

A GUIDE FOR THE PEOPLE IN MY LIFE

MY LIFE WITH IgA NEPHROPATHY

www.mykidneyhouse.com

I have a rare health condition called **IgA nephropathy** (pronounced: “aye-jee-ay nef-rop-path-ee”). It stops my kidneys from working as well as they should. Because it’s invisible, my condition may not be obvious to others, and this can be confusing. This guide will help you understand how it affects me. Thank you for taking the time to read it.

HOW IgA NEPHROPATHY AFFECTS:



My kidneys

- Our bodies naturally produce waste products and extra fluid, and healthy kidneys remove them in our urine
- However, IgA nephropathy causes my immune system to attack the filters in my kidneys (called glomeruli), leaving damage and scarring
- This allows waste products and extra fluid to build up in my body, and blood cells and protein to leak into my urine
- When a protein called albumin leaks into my urine, the level of albumin in my blood goes down
- This can make my body retain fluid, which may lead to swelling



How I feel

- Because of my condition, I might feel:
 - Too exhausted to engage in my usual activities or social life
 - Swollen and uncomfortable
 - Pain around my kidneys or the swollen parts of my body
- Symptoms tend to become more frequent as the condition gets worse, but they show up differently from person to person, and some people don’t get any symptoms at all



My body

- When waste products and extra fluid build up in my body, it can cause problems like:
 - Severe tiredness (fatigue)
 - Brain fog
 - Pain
 - Swelling in my hands and feet
 - High blood pressure
 - Digestive issues
 - Fever
 - Respiratory infections



My quality of life

- Living with IgA nephropathy might also impact my quality of life and mental health, causing me to feel:
 - Depressed and anxious
 - Isolated and lonely because of how it affects my social life
 - Self-conscious because of how the swelling has changed my appearance
 - Frustrated that I am too fatigued to complete my usual tasks
- Since there is no cure and it can lead to kidney failure, I might also feel scared about my condition getting worse over time and possibly needing to go on dialysis or have a kidney transplant in the future

WHAT HELP AND SUPPORT CAN YOU OFFER?

Read this guide	Listen to me	Include me	Be patient with me	Remember that I am still the same person
You have shown support just by reading this guide to help understand my situation better.	Living with a rare, chronic condition can make me feel isolated sometimes, but when you listen to me, I feel seen and heard and this really helps.	Keep inviting me to social events and gatherings, even if sometimes I can't make it or need to cancel because of my symptoms.	Be patient with me if I'm feeling fatigued, down or anxious.	IgA nephropathy does affect my life, but I am not my disease.

FREQUENTLY ASKED QUESTIONS:



What causes IgA nephropathy (IgAN)?

Doctors don't know exactly what causes IgA nephropathy. Some scientists think that it's an autoimmune disease because it is the body's own immune system that causes harm to the kidneys. It's not contagious, so you can't catch it from another person.



How is IgAN managed?

For some people with IgAN there are no symptoms, especially during the early stages. Symptoms tend to get worse as the disease progresses over time. People with IgAN will need to see their doctor often and have regular lab tests. Treatment for IgAN aims to slow down the rate at which the disease progresses, prevent further damage to the kidneys, normalise blood pressure and reduce the amount of protein lost in the urine. Many people with IgAN find that improving their diet and exercise habits can also help manage their condition.



How rare is IgAN?

At least 2.5 people in every 100,000 people will be diagnosed with IgAN each year.



How is IgAN diagnosed?

Doctors can see signs of IgAN in urine and blood, but a kidney biopsy must be performed to formally diagnose IgAN.

To find out more about living with IgA nephropathy, please visit:

www.mykidneyhouse.com