Talking about growing up with a rare kidney disease

Living with a rare disease as a young person

An amazing thing about people is that we are all different! We have different strengths and interests that make us unique. Sometimes, we can control these things but not always. Having a rare kidney disease is one difference you might be living with.

Growing up with any health condition, but especially a rare one, can be hard. Figuring out how to talk about your rare disease with the people around you can give you more control. It can also help people understand you better and know the best ways to support you.

What is a rare disease?

A rare disease is one that affects a small number of people. These diseases can cause damage to any part of your body, including your kidneys. Rare diseases that can affect your kidneys include:

- **Cystinosis**
- **Polycystic kidney disease**
- **Alport syndrome**
- **Lupus nephritis**

Anyone can have a rare kidney disease, including children and teenagers. You might feel alone because your condition is rare. But while one rare disease might only affect a few people, there are millions of people living with a rare disease.

Why should I talk about my rare disease?

If you have a rare disease, your life might look different than your friends or family members. You may take a lot of medicines, miss school regularly for doctor's visits or have days when you feel tired or are in a lot of pain. There may also be things you're not able to do like playing sports or eating some kinds of food.

Your rare disease might make you different, but that difference can be a superpower! You become a self-advocate, a creative problem solver, and a resilient person.

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How do I talk about my rare disease?

Talking about your condition can be scary, but with the right support and tools you can have meaningful conversations. Thinking about who, what, where, and when can help you make a plan.

WHO

A good place to start is to think about who you want to tell. This list can include anyone in your life that you want to tell:

- **Friends**
- **Family members**
- **Teachers**
- **Teammates**

WHAT

Next, you'll want to decide what you want to share. Here are some questions to help guide you:

- **What is the disease and how does it work?**
- **How does having the disease impact your life at home or at school?**
- **How do you take care of yourself and treat your disease?**
- **Is there anything that people can do to help you?**

It can be tricky to think about the things that you need in the moment. Keep a list as you think of things you need—this way, you can refer to it when talking to your support system

What you share might be different depending on the person. For example, your teacher might need to know about your medicines and doctors appointments, and your friends might need to know what kinds of activities that are harder for you to do and the ones that you enjoy.

WHERE

After deciding what you want to share, it's important to think about where you'll be the most comfortable sharing these details.

If you want to share in person, some options can include your house, at school, or even somewhere like a park.

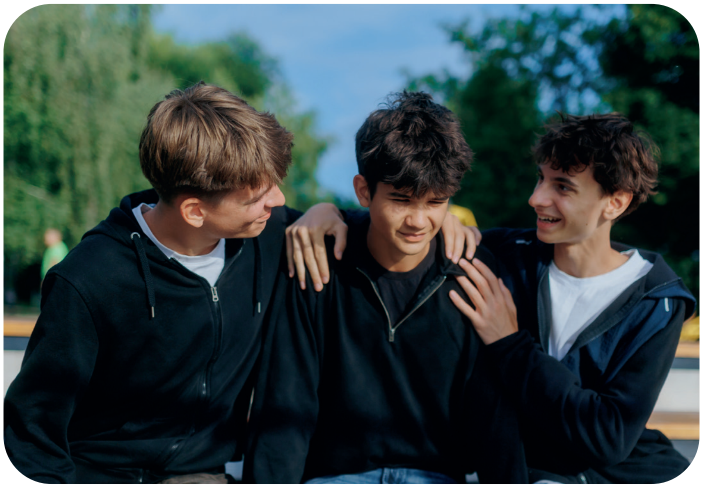
Sometimes you might feel more comfortable sharing over the phone. This could include a text, a phone call, or FaceTime.

You might want to have your parents or another trusted adult with you, especially if you're feeling nervous or unsure. They can help answer some questions that you may not know and even talk to other adults.

HOW

Here's a quick look at what this conversation might look like:

- **Talking to a friend**
- **At a park**



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Here is an example of how you can start a meaningful conversation about your condition.

Hey! Can you talk for a sec?
I want to share something important with you.

Sure! What's up?

I wanted to tell you about a disease I have, called polycystic kidney disease. It's a rare disease that affects my kidneys because cysts grow on them.

Oh wow, I had no idea. Thank you for telling me!

I can still do everything we usually do together, I just have to take medicine daily and I go to a lot of doctor's appointments to make sure everything is okay.

That makes sense, will you always have it?
Does this mean you need a kidney transplant?

Yeah, I'll have it for the rest of my life. It's possible I could need a kidney transplant in the future, but we don't know for sure.

That's a lot to think about. Is there anything I can do?

The most important thing to me is not treating me any differently! I might have some off days if I have a lot of pain or something. I will let you know if there is anything I need, thanks for listening!

I can do that! Thanks for telling me.

Now it's your turn!

Reach out however you feel the most comfortable, whether it's in person, over the phone, or by text messaging. Plan and practice what you'll say using the script below:

Hey! Can you talk for a sec? I want to share something important with you.

Sure! What's up?

I wanted to tell you about a disease I have, called _______________.
(disease name)

It's a rare disease that affects my _______________ _______________.

Oh wow, I had no idea. Thank you for telling me!

I wanted to tell you because _______________ _______________.
(reason for sharing)

Example reasons for sharing include:

- *"It's why I miss school sometimes"*
- *"It's why I take medicines everyday"*
- *"I felt like it was important for you to know"*

That makes sense, will you always have it?

Yeah, I'll have it for the rest of my life.

You could expand on sharing if you feel comfortable more about the medicine or surgeries you may need.

That's a lot to think about. Is there anything I can do?

Thanks for listening!

Let them know you appreciate it and if you have a specific question, now is the time to bring that up.

I can do that! Thanks for telling me.

To learn more about living with a rare kidney disease, visit our website.

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