

# NAVIGATE A COURSE WITH CARE

Helping your loved ones with IgA nephropathy



Caring for a loved one with IgA nephropathy can be challenging and rewarding at the same time. This guide provides information and tips on how you and your loved one can navigate what's ahead, **together**.

## Know the landscape

Even if you can't see their disease, it can still impact their lives. To support your loved one, it's important to first understand IgA nephropathy and the effect it can have on their kidney health.

### What is IgA nephropathy?

IgA nephropathy is a rare kidney disease. It occurs when immunoglobulin A (IgA)—a protein in the blood that helps the body fight infections—builds up in the kidneys and disrupts their ability to filter waste from the blood.<sup>1</sup>



#### Not everyone experiences symptoms

While as many as **40% of people living with IgA nephropathy have no recognizable symptoms when their disease is first suspected**,<sup>2</sup> patients may sometimes notice an unusual appearance to their urine:

- ▶ Foamy urine caused by large amounts of protein spilling into their urine (proteinuria)<sup>1</sup>
- ▶ Blood in their urine that can make it appear dark brown or cola colored<sup>1</sup>



#### IgA nephropathy over time

IgA nephropathy can lead to kidney failure. It is important for your loved one to stay on top of their disease.<sup>1</sup> The sooner they take action to lower the protein in their urine, the slower their disease will progress.

- ▶ **It is important to monitor proteinuria** as higher levels mean a higher risk of kidney failure.<sup>3</sup>

### Watch out for changes in their general wellness

Remember, even if someone doesn't have any symptoms, it does not mean that their disease isn't serious or getting worse.

## Be part of their journey

Everyone's story with IgA nephropathy is different. Understanding your loved one's personal experience with the disease can help you become a better care partner and resource on their kidney health journey.



#### There is no substitute for your support

Being there for your loved one is a major part of your role in their kidney health journey. You can assist them by researching the disease and by encouraging them to join support groups. Inspiring your loved one to take care of their mental, emotional, and physical health can be helpful for their overall well-being.

Visit [NavigateIgAN.com](https://www.navigateIgAN.com) for more care partner inspiration.

#### Term to remember

##### Proteinuria

(pro-teen-yur-ee-uh): increased amounts of protein spilling into urine<sup>1</sup>



## Doctor's appointments are key points of communication

To take advantage of this time, help your loved one be prepared with questions about their disease or general wellness.

These meetings are an opportunity for your loved one to share any changes in symptoms or health, as well as information that they might track between appointments.

Help your loved one better prepare for conversations with their doctor. Visit [NavigateIgAN.com](https://www.navigateigAn.com)



## Regular testing is an important part of disease management

Kidney health can be monitored in several ways, including tracking cholesterol, blood pressure, and proteinuria levels. Encourage

your loved one to keep track of their test results (their "numbers") and share them with their doctor.

**It's important to respect your loved one's comfort level in sharing how they feel. Sometimes simply being a good listener can make all the difference.**

## Lay the course

With a clearer understanding of IgA nephropathy and your loved one's personal experience with the disease, you can be better prepared to help them confidently navigate the path ahead.

### Take care of yourself, first

- ▶ As a care partner, remember to make time for your own health and well-being
- ▶ Have your own support network with whom you feel comfortable sharing
- ▶ Look for signs of personal exhaustion and ask for help if necessary

### Provide support at doctor's appointments

- ▶ Make sure your loved one is on board with your partnership in their care
- ▶ Offer to help prepare a list of questions and talking points for the visit
- ▶ Help your loved one take and save notes in a central location, like a journal

### Share tips to help manage their disease



Controlling your blood pressure<sup>4</sup>



Following a customized diet and finding ways to reduce salt intake<sup>4</sup>



After consultation with a doctor, exercising regularly and maintaining a healthy weight<sup>4</sup>



Committing to regular sleep<sup>4</sup>



Quitting smoking<sup>4</sup>



Avoiding nonsteroidal anti-inflammatory drugs (NSAIDs)<sup>5</sup>

**Ready to help your loved one with whatever lies ahead?**

**Discover  
NavigateIgAN.com**

**References:** **1.** Mayo Clinic. IgA nephropathy (Berger's disease). Accessed September 2022. <https://www.mayoclinic.org/diseases-conditions/iga-nephropathy/symptoms-causes/syc-20352268>. **2.** Barratt J, Feehally J. IgA nephropathy. *J Am Soc Nephrol.* 2005;16(7):2088-2097. **3.** Kidney Disease: Improving Global Outcomes (KDIGO) Glomerular Diseases Work Group. KDIGO 2021 clinical practice guideline for the management of glomerular diseases. *Kidney Int.* 2021;100(4S):S1-S276. **4.** National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). Managing chronic kidney disease. Accessed September 2022. <https://www.niddk.nih.gov/health-information/kidney-disease/chronic-kidney-disease-ckd/managing#eight>. **5.** National Kidney Foundation. Watch out for your kidneys when you use medicines for pain. Accessed September 2022. <https://www.kidney.org/news/kidneyCare/winter10/MedicinesForPain>.