

Doctor Discussion Guide

Talking With Your Doctor About Primary Periodic Paralysis: A Helpful Guide

Overview

Primary periodic paralysis causes symptoms of weakness that can affect many parts of your body. Your attacks may vary in how severe they are and how long they last. Although attacks typically last 1-2 hours, they can go on anywhere from 30 minutes to several hours, and infrequently for days.^{1,2} That's why it's helpful for your doctor to know the details about the attacks you are experiencing.

 **Preparation Pointer: Keep track of attacks and how they affect you**

- This is important information to share with your doctor to help him or her better understand how your treatment plan is working and make adjustments as needed
- Because primary periodic paralysis is a physically disabling condition, it can take a toll on your ability to confidently participate in everyday activities.¹ Only you know the impact this condition has on your life and the kind of improvement that is important to you.

 **Preparation Pointer: Don't hesitate to have open and honest conversations about how you are feeling**

- It is important to take action as your own advocate. Talking about your emotions may be uncomfortable, but your doctor needs to fully understand all aspects of your condition in order to best address what you need and expect from treatment

Preparing for Your Doctor Visit

Begin by putting together a record of how you've been feeling since your last visit. Your doctor needs to understand the details about your attacks, as well as how they are affecting you, your family, work or school, and other aspects of your life. This information will help guide your doctor in providing the care that is right for you and your lifestyle.

 **Preparation Pointer: Keep a record of triggers, symptoms, and every day examples**

- Be sure to include the number of attacks, how often they occurred, and how long they lasted, as well as all the medicines including prescription, over-the-counter medicines and supplements you are taking and if you are seeing any new doctors
- It's also a good idea to include a broader overview of your health that provides a summary of your experience over the past 3 to 6 months, including your medical history, and any other illnesses or medical conditions that you are currently experiencing

Starting the Conversation

Begin your appointment by telling your doctor that you have kept a record about how you've been feeling that you would like to review. The Daily Tracker Tool and 3-Month Diary have been created to enable you to capture this information in order to help you have more proactive conversations with your doctor. Your doctor will likely be very interested to know more about your attacks and how they have affected you since your last visit.

Preparation Pointer: Be prepared to discuss detailed information

- The more specific details about how you felt, the better. This will help keep the conversation focused on what is most important to you in managing your condition

If your symptoms are painful or restraining, it is important to let your healthcare provider know that primary periodic paralysis disrupts your daily activities.

During the Conversation

Along with your disease symptoms, it's important to discuss the impact of primary periodic paralysis on your life. Tell your doctor about the ways in which your daily activities have been disrupted, and what you would like your disease management plan to focus on so that your life is less dictated by your condition.

Preparation Pointer: If you're not happy with your current management plan, now is the time to talk about it.

- Ask your doctor if there are alternative treatment approaches you might try
- You should also consider asking him or her to keep you informed about any updates regarding primary periodic paralysis treatment

Finishing the Conversation

Before you leave your doctor's office, check the list of questions you prepared to make sure they all were answered. Use the end of your appointment to collaborate with your doctor on a management and monitoring plan to follow between today's visit and your next appointment.

Preparation Pointer: Be sure to take notes so you can remember your discussion

- Make a note of any new information you talked about
- Ask your doctor if there are different measurements he or she would like you to monitor or track for your next visit

References:

1. Charles G, Zheng C, Lehmann-Horn F, Jurkat-Rott K, Levitt J. Characterization of hyperkalemic periodic paralysis: a survey of genetically diagnosed individuals. *J Neurol*. 2013;260:2606-2613. 2. Cavel-Greant D, Lehmann-Horn F, Jurkat-Rott K. The impact of permanent muscle weakness on quality of life in periodic paralysis: a survey of 66 patients. *Acta Myol*. 2012;31:126-133.

900 Northbrook Drive, Suite 200
Trevose, PA 19053
United States
www.strongbridgebio.com

© 2017 Strongbridge Biopharma plc

STRONGBRIDGE BIOPHARMA™ is a trademark of Strongbridge Biopharma plc.

KEV014-01 03/2017

