

# **Brain on Fire: My Month of Madness Study Guide**

## **Brain on Fire: My Month of Madness by Susannah Cahalan**

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## Plot Summary

"Brain on Fire - My Month of Madness" by Susannah Cahalan is the story of the author's struggle with an rare disease that made her paranoid, hallucinatory and caused her and her loved ones to question her sanity. In the end, the source of her condition proved to a physical one, a unique disease with a name that does not make the nature of the disease immediately apparent to the lay person. However, the disease, anti-NMDAS-receptor encephalitis, is thoroughly covered by Cahalan in terms that are clear and understandable.

Susannah Cahalan was a bright and attractive twenty-four year old woman who lived in New York City and was a reporter for the New York Post. She had been with the Post since she was seventeen when she was hired as an intern. She earned her degree at Washington University in St. Louis. While a senior there and still associated with the Post, she got an exclusive interview with a notorious pedophile and kidnapper that garnered the nation's attention.

Cahalan's journey into a month of madness began with two small insect bites on her arm. She lived in New York City and at the time there was panic in the Big Apple that it was being plagued with a bedbug infestation. Cahalan was sure that the tiny pests had attacked her studio apartment. Even though the exterminator found no sign of bedbugs, Cahalan insisted that he spray for them just in case. Cahalan made sure she hid her bug bites from her co-workers. She feared that they would judge her harshly if they thought she had bed bugs. The "bed-bug" incident was just the tip of the iceberg. Cahalan began to hallucinate and become paranoid, fearing that people were plotting against her and that she, a formerly gregarious and confident young woman, was a big failure and loser.

Susannah's boyfriend, Stephen, her parents, and her co-workers all began to see a Susannah that they didn't know. Her mental and emotional issues were followed by physical ones. As the disease progressed, her movements became awkward, her speech became slurred, and she began having seizures. Although doctors kept insisting that her test results were normal and showed no presence of significant disease, her condition only worsened. Finally, a doctor admitted her into NYU's medical school hospital.

Susannah was in the hospital twenty-eight days before the accurate diagnosis was made. Prior to that doctors had suspicions of a plethora of conditions and diseases ranging from bipolar disease and schizophrenia to dire physical ailments including cancer. Finally, a doctor known for his ability to solve medical mysteries was called into the case. Dr. Najjar didn't take long to pinpoint Cahalan's problem. He gave her a simple "clock test." He asked her to draw a clock with all its numbers. When she drew the numbers, one through twelve, just on the right-hand side of the clock, he knew immediately that the right-hand side of her brain was inflamed. His startling diagnosis was confirmed with a brain tissue biopsy which was sent to Dr. Dalmau who had worked with patients who displayed schizophrenic symptoms and had brain inflammations. The



disease was known as Dalmau's disease and in more technical terms it was called, anti-NMDAS-receptor encephalitis. Simplifying the condition, the doctors told Susannah's parents that her brain was on fire and that her antibodies were attacking her brain.

The road to recovery was not easy but at least the doctors knew what was wrong with her and how to treat it. They never did isolate exactly how she contracted the disease although there were several possibilities. Susannah made it back all the way and returned to work seven months after she was first afflicted with the ailment. She wrote about her disease in an article that was run in the Post, which helped countless people who had loved ones suffering from the same rare condition. Susannah feels a lot like herself these days but she knows that her ordeal changed something within her forever. She see it when she catches her reflection in the mirror and looks deeply into her eyes.



# Part I: Crazy

## Part I: Crazy Summary and Analysis

In Chapter 1: Bedbug Blues, one morning Susannah Cahalan woke to find what she thought were two bedbug bites on her arm. She had been having dreams about bedbugs which had apparently infested New York City. She called in an exterminator who told her that her studio apartment was clear of the pests. But she was so fearful about them that she had him spray for them any way. At work in the newsroom of the New York Post she tried to appear nonchalant and made sure to hide her bites. Susannah who was now twenty-four had started as a seventeen-year-old intern with the Post.

Susannah asked Angela, her closest friend and a veteran reporter at the Post, if she knew anything about bedbugs. Before they could get into a discussion about the bugs, Susannah was called into Steven's office. Steve was the new Sunday editor and wanted her to pitch her idea for the Sunday paper. Susannah had nothing and she was panicked. In Steve's office, she sat next to Paul who had given her the break to become a reporter. Steve and Paul were both upset that she had no ideas and told her not to come to the meeting again with nothing. Susannah was upset the rest of the day about the meeting.

Preparing for the exterminator to spray the next day, Susannah spent the evening throwing away anything that she thought might harbor the little pests. She even threw clippings of some of her best articles away including the biggest story of her career. She had gotten an exclusive interview with Michael Devlin the man who kidnapped the little boy in St. Louis and kept him as a love-slave for years. She had been a senior at Washington University in St. Louis then and was able to get a jump on the story. Both the Post and Susannah took a lot of heat for the story. Her credentials and methods were questioned and Devlin's lawyers were out to get them. But the Post and Paul stood by her and Devlin was eventually sentenced to three life sentences.

Susannah made no connection between her fear of bedbugs, the purging of her personal items and her forgetfulness at work. She would later learn that a fear of bugs was a sign of psychosis. After packing up her items in trash bags she was struck by nausea and a sharp pain in her head. She thought she was getting a migraine and maybe the flu. It wasn't the flu but certainly something had invaded her body and mind.

In Chapter 2: The Girl in the Black Lace Bra, a few days later, all her problems seemed to vanish as she took her boyfriend of four months, Stephen, to meet her father and her step-mother, Gisele, at their brownstone in Brooklyn Heights. Her parents had been divorced since Susannah was sixteen. She was closer to her mother and didn't see her father that often. But the night was a success. The next morning she woke up in Stephen's apartment alone. He had already left for work. Suddenly she had an overwhelming jealousy that she had never experienced before and which led her to



snoop in his emails. She became enraged upon uncovering old emails from a girlfriend who he had broken up with long before. She looked around his apartment and found a box of letters and photos mainly of former girlfriends and became paranoid and angry. She caught a reflection of herself in her underwear and in a black lace bra in a mirror. She was shocked at her behavior. She had lost two hours digging through Stephen's former life. The migraine and nausea returned along with a tingling in her left hand. Eventually her left hand went completely numb.

In Chapter 3: Carota, the tingling continued for days but what bothered her more was her behavior at Stephen's apartment. She confessed to a co-worker, Mackenzie, who told her that her behavior was normal. She also confided in Paul who told her she wasn't crazy. The numbness began to travel down her body to her toes. Her co-workers told her to see a doctor. Although she at first rejected the idea, she finally contacted her gynecologist, Dr. Eli Rothstein. He told her to stop taking her birth control pills immediately and to see a neurologist as soon as possible.

The next day she saw Dr. Saul Bailey. The receptionist had her fill out a questionnaire about her health history. She had been diagnosed with melanoma five years before but it had been caught early and cured. She told Dr. Bailey about the numbness she was experiencing. He asked if she had ever contracted Lyme's disease. After a routine neurological exam, he recorded in her file that everything was normal but wanted her to take an MRI just to be sure nothing was wrong. A few days later, Dr. Bailey called her with the MRI results. Everything was normal except for a few enlarged lymph nodes in her neck. He suspected she had a virus, perhaps mononucleosis. Just to play it safe he told her to stay off the birth control pills which can cause strokes and blood clots.

In Chapter 4: The Wrestler, the next night Susannah and Stephen went out with his sister and her husband. She didn't eat her dinner and after they arrived at the music hall for the Ryan Adams concert she had been excited about seeing, Susannah couldn't walk. Her purse felt like it weighed forty pounds and she couldn't stand. She sat on the floor. Stephen helped her up and escorted her to her seat. But it was torture for her. Susannah couldn't remember the show at all.

Susannah's parents were concerned. Her father insisted on coming to see her. They met at a movie theater for an afternoon showing of "The Wrestler." Susannah's emotional reaction to the picture embarrassed her. She wondered if it was the movie about a father-daughter relationship that reminded her of her, at times, strained relationship with her own father.

In Chapter 5: Cold Roses, Susannah struggled at work and failed to provide story ideas to the editor that were up to muster. She was beginning to lose her confidence. The blood tests came back and were negative for mono. She told Dr. Bailey she felt better. He said she must have had a passing virus. Susannah talked Stephen into taking a few days off and go to Vermont. Two days passed without incident but on the third, Susannah decided to try skiing but became fearful and panicked and begged Stephen not to make her go down the hill. He finally convinced her and she made it to the bottom



without a problem. She learned later that her condition had peaks and valleys and retreats sometimes only waiting to pounce again.

In Chapter 6: America's Most Wanted, Steve gave Susannah an assignment to interview John Walsh of "American's Most Wanted" about a new episode that was airing on his show about submarines smuggling drugs. In preparation for the interview, Susannah asked the Post Librarian, Liz, for some video clips of the show. Liz was also a Wiccan priestess and instead of focusing on the video clips, Susannah asked Liz for a tarot card reading. From the reading, Liz assured her that she would be fine and in fact would be having a job change and do well financially. Back at her desk, she heard the news that a fellow reporter had died from melanoma. She was unable to concentrate the rest of the day. She didn't sleep well that night and took what time that remained before her interview to Google melanoma.

Susannah entered the interview room with absolutely no preparation. She blew the interview with Walsh, stumbling on her words and laughing at the wrong times. Walsh's publicist ended the interview early. After the interview, Susannah had trouble walking. The Walsh interview was the last she would conduct for the next seven months.

In Chapter 7: On the Road Again, Susannah had not slept well in over a week. Walking through Times Square on her way to work the next day, the moving signage and the vibrant colors were almost more than she could bear. She told Angela about her reaction to the bright colors who grew very concerned. Susannah had been showing more and more erratic behavior by the day. Susannah began crying and couldn't stop.

Susannah sought out Mackenzie for support. Like everyone else, Mackenzie told her to see a doctor. She advised her to tell the doctor everything - even things that seemed unimportant. Susannah ran back to her desk displaying more aberrant behavior - she threw everything on her desk in the trash to the astonishment of her fellow reporters. Paul noticed that she was talking extremely fast and asked if she was okay. Others had told him that she'd been behaving strangely. Later, she learned that Paul was certain she was heading for a mental breakdown. She began having out of body experiences during which she could see the top of her own head.

Paul had Angela take her to a nearby bar for a drink to try to find out what was going on. Taking the escalator to the eighth floor where the bar was located, Susannah had to get off three times to compose herself. After talking to Angela, Susannah had to admit that it was more than the usual stresses; that something was really wrong with her. That night Stephen cooked dinner for her which she didn't eat. They watched a PBS TV program. Everything went dark after that.

In Chapter 8: Out-of-Body Experience, that night Susannah woke Stephen with loud screeches and grunts. He thought she was asleep and having a nightmare but when he looked at her, her dilated eyes were wide open. Her body stiffened and she had no response to his repeated attempts to talk to her. He laid her on the floor, turned her head to the side so she wouldn't choke. He assumed she was having a seizure and called 911. She was indeed having a seizure which she didn't remember and would not



remember any of the many seizures she would have in the coming weeks. She was in a strange new world of paranoia and hallucinations in which she blacked out and lost time. She learned later that the strange behavior she had been exhibiting was caused from minor seizures.

Susannah's condition was caused by a disturbance in her brain's neurons which can result from disease, lack of sleep, withdrawal and other conditions. The result can be what Susannah had that night - a "tonic-clonic" seizure that is characterized by loss of consciousness and muscle rigidity - some victims even make dance-like and other involuntary movements. Left untreated, the brain can suffer cognitive defects and the victim can die. In addition to these seizures, Susannah was also suffering from partial seizures caused by over-stimulation of the temporal lobes which control emotion and memory. As she was wheeled into the hospital, she had an out-of-body experience and watched herself on the gurney.

In Chapter 9: A Touch of Madness, when she woke in the emergency room, she was struck with a fit of paranoia. She insisted she wanted out of there immediately and was sure that the medical staff was plotting to kill her. She whispered to Stephen that she was dying of melanoma. After having a CT scan and examination, the doctors found nothing wrong and had to release her. They recommended she see a neurologist. Stephen called Susannah's mother and step-father, Allen, who made plans to come in the morning. Later, Susannah learned that her mother and Allen thought she was having a breakdown resulting from on-the-job stress. But the seizure didn't fit into that scenario. After much coaxing, Susannah got in their car to stay with them in Summit, New Jersey, for a while.

Susannah wasn't happy there. She tried to focus on finishing a story about a dance troupe but found it difficult to concentrate. On one occasion, she awoke to find her mother sitting next to her, rubbing her feet. She had had another seizure that caused a painful charley horse. Her mother scheduled an appointment with Dr. Bailey for the next Monday. Susannah ignored most calls from friends and co-workers but took one from Julie whose mother was a psychiatrist. Her mother thought she might be suffering from bi-polar disease. Hearing that was almost a relief for Susannah. "It" had a name and was something she heard of and was a condition that was non-fatal and controllable.

Dr. Bailey ran her through the usual tests and again wrote "normal" on his notes. She told him she had a good amount of stress on her job and that she drank up to two glasses of wine at night. She hadn't taken drugs in years. He referred her to a psychiatrist to pursue the possibility that she was suffering from bi-polar disease. He prescribed Keppra, an anti-seizure drug, and told her that everything generally looks normal. Privately, Bailey told her mother that he thought she was partying too much and not getting enough sleep. Her mother was somewhat comforted by his words.

In Chapter 10: Mixed Episodes, Allen drove Susannah and her mother to see Dr. Sarah Levin, a psychiatrist on the Upper East Side. Susannah told Dr. Levin that she was sure she was bi-polar although she hadn't been diagnosed and was not on medication for it. After talking with Susannah, Dr. Levin concluded that she was having mixed episodes -





the manic and depressive moods that are characteristic of bi-polar disease. Her mother called Susannah's nineteen-year-old brother, James, at school. He didn't believe she drank too much and didn't believe she was bi-polar. Her mother didn't either.

In Chapter 11: Keppra, at home, Susannah still couldn't sleep. She began to think it was the Keppra that was causing her further problems. She wanted to stop taking it but her mother urged her to stay on the medication. That night she tried to gag herself and throw up the Keppra. She woke her mother in the middle of the night. She took Susannah back to her bedroom and slept there with her.

Susannah's father suggested she start keeping a journal of her thoughts and feelings. Reading them later, some of the statements were incoherent but others proved to be illuminating. She wrote about her passion for journalism which was at least a fragment of her real life at a time her mind was functioning normally. Reading her journal years later was difficult because it was evidence of just how sick she was. After announcing to her parents that she was breaking up with Stephen, leaving the Post and changing her lifestyle, she had another seizure and collapsed unconscious. She bit her tongue and was convulsing like a landed fish. Dr. Bailey scheduled her for a EEG on that weekend to test the electrical activity of her brain.

Stephen came and took Susannah out to dinner. While waiting for a table, she felt that everyone was staring at her and plotting against her. She didn't touch her dinner. She decided she needed to break it off with him or tell him she loved him. She chose the latter. He also professed his love for her. That night she began to smack her lips frequently.

In Chapter 12: The Ruse, initially, Susannah refused to have the EEG, saying she was fine. Finally, everyone convinced her to go. On the drive there, she "heard" Allen say that Stephen should know that she was a slut. She opened the car door in the back to jump out. Stephen grabbed onto her coat and stopped her without a second to spare. She insisted they stop for breakfast but when it was served she refused to eat it. Susannah felt powerful. All she had to do was snap her fingers and people did what she wanted.

At the medical facility, the technician pasted electrodes all over her scalp. The tech told her to relax and breathe deeply. After the exam, the technician told her there was nothing wrong with her. Maybe it was her stressful job. When she emerged from the examination room, she accused her mother and Allen of cooking the whole thing up and perpetrating a ruse on her.

In Chapter 13: Buddha, Susannah wanted to return to New York. The only way her mother would take her to stop by her apartment was if she agreed to stay at her father's that night. Susannah's father and Gisele cleaned the apartment and threw away rotting food and trash. When it was time to go, Susannah agreed to go only after a half hour of pleading and cajoling. As soon as she got outside, she had a fit and accused her father of plotting against her. She screamed to passersby that she was being kidnapped. Once at home, her father made her favorite dinner. After dinner, she asked the father to stay



with her in the study during the night then told him to get out! She couldn't remember what she said but it made him cry. Later in the evening she locked herself in the bathroom. She thought of jumping out of the window but spotted a smiling Buddha that made her feel that everything would be okay.

In Chapter 14: Search and Seizure, the next morning Susannah's mother and Allen came to get her. They took her right to Dr. Bailey's office. Dr. Bailey reiterated his earlier findings - everything was normal. Her mother quickly responded that she wasn't normal at all. Dr. Bailey said she was drinking too much and exhibiting signs of withdrawal. Her mother responded that she'd been closely monitored over the last week and had not had one drink. Bailey made some calls and arranged for her to be admitted to NYU immediately for a twenty-four hour EEG monitoring. She had a seizure while waiting to be admitted. She remembered only bits and pieces, mostly hallucinatory, from her time in the hospital.



# Part Two: The Clock

## Part Two: The Clock Summary and Analysis

In Chapter 15: The Capgras Delusion, Susannah was admitted on March 23rd, ten days after her first seizure. NYU's Langone Medical Center has one of the top epilepsy units in the world. Susannah wound up in a four-person room with severe epilepsy patients. This room had constant video monitoring which would help Susannah later understand what happened to her. After being settled in her room, her vitals were taken and they were all in the normal range. Susannah fought off a technician who began applying adhesives for the electrodes. Her mother tried to calm her with little success. She finally calmed down but when Allen came in the room she began screaming that he had tried to kidnap her.

A neurologist noted that she had mood swings, skipped rapidly from topic to topic and was hallucinating. He prescribed an anti-psychotic drug that is used for treating schizophrenia. She was experiencing Capgras syndrome which is defined as having hallucinations that people were turning into different people, also a symptom of schizophrenia. She believed that the staff and technicians were going to harm her. She was stopped later that night when she tried to escape.

In Chapter 16: Postical Fury, the next morning, Susannah was examined by another neurologist, Dr. Deborah Russo. She told the doctor that people on TV were talking to her. She kept insisting that she didn't belong there and needed to leave. She did correctly answer basic questions like what year it was and who was president and where she was. When she tried to burst out of the room, she was restrained and given another anti-psychotic drug, Haldol. The doctor noted that she seemed to be psychotic and manic and that she displayed bi-polar symptoms rather than postical psychosis - which is characterized by multiple seizures. Dr. William Siegel arrived that afternoon and assured Susannah's mother that they would figure out what was wrong with her daughter.

In Chapter 17: Multiple Personality Disorder, the next day, Dr. Sabrina Khan from the Department of Psychiatry came to see Susannah. The doctor noted that she had a disheveled appearance which is common to mania. Susannah announced to Dr. Khan that she had multiple personality disorder also known as dissociative identity disorder (DID). She claimed she was diagnosed with bi-polar disorder but refused to take the medication that she was given. Dr. Khan noted that she showed signs of paranoia and schizophrenia. She recommended that they look for neurological causes because of her history with melanoma. As she looked at the doctor and then at Stephen she realized that she had the power to make them age right before her eyes. She felt powerful and stronger than she ever had in her life.

In Chapter 18: Breaking News, Dr. Ian Arslan, a psychopharmacologist joined the team of doctors that now numbered five. He talked to Susannah's mother to learn about her



recent behavior and symptoms. He wanted to rule out postical psychosis and schizo affective disorder which is a condition that has characteristics of both bipolar disorder and psychosis. Later, Susannah watched a video of herself having an outburst and battling with the staff. Watching the TV news she hallucinated that her illness was being reported on TV and that her father had killed her mother. She thought the patient in the next bed was recording her every word. She grabbed the wires off her head and pulled out chunks of her hair. She tried to escape but was stopped by a nurse. Then she passed out.

In Chapter 19: Big Man, after making her second escape attempt, a guard was assigned to watch Susannah. After another attempt the nurse warned her father that if she kept trying to escape, she would be moved to the psychiatric ward. Her father was retired and spent most days with her. Her mother came at lunch and after work. She was calmer when she wasn't alone and her parents were determined to keep her out of the psych ward. Tests for hyperthyroidism which can cause psychosis came back negative. Stephen's presence also seemed to calm her. He was devoted to being with her as much as he could.

The fourth day, doctors six, seven, eight and nine appeared. There was an infectious disease specialist, a rheumatologist, an autoimmune specialist and an internist. Dr. Friedman, the internist, found her blood pressure to be dangerously high and prescribed two different medications. Dr. Friedman assured her father that Susannah would improve. Her father broke down from the stress and worry of the situation.

In Chapter 20: The Slope of the Line, Susannah's father was taking her condition very hard. He was keeping a journal himself and had broken down several times. She woke from a deep sleep one afternoon to find him there. He suggested they take a walk around the floor. Walking wasn't like it used to be for Susannah. Her movements were awkward and slow. He told her to keep her mind on the slope of the line - she was making progress every day. Susannah's physical state was deteriorating but her psychosis was subsiding enough for her to have a spinal tap. Her psychosis had been replaced by passivity. Still her paranoia could come back any time.

In Chapter 21: Death with Interruptions, the family fell into a routine. Her father would stay with her during the morning. He'd feed her yoghurt for breakfast and played games with her. He brought her gourmet food which she would often give to Stephen because she still wasn't eating much. Her mother came at lunch and after work. Stephen would arrive faithfully at seven in the evening and stay until she fell asleep around midnight. They would often watch the same DVDs together but Susannah would never remember watching them. Her short term memory had been obliterated which was a condition that originated from the hippocampus of the brain. She had lost part of that brain function. She became fixated on apples and would devour them. Apples have anti-inflammatories and antioxidants. Maybe her body knew something that her doctors didn't. She also became obsessed with cleanliness, insisting on clean clothes every day.

In Chapter 22: A Beautiful Mess, new symptoms appeared during the second week in the hospital. She began slurring her words and slobbering. She was unable to talk in



complete sentences. Susannah was also making constant chewing motions. Her arms would stiffen before her as if she was reaching out for something. The doctors started to suspect that there was a problem with her brain stem or limbic system. Dr. Siegel arrived with some news. The spinal tap indicated an increased level of white blood cells, a sign of infection. Her mother felt relieved that perhaps the problems were physical.

Katie, a friend from college, was allowed to see her although most friends and co-workers weren't. She was shocked to see how frail Susannah was and the declining physical state she was in. Angela and Julie from work came to see her. The three friends laughed a lot during their hour visit. After they left, they wondered if Susannah would ever be the same. Although she couldn't read, she could still write. Her father gave her a notebook. She wanted to write thank-you notes for the flowers she received. But she never got a chance to send them out because things got worse.

In Chapter 23: Dr. Najjar, the blood tests came back and revealed all the diseases and conditions that Susannah didn't have but not the disease she did have. The doctors were become dismayed and wondered privately if they'd ever find out what was wrong with her. Her mother's favorite doctor, Dr. Siegel, was off the case. Dr. Russo and Dr. Najjar felt that a second spinal tap was necessary. Her mother asked who Dr. Najjar was and Dr. Russo only replied that he was brilliant.

Dr. Souhel Najjar joined the team upon a request from Dr. Siegel. He had a reputation for solving mystery cases. Just on hearing the symptoms, his first guess was that Susannah was battling some variety of viral encephalitis, an inflammation that is caused by the herpes virus. He recommended that she be treated with an antiviral drug, IV acyclovir. But the virus test came back negative and he stopped the drug. His second guess was that it was an autoimmune reaction which could be treated with an experimental immunotherapy that had helped other patients. He ordered that the treatments to begin immediately.

In Chapter 24: IVIG, on April 2, the new treatments, known as IVIG, began. IVIG is comprised of serum antibodies called immunoglobulin. It is approved for treatment by the US Food and Drug Administration for a variety of conditions including transplantations, leukemia and pediatric HIV. Side effects of the drug include flu-like symptoms such as headache and fever. The IVIG infuses the body with fresh antibodies that neutralize the sick auto-antibodies. Her parents had kept her brother, James, largely in the dark so he wouldn't worry and be distracted at school. He called one afternoon and had to choke back the tears. He told Susannah she'd get better and that he was coming home.

On the second day of treatment, Susannah's speech pattern worsened. Dr. Arslan made a comment about catatonia which occurs when neurons misfire and cause the awkward movements that Susannah was displaying. Stephen told her father that they would get the real Susannah back.

In Chapter 25: Blue Devil Fit, on April 9th, a second spinal tap was conducted. Susannah's condition was worsening after being in the hospital eighteen days. Later,



she would see on a video how Stephen tried to explain some of the symptoms she was having that night; he clenched his arms and gritted his teeth to illustrate. Nurse Adeline said she was having a blue devil fit, perhaps trying to get his attention. Susannah began complaining that her heart hurting and that she was having trouble breathing. She would exhibit these same behaviors night after night especially when Stephen was there.

The brilliant Dr. Najjar had yet to make an appearance. Susannah's family was losing hope. They feared she'd wind up in a psych ward. The second spinal tap indicated that the white blood cell count was still increasing which meant that her brain was inflamed - the doctors had to figure out why. Dr. Russo wrote on her chart "encephalitis of unknown origin." (123) The doctors needed to do more blood tests and Nurse Edward was elected to draw the blood. There was a little struggle but he got the blood.

In Chapter 26: The Clock, the day that the mysterious Dr. Najjar finally came, Susannah was drooling and smacking her lips and moaning for "waher" (water). Her parents were upbeat, hopeful that the magical doctor would have all the answers. Dr. Najjar had a thick mustache and a slightly sloping back probably from his hours hunched over a microscope. First, the doctor spoke with Susannah's parents to gain as much history as possible. Then he spoke to Susannah as a friend instead of a patient. He had an incredible bedside manner and had great sympathy for the weak and powerless. Although he hadn't done well in school as a young boy, he eventually graduated at the top of his medical school class.

Dr. Najjar took a lot of notes during his examination, it seemed more than the other doctors. When he asked her to walk in a straight line, he noted her ataxia, a lack of coordinated movement. He saw similarities between her behavior and that of his Alzheimer's patients. He decided to give her the "clock test" which is used to diagnose problem areas of the brain in Alzheimer's, stroke and dementia patients. It simply requires the patients to draw a clock. After several stabs, Susannah drew a circle. She drew all the numbers - one through twelve but all on the right-hand side of the circle.

Dr. Najjar was thrilled. It showed him that it was the right side of Susannah's brain that was inflamed because she couldn't complete the left side of the clock. It also explained the numbness that she felt on her left side and learned later that it was responsible for the paranoia, seizures and hallucinations that she was suffering from. Dr. Najjar strongly felt that the inflammation was caused by a reaction of her autoimmune system. The only way to begin to understand the cause of the inflammation was to do a brain biopsy - slicing off a small piece of her brain to examine and analyze. He told her parents that her brain was on fire and was under attack by her own body.

In Chapter 27: Brain Biopsy, after the inflammation was confirmed, Dr. Najjar said that the next course of treatment would be with steroids. Susannah's parents resisted at first, but finally agreed to the biopsy. Dr. Najjar said he would recommend it for his own child. Her father walked over to a nearby chapel and got down on his knees and prayed. Her mother prayed in a circle with her co-workers that afternoon. Susannah didn't understand the riskiness of the procedure but was distressed by it.





The surgery was done the day after Easter. It was performed by neurosurgeon Dr. Werner Doyle. During the procedure he was guided by a new MRI. He chose an area that was furthest away from the parts of the brain responsible for motor functions. The doctor made an S-shape incision over the right frontal region of the brain. With a high-speed drill, he made a small hole in the skull and then cut several small pieces of tissue for specimens. He then closed the hole up by reinserting the bone plate and securing it with a small metal plate and screws.

By eleven that night, a nurse informed Susannah's father that she was out of recovery and in the ICU. Her father ambled into the ICU where he found his daughter awake. He panicked when she told him she couldn't move her legs. She was rushed out for an emergency MRI but it was a false alarm. She did have feeling in her legs. He claimed he lost five years of his life from the experience.

In Chapter 28: Shadowboxer, the biopsy confirmed Dr. Najjar's assessment. Her brain was inflamed. Slides from the biopsy showed "angry inflammatory cells from my immune system attacking nerve cells in the brain, a signature of encephalitis." (143) It convinced Dr. Najjar that Susannah was suffering from an autoimmune disease and the decision was made to begin steroid treatment. The Solu-Medrol steroid dripped into Susannah's system and began switching off inflammatory chemicals called cytokines. Because of the drug's interaction with blood sugar levels, she developed a temporary form of Diabetes II which they combated with a sugar-free diet. Her overall condition did not improve immediately. It got worse.

In Chapter 29: Dalmau's Disease, the doctors narrowed the possible diseases that Susannah was suffering from. They strongly suspected that she had been exposed to hepatitis which can cause encephalitis. Dr. Najjar was leaning toward autoimmune encephalitis. Dr. Russo thought that the condition could be linked to her melanoma, that an underlying cancer could be present - something Susannah's mother didn't want to hear. Dr. Najjar had the brain specimens sent to Dr. Josep Dalmau at the University of Pennsylvania for further analysis. Dr. Dalmau had done extensive work on patients who developed psychiatric symptoms and encephalitis. His research led to the discovery of a condition that involved NMDA receptors and was ultimately named Dalmau's Disease. By the time Susannah's specimens arrived, he had developed several tests that could quickly diagnose the ailment.

In Chapter 30: Rhubarb, feeling that they were going in the right direction, the doctors decided to take base line measurements of Susannah's current condition so they could measure progress going forward. They tested both her physical and cognitive abilities. The general assessment was that Susannah was dramatically different from the person she was before she became ill. When one doctor tested her memory and asked her to name five vegetables and fruits, she was surprised when Susannah came up with "rhubarb", an uncommon choice. It indicated to the doctor that Susannah had a wealth of knowledge but the problem was retrieving it. The doctor strongly recommended that Susannah eventually undergo cognitive therapy.



In Chapter 31: The Big Reveal, the doctors told Susannah's father that they heard back from Dr. Dalmau who confirmed a diagnosis of anti-NMDA-receptor encephalitis. Although there were a lot of terms thrown at him he gleaned that the substance of what he was being told was that his daughter's immune system had gone off the rails and began attacking her brain. As doctors explained the disease, he saw that the symptoms and progression of the disease matched exactly with Susannah's condition. The rate for full recovery is 75 percent. Twenty percent are permanently disabled in some way and four percent die. Half the time the disease is caused by a tumor in the ovary; the other half of the time the causes are unknown. The next step would be to discover if Susannah had any tumors and to learn if there was any link to her melanoma. If the melanoma was a root cause, she would have to undergo chemotherapy. Bottom line, Dr. Najjar believed that they could get Susannah back to 90 percent of her former self.

In Chapter 32: 90 Percent, after a thorough exam, the doctors were confident that there were no signs of melanoma. That evening she was wheeled down to the radiology department where she would be given an ultrasound of her pelvic area to learn whether there were any tumors. There were no teratomas, the kind of tumor associated with Susannah's condition. Dr. Najjar decided that the course of action should be an aggressive treatment with steroids, IVIG and plasmapheresis. The steroids would reduce the inflammation, the plasmapheresis would flush the body and the IVIG would neutralize the antibodies. Most of the treatment could be conducted at home. She could go home right away. She was released the next morning after 28 days in the hospital. But she was in no way through with doctors. She would see Dr. Najjar every week and would be scheduled for a full-body scan and be enrolled in cognitive and speech therapy. She would have twenty-four hour nursing care and would be on the treatment plan that the doctor had prescribed in addition to other medications for the side effects of the disease and the residual effects of the medication.

In Chapter 33: Homecoming, the first thing Susannah did when she got to her mother's house in Summit was to go and take a real shower. Stephen cooked a pasta dinner in celebration of her return. Her friend Lindsey from college was there. In her paranoia, she thought that Lindsey was trying to take Stephen away from her. Susannah's mother reported the paranoid behavior to Dr. Arslan thinking NYU had let her go home too soon. The doctor was concerned that she may be reentering a psychotic state. Later, it was learned that recovery from the condition she had passes back through the same stages she had originally gone through.

In Chapter 34: California Dreamin', at the end of April, Susannah returned to NYU for a week of plasma-exchange treatment. A catheter was inserted directly into the jugular vein in her neck. The very uncomfortable needle had to stay in place for a full week. Angela came to see her and was shocked at her frail appearance. Stephen drove her home after the treatment was completed. The radio played "California Dreamin'" and Stephen knew Susannah was coming back when she belted out the lyrics with him.





## Part Three: In Search of Lost Time

### Part Three: In Search of Lost Time Summary and Analysis

In Chapter 35: The Videotape, Susannah was stunned when she watched a video tape of herself. The girl she saw before her was completely unhinged and unguarded. Watching it, it was impossible for Susannah to imagine what it had been like going through that. She only had the video to tell her. She remembered none of it.

In Chapter 36: Stuffed Animals, Stephen brought Susannah to his sister Rachel's house. Rachel and another sister, Bridget, were there with their kids. Bridget had a difficult time adjusting to Susannah's appearance and behavior. The older kids steered clear of her. The kids were thrilled when Susannah gave them all the stuffed animals she had received in the hospital. She had appreciated them but they were reminders of some very dark days and a lot of lost time. Susannah spent most of the visit in silence. She had an emotional reunion with her younger brother, James. He was devastated by her appearance. The look on his face made her fully realize for the first time just how sick she was.

In Chapter 37: Wild at Heart, it took a week for James to adjust to his "new" sister. Even though she wasn't good company he spent a lot of time with her while he was home. Her mother allowed her to walk alone to get coffee in the quaint little township that was nearby. James would drive her sometimes twice a day to get ice cream. She asked James to drive her to town so she could get a pedicure for her step-brother's wedding. She had a seizure at the salon and was passed out for quite a while. Sadly, no one made a move to help her. Her father who had been out looking for her finally found her there. She was crushed when she ran into an old friend while on a shopping trip with her mother. She couldn't put a complete sentence together. But there were signs that the old Susannah was emerging.

In Chapter 38: Friends, Susannah spent most of her time waiting for Stephen to come. She was grateful for the love and devotion that he showed during her ordeal. She loved him for him for staying with her and providing her with just what she needed. Later, he would tell her he stayed because he loved her and always saw the real Susannah even on the darkest days.

At a party Stephen had for a friend, Susannah felt that everyone was gawking at her. She didn't talk much, no one asked about her condition but later she learned that she had a big plastic smile plastered on her face almost the entire time. Of course, Stephen was always at her side to protect and defend her. Her second big social outing was at her step-brother's wedding. She had originally been slated to be a bridesmaid but that was obviously not possible. She felt hurt and wanted to prove to everyone that she was back. She took pains with her appearance and she and Stephen almost looked like a normal couple.



Susannah concentrated on the hors d'oeuvres. Her appetite had become ravenous from the steroids. She drank more champagne than her mother wanted her to and she danced the twist with Stephen. Later, her family told her she moved like a robot and looked dazed. Her mother was glad to see her having a good time.

In Chapter 39: Within Normal Limits, although she was making progress in her recuperation, Susannah had to take medications six times a day. The medication symbolized to Susannah her lack of independence. Her mother took on the responsibility of meting out the medication for Susannah and she was sometimes the target of her daughter's frustration that manifested itself in coldness and even cruelty. And even though it wasn't true and she didn't remember much about her hospital stay, she had it in her mind that her mother didn't spend enough time with her when she was there. It hurt her mother because they had always been so close.

Dr. Najjar was reducing the dosage of the steroids and Dr. Arslan was reducing the other drugs in tandem with the decrease in steroids. Susannah attended NYU's Rusk Institute of Rehabilitation Medicine. One doctor noted that she seemed disconnected from the external world. Concentration and memory tests placed Susannah in the borderline impaired range. She could only repeat 25 percent of simple word problems told to her. Her visual memory was worse. She could not conjure up words from her memory and could not replicate the image of a shape that was shown to her. However, her verbal skills were superior and the testing showed that she was capable of complex analytical thinking. Susannah's ability to recognize her own weaknesses was seen as a strength.

In retrospect, what kept Susannah from healing faster was a disunity she felt within and her inability to face how bad off she really was.

In Chapter 40: Umbrella, Susannah was despondent when Dr. Najjar wanted her to return to the hospital for a second round of IVIG treatments. To take her mind off of it, her father had her and Stephen over for a cook-out. They were spending a lot of time at her father's house. She mainly stayed silent while the others chatted. She thought she was boring and had nothing to say. The cause of her lack of spirit could have been because the electrical impulses between neurons in her frontal lobes weren't firing. They may have been taking longer to heal than normal but they were showing progress from where she started. She danced to Rhiana's "Umbrella" and her movements were noticeably less robotic.

In Chapter 41: Chronology, the brain is very resilient. It can "create new neurons and make new connections through cortical remapping, a process called neurogenesis" (p. 197). Like spring flowers, Susannah's brain was sprouting new receptors. The journal she kept during her third hospital stay provided more information for her in terms of what she was experiencing than her first stay when she was paranoid and hallucinating. Even her handwriting appeared more like her own than the infantile scratchings during her first visit. Her father who hated to revisit that time none the less helped her fill in some gaps that eluded her memory. Her father also hated to discuss her condition with well-wishers. Even when James called for an update it was difficult for his father to



speak about it. Her father gave her the journal that he kept to help her understand what she had gone through. It allowed her to relive the hospital stay from his perspective. He was all for leaving the past behind and moving on. After her recovery, she was closer to her father than she ever had been. They'd been through a war together and had achieved a special bonding.

Susannah's relationship with her mother suffered - perhaps because they had started out so close. Her mother was the medicine cop and a reminder of Susannah's dependence. Her mother tried to rewrite the narrative by claiming that Susannah wasn't that bad and that she always knew she'd be fine. One night at dinner her mother broke down and admitted how afraid she had been. It was a turning point in their relationship because her mother was finally being honest thus giving Susannah permission to fully accept how ill she had been.

In Chapter 42: Infinite Jest, Susannah's disability payments were cut in half and she could no longer afford to keep her apartment. She and her father went to pick up her personal belongings. She hated giving up her independence and her first apartment. Her home was now at her mother's house. But the reality was she was not capable of living on her own yet. She began making to-do lists so she could have the satisfaction of crossing tasks off of them - a sign that her frontal lobes were healing. She studied for the graduate Record Exam and she read "Infinite Jest" a thousand page novel that made her to stop and look up every other word in the dictionary.

Susannah became obsessed with her physical condition. She had gained weight and her legs had become cellulite covered. She gained 50 pounds after leaving the hospital - part of which was from the steroids. She hated to look in the mirror and when she did she hardly recognized herself. She took a spin class to try to take off some pounds. It was easier to be obsessed with her outward appearance than grapple with her cognitive problems which were much more complex. Inner doubt still plagued Susannah. Would she ever fully recover?

In the mail that piled up at her apartment while she was gone was a letter from the first place she had the MRI. Inside the envelope was her lucky ring that she had left there. Perhaps it was an omen for good things to come.

In Chapter 43: NDMA, Susannah was improving in all ways - her functioning and her personality. She became accustomed to people asking about her disease. Paul wrote and told her he wanted her back. She decided to try to summarize what had happened to her and explain her disease to him. She had many questions herself about her condition and her future. She wrote a brief description of her ailment for Paul who said he could see that her writing was greatly improved from the emails he received when she was in the throes of the disease.

Studies seem to point to the probability that autoimmune diseases are two-thirds environmental and one-third genetic. Did she catch some air borne virus or did her birth control patch cause it? Her gynecologist refused to put her back on the patch just in case there was a connection. Was it her cat who Angela adopted? Angela learned that



the cat had a bowel inflammation caused by autoimmune disease. Her doctors thought it was a combination of external factors and a genetic predisposition toward developing the aggressive antibodies that caused the damage. But most patients survive and recover. She is grateful for Dr. Najjar and Dr. Dalmau. She hates to think where she would be without them.

In Chapter 44: Partial Return, Dr. Najjar continued to reduce her steroid dosage and she was able to have her IVIG treatments at home. Paul stayed after her about coming back. They decided that she should drop by without a big to-do and say hello to everyone. She took the train by herself to the City. When she got to the News Corps building she chickened out. She wasn't ready and she had Paul come down and meet her. They were both nervous. She explained that she was still taking a lot of medication. She told him she'd be off most of them when she came back. He told her that her desk was ready for her. As a friend Paul hoped for the best but as a boss he wondered if she would ever be able to come back.

A short while later, Mackenzie called and asked her to write an article for "Pulse" the entertainment section of the paper. She jumped at the chance. But she got confused when she looked at the blinking cursor on her computer. And she recalled her inability to write the last article assigned to her before she got sick. She felt like a failure. None the less, she forced herself to write the article. It was slow at first and then the words seemed to flow. It was rough and needed a lot of editing but she finished the article and it ran on July 28th. That article meant more to her than all the hundreds of her other articles that had been published. She finally worked up the nerve to visit the newsroom. She felt uncomfortable but as one of the reporters put it, "Why are you nervous? We all love you" (p. 213)

In Chapter 45: The Five W's, Susannah returned to work in September, seven months after she had her breakdown at work. Human Resources wanted her to go slow, part-time at first. But she soon jumped backed in full force. Her first two assignments were trivial and brief. She was being eased back into the daily job of reporting and writing. She didn't mind the easy assignments. She had more enthusiasm about her job than she ever had before. Susannah spoke slower than she normally did and she typed much slower so she recorded most of her interviews.

Susannah was doing so well that her her medication doses were only negligible. Dr. Arslan told her she was no longer "interesting" and released her from his care. He felt she had returned to full health. Despite his assessment, she knew she had a ways to go before she became the person she once was. Dr. Dalmau told her full recovery could take between two and three years. Patients can return to their former lives before that but it's a struggle.

Dr. Najjar gave her permission to get her hair streaked. Hair couldn't grow back on the scar from her incision so the stylist cut wispy bangs that covered the bald spot.

In Chapter 46: Grand Rounds, Susannah, her mother, Stephen and Angela attended a lecture by Dr. Najjar on anti-NMDA-receptor autoimmune encephalitis at NYU's grand



rounds which is venue in which a doctor presents cases to students and peers. They were a little late in arriving and didn't hear Dr. Najjar refer to the case he was presenting as patient SC. But after he talked for a while, they all realized he was talking about Susannah's condition. It was a strange experience to know that all the people in the auditorium were looking at slides of her brain! The doctor concluded his remarks by saying that the patient was back to normal and back to work.

Angela told Steve about the meeting and he asked Susannah if she would be willing to write a first-person piece about it. The deadline was just in a few days and Susannah felt overwhelmed but she was determined to do it.

In Chapter 47: The Exorcist, Susannah interviewed her family and Dr. Dalmau and Dr. Najjar for the article. One burning question that she had was how many people suffered from the disease without being diagnosed. The medical field believed the disease had been around since the beginning of time. For decades doctors have noted the same symptoms and behaviors that Susannah had displayed and attributed them to encephalitis from unknown sources.

As she learned more about the history of the disease, the more horrific it became for her. The image of children convulsing, moving in stiff and awkward manners and slurring their speech summoned up the possessed girl in "The Exorcist." It made her wonder how many children were "exorcised" over the years and then left in their misery to eventually die or be thrown in psych wards. How many people with this condition are currently considered psychotic and have a life sentence in mental institutions? Dr. Najjar estimated that during the time that Susannah suffered from the disease 90 percent of those afflicted with the ailment went undiagnosed. Susannah realized how close she had been to that fate.

Susannah also learned from Dr. Dalmau's colleague, Dr. Rita Balice-Gordon, that a small percentage of those diagnosed with autism and schizophrenia may actually be victims of autoimmune encephalitis. Unfortunately, due to costs and logistics, it is impossible to administer the necessary diagnostic tests to all the millions diagnosed with mental disease. It had cost \$1 million to treat Susannah but most of it was covered by her insurance. It puts pressure on the doctors to break down the barriers that exist between psychiatrists and neurologists.

Dr. Najjar believes that many forms of psychosis and psychological disorders result from an inflammation of the brain. Doctors need to be encouraged to be on the look-out for the disease- just because an illness seems like schizophrenia doesn't mean that it is. There is much progress. Susannah was the 217th person to be diagnosed with anti-NMDA-receptor autoimmune encephalitis. A year later, that number doubled and currently thousands have been so diagnosed. Yet when she contacted Dr. Bailey, who was considered one of the best neurologists in the country, he still hadn't even heard of the disease! Her article was in newspapers around the globe. Dr. Bailey is a symbol of the dysfunction in the medical field. The most difficult part of writing the article was turning over the EEG tapes to the photo editor. She had to avert her eyes from the skinny crazy image who was unrecognizable.



On October 4th, the most important story of Susannah's career ran with the headline: "My Mysterious Lost Month of Madness."

In Chapter 48: Survivor's Guilt, anti-NMDA-receptor autoimmune encephalitis is only one of more than a hundred kinds of autoimmune diseases that afflict 50 million people each year in the United States alone. Seventy-five percent of these diseases strike women and are the number one cause of disability in women. There is no definitive explanation for why these diseases impact women disproportionately although some experts believe it could be due to the more complicated immune system that women have for childbearing. Dr. Dalmau has discovered six other types of antibodies that target receptors in the brain.

After the article ran, Susannah's in-box was filled with emails from the concerned family and friends of people diagnosed with the disease or displaying the symptoms she described in her article. All the stories did not have happy endings. She read of girls having their ovaries removed because teratoma tumors went undiscovered. She heard from others whose loved ones had died from the disease. Almost everyone one who contacted her spoke of the paranoia and hallucinations that are side-effects of the condition. In fact she got phone calls from victims of the disease who told her that her phones were bugged and that there was a plot against her. Susannah passed on the names of her doctors to everyone who wrote to her with more questions than she could answer.

If there was any upside to having the condition, it was the friends that she made in its aftermath. She was also thankful that she gave hope to victims of the disease and their families with the information she provided them with. The most dramatic case was when a man named Bill who Susannah had been corresponding with literally shoved Susannah's article in a neurologist's face and demanded that he read it. He was treating his daughter, Emily, who displayed the same symptoms that Susannah had. The doctor read the article and agreed to test Emily for the rare form of encephalitis. Emily, who had been near death, was air-evacuated to the University of Pennsylvania where Dr. Dalmau's staff diagnosed her with anti-NMDAS-receptor encephalitis. Bill told Susannah that if he hadn't had her article with him, he was sure Emily would have died.

In Chapter 49: Hometown Boy Makes Good, Dr. Najjar benefited from Susannah's article. He invited her over to his house in New Jersey where she met his wife and three teenaged kids. His father in Syria had seen her article. It had been translated into Arabic and placed in multiple papers in the region. After the article ran, Dr. Najjar was honored by the Syrian Ambassador to the UN. Stories ran in Syria about the Syrian boy who became a miracle doctor in America. He was named one of the America's top neurologists by New York Magazine.

In Chapter 50: Ecstatic, by the time Susannah was a guest on the Today Show to discuss her illness, the doctors had taken her off all medication. After her mother and Allen sold their house in Summit, Susannah and Stephen decided to get a place together. She still was uncomfortable in her own skin. The Susannah that emerged after the ordeal is a lot like the old Susannah but there are differences. She talks fast again





and does her job with ease but she sees something new when she looks into her eyes in the mirror. She talks in her sleep every night now. She has fears of relapsing and hallucinating. Those close to her are changed as well. They worry about her and are protective and defensive of her like never before.

In Chapter 51: Flight Risk? Susannah still has trouble sorting through what was real and what was hallucination. She came to terms with the reality that she hadn't been psychotic, that having hallucinations does not mean one is insane or schizophrenic. For much of her time in the hospital, hallucinations were Susannah's only memory. Because hallucinations are self-generated they are believable to that person. When the amygdala of the brain is branded with an experience, either real or imagined, it is likely to be preserved because that region is a vital part of a brain's emotions and memories. For example, Susannah hallucinated that her hospital bracelet was stamped with "flight risk." It wasn't, but to this day she can summon up that image in her mind as if it really happened.

In Chapter 52: Madame X, a year after Susannah left the hospital, she went to a pub with her friend, Colleen. The pub called Egan's seemed familiar to her but she couldn't remember if she'd been there before. At first she was sure she hadn't been there but when she looked at the large chandelier, it sparked a memory. She had been there with Stephen and his sister and brother-in-law. The memory came rushing back to her. It made her wonder what else she would remember. It was a little frightening because it was the unknown. She knows that with every memory that returns, there are hundreds perhaps thousands more that may also someday emerge again.

In Chapter 53: The Purple Lady, two years after her release, Susannah returned to NYU's Langone Medical Center. She took the elevator up to the twelfth floor and imaged how many times her parents and Stephen had taken that same elevator. Nothing looked familiar but it wasn't her memory - the epilepsy unit was in the west wing not the east wing where she was. She found the epilepsy unit but very little looked familiar to her. Then she saw a nurse she had called the purple lady. She wasn't sure if she remembered Susannah at first. When she told the nurse who she was, the nurse immediately knew who she was. She looked so different! The purple lady embraced Susannah and kissed her on the cheek.



# Characters

## Susannah Cahalan

Susannah Cahalan was a vibrant twenty-four-year old young woman who lived in New York City and worked as a reporter for the New York Post when she was afflicted with a rare condition known as anti-NMDAS-receptor encephalitis. It was condition that sparked her own antibodies to attack the receptors of her brain. In fundamental terms, her brain was on fire and she was being attacked by her own antibodies that were determined to destroy her.

Susannah's month-long journey into madness began when she noticed two bug bites. She was sure that they were bedbugs and had her apartment sprayed even though the exterminator assured her that there were no bedbugs. Later she learned that a fear of insects was a sign of the kind of paranoia that was associated with her condition. She began to become more paranoid and began to hallucinate - her hallucinations were more real to her than her reality. Her mental condition continued to deteriorate and soon her physical state began to decline as well. Her speech became slurred, her movements were awkward and stiff and she began to have numbness down her left side.

Susannah's parents both were devoted to her during her ordeal and kept prodding the doctors for answers. The the doctors didn't have answers and called in Dr. Najjar who was known as a magical doctor who could figure out the most rare and bizarre of medical conditions. Dr. Najjar did isolate her condition and finally Susannah was able to receive the treatment she needed.

But her road to recovery was long and had many set-backs and obstacles. After seven months, she was off her medication and back to work. However, the horrible affliction that she had developed was devastating and had changed her forever. She had gained a knowledge the hard way - the unknown can strike at any time and turn one's life upside down.

## Stephen

Stephen was Susannah's boyfriend of just four months when she was stricken with a debilitating and life-threatening form of autoimmune encephalitis. Like Susannah and her family, Stephen had no idea about the wild and terrifying ride that they were all about to take with Susannah. Susannah and Stephen had met years before but at the time he seemed too old for her. When they met again, she was more mature and his age seemed just fine.

An early sign of Susannah's condition emerged when Susannah had spent the night at Stephen's apartment. He was gone when she woke up and a raging jealousy consumed her. She snooped into his email and into some old letters and pictures. Even though she





couldn't control herself, she knew what she was doing was wrong and so unlike her. Stephen began to realize that something was gravely wrong with his young girlfriend when she was unable to walk to her seat at a concert. When she sat on the floor, he coaxed her up and carried her to her seat.

Through all her paranoia and hallucinations, Stephen had many opportunities to give up on her. After all they'd only been together a few months. But in those four months he had begun to fall in love with her. He wasn't about to abandon her in what would become her hour of genuine need. Stephen would come to the hospital every night after work. He would stay until midnight when she fell asleep. After she was released from the hospital, he made the drive from New York City to Summit, New Jersey, every night. His visit is what Susannah looked forward to all day.

After Susannah recovered, she and Stephen decided to move in together. Susannah later thanked him for sticking by her. But he wanted no thanks. He stayed by her side because he loved her.

## **Dr. Saul Bailey**

Dr. Saul Bailey was the first neurologist that Susannah saw. He totally misdiagnosed her condition and even afterward when there was a lot of publicity about the case, he still had never heard of the affliction.

## **Dr. Souhel Najjar**

Dr. Souhel Najjar was known as a magical doctor who could figure out the most mysterious diseases. After giving Susannah one simple test, he surmised that she had a form of autoimmune encephalitis.

## **Dr. Joseph Dalmau**

Dr. Josep Dalmau of the University of Pennsylvania was sent the biopsy of Susannah's brain and was able to confirm that she had a rare form of encephalitis that involved the receptors of the brain.

## **Susannah's Mother and Step-Father**

Susannah's mother and her husband, Allen, did everything in their power to help Susannah. When she was released from the hospital, Susannah stayed with them at their Summit, New Jersey home.



## Susannah's Father and Step-Mother

Susannah's father was retired and spent everyday with his daughter. They were not extremely close before her illness but bonded during and after her ordeal. His wife Gisele was supportive of Susannah during her illness.

## James

James is Susannah's younger brother. His parents kept him in the dark about Susannah's condition so he wouldn't worry about her while he was away at school. The two were extremely close and when he first saw her, he was shocked by her frail and deteriorated appearance.

## Angela

Angela is a fellow reporter at the New York Post. When Susannah first became ill, she confided some of her strange symptoms to Angela.

## Paul

Paul hired Susannah as an intern when she was seventeen and later promoted her to reporter. When he first saw her after she'd been ill, he questioned whether she could ever return to her job.



## Objects/Places

### The New York Post

Susannah Cahalan worked as a reporter in the newsroom of the New York Post, which was established by Alexander Hamilton in 1801.

### Washington University

Susannah attended Washington University in St. Louis, Missouri. When she was a senior there, she got an exclusive interview with Michael Devlin who was a notorious kidnapper and pedophile.

### New York University Medical School

Susannah was admitted to NYU Medical School's hospital after doctors were unable to identify what was wrong with her. She stayed there for twenty-eight days.

### University of Pennsylvania

After a brain biopsy, Susannah's specimens were sent to Dr. Josep Dalmau at the University of Pennsylvania for analysis. He was able to confirm that her brain was inflamed.

### Capgras Syndrome

Susannah suffered from Capgras Syndrome which is defined as having hallucinations that people the patient knows are turning into different people.

### The Clock Test

Dr. Najjar suspected that Susannah was suffering from a form of inflammatory encephalitis. He had her draw a clock and when she drew all the numbers on the right-hand side of the circle and none on the left, he knew that her right brain was inflamed.

### Anti-NMDAS-Receptor Encephalitis

Susannah was diagnosed with anti-NMDAS-receptor encephalitis. It was a condition that caused her own antibodies to attack the receptors of her brain.



## **NYU's Grand Rounds**

Susannah and her mother attended a lecture by Dr. Najjar on anti-NMDA-receptor autoimmune encephalitis at NYU's grand rounds which is a venue in which a doctor presents cases to students and peers. Part way through the lecture, Susannah realized that he was discussing her case and showing slides of her brain.

## **Summit, New Jersey**

Susannah's mother and her step-father, Allen, lived in Summit, New Jersey. Susannah recuperated there after she was released from the hospital.

## **First-Person News Article**

Susannah wrote a first-person article for her newspaper entitled, "My Mysterious Lost Month of Madness," which ran after she recovered from her ailment.



# Themes

## Loyalty and Abandonment

Tragedy and fear can bring a lot out in people. Sometimes the result isn't noble or something to be proud of. People abandon others, even loved ones, when the tragedy and fear is too difficult to bear. Children are abandoned in some countries due to birth defects, which could be more cultural than personal. People who are accused of crimes are sometimes shunned by others, even close friends and relatives, even after their cases are dismissed. It's just too frightening to be around a deformed person or someone who might be a criminal.

However, in many cases, tragedy draws people closer together. The good and caring element of the human experience is that most people have a deep empathy for their fellow man. And when a loved one is in trouble, those who love him rally their support and see him through to resolution. It was Susannah's good fortune that the people in her inner circle supported her and would not think of abandoning her even on the darkest days and there were plenty of those.

Her father, mother, and boyfriend stood unflinchingly by Susannah's side. They never gave up even when the doctors mentioned horrible words like schizophrenia and cancer. They didn't believe it when one misguided doctor was of the opinion that Susannah had bipolar disease. They shook their heads in dismay when another doctor had Susannah pegged for a party girl who drank too much. They knew that wasn't Susannah and although she seemed like a different person when she was deeply in the throes of the disease, they all could see the Susannah in her eyes - the Susannah that they knew and loved.

Susannah's loved ones were determined to do everything in their power to keep her alive and to keep her out of the psych ward. They knew she didn't belong there. She belonged back home with them. And they would never abandon her and would not be satisfied until they had the real Susannah back in their arms. She had never left their hearts.

## Changes and Challenges

Life is a series of changes and challenges. We all start out life as helpless babies and develop through childhood and adolescence and ultimately to adulthood. That's the way the story is written for all of us. Just when we grow accustomed to where we are in life is when, it often seems, that things change. Some of the changes come as a result of a challenge and often that challenge is not one that we voluntarily take on as it was in the case of Susannah Cahalan. Her challenge was a completely unexpected and unique disease that, to this day, the experts really don't know exactly how she contracted it or how it developed.



We can walk away from some challenges. When the mountain seems too high to climb when we're standing at the bottom looking up, we can turn our backs on it and leave. But there are cases when we are not able to turn our backs on a challenge. A good parent will deal with the challenge of an unruly child. A good worker cannot normally turn down a big project that his boss gives him. When Mother Nature strikes and destroys our homes and communities, we must rebuild. So it was in the case of Susannah Cahalan when a mysterious condition uprooted her very happy life and disrupted her bright future. There was no turning away. In the case of a disease or accident, we are not able to walk away.

Susannah resisted treatment because she wasn't thinking right so her parents and boyfriends took over and prodded her on. Their challenge was to do whatever they could to keep her alive and get the old Susannah back, the young woman that they seemingly had lost. It was difficult for parents to hear her doctors say that their daughter was fine. They knew she wasn't. And when the doctors finally recognized that there was something seriously wrong with Susannah, they had to brace themselves for the worst. Some doctors speculated that she might be bipolar, schizophrenic or even have an underlying cancer that was causing her strange behaviors and symptoms. None of that was easy to hear for Susannah's loved ones. It was a challenge for them just to hang on to the sliver of hope they were able to salvage from the ordeal.

There is a saying that what doesn't kill you makes you stronger. Susannah's horrific disease didn't kill her although it could have. And her affliction not only made her stronger, the unwanted challenge made her and her loved ones stronger and aware how in an instant changes can disrupt one's life and present a challenge that can't be ignored.

## The Unknown and Unexpected

While the story of Susannah Cahalan is one of illness and recovery, it is also an example of what life can unexpectedly hand a person. All of us are in this together and what happened to Susannah could happen to any one of us. The story is uplifting in that she saw the struggle through and largely recovered; however, the story is difficult to fully embrace because it's frightening to acknowledge that there are unknown demons like autoimmune encephalitis waiting to pounce upon us at any time.

Everyone has a natural fear of contracting or developing the diseases and conditions that are common, though unpleasant, and known to all. Who isn't fearful of cancer, heart disease or schizophrenia? But what is more frightening than what we know is what we don't know. Susannah's story confirms that there are rare conditions that lurk in the shadows that even mystify doctors and specialists. Unexpected ailments like that which afflicted Susannah are confusing and confounding to the victim and to the victim's loved ones. Her parents feared she was going insane but when the doctors mentioned that cancer could be an underlying cause of her condition, they didn't want to hear that either.



The term, "fear of the unknown" often conjures up images of those who would harm us, natural disasters, financial ruin and of course illness or injury. However, when the "unknown" is genuinely unknown, a disease that even stumps the doctors, the concept is terrifying. It is conventional wisdom that half the battle is knowing and facing your problem but when its source and nature is unknown, how can one emerge victoriously? No matter what the challenge, man must believe he can survive but he can only withstand an external assault when he knows from which direction his enemy is attacking.

In Susannah's case, her attacker - one that was bent on destroying her - was her own autoimmune system. Nothing could be more terrifying than to learn that the unknown enemy is yourself.

# Style

## Perspective

"Brain on Fire - My Month of Madness" by Susannah Cahalan is an autobiographical work that recounts the ordeal she endured after being afflicted with a rare autoimmune disease known by the technical name, anti-NMDAS-receptor encephalitis. In layman's terms, the condition caused her own antibodies to attack the receptors of her brain. As one doctor put it, her inflamed brain was on fire and her body was attacking her and apparently determined to destroy her.

During the majority of her stay at NYU's medical school hospital that totaled 28 days, Cahalan was paranoid and hallucinating. Her hallucinations were stored in her memory and she didn't have a clue about what really took place during most of that time. So, in order to write "Brain on Fire," Cahalan had to interview her parents, boyfriends, friends, co-workers and her doctors. She also kept daily logs some of which looked to her like they were written by a five-year-old. On her second trip to the hospital, she had recovered enough to make some entries in her log that made sense to and aided her in writing her book. Susannah also relied on the daily log that her father kept during the ordeal. She was in the epilepsy unit which ran videos of their patients 24/7. She was able to see herself and her strange behavior for herself. It was difficult for her to watch the videos. The only way that she could bear to watch was because the person in the tapes looked and acted nothing like her.

Susannah Cahalan is a professional writer. She is a reporter for the New York Post and is the recipient of several awards for outstanding journalism.

## Tone

"Brain on Fire - My Month of Madness" by Susannah Cahalan is written in a clear and understandable style. Even the more technical descriptions about Cahalan's ailment which are quite complex and employ medical and technical jargon that the common lay person is not familiar with are parsed by the author and explained in a step-by-step manner.

The story is an account of the author's own battle with a unique disease that at first no one could identify; even some of the top experts in the country were at a loss. Cahalan writes about her personal ordeal in a style that evokes empathy but not pity. Even in her darkest days, when she was at her paranoid and hallucinatory worst, a survivalist spirit somehow shined through which was conveyed in the retelling of a chunk of her life that truly turned her world upside down.

The gratitude and respect for her doctors who literally saved her from either death or from a life sentence in an insane asylum is obvious in her writing. Her team of doctors was dedicated but it took a doctor known for his ability to diagnose "mystery" diseases





who isolated exactly what Susannah was suffering from. She, of course, conveys an extra dose of thanks to him.

Cahalan turned her bout with the devil into a positive by writing a first-person account about her disease. At the request of her editor, she agreed to write the article although it was difficult for her to fully face what she had been reduced to by the disease. It ran in the paper where she was a reporter after which she received countless responses from people with loved ones who were going through the same struggle. It is obvious that Cahalan was happy that she was able to provide information that could help others who found themselves facing the same terrifying ailment that she had.

## Structure

"Brain on Fire - My Month of Madness" by Susannah Cahalan is structured in a basically straight-forward chronological manner; however, there are episodes that are revisited as the story progresses. The time frame of the story is approximately three years. The story begins when Cahalan begins displaying strange behavior including paranoia and is plagued by a strange self-doubt. The book is separated into three sections: Part One: "Crazy" chronicles the onset of the author's strange disease and disability and the efforts of her and her family to find a resolution and treatment for it. This section has fourteen chapters.

Part Two: "The Clock" depicts the further mental and physical decline of Cahalan and her family's frustrations with the team of doctors who seem to have no answers for them. Finally, one doctor comes to the rescue. Dr. Najjar was known as a miracle doctor, a physician who could figure out the cause of the most mysterious of disorders. He and a colleague, Dr. Dalmau, finally have a name for Cahalan's condition and though the ultimate recovery is still an uphill battle, the doctors at least know what they're up against and how to approach it with the appropriate treatment. Part Two has twenty chapters.

Part Three: "In Search of Lost Time," which has nineteen chapters, recounts her long and bumpy road to recovery. After a year, she has returned to her former self; however, she knows that the disease and the battle she was thrust into has changed her forever.

Included in the story are several charts and illustrations to help explain Cahalan's story and her condition. Other sections include "Author's Notes," "Preface," "Notes," and "Acknowledgments."



## Quotes

"I readjusted my scratched-up wide-framed Annie Hall glasses, which a publicist friend once described as my own form of birth control because 'no one will sleep with you with those on'" (Chapter 1, p. 6).

"Like most fathers, had had chastised me when I was a teenager about allowing my room to get filthy, so I was used to that. But today I felt ashamed, as if the room was a metaphor for my screwed-up life. I dreaded the idea of his seeing how I was living" (Chapter 4, p. 22).

"I would soon learn firsthand that this kind of illness often ebbs and flows, leaving the sufferer convinced that the worst is over, even when it's only retreating for a moment before pouncing again" (Chapter 5, p. 26).

"The healthy brain is a symphony of 100 billion neurons, the actions of each individual brain cell harmonizing into a whole that enables thoughts, movements, memories, or even just a sneeze. But it takes only one dissonant instrument to mar the cohesion of the symphony" (Chapter 8, p. 41).

"The mind is like a circuit of Christmas tree lights. When the brain works well, all of the lights twinkle brilliantly, and it's adaptable enough that, often, even if one bulb goes out, the rest will still shine on. But depending on where the damage is, sometimes that one blown bulb can make the whole strand go dark" (Chapter 17, p. 83).

"One of the remarkable things about Dr. Najjar was his very personal, heartfelt bedside manner. He had an intense sympathy for the weak and powerless, which, as he told me later, came from his own experiences as a little boy growing up in Damascus, Syria" (Chapter 26, p. 128).

"Finally, he sat down on the bed near me. He turned to my parents and said, 'Her brain is on fire... Her brain is under attack by her own body'" (Chapter 26, p. 134).

"These masses of tissue [teratomas] range in size from microscopic to fist sized (or even bigger) and contain hair, teeth, bone, and sometimes even eyes, limbs, and brain tissue" (Chapter 31, p. 158).

"Fear of this sort is not something we typically capture in photographs or videos of ourselves. But there I am, staring into the camera as if I'm looking death in the face. I have never seen myself so unhinged and unguarded before, and it frightens me" (Chapter 35, p. 175).



"My hair was unkempt, and the angry red bald spot from the biopsy was exposed, complete with metal staples still suturing my skin together. Yellow crust covered my eyelids. I walked unsteadily, like a sleepwalker with my arms outstretched and stiff and my eyes open but unfocused" (Chapter 36, p. 176).

"As I watched him enter the car, I was suddenly filled with an aching feeling of gratitude that I have found such a selfless, devoted person. It's not as if I hadn't known that all along; it was just that at that very moment, I couldn't contain the deep love I had for him, not only staying with me, but also for providing me with security and meaning at a very difficult time in my life" (Chapter 38, p. 184).

"'He's talking about my brain,' I whispered, although I didn't understand then what these slides portrayed. All I knew was that a very intimate part of myself was on display in front of a hundred strangers. How many people can say that they've allowed others to literally see inside their heads" (Chapter 48, p. 218).



## Topics for Discussion

What symptoms did Susannah display that made some of her doctors think she was bipolar or schizophrenic?

Why did Susannah, who had no memory of most of her stay in the hospital, remember her hallucinations? Why did they seem real to her even after she recovered?

What two doctors does Susannah attribute her diagnosis and ultimate recovery to? How did their approach differ than that of the other doctors?

What impact did the article that Susannah wrote about her illness have on others? What were some of the specific experiences with the diseases conveyed by people who contacted her after her article ran? Whose life might her article have saved?

What is a teratoma and what unusual physical characteristics might it have? How is it related to the unique type of autoimmune encephalitis that Susannah had? Did Susannah have a teratoma?

What causes anti-NMDAS-receptor encephalitis? What caused or might have caused Susannah's disease?

Why did Susannah remain afraid long after she was declared cured by her doctors? In your opinion, will she ever be free of fear? Why or why not?

What mistakes did Dr. Bailey make? What was surprising about his knowledge about anti-NMDAS-receptor encephalitis? How did his approach compare with that of Dr. Najjar?