




# Kidney Disease Tips for Teens Living with Cystinosis



Dialysis Patient Citizens  
Education Center



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The information in this booklet does  
not replace the medical advice  
of your nephrology team.

## CYSTINOSIS

I've been living with cystinosis, a rare genetic disease, most of my life. Cystine, an amino acid, builds up in my body and forms crystals, which can harm my cells and organs. I've learned to take my cysteamine and other meds as well as my eye drops on the required schedule, and that has slowed down the growth of the crystals.



## NEW SYMPTOMS

One day I noticed my ankles and feet were puffy and swollen. Then my lower back started hurting, and I had a fever. I felt tired, even when I got more sleep. I wasn't very hungry, I picked at my food, and I just felt sick. I told my mom I thought I had the flu, and she made an appointment with our family doctor to check it out.

## MY KIDNEYS

Although I didn't know it at the time, I learned that the ways I had been feeling were all possible symptoms of kidney disease. I learned my kidneys were not working normally. Even with two kidneys, neither one of them could do their job enough. When your kidneys stop working, it affects your ability to pee. Your kidneys help control the chemical balance in your body and your blood pressure. They also help make Vitamin D, keep your bones healthy and help make the red blood cells that your body needs. Who knew that these two little organs did all those things?



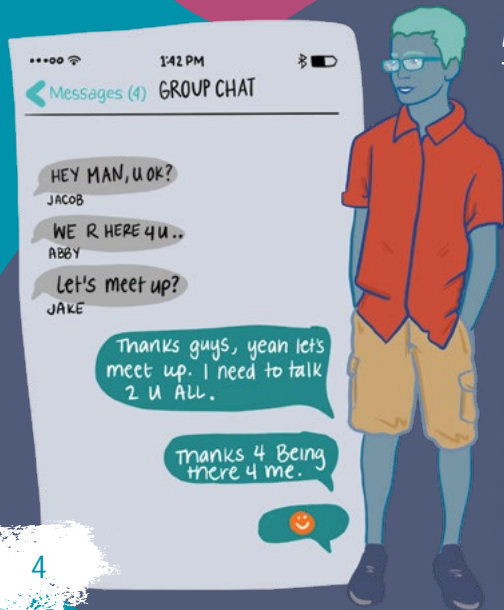
After the doctor did an exam and some blood work, I was diagnosed with Chronic Kidney Disease (CKD) and told that it had progressed to End-Stage Renal Disease (ESRD). This meant that my kidneys were not working well enough to remove the daily waste from my blood, and the fluid was building up in my body with no way to escape.

I wondered what it would mean to live without working kidneys. I was scared when I heard I will have kidney disease for the rest of my life, along with cystinosis. Luckily, it can be treated, and I will feel better. I learned I will need dialysis or a kidney transplant to stay healthy. I will go into more detail about the treatment options later.

Having kidney disease made me feel both angry and sad. My parents wanted me to see a counselor and said they would help me find one that I liked, even if it meant checking out a few different ones. I liked the first one I met, and the counselor helped me accept that I have kidney disease and that it is ok to be sad about it. After a few visits, I started to feel better. Now, instead of seeing myself as a sick patient, I accept that I am a teen who is just going through one more hurdle growing up.

## TELLING OTHERS

My friends wanted to know what was going on with me. They know and accept I have cystinosis, but they were worried that I didn't feel like doing much. Now I had to decide whether I would tell them that I have kidney disease. Would they tease me, feel sorry for me or just accept me as having one more thing going on? I chose to tell them, and they had lots of questions. I answered what I could and shared an internet link with more information about it so they could learn more too. I also told them that I need to choose specific food and snacks to eat, but I assured them I can still do sleepovers and parties! My parents also talked to the principal at school just as they had when I was diagnosed with cystinosis. That helps my teachers know I might have to miss even more school at times.



## BUILDING A TEAM

Having kidney disease means I need another medical team to help me with kidney issues. In addition to being part of my Cystinosis Team, I am now part of my Kidney Team as I like to call them. I need both teams to help me understand the two diseases, their treatments and how to best develop an action plan for living with both conditions. It is also important that each knows what the other team is doing. My parents and I keep them informed, they talk to each other and sometimes we all talk together. My Kidney Team consists of my parents, pediatric nephrologist (kidney doctor), nurse, dietitian (a major player on the team), social worker, pharmacist, child life specialist, child psychologist and myself of course. Sometimes a transplant surgeon joins the team right from the start, but mine joined my Transplant Team a little bit later. We all work together to talk about how I can get the best treatment for my kidney disease.



Both the social worker and the child psychologist on my team check in with me to see if I have any concerns about school, family or getting along with friends. They also are there to help me when I feel angry, sad or can't decide the best way to handle an incident related to having kidney disease. We also talk about ways to get along better with my brothers. They think I get lots of attention, while I wish I didn't get so much attention.

And we talk about my parents who now want to keep a closer watch on me, which makes me feel smothered. Instead, I want more privileges and independence. Life gets complicated sometimes!







My parents and I stay in close contact with the dietitian on our team. She helps us learn what foods are good for me to eat, what foods to avoid and which ones I can have sometimes in small quantities. She also taught us that the types of dialysis treatment can change what a person with kidney disease can eat. Thanks to her, I also know how protein, sodium, phosphorus and potassium can affect people with CKD. We

learned how much of each of these I can have daily and how to read food labels to count them. She also taught us that portion size matters and that it is helpful to measure food. Whenever I see my dietitian, she gives me good food tips and fun, yummy recipes. Now my whole family eats and enjoys kidney-friendly meals too.



#### My Kidney

Team lets me know how much fluid I can drink, which varies with the type of dialysis treatment I do, my size, how much I still pee and the results of my monthly blood tests. They said that many children with cystinosis still make lots of urine on dialysis, so they may not need strict fluid restrictions. However, this can vary, so you will need to discuss it with your Kidney Team. And it doesn't apply to me as I need to count and measure how much fluid I have daily. The dietitian helps me learn how to measure the amount of liquid I have daily, both in what I drink and in what I eat. For instance, although I can have a small portion of watermelon, it is 92% liquid and so it gets counted in my fluid intake for that day. It also has potassium and so it gets counted for my total amount of potassium for that day too.

I also learned not to compare what I can have with what another teen with kidney disease can eat or drink as it can be different for each of us.

Always ask questions; it is one of the best ways to learn. And speak up about any concerns—you will always be one of the most important members of your team!

## TAKING MEDICINE

My Cystinosis Team taught me how important it is to take my medicine at the right time in the right amount and to never skip a dose.

My Kidney Team taught me about the medicine I need to take for my kidney disease every day. Even though I might not feel differently if I skip a dose of meds here or there, it silently affects my body and can have serious harmful effects later. To stay healthy and keep my heart and bones strong, I need to take my meds at the right time in the right dosage. That means I take my pills even when I don't feel like it, even when I'm with my friends, even when I'm doing something special or on vacation, and even when I'm sick. It's that important.

MEDICATION

H<sub>2</sub>O

Find ways to remind yourself to take these additional meds! You can set an alarm on your watch or cell phone, wear a special reminder bracelet or ring, have an app that alerts you and use pill boxes. Some kids carry cool pill cases when they go out—there is quite a variety online—or you can create your own that shows off your personality. Just find what works for you. Your parents might help remind you too, but you are the one that will need to do it for the rest of your life, so you might as well start to figure out what works for you now.



## TREATMENT CHOICES

Overall, the main treatment choices for kidneys that are not working well are dialysis or a transplant. Very simply, dialysis helps to clean your blood since your kidneys no longer can and a transplant is getting another person's kidney put into your body to do the work of your kidneys. A transplant is usually the first choice for teens. However, it is not always possible to get a transplant before the kidneys stop working, and therefore, dialysis is needed. Doing dialysis at home is usually preferred over going to a facility for treatment, but that's a choice that will need to be made after gathering a lot of information.



My Kidney Team was great about answering questions and getting my input about the best treatment choice for me. Each member of my Kidney Team asked questions, including my parents and me! It was a team approach since there was a lot of stuff to consider. We talked about what activities I did, both in school and outside of school, where I lived and the space in our home, the advantages and disadvantages of each treatment choice, and which one would be the best choice for me. For example, they said if I want to do dialysis at home, I need to have space for supplies. If I decide to go to a pediatric dialysis facility, I need to know how far away it is and if I can easily get there three times a week. If I go to an adult dialysis facility, I need to know if they take people my age, how I will feel if I am the only young person around a lot of older people and if their treatment schedule fits my school schedule. They also told me that some teens start on one type of treatment and then switch to either another type of dialysis or a transplant as they get older or their needs change.

## DIALYSIS

You will have two choices for dialysis—doing it at home or doing it at a dialysis center.

At home, you can do **Peritoneal Dialysis**, either at different times throughout the day or at night when you are sleeping. You can also do **Hemodialysis**, either at home or at a dialysis center. Usually, you do not eat or drink during dialysis treatment, but check with your Kidney Team for what is best for you. Sometimes dialysis makes you feel tired afterwards. Dialysis also will make you feel better and it will become a part of your life until you can get a transplant, if that is an option for you.





Peritoneal Dialysis is a type of dialysis that you can do at home, and most people think it is easy to learn. Instead of your kidneys, it uses another part of your body to help clean your blood. It doesn't use any needles, and your blood stays in your body. Inside your belly is the peritoneum, which is the lining of your belly. A tube, called a catheter, is placed in your body near your belly button during a special surgery. I asked my team if other kids would be able to see the catheter through my clothes. They said that most clothes cover the catheter easily and other kids don't see it or notice anything, especially since the tube is often taped down.

When you do peritoneal dialysis, a bag of dialysate—which is a solution that cleans your blood—is attached to the catheter and goes into your abdomen by either using a machine to put it in or by hanging the dialysate higher than your body and using gravity.

The dialysate then stays in your body for a certain amount of time to do its work of moving the wastes and extra fluids into your peritoneal cavity. While the dialysate is in your belly, you can go to school or walk around and do stuff, like watch movies, do your homework, visit with friends, play video games or even do chores. The dialysis session, or exchange as it is called, then ends when the dialysate with the waste products and extra fluids is drained out of your peritoneal cavity through the catheter. You will want to do your exchanges in a clean room that is off limits to any pets you might have. You will also need space in your home to store the bags of dialysate. If you live in a small home, you and your parents can get creative about where to store them.



Some teens dialyze during the night while hooked up to a machine called a cyclor that is near their bed. During the night, the machine does the exchanges. In the morning before getting up, the machine fills the peritoneal cavity with the dialysate, which stays there all day. You need to have enough room in your bedroom for the dialysis machine. When I asked the team if kids can sleep at night while they are hooked up, they smiled at me and said most kids sleep just fine.

Hemodialysis, which uses a machine with a special filter to clean the blood and remove extra fluid, can be done at home or at a dialysis facility. It performs one of the jobs of your kidneys by removing your blood through one tube to clean it through a filtering process called a dialyzer. The dialyzer has two parts, which are separated by a thin membrane that acts like a strainer, allowing the waste products and extra fluid to pass through, but not the blood. It does this by using a cleaning solution called dialysate. This process may take a few hours, and then your cleaned blood is pumped back into your body through another tube. The tubes connect to your body through needles attached to your skin, often in the arm. I asked if the needles hurt when inserted, and the team said that sometimes they do. However, there are ways to decrease or numb the pain.

Some teens have their own dialysis machine and do **Home Hemodialysis**. You and your parents would be trained how to set up the machine, do dialysis and clean the machine. You set up a regular place for dialysis and do your treatments around the same time of day. Your Kidney Team will tell you how often and how long you need to do the treatments. You can do your homework, watch TV, chat with friends, read or surf the internet depending on what you and your parents decide. Your Kidney Team may also have some suggestions on what to do while you dialyze, and they are available to help with any questions or concerns during your dialysis treatments.

Sometimes teens can't do dialysis at home or would rather go to a dialysis center, which is called **In-Center Hemodialysis**. You might go to a pediatric center in a children's hospital, where you will be with other kids, or you might have to go to an adult facility, where you are the only kid. It will depend how far away the pediatric facility is and if you are a candidate to even do dialysis at a closer adult unit. Going in-center, means you go to a facility that has a trained staff, and they set up your machine, place the needles to connect you to the dialysis machine, get you started and check on you throughout your treatment. You may be taught to participate in your dialysis treatment by the dialysis staff, depending on the rules of the center. You will have a specific time to be there, and it is important to be on time as other people may be scheduled before and after you. You will need to let them know if you will not be able to make a treatment and will have to work around their availability if you need to reschedule. It might be noisy, and there often is little privacy. If you go to an adult dialysis facility, you may see a lot of older people who look sick, sometimes moan and who often sleep during dialysis.

When you do dialysis at home, you usually have more leeway in the foods you can eat and how much you can drink because you are dialyzing more often than when you go to a dialysis center three times a week. You also have more control of your dialysis schedule, and you may feel better just being at home. You still will have check-ins and see your Kidney Team on a regular basis to monitor your health and kidney treatments.



## CONNECTING WITH OTHER KIDNEY KIDS

If you go to a pediatric dialysis center, you may meet other kids that you can talk to about living with kidney disease. If you dialyze at home, your Kidney Team can help you connect to other kids who dialyze at home. For example, my Kidney Team gave me contact information for two other kids who have kidney disease and dialyze at home. Both kids gave their permission to share their information with me, and I also gave permission to share mine with them. Now we often chat while we do dialysis.

If you are like me, you have already attended Cystinosis Family meetups and conferences. You may also want to check with your Kidney Team to learn what Kidney Camps are available in the area. They are a lot of fun, and I've made new friends from other cities and states. And, you can go every year! I've learned some new tips about living with kidney disease at camp. And the more I know, the more I can be actively involved on my Kidney Team. Keeping in touch with other kids who have kidney disease also helps me find the humor in my situation. The names that kids give their kidney machines and the jokes they make about having kidney disease make me laugh out loud sometimes. It helps to find stuff to laugh about while living with a lifelong disease because laughing, giggling and smiling are part of being positive about our lives and accepting what's happening. There's even research that shows that laughing is good for our health! And my friends and I roar with laughter when we watch funny movies at sleepovers.

Although I already use social media sites for cystinosis information and chats, I now go to sites for kidney disease as well. They help me know that I'm not the only one dealing with this disease at my age, and I've also learned some great tips from others.



## TRANSPLANT

Some teens with kidney disease do dialysis for a short time, some for years and some never need to do dialysis. If your Kidney Team, including you and your parents, decide that a transplant is a good choice for you, you will also need to have a Transplant Kidney Team to help you through the steps of getting a kidney. Ask lots of questions so that you understand what happens before, during and after the transplant. There will be lots of tests to do to make sure that you are a good candidate for a transplant and to then make sure that the potential kidney is a “good match.”

Having a kidney transplant means that another person’s kidney is put into your body; and it may be from a living donor or a deceased donor (someone who has died). A living donor is someone who chooses to donate one of their kidneys; it might be a relative, someone you know or a stranger.

Many people are fine living with only one kidney, so you won’t need to be worried about a person giving up a kidney.





## BEING A TEEN FIRST

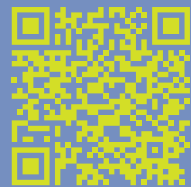
I am a teen who leads a busy life. I go to school, hang out with my friends and do stuff with my family. Sometimes I get tired, and when I do, I just rest more.

Today, I am a happy, responsible teen. Even though I didn't cause cystinosis or kidney disease to happen to me (you didn't either), I now accept that both diseases are a part of my life. I still get sad and mad sometimes, but overall, I feel good about my life and my future. I am getting more independence from my parents as they see that I take my meds without their reminders, I eat a healthy and kidney-friendly diet, do my dialysis regularly and use a calendar for doctor appointments and school functions. My mom still insists on going to my doctor appointments with me, but that's ok since I know it's hard for her to see me grow up.

You will still have chores and rules at home, homework to do, and you will still think your parents and siblings are annoying sometimes. But that's all part of being a normal teen. You can still have fun, hang out with friends, be a part of school activities and take vacations. You are a teen who just happens to have cystinosis and kidney disease. Have fun and enjoy the adventures of your life!



The Dialysis Patient  
Citizens Education Center, a non-profit  
organization whose board of directors are  
End-Stage Renal Disease patients, is dedicated to  
empowering kidney patients through education. Our vision  
is to create a world in which every kidney disease patient holds  
the power to improve his/her quality of life and is able to share that  
knowledge with others.




We invite you to view additional resources for teens and their parents on our website:  
<https://www.dpcedcenter.org/what-is-kidney-disease/pediatric-kidney-disease/>



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