HYPEROXALURIA GLOBAL ALLIANCE
A Community Without Boundaries

Primary Hyperoxaluria (PH)

Transitioning from Adolescence to Adulthood

What Does Transitioning to Adult Care Mean?

For people living with primary hyperoxaluria (PH), **transitioning to adult care means slowly taking on more responsibility for managing your health.**

This includes learning more about your condition, speaking up during medical visits, and working directly with your healthcare team.

This process happens over time. Support from family, providers, and the Hyperoxaluria Global Alliance remains important throughout the transition.

Steps Toward Independence

As you grow older, you can begin to build skills to manage your care:



Know your medications: Learn the name, dose, schedule, purpose, and possible side effects.

Practice communication: Sit in on calls with your parents or caregivers. When ready, practice calling the pharmacy or doctor's office yourself.





Track your care: Use a notebook, chart, or app to track water intake, medications, and treatments.

New Responsibilities in Adult Care

Adult care includes new tasks that may feel challenging at first:

Insurance/Coverage: Learn how your healthcare system covers medications and specialist visits. Ask your care team, family, or the Hyperoxaluria Global Alliance for help.

New doctors: You may need to find adult providers, such as a primary care doctor or nephrologist. Your care team, the Hyperoxaluria Global Alliance, or the PH community can be of assistance.

Questions you may ask a new doctor:

- What experience do you have treating patients with rare kidney diseases like primary hyperoxaluria?
- How do you support patients transitioning from adolescent care?
- Who else should be part of my care team — for example, a dietitian, genetic counselor, or other specialist?
- How will my medications and treatments be managed through your system?

for parents and caregivers

Supporting Transition

Parents and caregivers help teens build independence while offering guidance and support:

- Include your teen in health discussions and medical visits.
- Encourage them to ask questions and speak for themselves.
- Allow independence while staying available for support.
- Help build coping and advocacy skills, such as talking with friends or joining support groups.

Moving Forward

Transitioning to adult care can feel challenging, but with knowledge, practice, and support, people with PH can manage their care with confidence.

Visit the Hyperoxaluria Global Alliance to learn more or get involved: WeAreHGA.org

Disclaimer: This guide is for educational purposes only and does not replace medical advice. Always consult your healthcare provider for diagnosis and treatment. The Hyperoxaluria Global Alliance (HGA) is a program sponsored by the Oxalosis & Hyperoxaluria Foundation (OHF).

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