

# MILESTONES

ALONG YOUR CYSTINOSIS JOURNEY

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## Staying on Course During Dialysis

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Dialysis may become an important milestone in your cystinosis journey. **Dialysis is a treatment that does the job of the kidneys by removing waste from the blood.** Sticking to your cystine-depleting therapy (CDT) and other medicines while undergoing dialysis is important for your overall health.

### Things to Consider When Starting Dialysis

- When on dialysis, you may be spending more time away from work, school, and other regular routines. It's still important to take your CDT medicine at the same times each day.
- If you receive dialysis at a center, the staff may not know about cystinosis. You may have to let them know about the disease and how it affects you.
- Use the cystinosis community to get advice from people who have been through dialysis.



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



## Taking Care of Your Cystinosis During Dialysis

Remember, dialysis is not a cure for cystinosis, nor does it mean that you can stop taking your CDT. Whether you do hemodialysis at a center or peritoneal dialysis at home, dialysis may cause disruptions to your normal routine and it can be

easy to forget to take your medicines. During dialysis, it's critical that you champion and maintain your overall health and continue to take your CDT (and all medicines) on time.



## Owning Your Health Going Forward



Cystinosis is a lifelong condition, but treatments such as CDT and dialysis 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 about dialysis and taking care of your health, and cystinosis during dialysis, visit:*

- [Dialysis Patient Citizens \(DPC\) Education Center: Quality of Life](#)
- [American Kidney Fund: Dialysis](#)
- [National Kidney Foundation: Dialysis](#)



## Things You Can Do During Dialysis

Keeping a positive mindset is important. Consider looking at dialysis treatments as blocks of “me time.” Here are some ideas to help pass the time, recharge, relax, and learn:

1. ***[Listen to The Ultimate Dialysis Playlist on Spotify](#)***. The National Kidney Foundation created this motivational playlist of 109 songs suggested by and for kidney patients!
2. ***[Get out your phone or tablet and immerse yourself in a fun and educational virtual reality world](#)*** just for people with cystinosis. Do you want to relax? Take a tranquil walk in a Japanese garden. Feeling the need for speed? Get behind the wheel in the CDT Grand Prix. And if you dare, try to cross The Knowledge Bridge! ***[Visit Make It A Reality VR: A virtual reality experience designed to support you in your management of cystinosis](#)***.
3. ***[Practice mindfulness](#)*** to help ***[calm your thoughts](#)***, relax your nerves, improve your outlook.
4. ***[Create things](#)***. Have you always wanted to learn to knit? Do you enjoy newly sharpened colored pencils and an adult coloring book? Creating is a great way to lift your spirits.
5. ***[Immerse yourself in something new](#)***. Is there a book you have been wishing you had time to read? A podcast series or streaming TV series that all of your friends are talking about? Could you take an online class?
6. ***[Take a virtual tour](#)***. From the comfort of your chair, you can get an up-close look at the ***[Louvre](#)*** in Paris, explore the ***[Great Wall of China](#)***, get a look under the sea at the ***[Georgia Aquarium](#)***, explore street art with the ***[Google Art Project](#)***, do some ***[virtual walks through Yellowstone National Park](#)***, and take a peek at the ***[Atlanta Zoo PandaCam](#)***!
7. ***[Get some rest](#)***. You can always snuggle up under a cozy blanket, maybe put on noise-canceling headphones, and block out the light with a sleep mask and take a nap.