

Diagnosed with IgA Nephropathy? What You Need to Know



If you or a loved one has been diagnosed with IgA Nephropathy, also called IgAN for short, it's normal to feel scared or uncertain.

You may worry about what it means for your future or how it might affect your family, career and other life dreams. **You are not alone.** The IgA Nephropathy Foundation is here for you. We offer information, education, support, and hope for a cure.

Use this booklet to learn more about:

- **IgA Nephropathy** and some of the terms you may hear. Doing so will help you feel more in control and in charge of your kidneys and overall health.
- **The tests used to check how well your kidneys are working** and how the results can help guide your treatment.
- **How to manage IgAN** and help protect your kidneys.
- **Ways to advocate for yourself** – for example, by knowing what questions you might want to ask. We know that living with a chronic disease like IgAN can also affect your mental health and relationships, so speak up and build your village of support.

How do you say IgA Nephropathy anyway?

It's pronounced
"nuh-FROP-uh-thee."

Although it is rare, IgA Nephropathy is among the most common kidney diseases in younger people.

You can also find helpful worksheets at igan.org to keep track of important information, including your lab results, blood pressure readings, medications, and how you are feeling and coping in general.

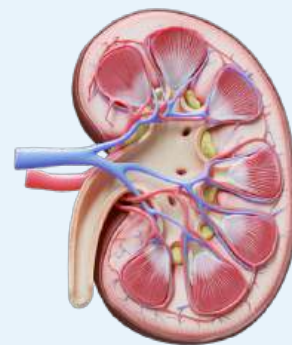
What is IgA Nephropathy?

IgA Nephropathy is a rare autoimmune disease that affects the kidneys. It happens when immunoglobulin A travels to and builds up in the kidneys. Immunoglobulin A is a protein we all have. It usually helps your body fight infection. In this case, it ends up where it's not supposed to be.

Over time, IgA deposits can clog the tiny filters in the kidneys. This damages the kidneys, and makes it harder for them to filter and get rid of extra water and waste in the urine.



As of now, a kidney biopsy is the only way to know for sure if someone has IgA Nephropathy. For this procedure, the doctor removes a small piece of kidney tissue and examines it under the microscope to look for disease or damage.

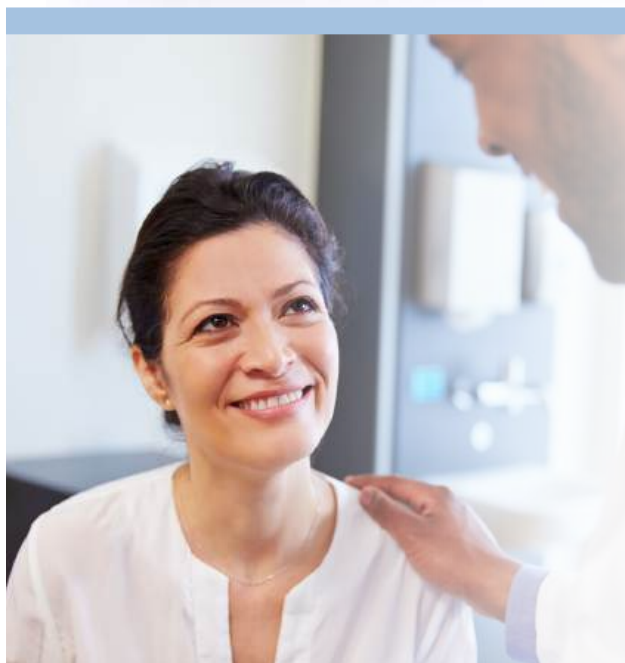


Cross section of a kidney

You have two kidneys. They are bean-shaped organs about the size of your fist.

Their main job is to filter and clean the blood. In fact, the kidneys filter about a half cup of blood every minute!

Each kidney has a million tiny filtering units called glomeruli. With IgA Nephropathy, IgA collects in and clogs these filters. This also causes protein to leak into the urine, which can result in more damage to the kidneys. IgAN affects both kidneys.



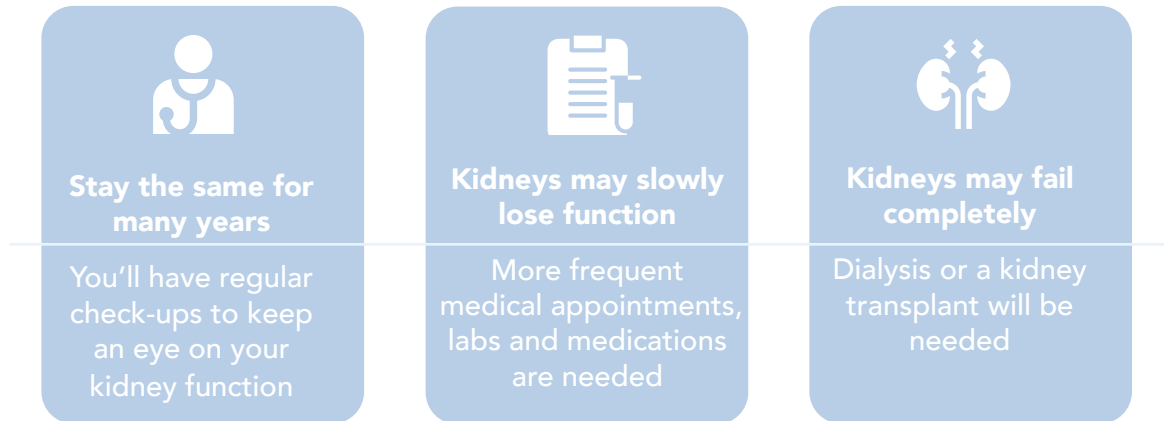
It can be very difficult to learn that you have IgA Nephropathy. But there are steps you can take to slow the rate of loss of kidney function, help prevent kidney failure and feel better. Today, there are more treatment options for IgAN than ever before, with many more drugs in clinical trials.

Try not to let the condition define you. Instead, play an active role in your care, ask questions and know we are here for you with information and support.

It's important to remember that no two people with IgA Nephropathy are the same. Some people have no symptoms, while others may feel very unwell. For some patients, kidney function stays about the same for a long time. For others, kidney function can decline quickly. Some patients will need to start dialysis or get a new kidney at some point.

How does it progress or get worse?

It's different for every person. The good news is that more often than not, IgA Nephropathy progresses slowly.



While there is no cure for IgA Nephropathy, there are steps you can take, together with your care team, to manage your symptoms and slow down how quickly your kidneys become damaged.

How to monitor your kidney health



With IgA Nephropathy, blood cells and protein can make their way into the urine. This doesn't happen with healthy kidneys. The good news is that simple urine and blood tests can be used to see how well your kidneys are working to filter your blood.

Results from these tests will help to:

- Monitor your kidney function and look for changes (there can be ups and downs, so the key is to look at trends over time)
- Know the stage of your kidney disease
- Help guide treatment decisions
- Check for certain health issues that can develop when the kidneys aren't working properly (for example, anemia, low levels of vitamin D, a build up of acid in the blood, heart disease)



Try to get your labs drawn at the same time of day. It's normal to feel nervous while waiting to see what your latest tests will show. Take a deep breath and focus on what you can control.

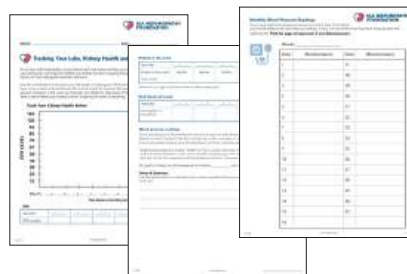
Your kidney biopsy results will also give you and your health care team important information about your kidneys.

Common tests used

<p>A blood test to measure your GFR (creatinine is measured in the blood and it is used in a mathematical formula to calculate the GFR)</p>	<p>A urine test to look for protein or albumin in the urine (this is called proteinuria or albuminuria)</p>
<p>GFR stands for Glomerular Filtration Rate.</p> <ul style="list-style-type: none"> • A GFR of 60 or higher is in the normal range. • A GFR below 60 may mean kidney disease. • A GFR of 15 or lower may mean kidney failure. <p>Creatinine levels go up in your blood when your kidneys are not working properly. So as creatinine goes up, GFR goes down.</p> <p>Your GFR helps you know your stage of kidney disease.</p> <p style="text-align: right;">Source: NIDDK</p>	<p>Your doctor or nurse may use terms like urinalysis, urine dipstick test, urine albumin, UACR, UPCR when talking about urine tests.</p> <p>With healthy kidneys, no protein/albumin is found in the urine. But with IgAN, protein/albumin can make its way into the urine. The less protein/albumin in your urine, the better.</p> <p>Albumin is a type of protein and may be measured rather than total protein.</p> <p style="text-align: right;">Source: NIDDK</p>

Your GFR or eGFR and the amount of protein in the urine can change. That's why it is helpful to see trends over time. Use our worksheet, **Tracking Your Labs, Kidney Health and Blood Pressure**, to write down your lab results. Always ask questions if you are unsure about what your lab results mean.

Visit our Resources section at igan.org to download these and other tools.



Don't forget to listen to your body too

In addition to your labs, let your doctor know if you notice any signs that could mean your kidney function is getting worse. For example:

- Red or tea-colored urine for many days
- Severe headaches
- Pain near your kidneys in the lower back
- Swelling or puffiness in your face, legs, ankles, or feet
- Feeling more tired than usual
- High home blood pressure readings
- Sudden changes in appetite

Watching your blood pressure is important for your kidneys too



Your kidney (nephrology) team has likely told you how important it is to manage your blood pressure. That's because high blood pressure and kidney disease often go hand-in-hand – and each makes the other worse.



High blood pressure can damage or weaken the blood vessels of the kidneys, ultimately damaging the kidneys.







Chronic kidney disease

Healthy kidneys usually help control blood pressure. When they don't work well, it raises blood pressure.

This is why some of the main medicines to manage IgA Nephropathy include those that lower blood pressure. Part of your treatment plan will be to monitor and track your blood pressure at home. Use our worksheet to write down your blood pressure numbers. You'll also find tips for how to get an accurate reading.

Treatment options to help manage IgAN

 <p>Following a healthy lifestyle</p>	 <p>Medications to ease symptoms or slow the progression of the disease by lowering blood pressure and reducing the amount of protein in your urine</p>	 <p>Clinical Trials to look for new and more targeted treatments</p>	 <p>Dialysis or needing a new kidney for more advanced stages of the disease</p>
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The main goal of treatment is to prevent or delay kidney failure and the need for dialysis or a new kidney. Medications and lifestyle changes can help to ease symptoms and slow down how quickly your kidneys become damaged. Work with your kidney team to develop a treatment plan that works for you.

Your treatment will depend on:

- Your current stage of kidney disease or how much kidney damage you have
- Any health issues you develop related to poorer kidney function; for example, a low number of red blood cells (anemia) or swelling in the legs or ankles (edema)
- Other health conditions you might have, such as heart disease, diabetes or high cholesterol
- What's most important to you when it comes to managing IgA Nephropathy, so speak up and advocate for yourself

Healthy lifestyle habits

Taking care of yourself and making healthy choices can help protect your kidneys.



Switch to a kidney-friendly diet as best you can. What you eat plays a role in your kidneys and overall health. It's important to cut back on salt (sodium) and choose healthy foods.



Get moving. Exercise is good for your body and mind. Finding ways to move your body more is good for your heart, your kidneys and your overall health. It also promotes better sleep and can boost your mood and energy levels.



Stay at a healthy body weight. Ask what you should weigh.



Get enough good quality sleep. Aim for 7-8 hours each night.



Quit or don't start using tobacco. Make a date to quit. There are resources to help.



Find ways to lower stress. Know your limits and speak up if you need more support. Try yoga, deep breathing or other types of meditation.



Make sure your other health conditions are well managed. These can also harm the kidneys. For example, if you have diabetes, try your best to keep your blood sugar low.

Medications



Medications – coupled with healthy lifestyle changes – are an important part of any IgAN treatment plan.

Exactly which medications, or combination of medications, your doctor recommends will depend on how well your kidneys are working and what medicines you've already tried. Visit igan.org for more information on specific medications that are used. Here you will find a worksheet to keep track of your medications and treatments you've tried before.

Be sure to ask questions and learn why you are taking each medication.

Clinical Trials



There are many promising clinical trials underway to find better, more targeted treatments for IgA Nephropathy.

Ask your care team if a clinical trial is an option for you, and which one might be a good fit. You will need to meet the study criteria to be able to participate (for example, a GFR within a certain range, not being on a steroid for a period of time, etc.). For a list of active clinical trials, visit igan.org/clinical-trials.

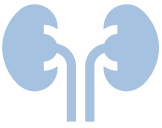


"The future is bright for people living with IgAN. It's an exciting time of discovery and new treatments."

- Bonnie Schneider

Co-founder of the IgA Nephropathy Foundation

Dialysis or kidney transplant for kidney failure



Not everyone with IgA Nephropathy will need dialysis or a kidney transplant. These treatments are for people with advanced kidney disease. But it's good to know these are options if you get to or are nearing that stage.

- **Dialysis** – uses a machine to remove wastes and excess fluid from your blood
- **Kidney transplantation** – replaces the damaged kidneys with a donated kidney.

In the U.S., patients can be assessed to get on the transplant list when their GFR is less than 20. A kidney transplant doesn't happen until it is much lower. The exact timing can vary by center though, so you may wish to start the conversation or ask for a referral earlier.

Getting a new kidney doesn't cure IgA Nephropathy. But it can help you live longer and with a better quality of life. IgA Nephropathy may come back in the transplanted kidney, but your kidney doctor will be watching out for this. Many of the new treatments for IgA Nephropathy are also likely to work in the new kidney.

Your emotional and mental health can affect your physical health too.
Talk about your emotions and how you are coping.



Tune into your emotional health

Living with IgAN can feel overwhelming at times. Be sure to:

- Share your feelings with your care team so they can help you.
- Join a support group with other people living with IgA Nephropathy.
- Check out our Coping and Caring for Your Mental Wellbeing information and tools at igan.org/mental-health/.

Advocating for yourself

One of the best things you can do to feel more reassured along your IgAN journey is to advocate for yourself.

- Learn all you can about the disease. Visit www.igan.org for information, tools and support.
- Find a kidney specialist you trust, someone who is knowledgeable about IgA Nephropathy and will work with your other health care providers to make sure everyone is on the same page to support your health.
- Remember, it's always OK to get a second opinion. Follow your gut.

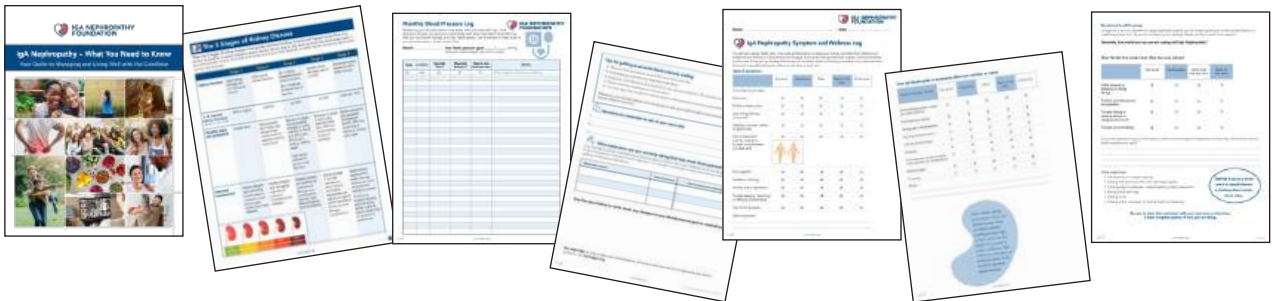
Ask questions. Here are some questions that people living with IgA Nephropathy have found helpful:



- How often should I have blood and urine tests done?
- What do my latest lab results mean?
- What could affect my lab results (for example, being dehydrated, eating a lot of salt or protein beforehand, etc.)?
- Can you explain the MEST-C score and other findings from my kidney biopsy and what they mean?
- Should I be taking my blood pressure at home?
- Why are you recommending this particular medication? How will it help? Are there side effects I should watch for?
- Can you refer me to a dietitian who specializes in kidney disease?
- I often have swelling in my hands, legs and feet. Could it be related to my kidneys?
- When should I call your office in between appointments (for example, changes in urine color or frequency, higher blood pressure readings, noticeable swelling, etc.)?
- How can I best manage IgA Nephropathy while also living my life?
- How do I make decisions about planning a family or pregnancy?
- What clinical trials are available, and which might be a good fit for me?
- I know many people never progress to kidney failure, but when would we know if I need to put my name on a transplant list?

Resources to help

The IgA Nephropathy Foundation has a growing number of resources, printable tools and ways to connect with other people affected by IgAN to help you on your journey. Join us today!



A 2-day, information-packed meeting to share stories and learn about IgAN



Peer Support:

Join a virtual support group to connect with others on the same path; one for patients and for caregivers



IgAN Journey:

Monthly podcast covering important topics



Patient Aid:

Learn about grants available to help with treatment costs

...and much more.

For more information, or to get involved, visit us at igan.org.



**IGA NEPHROPATHY
FOUNDATION**

Dedicated to finding a cure.