



Sharing your story: Talking about your rare kidney disease

What is a rare disease?

A rare disease is a health condition that affects a small number of people, usually fewer than 200,000 people. Some rare diseases affect the kidneys, like IgA nephropathy (IgAN), Alport syndrome and forms of polycystic kidney disease (PKD). These rare kidney diseases can make it hard for your kidneys to work the right way.

Living with a rare kidney disease can be physically and emotionally challenging. People around you may not understand what you are going through. Many people with rare diseases say that feeling alone or isolated is one of the hardest parts. Others may not even know what a rare disease is and how it impacts your daily life. That's why talking about your condition can be empowering. Sharing your story gives you the chance to take control, educate others and build stronger connections.

Why share your story?

Talking to family and friends about your rare kidney disease can help you:

- **Feel less alone**
- **Build a strong support system**
- **Help others learn more about your condition**
- **Let others know how they can show up for you**



Your story can inspire others, too. When you share, you remind people how strong and resilient you are.

Talking about your rare disease: where to start

When you feel comfortable and ready, sharing your story can help others understand what you're going through. You can decide:

- **Who you tell**
- **When you tell them**
- **What you choose to share (this may depend on your relationship with the person and your purpose – are you asking for support from family or friends, or trying to educate and raise awareness?)**

Remember that this is your story, and you don't have to share anything you don't want to. It's okay to set boundaries and to ask people you do share with to respect your privacy. You might say:

- **"I don't feel comfortable talking about that."**
- **"Please keep this between us– I'm not ready for others to know yet."**



Tips to start the conversation

Talking about your rare kidney disease can feel scary – but you don't have to do it all at once. To start, think about why you want to share and what you are hoping will result from the conversation.

When you're ready to share, here are some tips to guide you through a productive conversation and help you feel more prepared and confident when talking to others. You've got this!

Step	Strategy
Reflect	Ask yourself: What do I want people to know and why? What do most people not realize about my condition and its impact on my life? What am I not ready to talk about?
Decide who you want to share your story with	Start with someone close to you who you trust (like a parent, sibling or friend).
Pick the right time and place	Choose a place where you feel safe and comfortable. Avoid times when you or the other person may feel rushed or stressed.
Prepare	Write down a few things you want to say and practice saying them. You can also bring resources with information about your disease to leave with the person, so they can learn more in their own time.
Use simple words	Try to explain your condition in a way others can understand. You can say something like: <i>I have a rare kidney disease. My kidneys don't work the way they should, so I see a special doctor and need treatment to stay healthy.</i>
Be honest	Be open and honest about how you feel, this can help you better connect with others. You can say something like: <i>I've been diagnosed with a rare kidney disease, I want to tell you more about it and how you can support me.</i> or <i>This is hard for me to talk about, but I want to share with you about my rare disease and how it impacts me.</i>
Give them time	People may need time to process the information you share. You can say something like: <i>It's okay to take time to think about this</i> or <i>Just listening means a lot to me.</i>
Ask for what you need	Be clear and specific in letting others know what you need from them and how they can help you. You can say something like: <i>I may need help after my treatments</i> or <i>I need help remembering to take my medicine.</i>
Be kind to yourself	Talking about a rare disease you are living with can be emotional. Take care of yourself after having these conversations. Go for a walk, read or do something that makes you feel good. You should feel proud of sharing your story and advocating for yourself.

How others can help you

Sometimes people want to support you, but they aren't sure what exactly that looks like. You can guide them by being clear about what you need both from an emotional and practical standpoint.

Here are some ways people can help you:

- Check in on you regularly with a quick phone call or text to show they care and are thinking about you.
- Go with you to your doctor's appointments. They can help ask questions, take notes and be an extra set of ears so you don't miss anything important.
- Help with daily errands like grocery shopping, cooking or doing laundry.
- Read and learn more about your condition to better understand how to support you.
- Attend a community or advocacy event with you.

Your story matters

Living with a rare kidney disease can feel lonely—but your story has power. Every time you share your story, you help people understand more about rare disease. You also inspire those around you and make it easier for them to support you.

Even though rare kidney diseases affect a relatively small number of people, connecting with other people who have a rare disease diagnosis is a great way to build your support system. You are not alone. Being open about your journey can help you feel stronger, more connected and supported.



The American Kidney Fund's Rare Kidney Disease Action Network (RKDAN) helps make sure the voices of people like you are heard. By joining, you can empower and advocate for other rare kidney disease patients by helping to shape important laws and policies at the state and national level.

