

# STIFF PERSON SYNDROME

FOLLOW-UP PATIENTS



JOHNS HOPKINS  
M E D I C I N E

# NOTE TO CLINIC VISITS

Anticipate your face-to-face visit with Dr. Newsome and his team to 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.

## FREQUENTLY ASKED QUESTIONS

Appointment logistics & points of contact

*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 a treatment plan that best meets your unique needs.

*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 via MyChart. We will help you schedule any additional tests or visits as necessary.

*What is the best way to contact your office?*

For non-urgent matters, Mychart is the best way to communicate with Dr Newsome and his staff. If you do not have an account set up, please call: 1-855-389-6928.

If your provider would like to speak with Dr. Newsome, they can reach him by email, [snewsom2@jhmi.edu](mailto:snewsom2@jhmi.edu)

# Symptoms, condition progression, & treatments

## *Will I end up in a wheelchair?*

It is difficult to predict the course of your condition. While some of our patients require a wheelchair, many do not.

## *How long will I be on a treatment for?*

Most often we see and treat our patients with SPS for a lifetime. The majority of treatments take time to become effective, and may require changes over time.

## *What medications should I not take?*

You should avoid serotonin-norepinephrine reuptake inhibitors (SNRI), tricyclic antidepressants (TCAs), and narcotics.

- **Common examples of SNRIs** include: duloxetine (Cymbalta) and venlafaxine (Effexor).
- Some **common narcotics** are oxycodone, hydrocodone, morphine and their derivatives. Do not take medication combinations that contain them, such as Percocet.
- **Common examples of TCAs** are: amitriptyline (Elavil) and nortriptyline (Pamelor).

Drinking alcohol may interfere with some SPS treatments.

## *Why do I need to repeat blood work/EMG/MRI, etc?*

Repeat bloodwork is an important way to monitor for the development of any other conditions that may be associated with SPS.

An electromyography (EMG) is often redone at Johns Hopkins since the experts here know what to look for in SPS patients. The EMG is a diagnostic test that evaluates the body's nerve and muscle function and assesses for the presence of a potential neurological disease.

### *What other things have been helpful?*

Treating anxiety/depression and reducing stress have helped our patients.

### *Is anxiety part of the disease?*

Yes, talk to your healthcare provider about how to help this part of SPS. Medications and other treatments might be needed.

### *Am I allowed to exercise?*

Yes, exercising and staying active is important.

## NOTE TO EMOTIONAL WELL-BEING

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Chronic or long term conditions can heavily impact the quality of the patient's life and their emotional wellbeing. It is important to treat this part of your condition. Talk to your doctor about medications, counseling, and other treatment options.



# GET INVOLVED

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## DONATE

When donating please specify SPS Center and/or Dr. Newsome.

[https://www.hopkinsmedicine.org/neurology\\_neurosurgery/about\\_us/charitable\\_giving/neurology/index.html](https://www.hopkinsmedicine.org/neurology_neurosurgery/about_us/charitable_giving/neurology/index.html)

## BE PART OF RESEARCH

Become part of our SPS Center research! Some of our main research goals include defining the full clinical spectrum of SPS (helps promote awareness), identifying biomarkers of disease burden and pathogenesis (cause of SPS and response to treatment), and developing/finding better ways to treat SPS.

*There is little to no time commitment outside of your regularly scheduled visits.*

# 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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