

Lupus Brain Fog



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Lupus Fog

- Lupus fog is a general name for the neuropsychiatric symptoms that often appear with Lupus
- These cognitive problems are often worse during flares
- Patients with other autoimmune disorders also suffer from similar symptoms
- Approximately 50% of Lupus patients experience brain fog
- Around 80% of patients report problematic fatigue, but fatigue has an unclear relationship with disease activity and is often prominent in patients without active disease

Brain Fog Symptoms

- Lack of concentration
- Memory problems
- Confusion
- Fatigue
- Headache
- Critical thinking
- Rushed speech
- Difficulty navigating
- Altered mood (depression, anxiety)
- Difficulty expressing oneself
- Decreased problem-solving skills
- Decreased decision-making skills
- Organizing information
- Difficulty with word finding



Good News/Bad News

Good News

- Most symptoms are chronic and of unclear causes but are not associated with serious problems seen in brain imaging
- Lupus fog does not get worse over time
- Brain fog effects all patients differently

Bad News

- These symptoms are often referred to as “minor neuropsychiatric symptoms”
- Brain fog has a dramatic impact on quality of life
- This can be extremely frustrating to Lupus patients
- There are no biomarkers indicating whether the symptoms have an inflammatory basis or not and there are no specific guidelines for treatment



Treatment: From the Doctor's Point of View

- Being that there are no biomarkers, it's difficult to determine if a patient will benefit from immunosuppressant, psychotropic, or psychological treatment, or a combination of all of the above
- Physicians struggle with the treatment of neuropsychiatric symptoms
- The most common treatment is anti-depressants and psychotherapy, especially in the case of depression and/or anxiety
- Other treatment options
 - Changes in immunosuppressant therapy
 - Decreasing steroids is warranted if it is related to depression
 - There is no treatment for lupus fatigue, and this is a huge unmet need
 - Exercise is also recommended

Psychological Challenges with Lupus

- Stress can be major factor in lupus fog
- Lupus patients are stressed by the following:
 - Not knowing when the next flare will occur
 - The unpredictability of what will happen tomorrow or next week
 - Disability resulting from fatigue and pain
 - Lupus symptoms are often invisible to others, and we are accused of being lazy



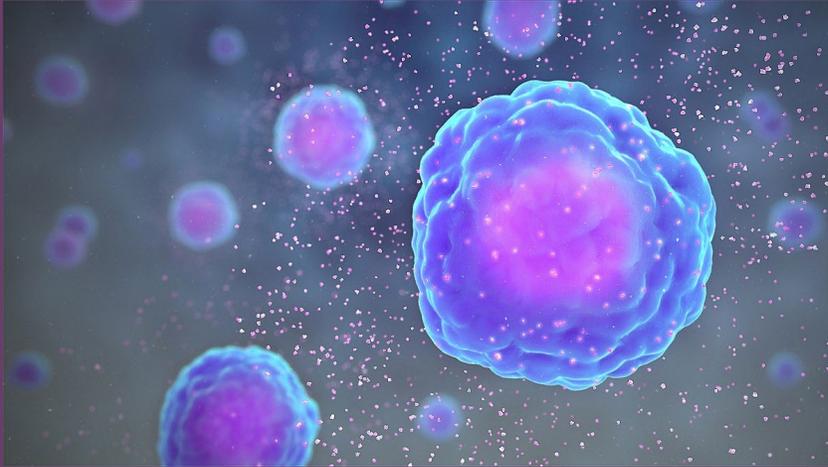
Medications

- Steroids have complicated and underappreciated negative effects on psychological health
- Steroids are associated with an increased risk of depression, mania, delirium and panic disorder, as well as a 7-fold increase in the risk of attempted or completed suicide
- Symptoms are somewhat dose related and can occur during initiation, maintenance or weaning of steroids

Infections

- Lupus patients experience frequent infections, which can increase mood episodes
- The risk of a mood disorder (depression, anxiety, pain attacks) are particularly high for the first year after a hospitalization for a serious infection



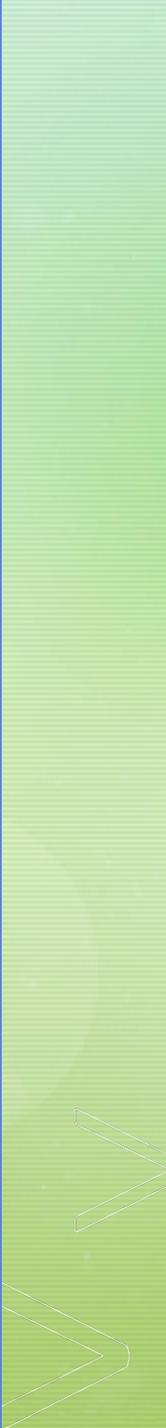


Inflammation

- The mechanisms of inflammation that contribute to neuropsychiatric symptoms are largely unclear
- Some lupus autoantibodies cross-react with NMDA, a brain glutamate receptor
 - These antibodies are increased in acute confusion states in lupus, but there is no clear correlation between mood alterations and fatigue
- Some experimental studies show that inflammatory cytokines released by the immune system can cause mood disorder and fatigue and that they can alter behavior however
- It is unclear to what extent immune activation and cytokine release can contribute to fatigue and altered mood in Lupus



Lupus Fatigue

- Around 80% of patients with lupus report problematic fatigue
 - Fatigue also has an unclear relationship with disease activity
 - It is often prominent in patients with without disease activity
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Lupus Fog and Employment

- Lupus is one of the leading causes of work disability in the US, accounting for about 20% of the more than estimated 1.5 million Americans with a work disability
- Brain fog can contribute to disability in Lupus
- It is important to implement strategies and use job accommodations such as establishing routines to conserve energy using organizers, developing lists of thing to do and to retain information and pacing oneself
- Lupus patients who are able to change jobs with their current employers have better job retention than those who change employers

Treatment for Brain Fog

- There's no absolute cure for lupus fog
- Although no drug therapy exists to relieve the symptoms of lupus fog, several techniques can help one proactively manage these side effects
- The most popular alternative therapies is brain exercise, which helps strengthen nerve connections to improve information recall
- Develop a routine for coping with lupus fog, doing the same things every day to make it easier to move past the memory loss frustration

Tips for Coping with Brain Fog

- Make lots of sticky note reminders
- Create lists, writing things down as soon as possible
- Use your cell phone to set alarm reminders
- Tell someone your plans so that they can help you remember
- Make sure to get plenty of rest, if you are able
- Try relaxation techniques to ease the stress of a fog episode
- Send yourself text message reminders
- Try to focus on one thing at a time
- Try to forgive others for not understanding and/or supporting you
- Don't judge yourself harshly when you do forget things. Remind yourself it's not your fault.



More Tips for Coping with Brain Fog

- Make a plan and make notes for yourself
- Take your time; stop rushing
- Trigger your memory with visual cues
- Stop multi-tasking; do one thing at a time
- If you can't remember a word, start with a related word that you can remember
- Monitor your symptoms; let your Dr know that the symptoms occur
- Be gentle to yourself; focus on what is working well for you

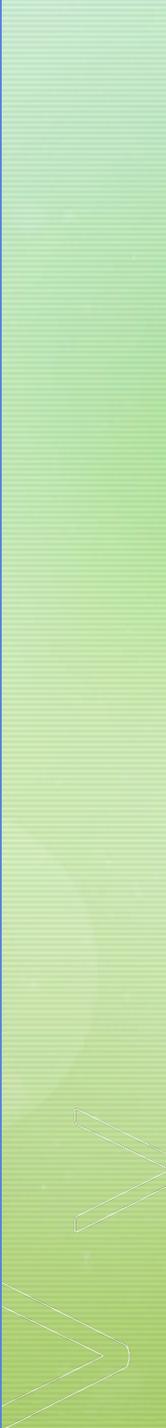


Know Your Brain Fog Triggers

- Steroid medication
- Stress
- Lack of sleep or not enough sleep for a periods of time
- Overdoing
- Feeling overwhelmed and knowing when you are in “too deep”
- Lupus flares



A Few Thoughts About Neuropsychiatric Testing

- Could be potentially helpful in more severe cases
 - Can take up to 8 hours, usually divided into 2 or 3 days
 - May not be covered by your insurance and is expensive
 - May provide you some helpful techniques for compensating for your losses
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Summary

- Neuropsychiatric symptoms in general in lupus are poorly understood
- Brain fog is fairly common in lupus patients
- There are no specific medical treatments for lupus fog
- There is little research on lupus fog
- Focus on the most annoying symptoms and try some of the techniques that were presented
- Be aware of your lupus fog triggers and reduce/avoid the triggers

Questions and Answers

