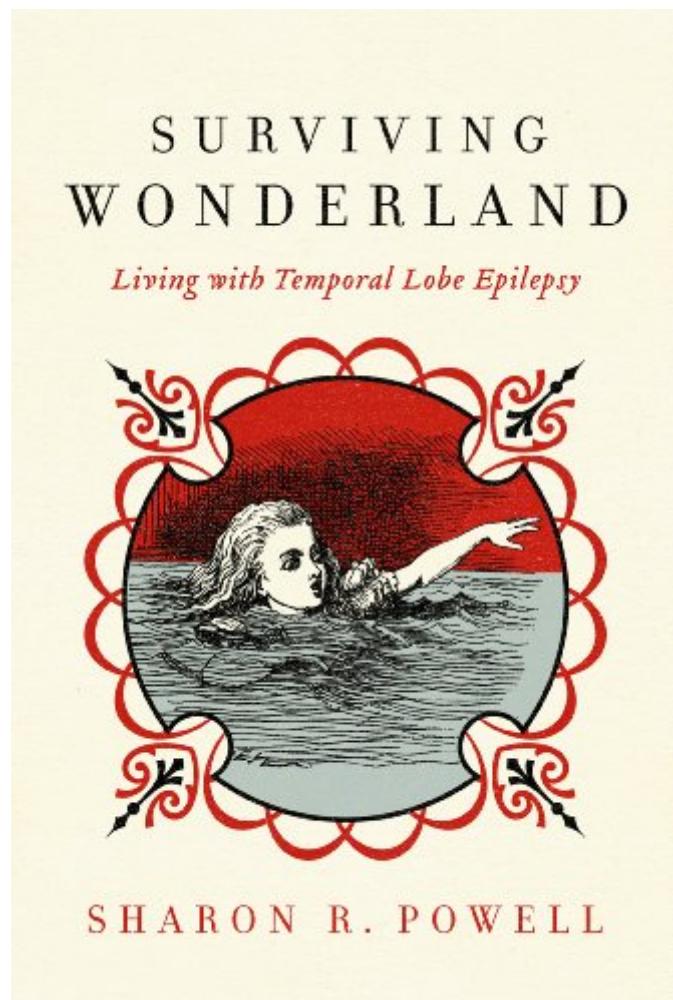


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# Surviving Wonderland: Living With Temporal Lobe Epilepsy



## **Synopsis**

Surviving Wonderland: Living with Temporal Lobe Epilepsy is the story of one womanâ™s journey down the rabbit hole and into the Wonderland of temporal lobe epilepsy. Sharon tells of her life starting with the diagnosis and moving through seizure-related issues, the isolation associated with a condition still carrying a negative stigma, to the eventual insights into the value of the experience. For people with TLE and their families, this book can serve as a guide through the maze of a condition still not easily recognized by healthcare providers or accepted by the general public. Medical experts agree epilepsy affects between one and two percent of the worldâ™s population, with TLE making up about half of that number. This accounts for more than 1.5 million in the US, or roughly the population of Philadelphia. The actual number may be much higher, however, because TLE shares many of the symptoms of migraines, anxiety disorders, post traumatic stress disorder, bi-polar disorder, and schizophrenia. A limited number of books exist on this type of epilepsy. Most books come from the standpoint of the healthcare provider. The reality, though, is that sometimes what the provider understands about TLE and what the patient experiences are hard to reconcile. Finding information from a patientâ™s standpoint may be the most valuable thing for someone suffering from a condition that is both physical and mental, with myriad symptoms and challenges. Powellâ™s personal and professional experiences have shown her that a huge gap separates the patient from the doctor. For this reason, a book from the patientâ™s standpoint is a tremendous asset to those with temporal lobe epilepsy who are making their own way through the Wonderland of medicine and emotion, and those living with them.

## **Book Information**

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## Customer Reviews

I have sympathy for the writer, as it seems she's had a tough road to get help with her epilepsy. I could relate to that, but often found the book read a like collection of antidotes with a lot of copy/pasted lists to stretch the book's length. While I "get" the frustration she has felt (or feels) when it comes to the medical system, it often read like open anger with nowhere to go. I applaud anyone who can express that sort of feeling (it's healthy to get mad); however, I would have found it helpful if more insight was drawn from those parts of the journey and/or if they were added or at least expounded on more than they were. I found the book, *The Sacred Disease: My Life with Epilepsy*, far more helpful if you are looking for a way to understand both the journey in getting a diagnosis, a general sense of living with it (including the stigma), and how to cope with the possibility it may well be a central factor in one's life. It's not a bad book, but it's not a particularly good or memorable book either.

This book was amazing to me! My son had both Temporal and frontal lobe epilepsy. He also had schizophrenia. I work in mental health now. I am sending this title to his Psychiatrist who now works in research for Schizophrenia. My son died several years ago. I am taking another look at whether his voices were from his epilepsy or Schizophrenia!! This book sounds so much like my son~~ his voices came and went starting at age 12. Thank you SO Much for this book~

I have TLE and have never had the words to explain it as well as you did. We have a lot of the same symptoms and some different. My doctors have never told me the ideas that I got from your book. I am 43 and have lived with Epilepsy since I was a child, but was not diagnosed until high school. I am going to start looking into support groups and different ideas as I have hit a wall and am ready to give up. Thanks :)

The author had a far tougher time with her temporal lobe seizures than I have. There is a lot of anecdotal material, but some misinformation. First, the whole theory of left-brain / right-brain

learning is no longer valid; while acceptable for many years, it's generally thought to be inaccurate and misleading. Second, "grand mal" is old verbiage, the proper phrase is "tonic clonic". There are others. I can appreciate the authors' problems, but I gave up about half-way through the book. Great title, however; it reminded me of the *deja vu* I used to experience when first diagnosed.

The author has many other things going on that may influence her symptoms. Her sister was murdered, she has PTSD, anorexia, and migraines. She also believes in some "magical" things like epilepsy medications closing off the veil to another world and epilepsy breaking through to that world. The latter issue made the book challenging to read even though it was written to describe her own experiences. She also went overboard with analogies. I have what she calls TLE, which is more currently called Complex Partial Seizure Disorder. I can relate to her work difficulties and the comfort brought by art. Personally meditation helps me, and I wish she had been exposed to a less esoteric method, but can totally understand why she didn't pursue it.

I am extremely thankful to have a book that portrays this condition so well. As a 29 female who was diagnosed with late onset TLE last year, I can attest to the accuracy and insight provided. Since I lose my ability to verbally communicate after or around the time of my seizures, I can't even try to explain how I feel to people. This book allows me to give the people in my life perspective into what I am going through. It provides hope for people who are trapped in the loneliest place in the world. Highly recommended for anyone who is trying to understand or cope with TLE. P.S., love the title!

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