

Empowering Independence

Preparing teens with PKU for the road ahead

Building their confidence with PKU care

As your teen matures, it's important to let them take on a larger role in their PKU treatment to prepare them for their transition to adulthood. **Start by talking with them about goals, expectations, and their feelings about life with PKU.**

This process can be challenging for both you and your teen. That's understandable. You have guided them through this journey for years, and they know you will still be there to support them.

By empowering your teen to take ownership of managing their PKU care, you will help them:

- ✓ Better communicate with others about PKU
- ✓ Take pride in caring for their health
- ✓ Establish a stronger relationship with you as their PKU care partner
- ✓ Recognize PKU symptoms and how to manage them early



A moment for conversation

It's important to have a plan to help your teen learn how to properly manage their PKU

PKU affects brain health, and experts recommend managing it throughout every stage of life. The more PKU care skills your loved one learns now, the better off they will be in the future.



Use this guide to get the conversation started and help your teen build the confidence and skills they need to manage their condition successfully.

Starting the conversation



You know your loved one better than anyone—and that includes knowing how to best bring up important topics.

Consider the following tips when talking to your loved one and adjust them to best suit your needs.



Pick a comfortable time and place with minimal distractions

Plan ahead by working together to get out of your usual environment—this can help make you both more open and receptive to a deep conversation



Let them drive the conversation

Teens are still building communication skills, and if they're experiencing high Phe levels it may make focusing or holding a conversation difficult. Give your teen the time they need to open up



Be an active listener

There's a lot going on in your teen's life. They may need to vent a bit or just talk about their day before they're ready to discuss their PKU



Agree on a plan of action

Pick something your teen can do each day or week to make this plan achievable, and set up check-ins to help keep them on track

3 actionable steps your teen can take to start having more ownership of their PKU management:



Keeping track of symptoms

Writing down symptoms in a journal or their phone



Managing appointments

Adding clinic and doctor's visits to a shared family calendar



Becoming more involved in PKU-friendly meal planning

Taking the lead on cooking one PKU-friendly meal per week

Visit [PKU.com](https://www.pku.com) for these helpful tools and resources

[Try the Symptom Checker](#)

[Use the Clinic Finder](#)

[Find PKU-friendly recipes](#)

My PKU Goals

For Caregivers:

Work together with your teen to write down the goals and action steps you will take to help them gain more independence with their PKU management.

Goal #1

Goal #2

Goal #3

Action steps

Action steps

Action steps

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Keep the conversation going at PKU.com

Find community events, PKU-friendly recipes, and other helpful resources for PKU management.



Scan the QR code
to visit PKU.com

My PKU Goals

For Teens:

Work together with your parent or caregiver to write down your goals for taking more ownership of your PKU management, along with the action steps you will take to reach these goals.

Goal #1

Goal #2

Goal #3

Action steps

Action steps

Action steps

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