



## Neurorehabilitation after autoimmune encephalitis

As autoimmune encephalitis is a newly discovered disease, there is not a lot of information or published research about the rehabilitation needs specifically for AE survivors. There are a few studies beginning to address the potential long-term outcomes and the AE Alliance is honored to be participating.

Autoimmune encephalitis may produce what is called an acquired brain injury (ABI), similar to a traumatic brain injury (TBI). In searching for help, it may be beneficial to look for professionals with experience in treating the symptoms of TBI as ABI is closely related but not as prevalent or well-known. Many of the same types of challenges occur in both types of injury. The specific areas of the brain that were affected by AE may determine the types of deficits that result. With the many different antibodies and types of AE, each patient is a little different so doctors have told us an individualized plan is essential. The good news is that the brain is known to have a large amount of “plasticity,” the ability to find new ways to do old things. This is very useful for recovery.

Currently many neurologists and rheumatologists treating AE will refer patients to a rehabilitation center if they need intensive physical, occupational or speech therapy. This may be conducted on an inpatient or outpatient basis. However, the cognitive and behavioral challenges after AE may be subtle and easily overlooked in a neurological exam. These aspects may remain untreated if the patient does not need ongoing physical or occupational rehabilitation at an inpatient facility.

Patients and caregivers should ask their neurologist or rheumatologist for referrals or known resources. In larger academic hospital settings these needs may be addressed by referral to a neuropsychologist, a professional who specializes in the testing, diagnosis and treatment of impairments due to neurological disease. However, other professionals are able to assist in cognitive and behavioral rehabilitation as well: occupational therapists, social workers, psychologists, psychiatrists, and counselors. If a physician is not aware of local resources, the patient or caregiver may need to make phone calls and try various professionals. This is time-consuming but usually worth the effort. It is a good idea to be creative and flexible in putting together a recovery plan, remembering that this is a newly discovered disease (only 10 years ago), so many professionals will not be familiar with it.

Early studies have shown that even several years out from the illness, a patient may find they are suffering from lingering challenges such as difficulty with memory, concentration, learning, attention, behavior, impulsivity, anxiety, irritability, depression, decision-making, planning and completing tasks, emotional regulation and other deficits. The common “activities of daily living” such as traveling alone or managing one’s finances may prove difficult. It is often hard to know whether these challenges are occurring during recovery from the original illness or whether the patient is relapsing. Please follow up with your physician if you are unsure. Time for recovery can be many months or even several years.

In addition, a book published for laypersons on TBI includes information useful for AE survivors who may have suffered an ABI. The second half of the book contains information about coping with the various symptoms including memory, anxiety, depression, impulsivity, and many others. It was written by two physicians intimately involved with brain injury patients.

*The Traumatized Brain, a Family Guide to Understanding Mood, Memory, and Behavior after Brain Injury*  
By Vani Rao, MD and Sandeep Vaishnavi, MD.