

Talking to Your Doctor About Neurogenic Orthostatic Hypotension (nOH)

Use this guide to learn more about nOH and to get tips that will help you prepare for your next appointment. Take it with you when you see your doctor and make sure to get all your questions answered.

About nOH

nOH is a condition that causes abnormally low blood pressure after standing or changing positions in people with nervous system disorders like Parkinson's disease, multiple system atrophy (MSA), pure autonomic failure (PAF), and other autonomic conditions. nOH causes symptoms like dizziness, lightheadedness, blurry vision, or fatigue. People may assume that these symptoms are due to their underlying nervous system disorder when they may actually be the result of nOH—a separate condition that can also be managed.

Some people with nOH may have an increased risk of falling due to their symptoms. If you suspect you have fallen as a result of the symptoms of nOH, make sure to tell your doctor.

Preparing for your doctor's appointment

If you think you may have nOH, these tips can help you prepare for your next doctor's appointment so you're ready to start a conversation about nOH and symptom management.



Track your symptoms. Use a tracker or a notebook to write down the symptoms you experience so you can discuss them with your doctor. Visit nOHMatters.com/SymptomTracker to download a copy of this helpful resource.



Ask for blood pressure readings in different positions. This is very important to diagnosing nOH and determining management options. Remember to ask your doctor to check your blood pressure when you are lying down, sitting, and then standing.



Be honest about your symptoms. Describe how you feel when standing up or changing positions, and be as specific as possible. Include when you experience these symptoms, and whether your symptoms get better when you sit or lie down.



Talk about what's important to you. Tell your doctor what impact the symptoms are having on your life (e.g., limiting your daily activity, interfering with your hobbies). It's important to discuss how your symptoms are affecting you so that you and your doctor can develop a management plan together.



Bring someone with you. A friend or care partner can take notes for you to help you remember everything your doctor has said. He or she can also provide support during and after your appointment.



Ask for resources. Be sure to ask your doctor for any educational resources he or she can provide that can help you understand your symptoms and/or diagnosis. If there aren't any materials in the office, ask for a list of helpful websites.

Questions to ask your doctor

Now that you've spent time preparing, here are some questions you may want to ask during your visit.

- 1) Given that I have a nervous system disorder and my symptoms occur after standing or changing positions, could I have nOH?

My doctor said: _____

- 2) Can you explain what is happening inside my body that is causing these symptoms?

My doctor said: _____

- 3) Can you take my blood pressure lying down, sitting, and standing, and explain what the readings could mean?

My doctor said: _____

- 4) What symptom management options are available?

My doctor said: _____

- 5) Are there lifestyle changes you would recommend?

My doctor said: _____

Remember, your work isn't done after your visit! It's important to continue monitoring symptoms and blood pressure readings between appointments so you can share this information with your doctor whenever you see him or her.

Hearing from others who are going through a similar experience can be extremely helpful when living with nOH. Ask your doctor if he or she knows of any support groups in your area, and visit [Facebook.com/nOHMatters](https://www.facebook.com/nOHMatters) to become part of our online community.

The health information contained herein is provided for educational purposes only and is not intended to replace discussions with a healthcare provider.

