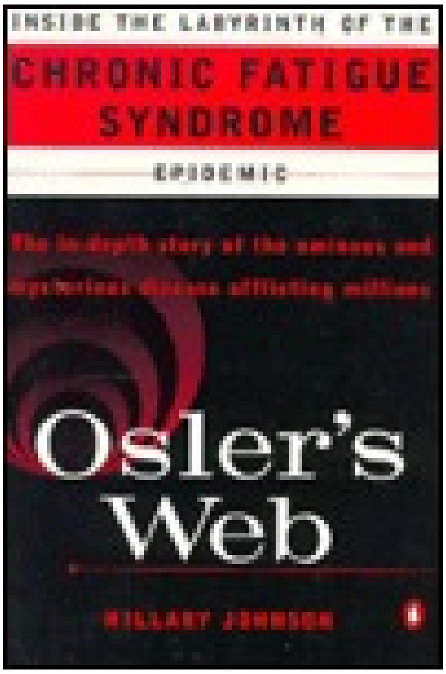

Osler's Web: Inside the Labyrinth of the Chronic Fatigue Syndrome Epidemic

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For more than a decade a devastating disease has been allowed to spread through our country - unchecked, insufficiently researched, and all but ignored, if not denied, by the medical establishment. In many circles this disease, still known as Yuppi Flu, is dismissed as a psychological aberration. For the nearly two million people who have endured its traumatic and very real debilitating physical effects, however, Chronic Fatigue Syndrome is no joke.

Osler's Web: Inside the Labyrinth of the Chronic Fatigue Syndrome Epidemic Details

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From Reader Review Osler's Web: Inside the Labyrinth of the Chronic Fatigue Syndrome Epidemic for online ebook

~?~Autumn♥♥ says

This book is very shocking and upsetting but a person should know the truth.

Janelle says

My mother bought this behemoth of a book for me, so I really should read it. But on perusal it looks very dry, and while I'm sure it includes much that is important, I don't think I'd ever be able to stand reading it.

Andrea says

It was good to read an investigative approach to the history behind the diagnosis of Chronic Fatigue Syndrome and how that history affects the way the disease is perceived, researched, and treated today. There is a lot of insight here. However, the author takes WAY too long to tell the story, annoyingly leaving the reader hanging every couple pages at mini "cliffhangers" in each of multiple co-occurring stories. If you have CFS, you know how hard it is to hold short term "RAM" memory, so for anyone, especially those wit CFS or similar condition, this gimmick for creating suspense and intrigue just gets old and frustrating.

Jessie says

A real nasty story that makes the CDC's work in "Contagion" seem like a fairytale. But unfortunately, as much as Ms. Johnson relays the complex and unjust political history of the illness, she seems to want to simplify the complexity of the illness itself. Its been 15 years since this book was published, and although there is still some stigma involved with the diagnosis, a person today who comes to their doctor presenting with CFS is much less likely to be laughed out of the office than he or she would have been in the 80s or 90s. Nonetheless, the consensus on what causes CFS, or even more importantly, how to treat it, is still a bucket full of guesses. We'll (hopefully) see where the cards fall on the etiology of the illness in the coming years, but it seems that the source of injustice that Ms. Johnson doesn't fully acknowledge in this book is that CFS may well be an illness that with today's (let alone yesterday's) medical knowledge is unable to be understood. Still, after reading about all the losers in positions of power at major governmental ($$$$$) medical establishments... can't help but wonder "what-if" .

Adrian says

Wow, this book is intensely detailed. 700 pages telling the story of CFS from 1980 to 1995. Having CFS myself, I did not have the time to dedicate to reading this entire tome, but the story it tells is eye-opening and shocking. Hillary Johnson, the author, is a seasoned journalist and, had she not so well covered both sides of the story, I would have thought it was sensationalist. But it's not. Things have changed a lot in the me/cfs world since 1995, but the work Ms.Johnson assembled is a record worth reading of how it all went horribly wrong from the start.

Joseph Harriott says

this is one heck of a thorough investigative trawl through the history of American research into CFS. As a man who's had moderate CFS for 8yrs, I was sure interested to learn what a mess of misunderstandings have led to the current stupidly dominating view that CFS cases should be handed to psychiatrists. There isn't another book that interprets so thoroughly for the educated layperson the various attempts to seek better clinical understanding, and the lack of overall co-ordination, or even acceptance that CFS exists as an identifiable disease. It sure was daunting to try to read, so I skimmed my way through, and got an idea of how hard CFS is for medics as well as for patients. New breakthroughs will come, of course, because there are always a few brilliant researchers with the right hunch; or maybe, like vitamin C for sailor's scurvy, the answer's already out there but being systematically ignored. I haven't found it, it's not in this book. So, still exhausted with CFS, but a little better informed, I got back to what works for me, which is rest, good humour, and mindfulness.

Robert says

Fascinating history of this controversial disease. Anti-climatic end,

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Ali Langsather says

I must have ordered this book about two years ago--when I finally had found a diagnosis to what I'd been battling for seven years at that point. I kind of chuckled when I saw how big it was and thought, "I'm never going to read that!" as I put it on my shelf. However, after going through a 20 month period working with a Functional Medicine Doctor (which I highly recommend), I finally felt up to the challenge and was hungry for some more information on what I had gone through. It surely couldn't have all been caused by gut flora, could it?
I loved it! And found the chronological journey of researchers, doctors, and scumbags to be fascinating. I could hardly believe how she had got so much detailed information, surely she wasn't at all of the meetings? (She alluded to being at at least one in person.) She revealed some pretty blatant sabotage from the establishment which I can't help but expect came from the top down somehow, although it could also have been sheer stupidity and bias. Defreitas could have found the virus, if only...! I was pretty riled up after reading it, but now that a few weeks have passed, I'm a little less so, but that's probably only because I myself am feeling better. No doubt the CDC and NIH's denial has ruined the chances of those who are bedridden to ever get their lives back at least with a drug.
The book gave me a lot more faith in and respect for good researchers and doctors than I had had before (I thought they were mostly idiots who could process nothing that wasn't in their textbooks already, forget about common sense or faith in humanity.) It does seem like a traditional cure is possible.
I, however, had already turned my attention to more natural medicine which led me to the Functional

Medicine which is on the cutting edge of understanding how the systems of the body work together and the energy systems, thyroid, hormones, neurotransmitters, metabolism, etc. This is what I recommend, because after 20 months of all the supplements, etc., I am feeling like myself again: feeling good enough to write!

Chris says

Doctors and scientists are infallible and without prejudice. Yeah, right! Read this and see how untrue that is. A strong account of how the medical and scientific establishment willfully ignored the evidence of Chronic Fatigue Syndrome and Fibromyalgia.

Richard says

Another story about medicine not listening to patients and allowing a series of symptoms to get out of control. Never minding about the cause(s), just focus on the treatment and cure if there is any.

Jodi says

This book really gives you an understanding of how and why M.E. has been stigmatized, ridiculed and ignored as much as it has. It makes it very clear that it was not a mistake or an oversight at all but that it was in fact utterly deliberate.

The pure stupidity and lack of basic human compassion involved is astounding. It's important to know how we've ended up in this mess so we can see how we might get ourselves out I think. It's also important that we not underestimate how low these people will go - its lower than you could even imagine.

This is a must read if you are well enough to tackle such a long non-fiction book, it'll just blow your mind and really fire you up about how badly we have all been treated historically and the...well you'd have to call them evil, people behind it all. Whether you have M.E. or one of the many other diseases commonly misdiagnosed as 'CFS' you'll be outraged.

It is also very important to read this book together with information which explains why 'CFS' as a concept must be abandoned and why renaming 'CFS' as M.E. or 'ME/CFS' is not the way forward.

You need to also know that:

M.E. patients were treated appropriately and correctly diagnosed until around 1988, when there was an increase in the number of M.E. patients and outbreaks in the US. Some medical insurance companies (and others) decided that they would prefer not to lose many millions of dollars on so many new claims and so they created a new vague fictional disease category called 'Chronic Fatigue Syndrome' to try to confuse the issue of M.E. and to hide M.E. in plain sight.

Under the cover of 'CFS' certain vested interest groups have assiduously attempted to obliterate recorded medical history of M.E.; even though the existing evidence has been published in prestigious peer-reviewed journals around the world and spans over 70 years.

M.E. is a distinct, scientifically verifiable and measurable, acute onset, organic neurological disease. 'CFS' in contrast, is not a distinct disease. 'CFS' doesn't exist. Every diagnosis of CFS - based on any of the CFS definitions - can only ever be a misdiagnosis. A watebasket diagnosis.

The fact that a person qualifies for a diagnosis of 'CFS' (a) does not mean that the patient has M.E., and (b) does not mean that the patient has any other distinct illness named CFS.' M.E. and 'CFS' are not the same.

Far fewer than 0.5% of the population has the distinct neurological disease known since 1956 as Myalgic Encephalomyelitis.

Chronic Fatigue Syndrome is an artificial construct created in the US in 1988 for the benefit of various political and financial vested interest groups. It is a mere diagnosis of exclusion based on the presence of gradual or acute onset fatigue lasting 6 months. If tests show serious abnormalities, a person no longer qualifies for the diagnosis, as 'CFS' is 'medically unexplained.' A diagnosis of 'CFS' does not mean that a person has any distinct disease (including M.E.). According to the latest CDC estimates, 2.54% of the population qualify for a 'CFS' (mis)diagnosis.

The patient population diagnosed with 'CFS' is made up of people with a vast array of unrelated illnesses, or with no detectable illness. However, while 'CFS' is not a genuine diagnosis, those given this misdiagnosis are in many cases significantly or even severely ill and disabled. 'CFS' is made up of people with cancer, MS, Lyme disease, depression and hundreds of other unrelated conditions.

Sub-grouping different types of 'CFS,' refining the bogus 'CFS' definitions further or renaming 'CFS' with some variation on the term M.E. (such as 'ME/CFS') would achieve nothing and only create yet more confusion and help to continue and further entrench the mistreatment and abuse.

The problem is not that 'CFS' patients are being mistreated as psychiatric patients; some of those patients misdiagnosed with CFS actually do have psychological illnesses. There is no such distinct disease/s as 'CFS' - that is the entire issue.

Due to outrageous political influences on medicine and govermnent policy, the vast majority of M.E. patients will not be able to be correctly diagnosed with M.E. Most M.E. patients will unfortunately be misdiagnosed with 'CFS.' It is extremely important to note, however, that only a very tiny percentage of those told they have 'CFS' will be M.E. patients. The overwhelming majority of those misdiagnosed with 'CFS' do NOT have M.E. 'CFS' is NOT just another term for M.E.

The name Myalgic Encephalomyelitis must be fully restored (to the exclusion of all others) and the World Health Organization classification of M.E. (as a distinct neurological disease) must be accepted and adhered to in all official documentations and government policy. M.E. patients must again be diagnosed with M.E. and treated appropriately for M.E. based on actual M.E. research. For this to happen, there is a real need for patients (and others) to participate in genuine advocacy and activism.

The bogus disease category of 'CFS' must be abandoned. All those misdiagnosed with 'CFS' must immediately reject this harmful misdiagnosis and begin the search to find their correct diagnosis whether this be M.E., PVFS, depression, cancer, or any other disease. Correct diagnosis is vital in obtaining the correct treatment.

M.E. is not the same thing as CFS or CFIDS or 'ME/CFS' but this book is a M.E. book in most of the descriptions of the disease, absolutely. We do know that M.E. is not caused by a retrovirus but an enterovirus with a 4 - 7 day incubation period however. For political information on M.E. and why M.E. is not 'CFS' see books and articles by Dr Hyde and Dr Dowsett.

Jodi Bassett, The Hummingbirds' Foundation for M.E.

Michael Perkins says

The disease described in this book has since been identified as Myalgic encephalomyelitis/Chronic fatigue syndrome (ME/CFS). It's a chronic, debilitating multi-system illness affecting the neurological, endocrine, and immune systems. For an updated account of this affliction, I recommend the recent documentary "Forgotten Plaque: M.E. and the Future of Medicine," available to stream on Amazon.

Though this book came out more than 20 years ago, it still has something to say about the world of medicine. My father was an M.D. who practiced for 40 years (44, if you include his four years serving as a medical office in France during WW II). He told me more than once that doctors are egomaniacs who can't bring themselves to say: "I don't know." Meanwhile, we live in a society in which if something cannot be measured, then it doesn't exist. Here's a clue folks: there are a lot of things that exist that we have not measured and may not ever measure.

This attitude is a roadblock to knowledge, demonstrating a lack of imagination and flexible intelligence, and too easily dismissing what we don't understand as psychosomatic or a hoax.

On the positive side, real medicine is an effort to seek answers and make new discoveries, as described in another recent book I read: "The Emperor of All Maladies: A Biography of Cancer." There is no progress without this attitude.