

# STIFF PERSON SYNDROME

NEW PATIENTS



JOHNS HOPKINS  
M E D I C I N E

## WHAT IS STIFF PERSON SYNDROME?

Stiff person syndrome (SPS) is a rare autoimmune neurological disease that most often causes muscle stiffness and intermittent painful spasms. SPS can also cause unsteadiness and double vision along with other symptoms. Symptoms can worsen with quick movement, cold temperature, stress, and/or unexpected loud noises.

### What should I expect from my FIRST visit?

Due to how rare and complex this disease is, a definitive diagnosis will not always be provided right away. Testing is needed that may include the following:

- **Blood work** is done during your first visit and on many follow up visits.
- An electromyography (**EMG**) is often done during your first visit at Johns Hopkins Hospital, even if this test was previously done. An EMG is a diagnostic test that evaluates the body's nerve and muscle function. We will let you know if an EMG needs to be scheduled. If an EMG is requested, we ask that you be off of all muscle spasm/relaxer medications for at least 24 hours before your EMG. Common examples of these medications include baclofen, clonazepam [Klonopin], diazepam [Valium], alprazolam [Xanax], lorazepam [Ativan], and tizanidine [Zanaflex]. You may feel poorly the day of your EMG, but can take your medication(s) right after you finish the EMG study.
- If a **lumbar puncture** is recommended, it is usually done before your first visit, not on the same day.

Your face-to-face visits with Dr. Newsome and his team will likely be long. While we strive to remain on time, Dr. Newsome also strives to be as thorough as he can be during your visit. Dr. Newsome is also committed to training the next generation of experts in SPS, so he often has fellows working with him.

*If your provider has questions, please have them email Dr. Newsome at [snewsom2@jhmi.edu](mailto:snewsom2@jhmi.edu)*

# BEFORE YOUR APPOINTMENT

## LAB RESULTS & CLINICAL RECORDS CHECKLIST

*Make sure all records are sent to Access Services (410)614-1522*

- Clinical notes from relevant subspecialties related to SPS (i.e. Rheumatology, Neurology).
- Prior Blood test results including anti-GAD (glutamic acid decarboxylase) 65 antibody level, amphiphysin antibody, and/or anti-glycine receptor antibody; as well as, several other serum autoantibodies, hemoglobin A1c and vitamin levels.
- Lumbar Puncture results, specifically the anti-GAD65 antibody result (if previously done).
- Radiological studies: MRI brain and spine, body CT scan, body PET scan, and mammogram/other breast imaging (if done) sent to our office (please send discs for uploading second opinions or upload the studies remotely through the AMBRA portal by going to <https://jhhsimagesharing.ambrahealth.com>).
- Neurophysiological study (EMG) reports and whether paraspinal muscle EMG was performed.
- Please have the contact information for all local providers that you would like to receive your consult note (including fax number).

# FAQs

## *How often will I be seen?*

This depends on the needs of the individual. It might be recommended for you to be seen more often early in your treatment to help create an effective treatment plan.

## *I am not local, is the travel worth the visit?*

In person visits allow us to develop treatment plan that best meets your unique needs.

## *Will I get admitted to the hospital after seeing Dr. Newsome?*

The majority of the care provided is done in the outpatient setting. This includes treatment and workup. Patients are rarely admitted to the hospital from the clinic.

## *When will I receive my test results and what do they mean?*

We recommend that you create a MyChart account to view your test results. Any relevant test results will be discussed with you during your office visit, by phone, or MyChart. We will help you schedule any addition tests or visits as necessary.

## POTENTIAL TREATMENTS

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Treatments are tailored for each patient, and may include a combination of medications to help one's symptoms (such as painful spasms or stiffness), medications targeting one's immune system, as well as non-medication interventions. It is important to do both medication and non-medication treatments as this has the best chance of helping.

### **Non-Pharmacologic Therapy** (partial list)

- Heating Pads
- Ultrasound Therapy
- TENS Unit
- Stretching
- Osteopathic manipulation
- Qi Gong
- Chiropractor
- Massage
- Yoga
- Acupuncture

# RESOURCES

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## Education

[https://www.hopkinsmedicine.org/neurology\\_neurosurgery/centers\\_clinics/stiff-person-syndrome/conditions-we-treat.html](https://www.hopkinsmedicine.org/neurology_neurosurgery/centers_clinics/stiff-person-syndrome/conditions-we-treat.html)

National Institute of Neurological Disorders & Stroke (NINDS)

National Organization for Rare Disorders (NORD)

## Financial Support

The Social Security Administration has included SPS in their Compassionate Allowances Initiative. This initiative helps patients with certain medical conditions, that cause severe disability, process disability claims quickly.

Please see their website for more information: <https://www.ssa.gov/compassionateallowances/>

## Social Support

Many patients will find support through their friends, families, other patients, and health care team. Additionally, there are open and closed Facebook Groups that have provided some people with support. However, these groups are not for everyone.

## CONTACT

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