Oxalosis &
Hyperoxaluria
Foundation
STEPPING STONES TO A CURE

# Transitioning from Adolescence to Adulthood

Transitioning from adolescence to adulthood is a time in life when there are a lot of changes happening all of a sudden from finishing high school to making new friends to going away to college. Having grown up with hyperoxaluria, teens and young adults in the hyperoxaluria community may actually know more about their health and how to manage their disease because they have had to before.

## What is Transitioning?

The concept of transitioning may also include navigating a variety of educational systems, from secondary school or special education services to college or a vocational program. The two most important keys to a successful transition are:

1. Understand your disease
2. Be your own advocate

Some healthcare institutions have structured programs to help with transitioning, while others may require families to do more of the work. Either way, if you are knowledgeable about your disease and you are your own advocate, you will have a successful transition.

Visit the OHF

## Managing Your Disease

Young teens should recognize what their medications look like and should be able to tell their parents and healthcare team the following:

- Name of each medication
- Dosage and schedule for taking each medication
- Purpose of each medication
- Side effects of each medication

Young teens are typically accustomed to their parents reminding them to take their medications. One recommendation is to explore ways to help them remember to take their medications on schedule. Below are a few examples of ways to help teens:

- Setting an alarm on a watch
- Sending texts
- Setting reminders on cell phones

## Moving Toward Independence

The transition years between being a teenager and becoming an adult can present difficult challenges. Young adults with hyperoxaluria are confronted with a unique set of stressors in addition to the normal stress that teenagers face every day. Hyperoxaluria can interfere with a teen's comfort in becoming independent... and parents may be resistant to a teen's efforts to be independent.

- The goal is to provide young adults with hyperoxaluria with education that will encourage a successful and healthy future. A parent's job is to provide information and resources to help adolescents think and live as independent adults.
- Parents cannot hold their child's hand forever, even if it is their heart's desire!
- Seek a balance between "normal" adolescence and the unique healthcare needs of having hyperoxaluria
- Involve teens in ALL health-related discussions (treatment choices and current concerns about their illness)
- Teach teens self-care skills related to their illness (from medications to calling the pharmacy or scheduling doctor's appointments). Parents should have their older teens sit in on phone calls, and then let them make the call themselves with adult supervision
- Encourage teens to monitor and manage their treatment needs as much as possible. They can fill out flow sheets of medicines or hydration, or keep a notebook.
- Encourage the development of coping skills to address problems or concerns that might arise related to their illness such as:
  - Talking to friends about hyperoxaluria
  - Participating in support groups
  - Expressing frustration or anger when needed
  - Using humor to defuse frustration or anger
  - Researching a problem
  - Participating in religious or social support activities
- Remember that the way parents cope sets an example for children
- Encourage use of problem-solving skills related to their illness. Parents and teens can role-play and ask each other questions such as, "What do you think you would you do if...?" or "What do you think would happen if...?"

## Dating and Social Relationships

Dating and social relationships can be tough enough when you do not have a rare disease. Similar to some of the topics we've covered already, it's really important to be comfortable with who you are. Be confident. If you are confident, then you will be more likely to feel comfortable and willing to engage.

## Choosing a New Primary Care Physician/Specialist

Whether you have insurance through your own employment or through your parent's plan, you will likely need to choose a Primary Care Physician (PCP). That person may coordinate your care and need to supply referrals, depending on your plan. The insurance company may be willing to have a nephrologist or other specialist coordinate your care, but you should try to find someone who will be a partner and advocate for you, regardless of prior knowledge of hyperoxaluria. As part of a generation of adults living with hyperoxaluria, you are also participating in educating a new generation of specialists and primary care doctors about the disease.

1. Get the list of Primary Care and Specialty MDs from your company or insurance plan
2. Find the physician's online bio, usually available within the website of their current academic appointment/medical center. This can tell you of any special interests and recent research
3. Specialization – Look for an MD with additional certification in Nephrology or Urology (or whatever specialty you feel would be most helpful for your unique situation)
4. Where did MD attend medical school and complete his/her residency?
5. Any special interests, fellowships, or NIH training?
6. Has the doctor ever seen another patient with hyperoxaluria? Check with other hyperoxaluria families in the area
7. Visit a website such as www.vitals.com and do a search for each person on the narrowed-down list of physicians that you are considering. This site has doctor ratings and feedback from patients. Look at reviews from people with complex medical needs

## Questions for HCPs

Below are a few sample questions to ask your new PCP or healthcare provider:

1. At what age does transition happen at this hospital?
2. Are there teen or young adult specific clinics?
3. Who will help coordinate transition?
4. Do you have adult specialists who you recommend?
5. Why do you recommend them over others?
6. Where are specialists located? How will we meet
7. them? Do we need referrals?
8. Are there adult physicians or specialists who are knowledgeable about hyperoxaluria?

## Working on Your Own

Individuals with hyperoxaluria in the workforce may experience a variety of unique issues and concerns. However, career choices should be based on each individual's intellect, ability, interests, and life goals. People with hyperoxaluria are not limit in choice of employment and work in a variety of professional and technical jobs. Be yourself. Be confident.

## Choosing Insurance

Once a job offer is made, there are important health insurance issues to consider. First and foremost, an individual with hyperoxaluria will need to know if there is employer-provided insurance. If so:

1. Does the plan cover your prescriptions?
2. Are your medications on the "formulary" or must they be ordered through a specialty pharmacy?
3. Will you have to pay out-of-pocket for specialty pharmacy orders?
4. Is there a mail-order option?
5. Does the plan permit you to see the providers you already have established relationships with and allow you to be hospitalized at the medical center of your choice?
6. Does the plan require referrals for each specialist visit, or do you simply need to choose "in-network" specialists?
7. What does it cost to go "out-of-network"?
8. For medications that may not be FDA approved, what will be the cost to you?