



## 15 Questions with Dr. Michael Luggen – Nervous System Issues

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Lupus can affect almost any part of your body, including the nervous system. The nervous system has three parts: the Central Nervous System, the Peripheral System and the Autonomic Nervous System. During July, the LFA invited you for the "Nervous System Issues" Q&A with guest expert [Dr. Michael Luggen](#). This is your opportunity to ask questions and learn from an expert.

### **1. How exactly does lupus affect the brain? Are there new medications that can ease this complication? Does it ever stabilize or does it become a concern during every flare up? Winsted, CT**

SLE can affect the brain in many ways. In fact, there have been some 19 different neuropsychiatric syndromes (NPSLE) identified. Others undoubtedly exist as well. The mechanisms by which lupus affects the brain are also multiple. It can affect the brain by the formation of auto-antibodies (antibodies directed at one's normal cells or tissues) which may kill brain cells or impair their function without causing cell death. It can cause brain damage by depriving the brain of oxygen and nutrients by blocking blood flow either through the formation of blood clots or by damage to the arteries themselves. It can also affect brain function indirectly because it can cause high blood pressure and accelerate the development of atherosclerosis.

The medications commonly used to treat more severe lupus can also help with CNS manifestations. These would include prednisone, other immunosuppressive medications like Cytosan (cyclophosphamide) and CellCept (mycophenolate), and blood thinners (heparin or warfarin). Benlysta (belimumab), which has recently been approved for the treatment of SLE, has not been tested in patients who have active NPSLE.

NPSLE does usually stabilize although its course is unpredictable. When the lupus is carefully controlled, flares are decreased, including flares affecting the central nervous system and not every flare results in an exacerbation of NPSLE.

### **2. I was just diagnosed with Lupus but for 20 yrs I have been evaluated for it. Over the years, my memory and concentration have diminished. I often walk into a room and forget why I went there or forget to accomplish a fairly routine task. Is this something that is seen with Lupus? Putnam, CT**

SLE can affect memory and other higher brain functions, but it probably does so directly in only a minority of patients. Other factors may affect cognitive function in lupus and may be more common causes of such problems. These would include pain, fatigue, anxiety, depression, and other, non-specific consequences of any chronic illness. In addition, medications used to treat lupus or its complications may at times also affect memory and concentration. Finally, there is the gradual decline in memory that occurs with age. One or more of the above could be contributing to your memory difficulties. It is difficult at times to sort this out and may require consultation with a neurologist and clinical psychologists in addition to your rheumatologist.

### **3. How common is vertigo and dizziness in NPSLE? Why does it occur? Sausalito, CA**

Vertigo is an uncommon problem in patients with lupus. More often than not it is caused by some other disorder. The frequency of this problem in lupus has not been systematically investigated, but it would appear to be rare. However, definite cases of vertigo, hearing loss, and the combination of both have been reported in those with lupus.

Some cases may be caused by vasculitis (inflammation of the arteries which leads to their narrowing which restricts blood flow) or anti-phospholipid antibodies (which predisposes to the formation of blood clots which can also limit blood flow). Others may have antibodies to components of the inner ear which may disrupt its function. SLE is one of several causes of the syndrome which has been called immune mediated inner ear disease (IMIED).

**4. I have been diagnosed with SLE for three years and I am now having a problem with what seems to be my nervous system. A nerve test was done and showed normal but I still feel something is wrong what other test can be done to determine affects on the nervous system? Perris, CA**

The investigation of potential nervous system involvement first requires a careful history of the problem and a complete neurological examination. On the basis of these results, further evaluation may be recommended. Among the tests which can be utilized to investigate potential nervous system problems include an EMG (electromyogram), if it seems as if the peripheral nerves may be involved, or an MRI of the brain or spinal cord, if it appears as if the cause of the problem may be from the central nervous system. On occasion, other tests may need to be performed such as a lumbar puncture (spinal tap) or angiogram (injection of dye into an artery or arteries). In addition, a consultation with a neurologist familiar with SLE should be obtained at some point in the diagnostic work-up.

**5. Lately, I have been having some hand tremors when I put something down or use a fork and knife. Sometimes I just fall down. Is this normal for lupus? My doctor feels that I am having these issues due to cerebral vasculitis. What information do you have on this? Lake Orion, MI**

The type of symptoms you describe could be due to lupus involvement of the nervous system. There are other possible explanations as well. If these symptoms are caused by lupus, then they could be due to vasculitis, but there are other possible explanations as well (see Question #1). I would suggest consultation with a neurologist if this has not already been done. On the basis of the information you have provided, I cannot determine precisely what is causing your problems.

**6. I have SLE and Peripheral Neuropathy. I have numbness, tingling and sometimes pain. Is there anything other than taking my Lupus Medications that I can do to help the neuropathy? Does it tend to get worse with age and progression of Lupus? Calhoun, GA**

The most important aspect of treatment for the peripheral neuropathy due to SLE is the treatment of the lupus itself. However, first one must be certain that the cause of the peripheral neuropathy is in fact lupus. A recent study found that approximately 40% of cases of peripheral neuropathy in patients with SLE were not due to lupus but were due to hypothyroidism, medications, or direct pressure on the nerve from bone spurs, tendinitis, or arthritis. If it is determined that the cause of the neuropathy is lupus, then the most important component of the treatment program is the treatment of the lupus itself. However, there are other medications which might be used to treat the symptoms of the peripheral neuropathy, most of which are also used to treat other types of neuropathy as, for example, might be found in diabetes. Among these additional medications are antidepressants (Amitriptyline, Cymbalta, Venlafaxine, etc.), anti-seizure medications (Gabapentin, Lyrica, Tegretol, etc), and pain medications (Tramadol, Hydrocodone, Oxycodone, etc.). These can provide substantial benefit but do not treat the underlying cause of the problem.

**7. Are sensations of numbness and/or tingling of the extremities (i.e. fingers, hands) considered neurological involvement in SLE? Is it possible for these symptoms to come and go?**

The symptoms you describe could be due to neurological involvement of SLE, either from involvement of the brain or involvement of the peripheral nerves. In either case, it is possible for them to be temporary. They could also be due to other conditions not related to lupus. There is no way to be certain without a careful evaluation by your rheumatologist and possibly by a neurologist as well.

**8. I have recently been diagnosed with Autonomic Neuropathy, which the doctor feels is due to my lupus. Are there any treatments for this specific ailment, or is the lupus itself treated? Can I expect any improvement, or has this caused permanent damage? Layton, UT**

There have been very few systematic investigations of autonomic neuropathy in SLE. The most recent publication suggests that it not uncommon, with up to 20% of patients demonstrating some suggestion of possible autonomic

nervous system involvement. There is no definitive information available concerning its prognosis or treatment. If the involvement is troublesome or progressive, then it would appear to warrant a trial at more aggressive treatment of the underlying lupus.

**9. I was diagnosed with SLE 18 years ago and lupus nephritis. Is it possible to develop psychosis with SLE? McAllen, TX**

Psychosis is a recognized complication of SLE. It has been reported in approximately 2% of patients, generally at the onset of the disease or during the first year after diagnosis. Lupus psychosis is characterized by delusions (false beliefs refuted by objective evidence) or hallucinations (perceptions in the absence of external stimuli). Prednisone at higher doses can occasionally cause psychosis and be confused with the psychosis caused by SLE. If mild and not associated with generalized flare of SLE, it is treated primarily with the usual anti-psychotic medications. More often, it is associated with a flare of lupus in which case it is usually treated with higher dose prednisone and oftentimes cytotoxic medications such as Cytoxan (Cyclophosphamide) or Imuran (Azathioprine). Most cases resolve within 2-4 weeks. A minority of individuals may have a more chronic condition which is usually not as severe as the acute form of the illness.

**10. Can SLE that affects the nervous system cause transient global amnesia? Are there any preferred treatments for this? Grand Rapids, MI**

I have searched the medical literature and have not been able to find any studies or even any case reports of SLE causing transient global amnesia.

**11. I was diagnosed with lupus in the spring of 2008. I did have a history of migraine headaches prior. Lately I seem to be getting not only migraines more frequently but tension headaches too. I'm currently going to physical therapy to help with the headaches but was wondering if my lupus plays any part in this. Saint Joseph, MO**

Severe headaches which respond only to aggressive immunosuppressive therapy have been reported to occur in patients with SLE. Meningitis, both due to infection and unrelated to infection, may also cause headaches in patients with lupus. Hypertension can cause headaches in some individuals with SLE as well. Recent controlled studies, however, have not found an increase in frequency of any of the usual types of headaches in patients with SLE. I suspect that your headaches are not related to your lupus.

**12. Is CNS lupus or NPL a risk factor for dementia? United Kingdom**

These are most difficult questions for which there is no consensus. Patients with SLE who have cognitive impairment have been reported to improve, worsen, or remain the same. The answer depends in part upon how cognitive impairment is initially defined and how long patients are observed. In my opinion, those who have significant impairment, that is, those whose higher cortical function is significantly lower than that of matched controls with other chronic diseases and who are also taking the same or similar medications, are unlikely to improve and may progress. On the other hand, those whose cognitive impairment is due to depression, pain, or sleep deprivation, are very likely to improve over time.

Anti-phospholipid antibodies (APL) have been found to be associated with a decline in cognitive function in patients with lupus in most, but not all studies. There are also reports of individuals without SLE who have anti-phospholipid antibody syndrome who have developed cognitive impairment and dementia.

**13. I have dystonia and blepharospasm. Are these connected to CNS Lupus? If so, would you address this please? Edmond, OK**

There have been rare case reports of dystonia in association with SLE and anti-phospholipid antibody syndrome. Whether lupus can actually cause this problem has not been conclusively established. In your particular case, it is probably unlikely unless there is a strong correlation of your lupus activity and worsening of these symptoms or improvement in these symptoms with treatment of your SLE.

**14. Can you provide information on Transverse myelitis? Can it come and go or is it a permanent situation? What are the best treatment options for Transverse myelitis? Indianapolis, IN**

Transverse myelitis is an uncommon, but well-recognized complication of SLE involvement of the spinal cord. It usually begins abruptly with sensory abnormalities (numbness, tingling, loss of sensation, or pain), weakness, and, at times, loss of bowel and bladder control. It is usually progressive unless treated aggressively with high dose prednisone and cyclophosphamide (Cytoxan). At times anticoagulation (blood thinning) may be of benefit if anti-phospholipid antibodies are present. Transverse myelitis may relapse as treatment is tapered but tends not to come and go spontaneously.

**15. If I do anything to move my legs or if the sheets of the bed rub my leg, they burn. It feels like a sun burn would but they are not. I have read that this might be nerve related. Is my lupus causing it? Mount Juliet, TN**

This could be a manifestation of nervous system involvement by lupus. Most of the time, however, if due to lupus, these abnormal sensations tend to persist throughout much of the day or are there all of the time. There are other possible explanations for this problem and the only way to know for sure is to undergo a comprehensive neurologic evaluation.

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