

A Review of “Ratgeber Autoimmune Enzephalitis”

20th March 2026

Ana Medina, Volunteer at Encephalitis International

For the past few weeks, I have been immersed in “*Ratgeber Autoimmune Enzephalitis*” (a guide to autoimmune encephalitis), a comprehensive resource edited by Professor Markus Krämer and Professor Frank Leypoldt, both distinguished medical practitioners at different German hospitals. The book serves as a collaborative effort and was published in 2025. Its chapters are written by different experts from universities, clinics, and institutes who confront autoimmune encephalitis every day.

As the editors note in the prologue, this book is designed for anyone affected by the condition: patients, survivors, relatives, and caregivers alike. In my case, I approached the book from the perspective of a relative and primary caregiver. My husband was diagnosed with autoimmune encephalitis in April 2022, and this is precisely the resource I wish I had at the time to navigate those difficult months. Despite being written by clinicians and academics, the style is accessible and highly informative. Even as a non-native German speaker, I found the text explanatory, comprehensive, and easy to digest.

Section I: What is autoimmune encephalitis?

The book is logically structured into three distinct sections. The first and most extensive is dedicated to the clinical aspects of the disease, spanning nine chapters. It begins with the fundamentals: how the nervous system functions, the intricate structures of the brain, and the mechanics of the immune system. From there, it continues into the symptoms, causes, and triggers of autoimmune encephalitis, differences between acute and chronic disease courses.

What I found particularly interesting, despite its brevity, was the historical context of the disease. It is disturbing to learn that while there are documented cases with symptoms matching encephalitis dating back to the Late Middle Ages, these patients were often subjected to exorcisms. It was not until 1960 that a medical relationship between the brain and the immune system was established. A "fun fact" included here is that humans are not the only ones affected; animals can also suffer from autoimmune encephalitis, the most famous case being [Knut, the beloved polar bear from the Berlin Zoo](#).

The concluding chapters of this section focus on therapy. They cover immediate inpatient treatments, such as various immunosuppressants, as well as post-hospital rehabilitation, like physiotherapy and neuropsychology. These chapters are highly specific to the German healthcare system. They provide practical guidance on insurance forms, domestic assistance, and the "six phases" of recovery recognized in Germany. For a relative, this information is very valuable; it mitigates that paralyzing "fear of the unknown" by outlining what comes next. Furthermore, the book addresses essential legal considerations, such as the documentation required to make medical decisions for a patient and the varying levels of disability.

Section II: Special advice for patients with autoimmune encephalitis

The middle section shifts its focus to practical advice for those living with the consequences of the disease. Across five chapters, the authors cover essential lifestyle topics, including nutrition, vaccination protocols for immunocompromised patients, and the management of epilepsy.

Two chapters were especially poignant for me, given my husband's experience: memory dysfunction and the fitness to drive. Memory issues are common consequences of encephalitis. The book offers some resources and advice for managing cognitive gaps on a daily basis. Regarding the ability to drive, it provides specific legal and medical criteria relevant to Germany. For us, this was a frequent point of stress during recovery, and a milestone for him to regain independence.

Section III: Testimonials from people affected by autoimmune encephalitis

Unfortunately, it often takes a traumatic experience for human beings to truly appreciate the small things in life we otherwise take for granted. The final section of the book offers a shift in perspective, featuring a collection of personal stories written by patients and their families. These deeply moving narratives serve as a reminder that patients and relatives should never underestimate the power of sharing their stories—both for their own healing and to help others feel less alone. During the early days of my husband's illness, similar resources provided by Encephalitis International (<https://www.encephalitis.info/your-stories/>) were very helpful for me as well.

One particular paragraph resonated with me: the importance of finding a doctor who truly understands autoimmune encephalitis. Because the disease is relatively rare and shares symptoms with many other conditions, it is frequently misdiagnosed as a primary psychiatric disorder. A delayed diagnosis often leads to a more difficult recovery and more severe long-term consequences, even death. I am certain this is exactly what would have happened to us if I had relied solely on our family doctor instead of driving directly to the University Hospital. This is where organizations like Encephalitis International (<https://www.encephalitis.info>) are indispensable. Their work in advocating for research, spreading awareness, and educating the medical community is literally life-saving.

Final thoughts

The book also includes a directory of the contributing authors, a list of links and resources (including links to Encephalitis International), a glossary of terms, and a bibliography of specialized medical articles.

Reflecting on my husband's time in the hospital, I remember the overwhelming feeling of confusion. It was 2022, and Germany was still navigating strict COVID-19 protocols. I couldn't visit him, and I often had to speak with doctors over the phone. While the medical professionals were excellent, they were under immense pressure and didn't always have the time to explain complex neurological concepts in a way that a worried relative could immediately grasp.

I spent countless hours researching medical terms online, trying to piece together how his symptoms related to his treatment. This book would have been really useful back then. It would have served as a steady anchor, helping me understand the diagnostic process, why certain medications were delayed, and what therapies we were entitled to access. I think that "*Ratgeber Autoimmune Enzephalitis*" can act as a roadmap for those lost in the complexity of a devastating disease. It is a resource that should be made publicly available in every German hospital.

If you are interested in purchasing the book, you can find more information here:

<https://link.springer.com/book/10.1007/978-3-662-70943-6>

The book "*Ratgeber Autoimmune Enzephalitis*" (a guide to autoimmune encephalitis) is a comprehensive resource edited by Professor Markus Krämer and Professor Frank Leypoldt, both distinguished medical practitioners at different German hospitals. The book serves as a collaborative effort and was published in 2025. Its chapters are written by different experts from universities, clinics, and institutes who confront autoimmune encephalitis every day.

The book is designed for anyone affected by the condition: patients, survivors, relatives, and caregivers alike. Despite being written by clinicians and academics, the style is accessible and highly informative. The book is logically structured into three distinct sections. The first and most extensive is dedicated to the clinical aspects of the disease, covering how the nervous system functions, the intricate structures of the brain, the mechanics of the immune system, the symptoms, causes, and triggers of autoimmune encephalitis... The middle section shifts its focus to practical advice for those living with the consequences of the disease. Across five chapters, the authors cover essential lifestyle topics, including nutrition, vaccination protocols for immunocompromised patients, and the management of epilepsy.

The final section of the book offers a shift in perspective, featuring a collection of personal stories written by patients and their families. These deeply moving narratives serve as a reminder that patients and relatives should never underestimate the power of sharing their stories—both for their own healing and to help others feel less alone. The book also includes a directory of the contributing authors, a list of links and resources (including links to Encephalitis International), a glossary of terms, and a bibliography of specialized medical articles. "*Ratgeber Autoimmune Enzephalitis*" can act as a roadmap for those lost in the complexity of a devastating disease. It is a resource that should be made publicly available in every German hospital.