

PKU Clinic Discussion Guide

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

Your clinical care team can help you determine if you are experiencing a symptom of PKU. Sometimes, however, it can be difficult to start the conversation.

This guide can help you begin a meaningful discussion with your 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 may need help with.

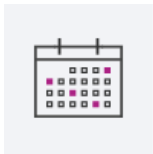


Symptoms

Talk to your clinical care team about any symptoms of high or unstable blood Phe levels you may have noticed. These symptoms may include anxiety, depression, trouble focusing or paying attention, irritability, difficulty with remembering or planning, difficulty with speaking, and moodiness.

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

Notes:



Planning

Talk with your clinical care team about anything new or different that requires planning, organizing, or detailed thinking. Be sure to note any challenges with remembering things or keeping organized. This could include issues with PKU management or everyday activities.

Discuss any events like vacations, holidays, or school/family gatherings that have occurred since your last visit to the clinic. Discuss any challenges that may have come up as a result of these events.

Notes:

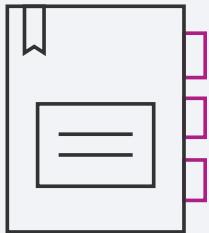


Daily life

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?

Discuss how you talk about PKU with friends, family members, and people you work or go to school with, as well as others in the PKU community.

Notes:



Take this guide with you on your visits to the PKU clinic

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.
