage, for instance – but still suffer from dissociative seizures or lose the use of limb(s). Their symptoms have an emotional origin instead.

“Psychiatric disorders manifesting as physical disease are at the very bottom of [the] pile,” O’Sullivan writes. “They are the charlatans of illnesses.” Indeed, early in her career she was likely to assume such patients were shamming. Although she does describe two patients who through video recordings were found to be faking seizures, in most cases the symptoms are real, but arise from the subconscious rather than a physical cause. Along with cases from her own career, the author writes about early doctors who developed the science of conversion disorders, including Jean-Martin Charcot and Sigmund Freud.

I read the book very quickly, almost compulsively; these are fascinating stories for anyone who’s interested in medical mysteries. That’s in spite of the fact that O’Sullivan does not strike me as a natural storyteller: her accounts of patients’ cases are often no more than just one thing after another, and in reports of her own conversations with patients she comes across as almost robotic and not always very compassionate. Ultimately I believe she does empathize with those with psychosomatic illnesses – otherwise she wouldn’t have written a whole book to illuminate their plight – but it would have taken the writing skill of someone like Atul Gawande for this to be a better book. I’m pretty surprised this won a major prize.

Note: Many of the low ratings you’ll see for this book are in relation to Chapter 7, about CFS/ME/fibromyalgia. These are controversial fatigue disorders, and O’Sullivan is aware that even mentioning them in a book about psychosomatic illnesses is “foolhardy to say the least.” I don’t think what she actually has to say about these conditions is offensive, though (and I say that as someone whose mother struggled with fibromyalgia for years). She allows that there may be physical triggers, but that emotional well-being and traumatic experiences or regular stress cannot be overlooked.

Chew on this: “More than seventy per cent of patients with dissociative seizures and chronic fatigue syndrome are women.” The author’s best guess for why this is? “On the face of it, women turn their distress inward and men turn it outward.”

Many of her patients are outraged by referral to a psychiatrist, as if they’re being told they’re making it all up, but it’s actually a holistic approach: acknowledging that the mind has a big influence on how we feel.

Petra says

Suzanne O'Sullivan is a neurologist consultant based in the UK. In It's All in Your Head: True Stories of Imaginary Illness she details the case histories of various patients who present with neurological symptoms. However, these patients have normal neurological test results, no organic cause can be found for their illness, but they still suffer from e.g. dissociative seizures or have lost the ability to move a limb. They suffer from a psychosomatic disorder. The cause of this is attributed to the patients' subconscious, their emotional well-being relating to present or past emotional stress and/or trauma. As psychosomatic illness is still "a socially unacceptable disorder", many of O'Sullivan's patients react in a defensive, sceptical, or even furious manner when faced with the suggestion to consult a psychiatrist, "so I'm crazy (mad)/a psycho now?"
I was really interested in reading this book because the best and most useful internship I spent during my training were four months in a psychosomatic clinic. In the end, it took me forever to finish this book. That's not to say that it wasn't good, but Ms O'Sullivan isn't a natural storyteller. In addition, the structure of the book made it really difficult to stay with it. The case studies, which I was most interested in, are interrupted by long passages providing historical background covering Charcot, Freud etc.
By the time the author returned to talking about a particular patient again, I often had trouble remembering who that patient was. Ok, maybe my problem as well for having a rubbish memory, but I wish the book had been structured differently.
In general, this is an informative introduction to psychosomatic disorders, especially if you are also interested in gaining some insight into the history of medicine/psychology, but I was keen to find out more about how these patients fared once they were transferred to a psychiatrist and how they dealt with their diagnosis. But I guess that doesn't fall within Dr O'Sullivan's remit, so I appreciate that some information was missing.
Some chapters, as shown by some reviews of this book, are controversial depending on your opinion regarding psychosomatic illness. Overall, I found O'Sullivan's stance respectful and empathetic. She comes across as a compassionate and honest medical professional. The title of the book isn't particularly helpful because the point is that these are not "imaginary" illnesses, as O'Sullivan points out herself, but very real for the tormented patients.
Recommended if you're interested in finding out about the power of the mind over the body and you like a solid introduction to psychosomatic disorders.
I received an ARC via NetGalley.

Liz says

I would like to give the book a much higher rating. I admire Dr. Sullivan's understanding and compassion for the very real suffering of patients with psychosomatic illness (but I cringe at the titles of both versions of her book with their long-standing negative connotations for the general public.)

However, applying the label of psychosomatic illness (even in a somewhat modified way as she does) to ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome) is just wrong. To her credit, Dr. Sullivan does say: "Do I know that for sure. No, nobody does." She says her reason for doing so is based on what she believes is the lack of evidence for an organic disease. In reality, (and despite the appalling lack of government funding in the US for research) there is a mountain of evidence which has been collecting since the 1980's from researchers dedicated to the study of this disease in the US and other countries, with some of the most profound research coming in the most recent years, some after the writing of this book.

Dr. Anthony Komaroff at Harvard Medical, both a researcher and clinician in ME/CFS since the 1980's, gives a summary of the evidence of biological disease from the 80's through 2013 in a video that can be googled entitled, "VIDEO: Dr. Anthony Komaroff - CFS Research: Recent Progress and Challenges".

For the sake of brevity in this review I will mention only a couple of recent highlights in research being done with new biological technologies.

Gene expression studies have demonstrated dramatic results in ME/CFS relative to fatigue and other major symptoms of the disease such as immune dysfunction and autonomic system dysregulation, as well as a new understanding of the complexity of the biology of fatigue. (An overview of some of this can be seen in a series of youtube videos by Prof. Alan Light, one titled "60. Gene expression markers of ME/cfs / ")

A name that must be mentioned is Dr. Ron Davis and his Open Medicine Foundation, End ME/CFS Project at Stanford University. Dr. Davis was recently named by Atlantic magazine as one of the 7 most outstanding innovators of the century for his landmark work in the field of genetics including the development of new research technologies (which led to the mapping of the human genome and more); he is presently working with 3 Nobel Laureates, 6 members of the National Academies of Science, and others creating new research technologies that are producing dramatic findings (work published 2016 and 2017).

Davis and his team have been examining energy production through metabolites (particularly relative to the mitochondria at the cellular level). They have found extensive alterations in the levels of over 100 metabolites in the serum of ME/CFS patients. Dr Robert Naviaux's research, according to Davis, marks the most "important and groundbreaking" development in ME research so far. Using 20 metabolites, Naviaux has discovered a 'diagnostic signature' for identification of ME/CFS at a more than 90% accuracy level. The disruptions in metabolism affect 7 systems in the body, not just the production of energy (giving biological evidence of the many other serious symptoms of the disease).

(For a brief insight, google the youtube video: Scientist Ron Davis Tells How We Are "Fast-Tracking" ME/CFS Research)

There is a saying in medicine (which Dr. Sullivan herself has used): FIRST DO NO HARM. ME/CFS patients have been grossly harmed for decades by the labeling of this devastating biological disease with the innocuous sounding name "chronic fatigue syndrome." The National Institute of Health in the US has all but ignored the funding of research. (AIDS gets 3 BILLION dollars; MS 250 million; ME/CFS 5 million--even though ME affects many more people than the other two). More inaccurate labeling of the disease as psychosomatic such as in this book, though I think well meant given Dr. Sullivan's level of information about the disease, is greatly adding to this harm.

If Dr. Sullivan and others are willing to revise their conclusion of psychosomatic disorder for ME/CFS based on the whole of biological research, my admiration for them will increase exponentially. Otherwise I fear, like the doctors of old clinging to their 'hysteria' explanations for epilepsy and multiple sclerosis, these doctors are doomed to come down on the wrong side of history, while ME/CFS patients needlessly suffer much more harm.

See also the outstanding TED talk from ME patient JENNIFER BREA "What happens when you have a disease doctors can't diagnose". Brea has produced a documentary called 'Unrest' which will be aired on Public Television the first part of next year.