



IQ LUPUS NEWSLETTER

For the latest lupus news and information

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Lupus and the Brain

Systemic lupus erythematosus (SLE) is an autoimmune disease that can involve almost every organ in the body, including the brain. When lupus impacts the brain it is referred to as neuropsychiatric lupus (NPSLE). You may have also heard the term central nervous system (CNS) lupus.

The central nervous system consists of the brain and the spinal cord. There is also the peripheral nervous system, which consists of the nerves that are outside your brain and spinal cord. These nerves relay information between your brain and the rest of your body.

Some Facts about Lupus & the Brain

- Brain symptoms are difficult to diagnose but many individuals with lupus experience them
- Neuropsychiatric lupus (NPSLE) is a broad term and includes many different types of neurological and psychological symptoms, ranging from mild to severe
- NPSLE lupus is often occurring at the same time that other lupus disease activity is happening, but researchers have not found specific markers or tests for NPSLE lupus
- Researchers believe there are inflammatory and ischemic (reduced blood flow) mechanisms that may cause some of these symptoms
- Some symptoms may not be directly caused by SLE, but due to treatment complications or the emotional burden of the disease (such as mood disorders)

What are the Symptoms of Neuropsychiatric Lupus?

Some of the more common symptoms are:

- Cognitive dysfunction (trouble with memory, concentration)
- Mood disorders (depression)

- Anxiety disorders
- Cerebrovascular disease (stroke)
- Headache
- Seizures

Less common symptoms are:

- Acute Confusional State (quick onset of disorientation, cognitive impairment)
- Psychosis (paranoid delusion with hallucinations of visual or hearing)
- Neuropathy
- Movement disorders
- Aseptic meningitis, transverse myelitis (rare)

Brain Fog

Brain fog is a general term that is often used to describe symptoms of difficulty thinking clearly, trouble focusing, trouble with word finding, or problem solving that some individuals with lupus experience.

Some individuals with lupus find brain fog is worse during disease flares, but some feel it more often. Brain fog may be associated with other feelings such as: anxiety, depression, pain, decreased activity, stress, poor sleep, fatigue.

Being diagnosed with lupus can be stressful and how you will feel each day is unpredictable. No matter the cause of brain fog, there are some strategies that can help including:

- Cognitive stimulation activities you can do at home such as: solving puzzles, reading a book/newspaper, word rhyming exercises
- Decreasing stress through meditation, deep breathing, exercise
- See website conquerlupus.com for a full list. Find resources under the “self care” tab

How is NPSLE Lupus Diagnosed?

- There are no specific criteria to diagnosis NPSLE Lupus
- A thorough physical exam and history will be completed by the rheumatologist
- Blood work to look for lupus disease activity and to look for other causes such as infection, electrolyte or metabolic abnormalities, etc
- Imaging tests such as MRI to look for brain or spinal changes if needed
- Lumbar puncture or “spinal tap” to test for infection or inflammation if needed

Treatment

- Treatment will depend on the symptoms an individual is experiencing
- Treatment of anxiety and depression are very important for an individual’s health and quality of life. Therapy and/or medications may be used for treatment
- High dose steroids will be used to control lupus inflammation in the body along with immunosuppressive agents
- Treatment of non-SLE factors if applicable such as infection, high blood pressure, diabetes, clotting disorders, etc

We want to stress that if you think you are experiencing anxiety, depression, or brain fog it does not necessarily mean lupus inflammation or disease is occurring in your brain. As mentioned previously, these symptoms can occur due to the burden the disease, treatment complications, or for another reason unrelated to lupus. It is important to talk to your doctor about these symptoms so we can help determine the appropriate treatment.

Patient Reported Outcomes

If you see a provider at our Lattimore office, you may receive an IPAD after check in. The IPAD will ask you a series of questions regarding your health. These questionnaires are patient reported outcomes (PROS) and they help patients and members of the health care team to better understand the impact of lupus in day-to-day life. The PROS we currently provide allow you to share your personal experience on pain, physical activity, mood, and self-efficacy (one's belief to meet the challenges that face them).

After you complete the questionnaire on the IPAD, the results go directly into your electronic medical record. There, we can track your progress over time. Currently, the questionnaires will be provided every 3 months. We hope to provide this at our Redcreek office in the future.

Please consider reading this article about patient reported outcomes to find out more:

<https://lupuscorner.com/patient-reported-outcomes-quality-of-life-and-lupus/>

COVID-19 Reminders

If you have COVID-19 symptoms such as fever, cough, sore throat, congestion, new loss of taste or smell, nausea, vomiting, or diarrhea, take an at-home test or get tested.

Let your health care provider know right away as you may be eligible for an anti-viral treatment.

- Anti-viral treatments should be started as soon as you test positive and within 5 days of symptoms starting
- Anti-virals such as Paxlovid or Lagevrio, are oral medications that stop the COVID-19 virus from making copies of itself in your body, and therefore lessen symptoms and shorten duration of the disease

For moderately to severely immunocompromised individuals, a total of 4 COVID-19 vaccinations are recommended: 3 doses of the primary series (Pfizer or Moderna) and 1 dose of the updated booster.

Research Corner

Clinical trials are a great way to get access to new potential treatments for lupus, while at the same time receiving good medical care. If you are interested in hearing more, please reach out to your medical team. Lupus clinical trials currently ongoing at UPMC Rheumatology:

MiSLE Trial-randomized double blind placebo controlled trial of mesenchymal stem cells

TOPAZ Trial-randomized double-blind placebo-controlled study to evaluate the safety and efficacy of Litifilimab

Recipe to try: Easy Baked Tilapia or Cod

Ingredients:

Frozen tilapia or cod fillets
Lemon
Butter (1.5 tablespoon melted)
Spices such as salt, pepper, paprika, parsley
Optional: Bread crumbs

Directions:

Step 1

Defrost fish per instructions on bag
Preheat oven to 400 degrees

Step 2

Drizzle with butter, squeeze lemon, add spices
Top with bread crumbs (optional)
Cook for 15 minutes or until fish is flaky and comes apart easily

Please contact the IQ Lupus Team for any questions, suggestions, or comments!

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