

Virtual doctor visits and cystinosis

When you have cystinosis, it is important to keep up with your doctor visits and treatments. This helps you slow damage to your kidneys and other parts of your body and stay healthy. Many doctor's offices now offer virtual visits (also called telemedicine or telehealth visits).

Virtual visits let you see your doctor from home – or wherever you are.



You may have a **virtual visit** between in-person visits, or in place of an in-person visit. In a virtual visit, you often use an app or online patient portal to connect with a doctor in real time from a distance.

Here is how to get the most out of your virtual visits:

1. Prepare for your virtual visit

Make sure your device is ready

Use a smartphone, tablet or computer with a webcam for your visit.

- Choose the device that has the best camera
- Test the camera and sound
- Make sure you have a good internet connection

Everyone doctor's office is different. Your doctor's office sends you a specific app or link to use. **Make sure you download the app or click the link before your visit to make sure it works.**

Right before your visit starts:

- Fully charge your device or plug it in so you do not lose connection
- Close other apps or programs

Set up the room for your visit

- Find a quiet, private place with little background noise – you may need to share personal details with your doctor that you would not want others to hear
- Make sure the room has plenty of light
- Sit eye-level with the camera – this helps you make eye contact with your doctor
- Keep your device steady during your visit, such as by propping it up on a table
- Make sure you are comfortable with your doctor seeing what's in your background

Gather what you may need

You may need:

- All your medicines, or a list of them, to review with your doctor
- Thermometer
- Flashlight – your doctor may ask you to shine a light to see a part of your body close up
- Blood pressure monitor
- Scale to check your weight
- Blood glucose meter, if you have diabetes



Wear loose, comfortable clothing – it will be easy to move if you need to show your doctor a certain part of your body

Write down a list of your questions before the visit starts

Here are some to start:

- What can I do to care for my symptoms?
- What should I do if my symptoms continue or get worse?
- What do my most recent lab results mean?

Tip: Make sure to get your lab work before your telehealth visit.

If you are preparing for a kidney transplant, you may want to ask:

- How long will the surgery last?
- How soon can I go home from the hospital after surgery?
- Can I have medicine if I feel pain?

2. Ask questions and get answers

Describe your symptoms to help your doctor give you the right care.

For example, tell them:

My symptoms include (check all that apply):

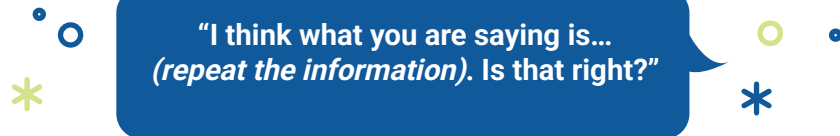
- Trouble seeing, watery eyes or sensitivity to light (your eyes react by closing or squinting when you see a bright light)
- Trouble swallowing
- Muscle weakness
- Feeling very thirsty
- Peeing more than usual
- Other: _____

My symptoms have lasted _____ (length of time)



Ask your most important questions first in case you run out of time.

Check that you understand what your doctor said by repeating the information back to them in your own words. You can say:



Ways to manage cystinosis between virtual visits

Focus on taking your medicine and caring for your health so you can keep doing all the other things you like!



To manage cystinosis :

- Keep taking your regular medicines for cystinosis as prescribed at the same time every day and stay on all medicines that your doctor prescribes for you to take after your transplant
- If you had a kidney transplant, take your immunosuppressant medicines as prescribed, too – they protect your new kidney from being attacked by your immune system
- Follow a healthy meal plan, including supplements if your doctor recommended them
- Be active most days of the week – pick activities you enjoy, such as walking, dancing or playing a sport
- Reach out to your family and friends when you need to talk – it is normal to have many feelings, such as feeling anxious, stressed or unhappy. You do not have to deal with your feelings alone.
- If you would rather talk to someone you do not know, ask your parents or doctor to help you find a counselor. You can also reach out to the Cystinosis Research Network (cystinosis.org), who can connect you to support groups and many other resources.

Learn more about cystinosis and kidney disease at [kidneyfund.org/cystinosis](https://www.kidneyfund.org/cystinosis)