

**#AskMeAboutAE:**  
**The Importance of Long-Term Outcomes**  
**in Autoimmune Encephalitis**

The collage features numerous individuals, including children and adults, holding signs that share their experiences with Autoimmune Encephalitis (AE). The signs often include a brain diagram with specific symptoms or challenges highlighted. For example, one sign lists 'CONFUSION', 'FATIGUE', 'MEMORY', and 'NERVE PAIN'. Another sign mentions 'My mom's brain doesn't like when I bark loud'. A central sign titled 'WALK ON WALK ON TOGETHER' lists symptoms like 'Constant Dizziness', 'Constant Loss of Independence', and 'The Major Neurological Disorder'. Other signs mention 'Concentration', 'My Energizer bunny mom stopped going!', 'My Sister has lost some of her childhood memories', 'My Spouse lost his fun', 'Total Body Acceptance', and '5+ years THEN NOW'. The signs also feature the #ASKMEABOUTAE hashtag and the SHES logo.



# Outcomes After Autoimmune Encephalitis

*While the recovery process is unique to each patient, early and aggressive treatment for autoimmune encephalitis leads to the best recovery. The various antibodies causing the autoimmune response can result in varying symptoms and respond widely in terms of recovery.*

A study in Lancet Neurology by Dr. Titulaer, Dr. Dalmau and colleagues found that 50 percent of patients with Anti-NMDA-receptor encephalitis, show improvement within four weeks of receiving treatment. According to the same study, 80% of patients with Anti-NMDA-receptor encephalitis eventually have partial or complete recovery. Some patients took up to 18 months to recover. This study was done in 2013 and focused solely on outcomes in terms of neurologic disability.

A recent study by Dr. Anusha Yeshokumar assessed the long-term impact of anti-NMDA receptor encephalitis on psychosocial outcomes, or emotional and social well-being. 91.8% of participants reported persistent symptoms (mean duration of 4.4 years since symptom onset), these included: **fatigue (73.8%), memory problems (72.1%), attention and concentration problems (59.0%), emotional or impulse control issues (55.7%), sleep problems (47.5%), headaches (45.9%), and seizures (13.1%)**. They also found that a return to work or school after the illness was negatively impacted by an initial misdiagnosis, and positively impacted by follow-up with a psychiatrist after hospitalization. They concluded that individuals with anti-NMDARE often have poor psychosocial outcomes despite literature reporting good outcomes in terms of neurologic disability. There has been an increase in publications addressing this topic.

These findings highlight the importance of improving current methods of determining outcomes, including patient perspectives in assessing outcomes. It also supports the incorporation of assessments that specifically evaluate these psychosocial outcomes.



*During this year's Brain Awareness Week, HESA and AE Alliance launched the #AskMeAboutAE campaign, visualizing the consequences of autoimmune encephalitis. We asked our AE community to share what they continue to struggle with in daily life.*



Autoimmune encephalitis is truly a life altering disease, many in our community have not been able to return to work or to school, and fatigue negatively impacts their quality of life. By understanding outcomes that matter to patients and caregivers, we can inform care and drive research and drug development forward in a patient centered way. We believe that a multidisciplinary approach to diagnosis, treatment and recovery will improve outcomes for those affected by autoimmune encephalitis.

## #AskMeAboutAE





# #ASKMEABOUTAE

AUTOIMMUNE ENCEPHALITIS AWARENESS

AUTOIMMUNE  
ENCEPHALITIS  
ALLIANCE

**HESA**  
Hypothalamic-Endocrine  
Symptoms Association

Watch the #AskMeAboutAE video above  
or visit [www.youtube.com/watch?v=fO7rmcw9a88](https://www.youtube.com/watch?v=fO7rmcw9a88) to view the video



## Additional Resources on Outcomes After Autoimmune Encephalitis

Gibson et al., Cognitive impact of neuronal antibodies: encephalitis and beyond, Transl Psychiatry. 2020; 10: 304  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7463161/>

Shim et al., Clinical outcomes of pediatric Anti-NMDA receptor encephalitis, Eur J Paediatr Neurol. 2020 Nov;29:87-91  
<https://pubmed.ncbi.nlm.nih.gov/33046392/>

Blum et al., Assessment of long-term psychosocial outcomes in anti-NMDA receptor encephalitis, Epilepsy Behav., 2020 Jul;108:107088  
<https://pubmed.ncbi.nlm.nih.gov/32375094/>

SK Wright, AG Wood, Neurodevelopmental outcomes in paediatric immune-mediated and autoimmune epileptic encephalopathy, Eur J Paediatr Neurol., 2020 Jan; 24:53-57  
<https://pubmed.ncbi.nlm.nih.gov/31879225/>

Lim et al., Development of the clinical assessment scale in autoimmune encephalitis, Ann Neurology, 2019 Mar;85(3):352-258  
<https://pubmed.ncbi.nlm.nih.gov/30675918/>

Armangue et al., Frequency, symptoms, risk factors, and outcomes of autoimmune encephalitis after herpes simplex encephalitis: a prospective observational study and retrospective analysis, Lancet Neurology, 2018 Sep;17(9):760-772  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6128696/>

Hebert et al., Long-Term Cognitive Outcomes in Patients with Autoimmune Encephalitis, Can J Neurol Sciences, 2018 Sep;45(5):540-544.

<https://pubmed.ncbi.nlm.nih.gov/29936915/>

De Bruijn et al., CHANCEStudy Group, Long-term neuropsychological outcome following pediatric anti-NMDAR encephalitis. Neurology. 2018;90(22):e1997-e2005.  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5980521/>

Yeshokumar et al., Neurobehavioral outcomes in autoimmune encephalitis, J Neuroimmunol., 2017 Nov 15;312:8-14.  
<https://pubmed.ncbi.nlm.nih.gov/28889962/>



[aealliance.org](http://aealliance.org)



[hesaonline.info](http://hesaonline.info)

## Additional Resources & Information on Autoimmune Encephalitis



# Meet Renata

## *How AE Changed My Life by Renata*

About my senior year of high school I had anxiety, panic attacks and some days I felt sad for no reason. College was hard and I always kept myself busy with work and school to occupy my mind. I used to be very fit, hardworking, and concerned about my physical appearance at the time, but regardless of my healthy habits, my body was changing.

There were times when I felt like no one understood me because I had little control over my emotions. Sometimes I would throw fits alone and try to hide how I felt without knowing why I felt that way. I would say and do things without thinking, then I would regret it. Small problems would become big in my head and trigger anxiety.

Then the headaches started, the fevers, the hair falling out, the swelling throughout my body and the weight gain regardless of my active life... my anxiety became harder to control. The pelvic pain I had experienced several years earlier increased and I became more emotional. I could feel something hard on my left side, it but I was so busy with work. The doctors always told me I was fine, so I did not bother to see a doctor at the time. I worked two jobs and exercised three times per week. My friends would take me to yoga and introduced me to essential oils to try to help with my symptoms.

Before being hospitalized, the last day I remember was Valentine's Day 2016. I had a fever, felt cold and extremely tired and could not focus or pay attention when people were speaking. I thought my body was fighting a cold or my homeostasis was off at the time because I had a low-grade fever for a few days. My axillary lymph nodes were also swollen. I felt like my mind was disappearing, as if I were asleep when I was really awake. My head hurt and I don't remember how I went to bed that night.



Months later I found myself at home, a different person with a lost memory. My appearance had changed, and my personality also. I felt lost and did not know who I was or what had happened to me. I feel like I missed out on a portion of my life because of the memory loss during that time.

During the months that I lost my memory many things had happened to me. I was hospitalized and misdiagnosed with psychosis, meningitis, and possibly schizophrenia. I was tied to a bed, put into an induced coma, and treated with anti-seizure medications. Then they found out I had autoimmune encephalitis. I was treated with immunotherapy and had an operation because I had a teratoma in my left ovary. I have no control of the things that I said or the things that I did during the time of my sickness. I was alive but dead and don't remember anything. After leaving the hospital I was sent to a rehabilitation hospital.



It has been almost two years now. My life changed completely and it was a long and hard road to recovery. I cannot say that I am back to normal; after something traumatic to our body like this, we change. I am grateful to be alive and I am grateful for the doctors and nurses who never gave up on me; I wish they could see how far I have come now.

# AE Lived Experiences



# Meet Susan

## A Puzzling Diagnosis by Susan

I was the most active, energetic person I knew. I never forgot anything to the point it drove others crazy. I could out work someone half the age of myself. Then it all changed.

I was in my mid 50's under a lot of stress in my personal life. I was working two jobs. I started to get so exhausted, headaches, joint aches. I felt like I was wearing a 500 pound weight. I could not walk up a curb or stairs to get into my home. I could not imagine what was the matter with me.

I finally decided it was time to go to a doctor, for which she said I was Hypothyroid. She said that is the reason for the symptoms, but I started to develop more symptoms. My memory was shot, I was scared I was going to forget something important, I had anger issues, headaches, I could not speak or say the words I wanted to say. I worked with customers and was so embarrassed. Could not swallow, my balance was awful, my hands started to turn blue. They diagnosed me with Raynaud's, Lupus, Scleroderma, but my legs got weaker, along with my arms. I had rashes, I had photosensitivity, I had such bizarre symptoms the doctors did not know what to make of me. I ended in the ER several times for having out of body type of events. I started to jerk, shake, and have tremors. I had no temperature control. I was a mess. I asked my primary if I could see a rheumatologist and a neurologist as I knew there was something very wrong.

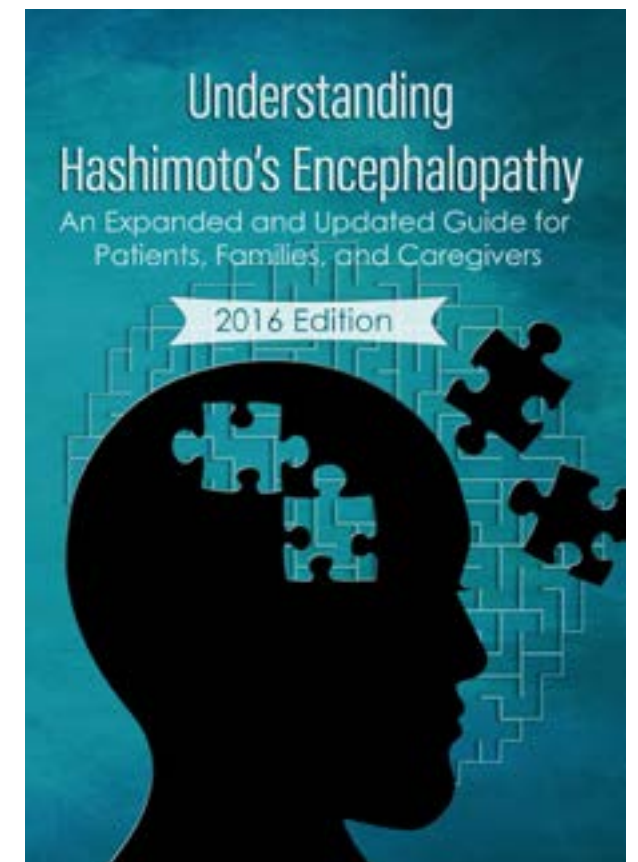
Between the two they started with many tests- MRI, Spinal taps, EEG, EMG, Cat Scans- you name it and I had it. My rheumatologist decided I had UCTD instead of Lupus and Scleroderma and later diagnosed me with



Sjogren's diffuse. My neurologist did a thyroid antibody test and it was very high, my EEG showed left frontal lobe slowing, combined with symptoms diagnosed me with HE. I was then started on high dose of methylprednisone for 5 days of

1000 mg and then a tapering dose. I was already on Imuran for my other diagnoses, and stayed on Imuran for the past 11 years along with IVIG for which I get once a week, every week. I have had relapses here and there along with my antibodies going up and down. I constantly have a positive ANA. I was declared disabled in my 50's at the insistence of my neurologist.

In 2011 when I was diagnosed, there was no information on AE. The difference the last 10 years has made on the amount of research that has been done is amazing to me, but there needs to be more. HE is one of the rarest of the AE with very little researched on. It remains a puzzling form of AE, thus the reason I started a non profit called HESA for research and support of others with HE/AE.



# AE Lived Experiences