

# PKU Clinic Discussion Guide

Be sure to bring this with you to your clinic visit.

## People with PKU may experience symptoms of high blood phenylalanine (Phe) levels without even knowing it.

Your clinical care team can help you determine if you are experiencing any symptoms of high blood Phe. Sometimes, however, it can be difficult to start the conversation.

This guide can help you begin a meaningful discussion with your clinical care team about your experiences living with and managing PKU.

Review these topics and questions before meeting with your clinical care team to identify the parts of your PKU treatment plan that you want to discuss.



### Symptoms

Talk to your clinical care team about any symptoms of high blood Phe levels you may have noticed.

Have you experienced any of the below symptoms since your last clinic appointment? Check all that apply and note examples of how they affect your daily life:

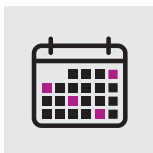
- |   |  |
|---|--|
| <input type="checkbox"/> Anxiety          | <input type="checkbox"/> Irritability                            |
| <input type="checkbox"/> Depression       | <input type="checkbox"/> Difficulty with remembering or planning |
| <input type="checkbox"/> Trouble focusing | <input type="checkbox"/> Difficulty with speaking                |
| <input type="checkbox"/> Paying attention | <input type="checkbox"/> Moodiness                               |



**Describe how your symptoms affect your daily life:**

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### Planning

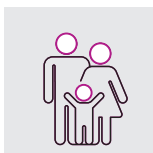
Talk with your clinical care team about anything new or different in your life or daily routine that requires planning, organizing, or detailed thinking.



**Describe any challenges with remembering things or keeping organized, including issues with PKU management or everyday activities:**

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### Daily life

Talk with your clinical care team about changes in your life since the last visit.

Is there anything new or particularly stressful that may be having an impact on your PKU management or life in general?



**Describe any changes at school, work, or home, or with relationships that could be impacting the healthy habits you've developed for managing PKU:**

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## Current management

Talk with your clinical care team about your current management routine.

My usual blood Phe levels are \_\_\_\_\_

My blood Phe level is \_\_\_\_\_

I collect blood spots every \_\_\_\_\_

My daily Phe/protein goal is \_\_\_\_\_

My usual diet routine is \_\_\_\_\_

My usual formula routine is \_\_\_\_\_

My medications/supplements include \_\_\_\_\_



**Describe any struggles you're having with your management routine:**

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**Before your clinic visit, write your top 3 goals or expectations**

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

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**During your clinic visit, write a visit summary and your plan**

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### Take this guide with you to your PKU clinic visits

PKU is a condition that requires lifelong management. It's important to keep motivated, and it's never too late to get back to better PKU management.

Many symptoms of high blood Phe levels can be improved by returning to active management. By knowing what to look for and how to best manage PKU, you can stay on track with your care.