



Explaining IgA Nephropathy to Family and Friends

IgA nephropathy may have an impact on your daily life that may be difficult to explain to people you care about. Use this guide to help get those conversations started.



Patient portrayal.



Explaining IgA nephropathy

IgA (immunoglobulin A) nephropathy can affect people both physically and emotionally. You know your life and your needs best. Let your family and friends know what symptoms you experience and what it can mean when you go about your day-to-day activities.

A few starting points

1

Share how you feel:

If you feel anxious, let your loved ones know, and try to explain why.

2

Give direction: If you feel overwhelmed, open up about how IgA nephropathy might affect your daily life, and how your loved ones can support you.

3

Speak up: Even if you don't want a deep discussion about IgA nephropathy, start by letting your loved ones know how you're doing and what you need from them.

Tips for Sparking Conversations



Stick to the basics

Don't overcomplicate the conversation with technical explanations of IgA nephropathy. Focus on how the condition might affect you and how you are managing it.

Let them know that IgA nephropathy is a chronic disease that affects your kidneys, and you may have or develop symptoms that could affect your daily life.



Tackle the big stuff first

If you're discussing your IgA nephropathy with friends or family for the first time, they may have a lot of questions about what it means for your day-to-day life. Cover the big topics first, from what IgA nephropathy is, to the symptoms you may feel, and how IgA nephropathy impacts your everyday life.



Set healthy parameters

Opening up about your condition can be stressful, but your friends and family are there to help you. Remember to set boundaries based on what's comfortable for you. Be open with your loved ones about how they can best support you. Ask your care team for resources that can help your loved ones learn more about IgA nephropathy.



Be open and honest, even with kids

Kids are more capable of processing difficult information than you might think, but younger children may better understand your day-to-day physical and emotional condition if you frame how you feel. You might explain that your condition isn't contagious like a cold, and it may often make you feel tired and require taking breaks more often.



For more information on IgA nephropathy to share with your loved ones, visit kidneyhope.com/iga-nephropathy

Tips for staying engaged

Even if you don't appear sick to other people, your symptoms could still be affecting you physically and emotionally. Keeping your friends and family informed allows them to support your overall well-being and helps you navigate your care.



Stay in touch

IgA nephropathy is a chronic condition, so you and your family and friends will all be managing your condition together.

It's important to keep your loved ones informed about

- How you are doing **day to day**
- Your ongoing **energy levels**
- Any tasks you are able or unable to do on a given day



Manage social expectations

You may have to miss social engagements or family plans occasionally, depending on your symptoms or needs.

Some important things to remember

- **Chronic fatigue** is a symptom that may persist, and may not be resolved with a good night's sleep
- **Let your loved ones know** that you're still there for them, and that occasionally, plans may have to change
- **Pace yourself.** You can still hang out with your family and friends, but prioritize how you're feeling



Take care of yourself

Don't overwhelm yourself by putting all your energy into others. Taking time and space for yourself is an important part of self-care.

Talk to your doctor about healthy stress relief activities like low-intensity exercise or deep breathing



Once you find a healthy activity that you enjoy, consider getting your family and friends to support or join you.

Your family and friends are a critical part of your support network

Discussing your condition with others doesn't let the disease define you; it helps others better understand what you're going through. You're still you.



For more patient tools and guides to help you navigate IgA nephropathy, visit KidneyHope.com

