

# MILESTONES

ALONG YOUR CYSTINOSIS JOURNEY

## Staying on Course While Transitioning From Pediatric to Adult Healthcare



**Transitioning to adult healthcare is an important milestone in the cystinosis journey.** Many people report it can be difficult because they are comfortable with their current doctors. There are things you can do to navigate your transition, be responsible for yourself, and gain independence. Sticking to your cystine-depleting therapy (CDT) and other medicines during this transition is important for your overall health.

### Things to Consider When Transitioning to Adult Healthcare

- Finding a doctor you feel confident in and comfortable with may take some time, but it is important and worth pursuing. Remember to focus on progress and not perfection.
- You may have to help educate your new doctor about cystinosis.
- Be prepared to speak up to ensure your providers are aware of how you're feeling physically, mentally, and emotionally.



*This brochure includes information and links to resources about cystinosis and transitioning to adult healthcare to help you stay on course. It does not replace the expert advice of your doctors.*



## Taking Care of Your Cystinosis While Transitioning to Adult Healthcare

You may feel overwhelmed by the shift to being independent and finding new doctors, but it is important to take your CDT on time, every time, to help prevent crystals from forming and causing damage throughout your body. Many adults with cystinosis report having regrets that they did not stay adherent to their

medicines while transitioning to adult care. Make sure your new doctors understand the medicines you take so you can refill your prescriptions as necessary. Also, stay up to date on your white blood cell cystine level testing so your doctor can monitor your progress.



## Owning Your Health Going Forward



Cystinosis is a lifelong condition, but treatments such as CDT and kidney transplantation have allowed people with cystinosis to live longer.



Even brief delays in taking CDT can lead to significant rises in cystine levels which can lead to crystals potentially forming in organs like the eyes and muscles.



It is important to stick to your treatment schedule.



As you continue on your journey:

- Follow your healthcare team's advice and directions for staying healthy.
- **Continue taking your CDT on time, every time.**
- Keep a positive attitude.



*For more information and tips for transitioning to adult care while taking care of your health and cystinosis, visit:*

- [Got Transition](#)
- [Cystinosis Research Network](#)
- [RAREis Community Transitions](#)