

British Sjögren's Syndrome Association

Originally published in the Autumn 2007, Volume 22, Issue 3 of Sjögren's Today magazine

Brain fog: Is it Sjögren's Syndrome?

When we talk about nervous system symptoms, often it is somehow okay if just a finger or toe is numb, but it is much scarier to have the brain be involved and to be experiencing cognitive difficulties.

In Sjögren's Syndrome the whole nervous system can be affected, but here we will focus primarily on the Central Nervous System (CNS), which consists of the brain and the spinal chord. There are many things that can happen in the CNS, causing such symptoms as motor or sensory hemiparesis (one-sided weakness or numbness usually occurring in the face, arm or leg), slurred or garbled speech, encephalopathy (non-specific brain illness), recurrent aseptic meningitis (inflammation of the meninges, the coating that covers the brain and spinal chord, without the presence of infection), seizures, psychological difficulties such as depression, anxiety or panic attacks, bladder dysfunctions, or extraparamital disorders affecting the muscle movements.

Another way the CNS can be affected is by brain fog. This is a condition that most people are familiar with, and yet there is no medical term for it and it cannot be researched by putting 'brain fog' into an Internet search engine. The closest term would be 'mild cognitive dysfunction,' but this encompasses a wide spectrum of often subtle changes.

Brain fog is often experienced as problems with memory or difficulty focusing or problems with processing information or numbers or with paying attention. It is an experience of feeling not quite 'all there' mentally. While some people may feel they are becoming demented or developing Alzheimer's disease, this generally is not the case, in that this is a different type of 'dementia' that is not likely to land a person in a nursing home for chronic care. In fact, brain fog is a relatively common condition that can be brought on by a variety of factors.

It is possible that patients with Sjögren's Syndrome might experience any one of these CNS symptoms during the course of their disease process. However, there are many other conditions that can cause these problems, some of which may be more serious and some of which may not. Therefore, it is important not to dismiss these things as being 'just part of my Sjögren's Syndrome.' Instead, it is worth checking with your doctor to determine how concerned to be about any problem you are experiencing and what treatment to embark on for it.

For example, many Sjögren's patients experience muscle weakness or neuropathies (pains or burning, especially of the feet); however, a stroke patient also may experience these symptoms. Brain fog may be seen in patients with a certain type of seizure disorder who experience 'staring seizures' where they space out and then drift back, or in those with a vitamin deficiency, a thyroid problem, or in those who are extremely fatigued. These days it is often seen as a side effect of medications.

In Sjögren's Syndrome, or in other autoimmune disorders such as multiple sclerosis or lupus, there may in fact be a different cause for brain fog. Though it has not been specifically proven,



most rheumatologists seem to think that it is somehow immune mediated, because of its occurrence in so many patients with these conditions. However, because of other symptoms such as depression and, often, pronounced fatigue, the lines are somewhat blurred, as these conditions also may contribute to a patient's cognitive difficulties. In some instances, brain biopsies show white blood cells inside the brain in the areas of inflamed blood vessels (vasculitis), which can contribute to brain fog or even strokes or seizures, depending on the area of the brain involved and the extent of the inflammation.

In terms of getting a diagnosis based on CNS symptoms that are experienced, whether it be diagnosis of a new symptom within the Sjögren's picture or an entirely new determination of Sjögren's versus another disorder, one of the most important things is to find a physician who will listen to you and take your complaints seriously. This is especially true in patients who already have a Sjögren's diagnosis or diagnosis of another chronic disease, so that the doctor evaluates these symptoms with an open mind, and not just against the background of 'it's just part of the chronic illness.' In fact, it may turn out to be part of the Sjögren's (or lupus, or multiple sclerosis, etc), and it may be a relatively less severe condition, but it may well be a treatable one. On the other end of the spectrum, it may be the development of an entirely new problem that requires a completely different intervention.

To determine if it is something other than part of the Sjögren's constellation of symptoms, it is recommended that the patient get a full history and physical, including a neurologic exam and a comprehensive review of systems (the '20 questions' your doctor does to determine the basic health of all the organs). As part of this work-up, the physician will ask about any medications

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being taken to help determine if the symptoms relate to that. One medication that is given for neuropathic pain in Sjögren's patients is Neurontin (Gabapentin), which has been shown anecdotally to affect a person's ability to perform high-functioning mental tasks, so that they just don't feel as sharp as when they are not taking it.

The doctor may also do blood tests to rule out possible causes. If warranted, any number of other tests may be ordered, based on the initial findings, including an MRI or EEG, a lumbar puncture to determine if there is any type of infection in the spinal fluid (such as viral meningitis), or a neuro-psychological work-up. Though the neuro-psychological testing is an expensive and exhaustive series of tests that can take five hours or so to complete and is often not covered by insurance, it is a very effective and comprehensive test of all the brain functions and can give a specific analysis of where any deficits may be present, so that recommendations can be made more appropriately in treatment. It also gives a wonderful baseline to determine the extent of any further progression of symptoms several years down the road.

With autoimmune diseases such as Sjögren's, there will be fluctuations of symptoms and not everything will warrant a visit to the doctor. Many times it is a progression of subtle symptoms, or a lingering of a problem that lets us know it may be time to get something checked out. Additionally, there are some red flags that should sound the alarm bell that says 'this I should look into.' These include high fever, night sweats, hallucinations, seizures, bizarre behaviors, hemiparesis (one-sided weakness/ numbness), or periparesis (weakness of both legs), double vision, facial numbness or droop on one side, difficulty swallowing, and severe headache. Though many Sjögren's patients experience headaches, and many people in general may suffer from migraines, the headache to be concerned about is the extreme one or the change in your usual pattern. With any of these

symptoms, a prompt doctor's visit is in order.

As for treating brain fog, if the doctor finds an underlying factor such as anemia or thyroid problem or medication side effect, it is necessary to treat for this and hopefully this will take care of the problem. In cases of immunosuppression the use of steroids is rather controversial. In mild cases of brain fog with minor cognitive impairment they are usually not given. However, if hemiparesis or seizures develop, a more aggressive treatment is indicated. Other useful additions to treatment are memory exercises or memory aids. These even may include crossword puzzles or any puzzle that works the brain.

For most patients with Sjögren's Syndrome, is the brain fog going to be related to the Siögren's? The answer is ves. it is likely the case as it is consistent with the Sjögren's picture. Is it diagnostic of Sjögren's? No, as it is seen in most of the rheumatologic diseases as well as many of the conditions discussed above. Particularly, multiple sclerosis can be confused with Sjögren's Syndrome, as they have very similar symptom pictures. So the best course of action is to talk to your doctor, and if you don't have a doctor who will listen to you and take you seriously, then find another doctor who will. Your doctor may not always agree with you as to what types of tests or treatments you may think you need, but he or she should at least be open to communicating about it.

This article was taken from a talk titled 'Brain Fog and Other Central Nervous System Symptoms: Is it Sjögren's?' by Susan McDermott, MD, at the SSF National Meeting in April 2003. The BSSA would like to thank SSF for allowing us to publish it in Sjögren's Today.