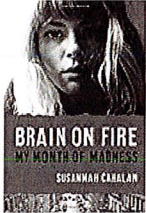


Brain on Fire (Calahan)

Summary | Author Bio | Book Reviews | Discussion Questions | **Full Version** | [Print](#)



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Brain on Fire: My Month of madness

Susannah Calahan, 2012

Simon & Schuster

288 pp.

ISBN-13: 9781451621389

Summary

One day in 2009, twenty-four-year-old Susannah Cahalan woke up alone in a strange hospital room, strapped to her bed, under guard, and unable to move or speak. A wristband marked her as a “flight risk,” and her medical records—chronicling a month-long hospital stay of which she had no memory at all—showed hallucinations, violence, and dangerous instability. Only weeks earlier, Susannah had been on the threshold of a new, adult life: a healthy, ambitious college grad a few months into her first serious relationship and a promising career as a cub reporter at a major New York newspaper. Who was the stranger who had taken over her body? What was happening to her mind?

In this swift and breathtaking narrative, Susannah tells the astonishing true story of her inexplicable descent into madness and the brilliant, lifesaving diagnosis that nearly didn’t happen. A team of doctors would spend a month—and more than a million dollars—trying desperately to pin down a medical explanation for what had gone wrong. Meanwhile, as the days passed and her family, boyfriend, and friends helplessly stood watch by her bed, she began to move inexorably through psychosis into catatonia and, ultimately, toward death. Yet even as this period nearly tore her family apart, it offered an extraordinary testament to their faith in Susannah and their refusal to let her go.

Then, at the last minute, celebrated neurologist Souhel Najjar joined her team and, with the help of a lucky, ingenious test, saved her life. He recognized the symptoms of a newly discovered autoimmune disorder in which the body attacks the brain, a disease now thought to be tied to both schizophrenia and autism, and perhaps the root of “demonic possessions” throughout history.

Far more than simply a riveting read and a crackling medical mystery, *Brain on Fire* is the powerful account of one woman's struggle to recapture her identity and to rediscover herself among the fragments left behind. Using all her considerable journalistic skills, and building from hospital records and surveillance video, interviews with family and friends, and excerpts from the deeply moving journal her father kept during her illness, Susannah pieces together the story of her "lost month" to write an unforgettable memoir about memory and identity, faith and love. It is an important, profoundly compelling tale of survival and perseverance that is destined to become a classic. (*From the publisher.*)

Author Bio

Susannah Cahalan is a news reporter at the *New York Post* whose award-winning work has also been featured in *The New York Times*. She lives in Jersey City, New Jersey. (*From the publisher.*)

Book Reviews

Brain on Fire is at its most captivating when describing the torturous process of how doctors arrived at [the] diagnosis...At its best, Cahalan's prose carries a sharp, unsparring, tabloid punch in the tradition of Pete Hamill and Jimmy Breslin.

New York Book Review

Cahalan's tale is told in straightforward journalistic prose and is admirably well-researched and described. Because she has no memory of her "month of madness," the story rests on doctors' notes and recollections, hospital films, her father's journals, both parents' recounting of what happened, and the reminiscences of her devoted boyfriend and those of her many friends and relatives. This story has a happy ending, but take heed: It is a powerfully scary book.

Washington Post

For the neurologist, I highly recommend this book on several grounds...First, it is a well-told story, worth reading for the suspense and the dramatic cadence of events... Second, it is a superb case study of a rare neurologic diagnosis; even experienced neurologists will find much to learn in it...Third, and most important, it gives the neurologist insight into how a patient and her family experienced a complex illness, including the terrifying symptoms, the difficult pace of medical diagnosis, and the slow recovery. This story clearly contains lessons for all of us.

Cognitive and Behavioral Neurology

The bizarre and confounding illness that beset the 24-year-old *New York Post* reporter in early 2009 so ravaged her mentally and physically that she became unrecognizable to coworkers, family, friends, and—most devastatingly—herself... She dedicates this miracle of a book to "those without a diagnosis".... [An] unforgettable

memoir.

Elle

In 2009, Cahalan was in a serious relationship and her career as a reporter at the *New York Post* was taking off. But suddenly, as she tells it in this engaging memoir, she began suffering from a bizarre amalgam of debilitating symptoms including memory loss, paranoia, and severe psychosis that left her in a catatonic state that moved her close to death. Physicians remained baffled until one extraordinary doctor determined that Cahalan was “in the grip of some kind of autoimmune disease.” Released from the hospital after 28 days, she had no memory of her stay there. DVDs recorded in the hospital were the only link she had to her startling condition. “Without this electronic evidence, I could never have imagined myself capable of such madness and misery,” she writes. Focusing her journalistic toolbox on her story, Cahalan untangles the medical mystery surrounding her condition. She is dogged by one question: “How many other people throughout history suffered from my disease and others like it but went untreated? The question is made more pressing by the knowledge that even though the disease was discovered in 2007, some doctors I spoke to believe that it’s been around at least as long as humanity has.” A fast-paced and well-researched trek through a medical mystery to a hard-won recovery.

Publishers Weekly

This fascinating memoir by a young *New York Post* reporter...describes how she crossed the line between sanity and insanity...Cahalan expertly weaves together her own story and relevant scientific information...compelling.

Booklist

New York Post reporter Cahalan details the madness that briefly robbed her of her independence and ability to write.... *Verdict*: A compelling, quick read with a moving message. Cahalan's hip writing style, sympathetic characters, and suspenseful story will appeal to fans of medical thrillers and the television show *House*. Brief, informative biology and abnormal psychology discussions throughout the text will interest science students without slowing the narrative. Because Cahalan's condition is rare and its causes unknown, this book may save lives and promote empathy for those struggling with mental illness. —*Chrissy Spallone, Philadelphia Yearly Meeting Lib.*

Library Journal

A young journalist's descent into her own baffling medical mystery. In her debut memoir, *New York Post* reporter Cahalan recounts her struggle to understand an unremembered month lost to illness. Cobbled together from interviews, medical records, notebooks, journals and video footage, the author conjures the traumatic memories of her harrowing ordeal..... Diagnosed with anti-NMDA-receptor

encephalitis—a rare autoimmune disease with a cure—Cahalan and her family embarked on the long, hard road to recovery.... A valiant attempt to recount a mostly forgotten experience, though the many questions that remain may prove frustrating to some readers.

Kirkus Reviews

Discussion Questions

1. A quote from the philosopher Friedrich Nietzsche appears at both the beginning and end of Cahalan's memoir: "The existence of forgetting has never been proved: we only know that some things do not come to our mind when we want them to." Why do you think Cahalan chooses to recall this quotation at both the story's start and end? How does it correspond to Cahalan's tale and its major themes? In addition to the content of the quotation, why is it particularly poignant that the author would choose a quote by Nietzsche to bookend her work?
2. Evaluate and discuss the style and genre of *Brain on Fire*. Cahalan describes the book as a memoir, but she also says that it reportage. She acknowledges using help from other sources since she has little to no memory of many of the happenings recounted in the book. In the author's note she goes so far as to describe herself as an "unreliable source." How does this detail affect our experience of and response to her story? What does this indicate about truth and bias in storytelling? What complex issues does it raise in our understanding of works designated as nonfiction?
3. In the author's note, Cahalan says that her book is "a journalist's inquiry into that deepest part of self—personality, memory, identity." What does her story reveal about these three subjects? How does her account challenge our preconceptions of these three subjects? Alternatively, how does her account confirm or bolster what we already know and believe about these three subjects?
4. *Brain on Fire* is divided into three parts and fifty-three chapters. Why is this structure meaningful and important? How does it correspond to some of the major subjects and themes of the book? How does this structure affect our comprehension of the work or our emotional experience of it as readers?
5. Consider and discuss the various reactions to Cahalan's illness as chronicled in her book. Are the responses uniform or varied? Are they expected or unexpected? What about Cahalan's own responses to her illness and what she endures? Consider the response she recalls having while she was suffering versus her response after her treatment and recovery. What does consideration of these responses reveal about our responses to the mysterious and the unknown?
6. Consider and discuss your own reactions as readers to what you encounter on the page—at the opening of the story and as the story continues to its conclusion. How did your thoughts, feelings, and opinions change throughout?
7. In Chapter 22 (p. 83), Cahalan refers to a quote by William F. Allman's book

Apprentices of Wonder: Inside the Neural Network Revolution: “The brain is a monstrous beautiful mess.” What does Allman mean by this? What does it reveal about the workings of the brain? How does this correspond to what we find revealed in Cahalan’s book?

8. The characters in *Brain on Fire*—friends, family, medical personnel, and even Cahalan herself—frequently consider if she may be suffering from some form of mental illness. What does the book reveal, then, about our way of thinking about mental illness? For instance, what does Cahalan’s story suggest about the relationship between psychology and neurology? What preconceptions does it reveal about our understanding of mental illness as a society? How does this story help to highlight the necessity of compassionate responses to those who are ill?

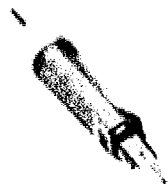
9. Cahalan incorporates many epigraphs, quotes, and references to famous figures—Nietzsche, Aristotle, Virginia Wolff, and many others—in her story. What may be the primary reason or reasons for these being included and why are they important?

10. Cahalan has titled her memoir *Brain on Fire*. What does this title mean and where does it come from?

11. Consider the role of faith in the story—not only religious faith, but also faith defined more broadly to include support for others, faith in one’s self (think not only of Cahalan’s story but of Dr. Najjar’s story), hope and resilience. What role does faith seem to play in success and recovery both for Cahalan and those around her?

12. What are some of the reasons that Cahalan may have chosen to share her story with the public? What lessons can we ultimately learn from her unique story?
(Questions issued by publisher.)

top of page (summary)

About the Author**Full text biography:****Susannah Cahalan****Birth Date :** 1985**Nationality:** American**Occupation :** Memoirist**Table of Contents:****Awards****Personal Information****Career****Writings****Sidelights****Related Information**

about this author

Awards:

Silurian Award of Excellence, 2012, for the article "My Mysterious Lost Month of Madness."

Personal Information:

Born c. 1985. **Education:** Graduate of Washington University, St. Louis, MO. **Addresses:** Home: Jersey City, NJ.

Career Information:

Journalist and writer. *New York Post*, New York, NY, reporter and book reviewer.

Writings:

- *Brain on Fire: My Month of Madness* (memoir), Free Press (New York, NY), 2012.

Contributor to periodicals, including the *New York Times* and the *Czech Business Weekly*.

Sidelights:

Susannah Cahalan, a reporter for the *New York Post*, knew she wanted to be a writer when she was in elementary school. She also developed an early appreciation for newspapers and journalism and eventually landed an internship at the *New York Post* when she was still a senior in high school. Later, Cahalan began her journalism career at the newspaper essentially as a cub reporter running errands and sorting mail until she advanced to become a full-time reporter and book reviewer.

Cahalan's career, however, was interrupted in 2009 when, at the age of twenty-four, she began to exhibit erratic behavior and paranoia. Initially, Cahalan thought it might be the stress and pressures of work or perhaps related to her new relationship. When she began to develop seizures and hallucinations that led to serious psychotic behavior and even catatonic states, Cahalan and her family sought help. In her memoir, *Brain on Fire: My Month of Madness*, Cahalan tells the story of her frightening descent into a month of insanity.

Cahalan reveals that the turning point came one day when she was with her boyfriend and went into a catatonic state with eyes wide open but unseeing. Then before her boyfriend's eyes, she had a grand mal seizure. "I was convulsing," Cahalan noted in an interview with *National Public Radio* Web site contributor Julie Stappen, adding: "And I bit my tongue so that blood and kind of a combination of blood and foam was coming out of my mouth." Fortunately for Cahalan, her boyfriend made the right decisions, turning her on her side and calling 911.

Cahalan ended up in the hospital for a month undergoing blood tests and brain scans. During that time, Cahalan's condition worsened as tests mounted and the hospital care eventually cost around one million dollars. Cahalan's parents and boyfriend stood watch over her, insistent that they would not let her go and that Cahalan would make it through this calamity. Still, doctors could not determine what was wrong until a neurologist named Dr. Souhel Najjar had her do some routine tests for neurological function. On one test he asked her draw a clock. When she put all the numbers, one through 12, on the right hand side of the clock, the neurologist gained an important clue to discovering Cahalan's problem.

Dr. Najjar realized that Cahalan was suffering from left-side spatial neglect. The doctor said that the right side of Cahalan's brain, which is responsible for the left field of vision, was, as he told Cahalan's parents, "on fire." In stepped Dr. Josep Dalmau from the University of Pennsylvania to finally pinpoint the problem, a rare autoimmune disorder called anti-NMDA receptor encephalitis. The disease often attacks the brain and may be the true cause of demonic possessions reported throughout human history.

Cahalan gives a full account of her descent into madness, treatment, and long-term recovery, noting that she does not do so from memory but from her skills as a reporter. Writing in *Brain on Fire*, Cahalan remarks that she remembers "only flashes of actual events, and brief but vivid hallucinations." The author goes on to write: "Because I am physically incapable of remembering that time, writing this book has been an exercise in my comprehending what was lost." Like any good reporter, Cahalan conducted numerous interviews to get to the root of her story, scoured medical records, and even referred to her father's journal and a notebook that her divorced parents used to communicate with each other.

"*Brain on Fire* is a riveting read--part medical procedural, part love story, part meditation on the human brain that questions how many 'insanity' cases have been misdiagnosed," wrote *Macleans*' contributor Anne Kingston. Writing for *USA Today Online*, Lindsay Deutsch noted the trauma of Cahalan's hospital stay but added: "More heart-wrenching, though, is her rich description of emotional helplessness and feelings of lost identity," noting that "Cahalan's reporting is solid: the science behind the madness is thorough and digestible."

Related Information:

BOOKS

- Cahalan, Susannah, *Brain on Fire: My Month of Madness*, Free Press (New York, NY), 2012.

PERIODICALS

- *Booklist*, November 1, 2012, Karen Springen, review of *Brain on Fire*, p. 8.
- *Bookseller*, February 1, 2013, Emma Henaughan, "Mind Games," review of *Brain on Fire*, p. 29.
- *Kirkus Reviews*, September 15, 2012, review of *Brain on Fire*.
- *Library Journal*, November 1, 2012, Chrissy Spallone, review of *Brain on Fire*, p. 84.
- *Macleans*, November 19, 2012, Anne Kingston, review of *Brain on Fire*, p. 101.
- *Marie Claire*, November 2012, Whitney Joiner, "Temporary Insanity: In a New Memoir, Susannah Cahalan Describes Her Harrowing Monthlong Fall into Madness and Back Again," author interview, p. 169.
- *Publishers Weekly*, September 24, 2012, review of *Brain on Fire*, p. 68.

ONLINE

- *Beth Kephart Books*, <http://beth-kephart.blogspot.com/> (April 3, 2013), Beth Kephart, review of *Brain on Fire*.
- *Big Think*, <http://bigthink.com/> (November 11, 2012), Kayt Sukel, "*Brain on Fire*: A Q&A with Susannah Cahalan."
- *Dawn.com*, <http://x.dawn.com/> (April 21, 2013), Muna Khan, review of *Brain on Fire*.
- *National Public Radio Web site*, <http://www.npr.org/> (November 14, 2012), Julie Stapen, "A Young Reporter Chronicles Her 'Brain on Fire.'"
- *New York Times Online*, <http://www.nytimes.com/> (December 21, 2012), Michael Greenberg, "Back from Madness," review of *Brain on Fire*.

November 2012 (/print-edition/179-november-2012)

SUSANNAH CAHALAN

A million-dollar medical mystery

BookPage interview by Alden Mudge (/search?contributor_id=52)

She thought she had mono. Then she decided she was bipolar. To her disgust, a famed New York City neurologist told her that she simply worked too hard and drank too much.

Susannah Cahalan's mix of Google-search self-diagnosis and hit-and-miss expert opinion might have been comical if her situation hadn't been so dire. At the age of 24, Cahalan, a reporter for the *New York Post*, began feeling less and less herself, then had a seizure, and then ended up in the hospital for a month, out of her mind for most of that time, while a small army of doctors and medical researchers tried to figure out what was wrong with her.

"It was one of those things that wasn't completely obvious at first," Cahalan says, remembering the onset of her mystifying disease during a call to the apartment in Jersey City she shares with her boyfriend Stephen, one of the heroes of **Brain on Fire: My Month of Madness**, her book about this harrowing experience. "Maybe if I had been working a more stable or less exciting job, I would have been more aware of what was going on. But because I was working at the *New York Post* and there are so many highs and lows to journalism, I wasn't aware of the fluctuations."

Stephen (her boyfriend of just six months at the time and a colleague at the *Post*, where she had begun working as a "copy kid" at 17) and her estranged parents, however, had become increasingly alarmed by her behavior just before her seizure. Later they would all become key informants as Cahalan tried to piece together what had happened to her during her month of madness.

"It's so hard for me to get to that person again," Cahalan says. "I did a lot of yoga trying to access these hallucinations and these lost memories. . . . I wrote by hand, which I thought would maybe help me better access these things. I do remember things, but I don't know if it's because I've spent so much time writing about them that I've created these memories."

"People who don't have a diagnosis have to be their own advocates. It's important to question medical authority."

So Cahalan's efforts to write **Brain on Fire** became an attempt both to reconstruct how she became the crazy person she briefly was and to understand the science that led eventually to a successful diagnosis. Early drafts of the book, Cahalan says, were very "science-y." The published book tends—reluctantly, she says—more toward memoir. Readers will likely find it a swift read, an intriguing mix of scientific detection and personal story. Cahalan includes excerpts from her medical records, from videos of her bizarre behavior in the hospital, and from her follow-up interviews with the two doctors at the University of Pennsylvania—Dr. Souhel Najjar and Dr. Josep Dalmau—who cracked her case.

Diagnosing her illness required a battery of sometimes redundant tests including CAT scans, blood tests, MRIs and a gruesome-sounding brain biopsy. Eventually, Cahalan became only the 217th person to be diagnosed with anti-NMDA receptor autoimmune encephalitis, a rare form of autoimmune disease.

Cahalan says one of her hopes is that **Brain on Fire** will in some measure help people with undiagnosed conditions and raise awareness about autoimmune diseases. "The brain gets all the attention," she says. "But when I was researching the science for the book, I realized we are just at the beginning of understanding how important the immune system is. Autoimmune disease is an amazing, emerging field of study. Right now 50 million people in the United States have an autoimmune disease. They're especially common in women, which is a mystery. The research that's being done now is basically blurring the lines between immunology, neurology and psychiatry. It's very exciting."

Treatment for Cahalan's disease was considered experimental at the time. It involved a regimen of nearly 20 intravenous immunoglobulin (IVIG) injections at \$20,000 a pop. The total cost of her hospitalization and treatment? Something to the north of \$1 million, she says.

In the final section of **Brain on Fire**, the section Cahalan found most challenging to write, she describes her long recovery and reflects on the physical and emotional challenges she faced after she left the hospital. On the plus side, she has grown closer to her father, who was distant from her after her parents' bitter divorce. For the length of time she was in the hospital, her parents united to become her chief advocates. "People who don't have a diagnosis have to be their own advocates. It's important to question medical authority. I couldn't be my own advocate in the hospital because I couldn't be there for myself. But my parents were."

Cahalan's boyfriend Stephen was her "rock in the hospital. The fact that he came every day when we'd only been dating about six months was amazing." But trouble loomed when she came home to recover. "I was dead set on moving ahead. I was getting better. I was back at the *Post*. Everything seemed fine, but he knew I still wasn't 100 percent. It was a scary experience for him. I think it changed him and he became a different person. Now it's been three and a half years since I was in the hospital and we've worked that out."

Still, the question of how fully she has recovered remains. When her doctors finally reached the correct diagnosis, they told her that treatment would bring her back to about 90 percent of normal.

"It's hard for me to say if I'm 100 percent recovered," Cahalan says. "I know I'm different from the person I was before and I know that has something to do with my illness because it was a huge life experience that I think about every day. But I was 24 then, I'm 27 now. I don't know how much of my change is due to getting older and being in different life circumstances and how much of it has to do with surviving this illness."