If you have been hospitalized for Autoimmune Encephalitis, chances are you were seen by many different doctors. Keeping them straight can be difficult if you are not sick, let alone if you have Autoimmune Encephalitis and memory issues. This can be particularly challenging if you are a patient in a teaching hospital and may be seen by different levels of doctors. Teaching hospitals often have doctors who are participating in research and are often at the cutting edge of diagnosis and treatment. So, although you may be seen by different doctors who are in training, you are adding to their knowledge of Autoimmune Encephalitis.

**What Types of Doctors are Seeing me and Why?**

**EMERGENCY ROOM DOCTORS**

If you enter the hospital through the emergency department, you will likely be seen first by an emergency room doctor. ER physicians are trained to identify and diagnose many different diseases and injuries. If a disease falls into a certain category, they may consult a specialist in that disease. For example, if a cancer patient comes into the emergency department an ER doctor may provide the initial treatment needed and then contact a doctor who specializes in cancer, called an oncologist, for treatment. Autoimmune Encephalitis patients who enter the emergency room should expect the ER doctor to consult a neurologist.

**NEUROLOGIST**

A neurologist, is a doctor who specializes in illnesses of the brain and nerves. Once admitted an AE patient will likely be under the care of the neurology service.
In a teaching hospital, there are different levels of doctors in training. When you see a group of doctors come in for rounds, they all may be from the neurology service but can include doctors at different levels in their training.

**INTERNS AND RESIDENTS**

Interns are doctors who are in their first year of residency. They have completed medical school and rotate to different areas of care in the hospital to learn from different specialties. Second- and third-year residents are further along in training. They may have been on that service before and are continuing their training. All of these doctors may be assigned to you are under the supervision of an attending doctor, who oversees the group.

**FELLOWS**

You may also be introduced to a fellow. A fellow is a doctor who has completed their residency and decided to specialize in a particular area of medicine. A teaching hospital may have 3-4 fellows in a particular specialty.

Fellows remain on the neurology service. Since this is their chosen specialty of practice, you may see them both in the hospital and in clinic, as they learn about neurological illnesses.

**ATTENDINGS**

The attending is a doctor who has completed their training in both regular medicine and their specialty. They are the doctor who is the doctor of record and is in charge of the service. The attending doctor may direct care through the fellows and residents. The doctors will normally have rounds on a daily basis. At this time, they may discuss the exam the intern or resident did and what the plan of care is. They may also discuss tests and treatments that they need to do.

What can be helpful to understand is that an aspect of performing rounds in a teaching hospital is to teach the interns and residents, while providing outstanding care to
patients. This is why you may see the attending doctor ask interns or residents questions and conduct open discussions regarding your care. You should consider yourself the most important part of the care team. Discuss any questions you have with the attending or fellow. If their time is too limited during rounds to adequately address your concerns, request that they return later that day to discuss your plan of care with you.

Due to the memory deficits that accompany Autoimmune Encephalitis, AE patients are advised to arrange to have a trusted family member with them during a hospitalization. During the Covid-19 pandemic, visits may be limited, and doctors may need to talk to family on the phone to share the plan of care.

The doctors should write their names on the dry erase board in your room to help you to remember their names. The nurses will do this at the beginning of their shift.

**Physiatrist**

There may be other types of doctors you see during your hospitalization. You may see a physiatrist. A physiatrist is a doctor who specializes in rehabilitation. If the neurologist feels that you will benefit from inpatient or outpatient rehabilitation, they may ask the physiatrist to see you. The physiatrist will do an exam and make rehabilitation recommendations for you to follow once you are released from the hospital.

Should an issue arise where the neurologist feels the patient would benefit from an evaluation by a doctor who specializes in a different area of medicine, they will make a referral. Example, some patients may develop a rash after receiving IVIG. If this occurs, the neurologist may refer the patient to dermatology. If a patient on seizure medication has elevated liver labs, a referral may be made to a gastroenterologist. Due to
the high association between anti-NMDAr encephalitis and teratomas, the neurologist may ask an oncologist to consult and conduct testing to determine if a teratoma is present.

**PSYCHOLOGIST AND PSYCHIATRIST**

When a patient is released to home, they will continue to see doctors who specialize in different areas. The patient will have on-going follow-up appointments with their neurologist. Some patients may see a psychologist to help them deal with the adjustments of no longer being able to work, for example, and the daily life adjustments of dealing with deficits received from Autoimmune Encephalitis. Patients may see a psychiatrist or neuropsychiatrist who specializes in cognitive recovery to help identify the patient’s strengths while supporting their weaknesses and improve functional independence.

**The Roles of other Medical Staff**

Once you have been diagnosed with Autoimmune Encephalitis, it can seem like a whirlwind of appointments tests and treatments need to be done. If hospitalized, a patient can be seen by many staff in a day and it can be hard to understand each person’s role and how they work together. The more you understand about the medical system, staff and their roles, the easier it is to direct questions and concerns to the proper person and ensure that what is needed for discharge is put in place.

**THE NURSING STAFF**

If hospitalized, the staff person who you will likely see the most during the day is the nursing staff. This includes the registered nurse, who is licensed to give medications, and treatments and they direct staff that assist in caring for patients. Other caregivers may include LPNs (licensed practical nurses) and nurse’s aides. The nursing staff provides the care throughout the day, administers IV (intravenous fluids), medications and some of the other treatments that Autoimmune Encephalitis patients receive such as steroids and IVIG. The nursing care team provides any care the individual with Autoimmune Encephalitis cannot
do independently including bathing, toileting, and eating. Plasmapheresis may be done by the nurse with the assistance of a pheresis technician trained in the pheresis machine.

**RESPIRATORY THERAPIST**

If you as the patient or your loved one, is on or has been on a ventilator, a respiratory therapist will be involved in caring for the respiratory support machine and providing additional therapies such as chest physiotherapy (CPT) and suctioning, which the nurse may also do as needed. The respiratory therapist may also encourage the use of a spirometer, which is a tool used that a patient breathes into and encourages the person to take a deep breath.

**SOCIAL WORKER**

The Autoimmune Encephalitis individual and family may be seen by a social worker, who will provide support and assess the home situation to determine if the person will need help at home. They can provide support to both the patient and family and often know of programs that can assist financially.

**NURSE CASE MANAGER**

In addition to the social worker there is likely to be a nurse case manager involved. The nurse case manager is involved in ensuring quality of care during the stay, ensuring that the person is receiving the right level of care that they need and planning for either discharge home or to a rehabilitation facility. If the person is being discharged home the nurse case manager will work with the family and the medical staff to put into place any care that is needed. If the person with Autoimmune Encephalitis needs to be discharged to a rehabilitation facility the nurse case manager will be involved in helping to facilitate that. The decision for discharge to a rehabilitation facility is usually based after a patient is seen by a physical therapist, occupational therapist and speech therapist. Therapists work with patients of all ages.
A physical therapist is a therapist who is licensed and trained in working with patients on movement, walking, balance. They can also help to train the family if the person going home needs help on how to safely transfer and move the individual.

An occupational therapist is a therapist who works with patients on fine motor skills, so things that involve writing, school work or computer work in the work environment. They can help to create adaptive ways for the person to do what they did before illness or injury.

Speech therapists see patients with Autoimmune Encephalitis to work on cognitive skills. They help them develop new ways to remember things. Strategies to be organized. All of the therapies work as a team to work together and should ask the person with Autoimmune Encephalitis what their goals are, both short and long term and help to make a plan to work on these goals.

Child life specialists are staff for pediatric patients. They help children understand their illness, the procedures and equipment in the hospital. They can provide support during procedures and can help prepare children prior to a procedure. They can help therapy services by providing play activities that include the therapy goals.

Vocational rehabilitation counselors are usually nurses who have been trained to work with patients and can help to determine if they are able to return to work, need a modified work plan or if they are unable to work and can direct the family to assist the person in applying for any disability benefits they qualify for. They also
assist if a person with Autoimmune Encephalitis would like to try to return to work by arranging a work trial. A work trial can be done in a job setting without putting the person’s job related benefits at risk.

During the trial the vocational counselor works with the person, the employer and the disability provider. During the work trial goals are set that are needed to do the job and any adaptations that the person needs are identified. If the person can successfully work, it is evaluated during the work trial and the number of hours they can work is set. The patient can continue to work with the vocational counselor from time to time to reevaluate the work and work schedule. If they find that they are not able to do the work either due to their ongoing disability or illness, then the work trial ends and the disability benefits continue.

**NEUROPSYCHOLOGIST**

Neuropsychologist, neuropsychiatric testing: after discharge and to obtain disability most individuals will need to see a neuropsychologist and have neuropsychology testing done by a person trained in testing. The testing can take up to 8 hours. The neuropsychology tester neutrally does the testing and the neuropsychologist will meet with the person with Autoimmune Encephalitis and family member to go over the results. The test results can be used to qualify for disability, to follow a patient’s cognitive progress, assist educational staff for school age patients, as well as help the rehabilitation staff understand the deficits that the person continues to have.

**PSYCHOLOGIST**

Psychologists are doctors who are trained to work with people with Autoimmune Encephalitis around two main issues. They help the patient adjust to the losses they experience after becoming ill. Challenges around school, work or perhaps not being able to work, how memory loss is impacting their daily lives and dealing with other deficits acquired from AE and the feelings around accepting and dealing
with the ‘new me’. They can also help work on cognitive issues assisting in developing adaptive strategies that will allow the person to function as well as possible.

**INSURANCE NURSE CASE MANAGER**

Insurance nurse case managers: Disability or healthcare insurance may assign their own nurse case managers to the individual with Autoimmune Encephalitis after discharge from the hospital or rehabilitation. They can assist patients and families in ensuring that they have been able to apply for work disability insurance and social security benefits. They may call to check in with the person and family to see if they have any other additional needs and can assist in helping in any issues accessing in-network care if there is a concern.

**THE PATIENT AND FAMILY CAREGIVERS**

The most important member of the care team is the person with Autoimmune Encephalitis and their family. They are the one who is most affected by the illness and has the best idea of how they are doing compared to their previous baseline. Their opinions regarding healthcare, needs, progress and questions should be included within the care plan developed by the medical professionals. Without their input, progress cannot be determined. The person with Autoimmune Encephalitis and family should not be afraid to ask questions to gain an understanding of the disease and the person’s progress.