



Asleep: The Forgotten Epidemic that Remains One of Medicine's Greatest Mysteries

Molly Caldwell Crosby

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Another fascinating foray into medical history from the author of *The American Plague*

In 1918, a world war was raging, and a lethal strain of influenza was circling the globe. In the midst of all this death, a bizarre disease appeared in Europe. Eventually known as encephalitis lethargica, or sleeping sickness, it would spread across the world, leaving millions dead or locked in institutions.

Then, in 1927, it would disappear as suddenly as it had arrived-or so the doctors at first thought.

Asleep, set in 1920s and '30s New York, follows a group of neurologists through hospitals and insane asylums as they try to solve this worldwide epidemic.

The symptoms could include not only unending sleep but dangerous insomnia, facial tics, catatonia, Parkinson's, and even violent insanity. Molly Caldwell Crosby, acclaimed author of *The American Plague*, explores the frightening history of this forgotten disease- and details the frantic effort to conquer it before it strikes again.

Asleep: The Forgotten Epidemic that Remains One of Medicine's Greatest Mysteries Details

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From Reader Review *Asleep: The Forgotten Epidemic that Remains One of Medicine's Greatest Mysteries* for online ebook

Cara says

When I picked up this book (\$1.75 at the library's used book sale!) I didn't pay attention to the fact that the author, Molly Caldwell Crosby, also wrote another book I read recently, *The American Plague: The Untold Story of Yellow Fever, the Epidemic That Shaped Our History*. That book was interesting, though not terribly well-written. When I realized it was the same author, I looked at the publication date, assuming *Asleep* must have been her first work. The writing style is terrible - extremely clichéd and amateur. In fact, *Asleep* is Crosby's second book. Most writers get better as they go along, but that's obviously not the case with Molly Caldwell Crosby. She ends practically every chapter with a cliffhanger, which is annoying in fiction and completely inappropriate in nonfiction. She spends more time describing 1920s New York than she does encephalitis lethargica, the purported subject of this book. Crosby apparently has a MA in science writing from Johns Hopkins University, so I can only assume that either she completely half-assed this book, or Hopkins is giving out degrees to any random person now.

In sum, not recommended.

Talulah Mankiller says

Ahem.

So we all know that I like diseases, right? I mean, I don't enjoy having them and if you had one I would be quite sad for you, but I like reading about them. Because I am a ghoul. I've tried to come up with other explanations for my fascination, but that's it: the Mankiller is a ghoul. Plain and simple. End of story.

What with being a ghoul and all, Molly Caldwell Crosby's *Asleep: The Forgotten Epidemic that Remains One of Medicine's Greatest Mysteries* definitely appealed to me. Because it's a relatively new book and my library didn't have it, I ordered a copy of it ON MY KINDLE. Man, was that ever a waste of money.

Asleep is a history of "the sleeping sickness" that swept the world in the wake of the Great Influenza of WWI. Encephalitis lethargica, as it is medically known, is an illness that begins with flu-like symptoms, then progresses into either an endless slumber (some people slept for as long as 180 days) or an insomnia so complete that it eventually kills the patient. For those who "recovered from" the illness—about a third of all victims—the prognosis was bleak: adult patients gradually lost most or all motor control, while the children who were afflicted suffered from horrible, unexplained changes in mood and behavior. Previously placid young people suddenly began physically attacking their friends, siblings, parents, teachers—and self-injurious behavior was distressingly common. One young woman Crosby mentions removed most of her own teeth and put out both her own eyes. When asked, the children said that they felt compelled to do these things, and exhibited a great deal of distress about their own actions; unfortunately for them, they were not sociopaths and did not enjoy hurting themselves or others. Something had just gone very, very wrong in their brains and they seem to have lost most impulse control.

PS: although a huge project to cure encephalitis lethargica ran all the way up through the 1930s, research into the disease was largely discontinued thereafter in favor of more wide-spread and reoccurring illnesses like polio. Encephalitis lethargica has no cure, and cases still periodically pop up. Cheerful thought, huh?

Clearly, I find the subject matter of *Asleep* fascinating because, well, how could you not? But unfortunately, Crosby's writing is dullsville, managing to destroy any moments of narrative tension, and also? The number of times she referred to the victims of encephalitis lethargica as "broken," or "damaged" or "destroyed" was frankly appalling. Look: it's wrong to say that about anyone simply because they happen to have some kind of illness. Period. But it's even worse when the people you're saying it about would have been/are fully conscious of the fact that you're saying it. One of the great tragedies of encephalitis lethargica is that the patients, even the seemingly catatonic ones, were aware. They were aware of their surroundings the whole time. In one case that Crosby described, a doctor told the parents of a patient that he fully expected her to die; believing the girl to be comatose, he said this right in front of her.

Even though she was "asleep," she cried.

Over and over again, Crosby described how the minds of these patients were somehow divorced from the actions of their bodies: they would scream, kick, bite, injure themselves, and not be able to understand why they did these things or—more importantly—how to stop doing them. Personally, I think it's wrong to call most anyone "broken," but to say that about someone who's fully capable of understanding what you're saying and what it means? Talk about fucking cruel. These people had (and in some cases have) a disease that caused them horrible pain and suffering; that doesn't mean they were "broken." They're not toys with snapped strings; they're human beings with an illness. Talking about them as if they are things just adds to the pain.

Ann says

I was disappointed in this book. I started it with high hopes, because the little I know about this "forgotten epidemic" indicated that it would make for fascinating reading. Encephalitis lethargica is now mostly remembered as a footnote in the history of Parkinson's Disease (described by Oliver Sachs in his book "Awakenings", but I was curious to know more about its origin, its relation to the great Influenza Pandemic, and its sequelae. This book left me frustrated. It felt like the author was not all that interested in the disease itself but more in the socio-economic changes that the US, especially New York City, was going through in the 1920s. The sections regarding some of the well-known physicians treating patients with the disease felt padded -much biographical detail, but little of it relevant to this disease. The same applied to the illustrations : why would a reproduction of a ballot for the president of the American Neurological Society be of interest to the reader? Why would a picture of a hospital years before or after it housed victims of encephalitis lethargica be of interest to the reader? The gimmick of naming each chapter for a patient fell flat, since the description of the patients often read like hurried afterthoughts- or sometimes there simply wasn't enough information available to make these case histories interesting.

I will admit that I did not finish the book and so if the second half was better than the part I slogged through, I will have missed that.

Conclusion : this fascinating disease deserves a better book than this.

Daniela says

This book and *Awakenings* should be read in tandem, Caldwell provides plenty of historical detail which can be tedious, instead of going directly to the point like Sack's book: description of patient's cases. Some historical tid-bits are good like J.P Morgan's wife case.

The long-lasting impression on both books would be how a damaged brain either by illness or chemicals can produce such bizarre and frightening behavior.

Laura says

I happen to catch an interview on BookTV wherein this author and Rebecca Skloot were the guest “interviewees”. Came away from that experience with a desire to read the books written by these two young women. In the case of Ms. Skloot, her book is a best seller [“The Immortal Life of Henrietta Lacks”]. This one is not as popular a read I guess. Mores the pity. Ms. Crosby has managed to write a piece of non-fiction that reads very much like a novel.

The “Forgotten Epidemic” which is the subject matter of this book is encephalitis lethargica aka “Sleeping Sickness”. *Asleep* is set in 1920's and '30's New York. This was a world wide epidemic that coincided with the Spanish flu pandemic. Of concern to all of us in the 21st century is the fact that doctors do not know whether encephalitis lethargica is caused by a virus, bacteria, or the body's own immune response. “They do know that it may reemerge in the wake of a new flu pandemic”.

“The kaleidoscope of symptoms ranged widely from unending sleep to dangerous insomnia, facial tics to catatonia, Parkinson's to violent insanity”. It struck all levels of New York society from the richest of the rich to the poorest of the poor. “Patients who fell victim to it, learned the worst fate was not dying of sleeping sickness, but surviving it”.

The one positive effect that emerged from this epidemic was the growth of the field of neurology. In this book you follow a group of neurologists through hospitals and insane asylums as they try to solve the mystery that surrounds this disease. Ms. Crosby provides you with an understanding of the life and times that these pioneers of medicine contend with in order to advance their understanding of this mysterious ailment. There are case studies where in you glean a clear and frightening knowledge of the devastating effects of this insidious affliction.

The good news is — “Antivirals, antibiotics, and steroids could all help a patient recover before encephalitis {a swelling of the brain} has a chance to cause damage. Scientists are committed to that work today”.

A highly readable read. Appealed to me on several levels, not the least of which is my unending interest in history.

Sarah Beth says

Asleep details the mysterious and alarming sleeping sickness that swept across the globe in the early twentieth century, and which still pops up in isolated cases today. Encephalitis Lethargica kills 1/3 of its victims who never wake up, and permanently alters/led to the institutionalization of another third. Yet it remains a mystery, and a largely unknown one at that.

Unlike many dry non-fiction (I'm looking at you, *The Emperor of All Maladies*), this was an easy read. Part of that was due to the structure which was centered around different patients suffering from encephalitis lethargica and their physicians. However, I found the intentionally narrative-like intro to each chapter a bit heavy handed. For example, "Jelliffe and Tilney sat in the deep red, velvet chairs of the auditorium. Outside, it was cold, and frost powdered the front steps of the building of the New York Academy of Medicine.

Across the street, in the early moonlight, the tree branches of Central Park reached like talons toward the nighttime sky." While it certainly made the text less dry, the style was almost too fiction-like for me. I can't help thinking that more non-fiction seems to be leaning towards more of a narrative feel since the popularity of *The Devil in the White City*. This is certainly not a bad thing, in my opinion.

This disease truly disturbed me. The fact that patients who recovered reported that they were lucid during their catatonic-like state horrified me, in much the same way as the plight of stroke victim condemned to only being able to move one eye in *The Diving Bell and the Butterfly*. Additionally, I was appalled by the multiple cases of severely altered personalities in those that recovered. Especially that of Rosie, who not only ripped her own teeth out, but tore both of her eyes out with her fingers. Holy mother...That ain't right. Somebody needs to get researching this disease yesterday.

Yet perhaps most mysterious is that despite the fact that millions suffered from encephalitis lethargica, no one today knows about or discusses the epidemic. As the author quotes Oliver Sacks, "such forgettings are as dangerous as they are mysterious." Why was this disease forgotten?

I have quite a taste for bizarre and unusual medical accounts, so this book was perfect for me. I do wish the book could have offered more of an actual medical account of the source of the disease rather than just case stories, however, I understand that that is largely dependent on the medical knowledge available to the writer. Perhaps more than any other non-fiction books I've read, this book really reminded me of another largely forgotten and greatly unknown plague detailed in *The Dancing Plague: The Strange, True Story of an Extraordinary Illness*. There are crazy things that can happen to your body out there. Including falling asleep for months or dancing until you collapse dead. Everyone beware.

Peter Hayashi says

I started with book with high hopes as the subject of the book is so fascinating and I have enjoyed a number of similar books. I was quite disappointed in this book however. My major complaint is that there was just a skimpiness of the story. There really was not much information about the epidemic and the disease in this book. Instead, we learn quite a bit (too much for my taste) about a couple of physicians, who studied the disorder and either set up or ran organizations that studied and treated the disease, but none made any substantive progress in understanding the disease. These figures are part of the story but I found none of them particularly interesting or noteworthy. The reader also learns much about the historic epoch most of it only modestly relevant. The author did quite a bit of novelizing, e.g. writing in some detail about what a particular person was feeling and wearing, the weather, the smells and sights that he or she encounters. but where is the beef?

Some of the thinness of the story no doubt reflects the state of the historic record but much more could have been done. How did they go about making the "vaccines" so often talked about late in the book? Given the frequency and salience of the obsessions and compulsions in the affected, what is the current science of other disorders that have obsessive and compulsive components? I liked the idea of the interspersed case histories but these too, I found lacking in depth. Are there really no better more detailed and more informative cases available?

Furthermore, the author also seems to lack basic understanding of some important issue. For example, on page 39 she wrote "Still it would be several more years before X-ray technology could identify emotions or brain death" ..huh? X-ray technology can do neither. Also, she does not seem to understand that the term "insanity" is a legal one, not a medical diagnosis,e.g. p. 124.

It has been years since I read Oliver Sacks book about the group of encephalitis lethargica patients that he treated and my recollection of it is thus a bit hazy. But I certainly would recommend it rather than this book to anyone interested in the subject.

Nenia ? Queen of Literary Trash, Protector of Out-of-Print Gems, Khaleesi of Bodice Rippers, Mother of Smut, the Unrepentant, Breaker of Convention ? Campbell says

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Reading a book about a disease that makes people go to sleep and never wake up again is probably *not* the best bedtime reading, but when it comes to books, I often make bad choices. In case you couldn't tell from the title, *ASLEEP* is about the sleeping sickness, also known as encephalitis lethargica, literally Latin for "that thing that makes your brain swell and makes you sleepy." It's a disease that's mostly been swept under the rug and in this book, which sews together the case studies of several people who were afflicted with the disease, Crosby discusses the "mystery" behind encephalitis lethargica and how it affected the infected.

For the most part, I thought *ASLEEP* was an interesting book and devoured it fairly quickly. Sometimes these medical history books can be too gruesome for me and yes, what happens to the victims in this book is truly awful (one case was particularly horrific, and I remember reading about that particular incident in one of my psychology textbooks in college as an example of how hospitals should exert more rigorous supervision over patients with a tendency to self-harm).

ASLEEP is a bit of an unsatisfying read though for two reasons. First, it's a mystery without a satisfactory ending. Doctors still aren't quite sure what caused the sleeping sickness, and while there are theories (autoimmune response? multiple diseases acting in tandem?), there is no solution. Contrast that to another medical mystery book I read a while ago about prions, where the book builds up to that one "eureka!" moment where people realize, "hmm, maybe eating brains is a bad idea!"

The second aspect of this book that was a bit of a downer for me was the way that the patients themselves were discussed. This book did not really read the way a psychologist or psychiatrist would talk about patients, and I looked up the author and it appears that she is a journalist with no psychology background that I can see (seems that she has a Master of Arts). I bring this up because one of the things that they teach you in psychology (or any other medical-related science) many, many times is to not fall into the trap of defining people by their disease. People make fun of PC-language but addressing people by the correct labels shows respect, and feeling that you are a respected human being is crucial to healing. Each case study is portrayed as a distinct "before" and "after" with the "before" being held up as the ideal and the "after" being this utterly ruinous thing that destroyed their lives and made them shattered shells of their former selves, etc. and I could almost hear all of my psych professors collectively groaning in my mind. This other review by Talulah on Goodreads goes more into depth on the specifics of the language used to describe the patients.

It felt a bit like tabloid sensationalism.

I realized that something about this book was putting me off and didn't realize what it was until I read the epilogue (which ties back to the prologue) about how the author's own grandmother being afflicted with sleeping sickness was one of the inspirations for her writing about the disease. I thought that was really interesting until I read the end part about how her when her grandmother was dying, she was trying to think about something to remember her by as a person but couldn't get over the empty space the disease had left in her (paraphrasing). Annd that's how the book ends. On that note.

I did enjoy *ASLEEP* but the writing could have been less sensationalistic and more delicate in how it handled the cases of the various patients who had the sleeping sickness. I get that this book is older, and people know more about the importance of proper "labels" now, and even Oliver Sacks, who endorsed this book, comes across as comparatively insensitive in his oldest book, *THE MAN WHO MISTOOK HIS WIFE FOR A HAT*, when you compare it to some of his more recent titles. Psychology is a new field and it's changing so fast that by the time some people finally feel competent to talk about it, some of the terms are already out of date. I mean, I still see people who make jokes that schizophrenia means multiple personality (it doesn't) or that you only use 10% of your brain (good luck with that). All it takes to change that is a little research and extra care.

3 stars

Jen says

I unabashedly love medical history. I find the whole "finding a cure" and "discovering a treatment" some of the best stories of human achievement. It's wonderful to read about what the human mind can accomplish.

The best part about these books is they usually have happy endings.

"Polio was awful and horrible and everyone was dying or disabled. Then Salk created the vaccine. And they all lived happily ever after."

"People died from scratches from thorns and got infected and pus was everywhere. Then they found penicillin. And they all lived happily ever after."

"People got the flu and they all died and it was awful and horrible, but turns out it was a lot of pneumonia-- and we have antibiotics now, so don't worry. And they all lived happily ever after."

Not this one. Nope. Around the time of the Spanish flu (1918ish), there was an epidemic of a condition where people just started being really sleepy, having dramatic shifts in personality, and pretty much being disabled or mentally unstable for the rest of their lives. Eventually, the condition was named encephalitis lethargica. Even if you didn't die from the fevers and the seeming unconscious state from which no one could wake you, you would be left with a personality different than how you started, in pain, mentally incapable of caring for yourself. Oh, and those times everyone thought you were asleep? Nope, you were conscious--

aware of things around you, including people discussing if you were dead or not. The movie Awakenings is about this condition. In essence, this condition was just frackin' awful.

It slowly petered off, with fewer and fewer people being affected.

The best part? No one knows what exactly causes the brain to swell, what cures it, or if it will strike again with the same frequency. There is no happy ending. None. No one lives happily ever after, especially not me because I now have something else of which to be terrified. Especially when I sleep late.

The book introduces each section with a case study--none end well, don't get attached. And the helplessness of the researchers is poignant and sad. It's well written, moving, and enough to keep you up in terror of this condition you can't predict, you can't fight, and you can't cure.

But, yes, you should read it.

Cathy says

I really wanted to like this book. It's my type of subject, it's an interesting disease.... but I just felt so disappointed. There was a lot of writing that I could've done without, mostly detailed descriptions of the weather, the sounds, the smells, the sights, the history of NYC, etc. I just wanted the book to cut to the story. I also didn't realize that it was going to almost be more a book about neurology than the disease itself, focusing more on the doctors than the patients.

I'm still really interested in learning more about the disease, but I think I'll skip to Awakenings instead. The book also never once mentioned that the movie Awakenings featured the disease, though it mentions the book. It's a film I've seen several times (stars Robin Williams) and I think it would've been nice to have mentioned that connection.

Tamara says

Such an interesting look at history and social issues: through the eyes of an epidemic

Debbie "DJ" says

I had never heard of this epidemic that occurred in the early 1900's. profound, scary, and still a mystery. A very interesting and historical read.

Jeanette says

This is a good review to the history of this encephalitis lethargica, commonly known as Sleeping Sickness. Terrible, horrific and rarely spoken about at all. All of us have heard repeatedly of the pandemic of Flu

following WWI that killed millions, but so little of this aftermath pandemic. 1918 through the 1930's. And it in so many cases throughout the entire world seemed to shimmy into the same grooves as the economic Depression- and with so much misdiagnosis!

This covers other subjects of the economics, health of cities, sanitation of water and foodstuffs, feminist onus to vote and other formerly non-traditional roles, and entwines them with the tales of the medical people who fought for knowledge and cure of this state of lethargia. It so often mixed the "eyes" of the times with other concurrent issues that, IMHO, an entire star was lost to the critical focus on this exact disease's "study" or progression toward knowledge to fight it.

The book is set into patient chapters and I did love that aspect. You got much more of particulars and various outcomes (no two patients seem to ever be alike in all symptoms)- and of the direct horrific knowledge that 1/3 die, 1/3 never fully "awake" again, 1/3 more do wake/ return to a "normal". But that last 1/3rd centers the most horrific details of all- because the original personality is hugely and negatively altered. Described most often in brain damaged, mind destroyed or insane perimeters. In one case a man was in an institution for 70 years after his "cure", for instance. But that is far from the worst scenarios.

My last composite take on this living death condition is that it is probably an immune reaction. Or some agent in the body causing an autoimmune response that results in damage to critical areas of the hypothalamus and other essential brain structures. But 5 million and so many teenagers, people in mid-life, children? And where has it gone? Most humans on the Earth at that time got that Flu, and this was an aftermath to the same people who had recovered from it? And how many were labeled as Parkinson's or some psychiatric label for other numerous insanity mental health descriptions? And the forms of warehousing! And how much of those progressions 3 years later, 10 years later etc. were never even recorded.

This was a scary read. Really, really scary. Trapped in a body that will not respond, and becoming insane to your own body cognition or position awareness (self-mutilating often) for years and years. This author puts up some strong arguments that both Hitler and Woodrow Wilson had after effects of this pandemic encephalitis with long term effects. In Wilson's case the altered states were labeled stroke, when the symptoms were not those of stroke in great majority. Much was hidden from the public too.

Will it happen again and is it related to how the immune system is left after another horrendous infection? Those answers are still very unclear.

At least 10 doctors or pivotal researchers in this quest were highlighted. I had not heard of any of them by name except one. It is worth reading for that aspect alone.

Kristi says

If you're at all interested in diseases, epidemiology, or even just scientific narrative this book opens up an amazing world of a disease that changed the way modern science regards the human brain. But just as quickly, this disease disappeared into medical history. This book chronicles not only its world-wide spread from the battlefields of WWI to the streets of New York City, but also discusses the history of literature that might hold clues of prior occurrences of the disease. I loved this book.

Evanston Public Library says

When most people hear the term sleeping sickness, images of the tropics, Africa, and mosquitoes come to mind. But as Molly Crosby explains in her thoughtful and measured book, a mysterious outbreak of an infectious disease with confounding and terrifying symptoms was also dubbed sleeping sickness mainly because sufferers would fall ill and sleep or half-sleep for a little as a few days or for as much as many months. Many succumbed to the illness literally dying in their sleep. Others awoke in good health, but showed profound personality changes, usually negative. Some lucky patients recovered completely, but years later were struck down with a cruelly aggressive form of Parkinson's disease. What further confounded researchers was an unfortunate coincidence: just as the first reports of this sleeping sickness, or encephalitis lethargica, were made, the global influenza pandemic of 1918 reared its ugly head. Were the two related? Maybe. Some patients had had mild flu cases and just before the onset of the sleeping sickness, but research into viruses and autoimmune diseases was in its infancy, and scientists, stretched to their limits with the flu pandemic, were no closer to nailing a cause or effective treatment for this bizarre disease. One positive outcome of the epidemic was the increase in interest in the specialty of neurology, and when the sleeping sickness outbreaks simply tapered off in the late 1920s, doctors had begun to delve into the secrets of the brain and nervous system which resulted in medical advances in the diagnosis and treatment of many conditions. Records of this strange outbreak, however, became almost forgotten in the archives of medicine. Today the concerns over the recurrence of a fast-moving, lethal flu pandemic have some researchers worried that if encephalitis lethargica is indeed related to flu, the modern world is terribly vulnerable. If you are intrigued as I am by medical mysteries, especially those still unsolved and posing a threat, you'll enjoy this fascinating if unsettling book. (Barbara L., Reader's Services)
