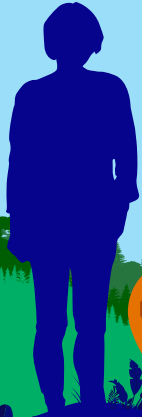


MILESTONES

ALONG YOUR CYSTINOSIS JOURNEY

Staying on Course During Transplant



There is always something new to learn and manage on the cystinosis journey. **One very important milestone is kidney transplant.** Whether it's your first or you've been through one before, sticking to your cystine-depleting therapy (CDT) and the other medicines you take is important for your overall health.

Getting Prepared for Your Transplant

- Remember that you have a full care team behind you. Learn as much as you can about the process, and keep asking questions.
- Build a support team of friends and family members. Let them know how you're feeling mentally and physically, and how they can help.
- Talk to someone living with cystinosis who's been through a kidney transplant. Get their advice.



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



Taking Care of Your Cystinosis and Your New Kidney

Once you have your new kidney, be sure to follow the directions of your care team to maintain your overall health. Your transplant nephrologist may be mostly concerned with the health of your kidney and making sure it's doing its job. But

remember, successful transplant is not a cure. It's still important to do the things you've always done to manage your cystinosis. With everything going on in this moment, that can be easy to forget.



Owning Your Health Going Forward

Cystinosis may be a lifelong condition, but cystine-depleting therapy and transplant have allowed people to live longer. Even brief delays in taking your doses of CDT can lead to significant rises in cystine levels. That can lead to crystals forming in other organs, like your eyes and muscles. You may not be able to feel the damage, even if it's happening.

That's why it's so important to stick to your treatment schedule.

As you continue on your journey:



Follow your health care team's advice and directions for staying healthy



Continue taking your CDT on time, every time



Keep a positive attitude



For more about taking care of your health and your cystinosis after transplant, visit the

[Cystinosis Research Network](#), [the American Kidney Fund](#) or the [National Kidney Foundation](#).