

Primary Periodic Paralysis

Daily Tracker & 1-Month Diary

This diary is for guidance purposes only.

The content within this diary is for personal use to aid in a discussion with your doctor and is not intended for self-diagnosis. The information contained here is not a substitute for medical diagnosis or professional treatment. You should consult your doctor about your diagnosis and any treatment options.

Daily Tracker Tool	1-Month Diary
<p>In this PDF, you'll find an easy-to-use, printable tool that enables you to keep a record of your episodes, including:</p> <ul style="list-style-type: none">▪ When they occurred▪ What triggers were involved▪ How severe they were▪ How they affected you	<p>Also in this PDF, you can print an at-a-glance record that lets you summarize your episodes over a 1-month period including:</p> <ul style="list-style-type: none">▪ A summary of your episodes▪ How lifestyle modifications and medications worked▪ How the episodes impacted your life
<p>Capturing this information will help guide you and your doctor in discussions about your condition and individual management needs.</p>	

Daily Tracker

DIRECTIONS: This form includes room for you to keep a record of episodes. Print a new copy as needed to keep an ongoing record that will help you:

- Capture important details about your Primary Periodic Paralysis episodes
- Get a clearer understanding of repeating patterns to help you understand and manage triggers
- Use your daily forms to complete a 1-Month Diary that you can share with your doctor to help him or her better understand how your condition has been affecting your life

Episode Experience	Date:	Date:
What potential triggers might have caused the episode?	<input type="checkbox"/> Rest after exercise or activity <input type="checkbox"/> Feeling cold <input type="checkbox"/> After high carb foods <input type="checkbox"/> Experiencing excitement or stress <input type="checkbox"/> After salty foods <input type="checkbox"/> Noise <input type="checkbox"/> Sudden changes in temp <input type="checkbox"/> Flashing lights <input type="checkbox"/> Alcohol <input type="checkbox"/> Menstrual period <input type="checkbox"/> Lack of sleep <input type="checkbox"/> Other; specify _____	<input type="checkbox"/> Rest after exercise or activity <input type="checkbox"/> Feeling cold <input type="checkbox"/> After high carb foods <input type="checkbox"/> Experiencing excitement or stress <input type="checkbox"/> After salty foods <input type="checkbox"/> Noise <input type="checkbox"/> Sudden changes in temp <input type="checkbox"/> Flashing lights <input type="checkbox"/> Alcohol <input type="checkbox"/> Menstrual period <input type="checkbox"/> Lack of sleep <input type="checkbox"/> Other; specify _____
How long did the episode last?	<input type="checkbox"/> Less than an hour <input type="checkbox"/> Between 5 and 10 hours <input type="checkbox"/> Between 1 and 3 hours <input type="checkbox"/> Between 10 and 24 hours <input type="checkbox"/> Between 3 and 5 hours <input type="checkbox"/> Longer than 24 hours	<input type="checkbox"/> Less than an hour <input type="checkbox"/> Between 5 and 10 hours <input type="checkbox"/> Between 1 and 3 hours <input type="checkbox"/> Between 10 and 24 hours <input type="checkbox"/> Between 3 and 5 hours <input type="checkbox"/> Longer than 24 hours
How bad was the episode?	<input type="checkbox"/> 1 = no complaints <input type="checkbox"/> 2 = mild complaints of muscle weakness but capable of performing daily tasks <input type="checkbox"/> 3 = capable of walking without help of a cane/walker, but not capable of performing daily tasks <input type="checkbox"/> 4 = only capable of walking with a cane/walker or with support of another person <input type="checkbox"/> 5 = bound to bed or wheelchair due to the episode <input type="checkbox"/> 6 = ER or ICU admission due to severe weakness or paralysis	<input type="checkbox"/> 1 = no complaints <input type="checkbox"/> 2 = mild complaints of muscle weakness but capable of performing daily tasks <input type="checkbox"/> 3 = capable of walking without help of a cane/walker, but not capable of performing daily tasks <input type="checkbox"/> 4 = only capable of walking with a cane/walker or with support of another person <input type="checkbox"/> 5 = bound to bed or wheelchair due to the episode <input type="checkbox"/> 6 = ER or ICU admission due to severe weakness or paralysis
What muscles were affected during the episode?	<input type="checkbox"/> Arms <input type="checkbox"/> Legs <input type="checkbox"/> Face <input type="checkbox"/> Other; specify _____	<input type="checkbox"/> Arms <input type="checkbox"/> Legs <input type="checkbox"/> Face <input type="checkbox"/> Other; specify _____
How did you manage the episode?	<input type="checkbox"/> Medication <input type="checkbox"/> Prescription; specify _____ <input type="checkbox"/> Supplements; specify _____ <input type="checkbox"/> Other; specify _____ <input type="checkbox"/> Nothing	<input type="checkbox"/> Medication <input type="checkbox"/> Prescription; specify _____ <input type="checkbox"/> Supplements; specify _____ <input type="checkbox"/> Other; specify _____ <input type="checkbox"/> Nothing
Check and rate any symptoms based on how you felt the first day after the episode, with 1 being mild and 5 being severe.	<input type="checkbox"/> Weak ____ <input type="checkbox"/> Tired ____ <input type="checkbox"/> Muscle stiffness/pain ____ <input type="checkbox"/> Other; specify _____	<input type="checkbox"/> Weak ____ <input type="checkbox"/> Tired ____ <input type="checkbox"/> Muscle stiffness/pain ____ <input type="checkbox"/> Other; specify _____
How did you feel after the episode?	<input type="checkbox"/> Anxious <input type="checkbox"/> Sad <input type="checkbox"/> Angry <input type="checkbox"/> Neutral <input type="checkbox"/> None of these <input type="checkbox"/> Other; specify _____	<input type="checkbox"/> Anxious <input type="checkbox"/> Sad <input type="checkbox"/> Angry <input type="checkbox"/> Neutral <input type="checkbox"/> None of these <input type="checkbox"/> Other; specify _____

1-Month Diary

DIRECTIONS: Print and fill in a copy of this form every month to help you assess how you've been feeling over this time. Then, take your completed form or forms to your next doctor appointment to:

- Assess trends in your episode triggers, areas of your body most affected, how severe your episodes have been, and how long they tend to last
- Provide your doctor with a snapshot view of your health and how Primary Periodic Paralysis has been affecting you since your last visit
- Help guide your discussions with your doctor so that he or she can better understand how you feel, and make any changes in your care that may be needed

From Date: _____ to Date: _____

Information	Detailed Description
Your personal and health information	Name: _____ Date of birth: _____ Phone: _____ <input type="checkbox"/> Mobile <input type="checkbox"/> Home <input type="checkbox"/> Office Diagnosis: <input type="checkbox"/> Hypokalemic periodic paralysis <input type="checkbox"/> Hyperkalemic periodic paralysis <input type="checkbox"/> Other type of Primary Periodic Paralysis; specify: _____ Affected gene (if applicable): <input type="checkbox"/> CACNA1S <input type="checkbox"/> SCN4A <input type="checkbox"/> KCNJ18 <input type="checkbox"/> RYR1 <input type="checkbox"/> Don't know Treatment for episodes; specify: _____ Family history of Primary Periodic Paralysis <input type="checkbox"/> Yes (<input type="checkbox"/> Mother <input type="checkbox"/> Father <input type="checkbox"/> Sibling <input type="checkbox"/> Other relative; specify _____) <input type="checkbox"/> None <input type="checkbox"/> Don't know Your current doctor and contact details: _____ Previous physicians you have consulted: _____
Overview of your episodes in the last 1 month	Most Common Triggers <input type="checkbox"/> Rest after exercise or activity <input type="checkbox"/> After high carb foods/meals <input type="checkbox"/> After salty foods/meals <input type="checkbox"/> Sudden changes in temperature <input type="checkbox"/> Feeling cold <input type="checkbox"/> Experiencing excitement or stress <input type="checkbox"/> Noise <input type="checkbox"/> Flashing lights <input type="checkbox"/> Alcohol <input type="checkbox"/> Menstrual period <input type="checkbox"/> Lack of sleep <input type="checkbox"/> Other; specify _____
How bad were the episodes?	<input type="checkbox"/> 1 = no complaints <input type="checkbox"/> 4 = only capable of walking with a cane/walker or with support of another person <input type="checkbox"/> 2 = mild complaints of muscle weakness but capable of performing daily tasks <input type="checkbox"/> 5 = bound to bed or wheelchair due to the episode <input type="checkbox"/> 3 = capable of walking without help of a cane/walker, but not capable of performing daily tasks <input type="checkbox"/> 6 = ER or ICU admission due to severe weakness or paralysis
Muscles most commonly affected	<input type="checkbox"/> Arms <input type="checkbox"/> Legs <input type="checkbox"/> Face <input type="checkbox"/> Other; specify _____
Total number of episodes per week	Week 1: _____ Week 2: _____ Week 3: _____ Week 4: _____ Total number of episodes for the month: _____
Impact on everyday living	I am unable to attend work or school <input type="checkbox"/> Always <input type="checkbox"/> Mostly <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely <input type="checkbox"/> Never I miss out on basic family time <input type="checkbox"/> Always <input type="checkbox"/> Mostly <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely <input type="checkbox"/> Never Other impact; specify: _____ <input type="checkbox"/> Always <input type="checkbox"/> Mostly <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely <input type="checkbox"/> Never I miss out of events with my family and friends <input type="checkbox"/> Always <input type="checkbox"/> Mostly <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely <input type="checkbox"/> Never I have had to give up my hobbies <input type="checkbox"/> Always <input type="checkbox"/> Mostly <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely <input type="checkbox"/> Never
Overall emotions & feelings	<input type="checkbox"/> Anxious <input type="checkbox"/> Sad <input type="checkbox"/> Angry <input type="checkbox"/> Neutral <input type="checkbox"/> Other; specify _____ <input type="checkbox"/> None of the these
Primary Periodic Paralysis management	Are you satisfied with the way your Primary Periodic Paralysis is currently managed? <input type="checkbox"/> Yes, why? _____ <input type="checkbox"/> No, why? _____ What are your treatment goals? _____

