



**IGA NEPHROPATHY  
FOUNDATION**

# IgA Nephropathy – What You Need to Know

Your Guide to Managing and Living Well with the Condition





**The IgA Nephropathy Foundation's**

**mission** is to be a patient-centric organization focused on finding a cure for IgA Nephropathy. Using the power of the patient community we are focused on funding research, using patient advocacy to empower our patients, and building a network of support.

As a patient run organization, we will work together with the hope of finding better treatment options and the ultimate cure.

**By patients, for patients.**

*This guide was made possible with support from Calliditas Therapeutics. Editorial content was developed solely by the IgA Nephropathy Foundation.*

# Your Guide to Managing and Living Well with IgA Nephropathy

**If you or a loved one has been diagnosed with IgA Nephropathy, it's normal to feel scared, uncertain and even overwhelmed. After all, these are your kidneys we are talking about. But you're not alone.**

This guide was developed by the IgA Nephropathy Foundation with input from patients and kidney experts to help you and your care team map out a plan for how best manage your condition and slow its progression. This resource will help equip you with basic information about IgA Nephropathy, what to look for and expect at different stages, helpful questions to ask, and tips for coping. It also includes worksheets to track important information, including your lab results, ways in which the condition is affecting different parts of your life and overall wellbeing, and medications.

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**Note:** This resource is intended to inform discussions with your care team and help you advocate for yourself or loved one. It should not be used as medical advice. Use it with your care team to map out a plan that's right for you.

**Patients often describe** the initial shock and fear that came with learning they had IgA Nephropathy.

Many didn't know where to turn, and were worried about their future. But there is hope. You can live a long, fulfilling life with good self-management. The important thing is not to let the condition define you.

Instead, play an active role in your care, ask questions and know there is support through the IgA Nephropathy Foundation.

**This guide can help.**



## What is IgA Nephropathy

IgA Nephropathy (pronounced “nuh-FROP-uh-thee”) happens when immunoglobulin A (IgA) builds up in your kidneys. IgA is a protein that is made by the immune system when it detects harmful substances. But in the case of IgA Nephropathy, the immune system is actually attacking the kidneys, not a foreign invader. Over time, IgA deposits accumulate in and can damage the kidneys, making it harder for them to do their job. IgA Nephropathy affects both kidneys.

It’s important to remember that no two people with IgA Nephropathy are the same. Some people may not have any symptoms, while others may feel very badly or quickly progress to needing dialysis or a new kidney.

### How it’s usually found

For many people, blood or protein in the urine is the first sign of IgA Nephropathy. For others, the first clue might be unexplained spikes in blood pressure, cola-colored urine or an abnormal kidney function test.

The only way to confirm you have IgA Nephropathy is with a kidney biopsy. For this procedure, the doctor removes a small piece of kidney tissue and examines it under the microscope. A biopsy can also help to see the extent of kidney damage.

### Is your IgA Nephropathy:

- Suspected based on blood or urine tests
- Confirmed with a biopsy of kidney

## The Mighty Job of the Kidneys

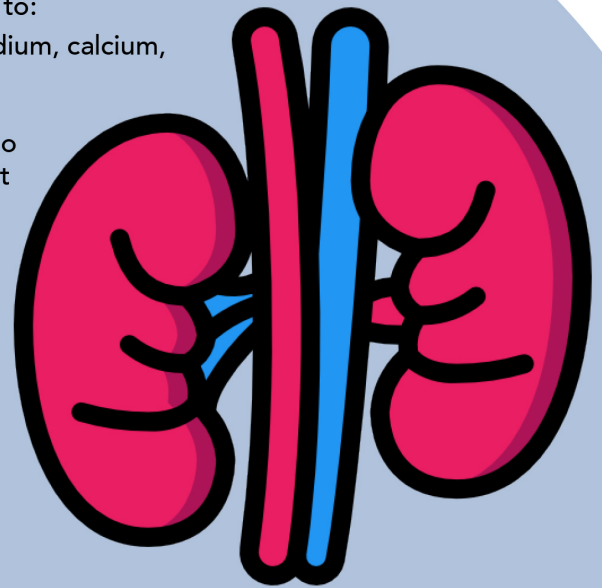
Did you know that 25% of the blood pumped out of the heart goes to the kidneys to be cleaned and filtered? That amounts to about 1.2-1.3 liters of blood a minute!

But your kidneys do more than clean your blood and remove waste and extra water from your body through your urine. They also help to:

- Keep a healthy balance of water and minerals, including sodium, calcium, phosphorus and potassium, in the blood
- Control blood pressure
- Make certain hormones, including those that tell the body to make new red blood cells, and vitamin D, which is important for good bone health and plays a role in supporting your immune system and vascular (blood vessel) health

If your kidneys aren’t working as well as they should, waste and extra fluid can build up in your body. This can make you feel unwell, and is usually worse with more advanced disease. Also, nerves, muscles, and other tissues/organs may not work as well when the usual balance of fluids and electrolytes isn’t maintained.

Source: NIDDK, Dr. Rizk SPARK 2021 presentation



### Fear is a common first reaction

If you talk with other people with IgA Nephropathy, most recall being really scared when they first learned about the condition. Their minds raced and quickly turned to questions like: “Am I going to die?” “Will I end up on dialysis?” “Am I going to lose my kidneys?”

The good news is that, in learning more about the disease – including how labs are used to keep a close eye on kidney function, the role that lifestyle changes and certain medications can play to help slow declines, not to mention opportunities to join clinical trials – they felt more hopeful and empowered.

One of the best things you can do is arm yourself with information and ask questions. Even though IgA Nephropathy is considered a rare disease, it’s one of the most common kidney diseases, aside from those caused by high blood pressure or diabetes. So there are many other people living with it. Be sure to find a kidney specialist (nephrologist) who you trust, is knowledgeable about IgA Nephropathy, and will work with your other providers to make sure everyone is on the same page.

While there is no cure for IgA Nephropathy yet, there are steps you can take, together with your care team, to manage symptoms and slow how quickly the condition – and related damage to your kidneys and the rest of your body – will progress.

*“I spent many sleepless nights curled up, worried about my future when I was first diagnosed. I’ve been living with it for over 32 years now.”*

**- Leah, 54**

*“It’s a little scary when someone says, ‘You have this disease that you’ve [likely] never heard of before, and there’s no known cure.’ But then you learn about the steps you can take to manage it.”*

**- Stuart, diagnosed 14 years ago**

### What’s the Usual Path with IgA Nephropathy?

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



Go away completely  
(This is more common with kids)



Kidneys may slowly lose function  
More frequent medical appointments, labs and medications are needed



Stay the same for many years  
You’ll have regular check-ups to keep an eye on your kidney function



Kidneys may fail completely  
Dialysis or a kidney transplant will be needed



# Monitoring Your Kidney Health

With IgA Nephropathy, blood cells and protein can make their way into the urine. Understanding the labs your clinician orders and what the values mean is very important. It can also help you feel more in control of your condition and engaged in your care.

## Protein in the urine

Protein circulates in your blood, but it's not usually found in the urine. Albumin is one of the most common types of protein found in blood. Having protein in the urine (called proteinuria or albuminuria if your doctor measures albumin) can be a sign of kidney damage. With IgA Nephropathy, the less protein in your urine, the better.

Urine tests may also look at blood in the urine, which can be microscopic (invisible to the eye) or visible, especially if you are sick or recovering from an upper respiratory infection or stomach bug.

## GFR stands for "glomerular filtration rate."

It is a measure of how well your kidneys are working to filter or "clean" your blood.

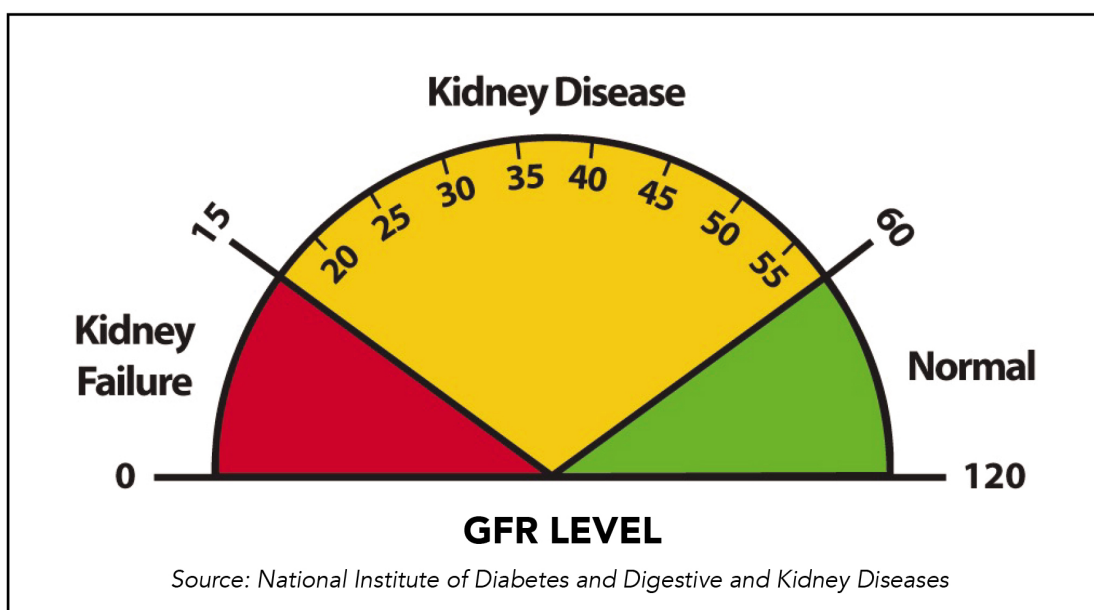
Anything over 60 is acceptable, according to the National Institute of Diabetes and Digestive and Kidney Diseases. A lower GFR signals that your kidneys aren't working as well as they should. As kidney function worsens, the GFR number goes down. Your GFR is used to help define what stage of kidney disease you are in (see page 6).

## Blood and/or urine tests are frequently used to:

- Monitor your kidney function and track changes over time (remember that there can be ups and downs, so the key is to look at trends over time)
- Determine what stage of kidney disease you have;
- Guide treatment decisions; and,
- Check for possible complications of kidney disease, such as:
  - Anemia – low red blood cell count
  - Bone disease – partly due to low vitamin D
  - Heart and blood vessel disease
  - Acidosis – a buildup of acid in the blood

## To check your kidney health, your care team primarily measures:

- 1) the amount of protein in your urine, if any, and
- 2) your GFR or blood creatinine level, which are markers of kidney function.



You may also see your GFR reported as estimated or eGFR on your lab report. The eGFR uses a formula that takes into account your serum creatinine level, as well as body size, age and gender to get a more accurate value. The body produces creatinine (a waste product of protein or normal wear and tear on muscles of body) at a steady rate; healthy kidneys should remove creatinine, so if there is a buildup of creatinine in the blood, it's a sign the kidneys aren't working as they should. Certain medications can also affect creatinine levels.

You can still have kidney disease with a normal GFR, but that's often during early stages of the disease when the body can compensate for any slight losses in function. Your doctor may decide to order imaging tests to look at your kidneys and see how they are working.



### **Blood pressure control and kidney health**

Not only can high blood pressure damage the kidneys, but damaged kidneys can also raise blood pressure. It can be a bit of a vicious cycle. One part of your treatment plan will be to monitor and track your blood pressure. Well controlled blood pressure is essential to protect your kidneys.

### **How Quickly Will Kidney Function Decline?**

This is a big question for many people with IgA Nephropathy. It's not always easy to know for sure. It depends, in part, on how early or late the disease was found. Your care team will consider several factors. For example:

- The amount of protein in your urine – more is worse
- Your blood pressure (you may be asked to take your blood pressure at home)
- Your estimated glomerular filtration rate (GFR) at diagnosis and follow-up visits
- Findings from your biopsy, including the extent of scarring and how severe the inflammation is in the kidney based on whether glomerular crescents were seen (MEST-C scores)

Studies show that between 20% to 40% of people with IgA Nephropathy will develop end-stage kidney disease within 20 years of their diagnosis and need dialysis or a kidney transplant. That also means many people with the disease never need dialysis or a transplant.

*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 – if your kidney function has stayed the same or if there's been a decline. Take a deep breath and focus on what you can control.*

### How often are labs needed?

It depends. Someone with more advanced disease will need closer monitoring. In this case, bloodwork and urine tests may be ordered every 1-3 months. For someone with stable or early-stage disease, once or twice a year may be enough.

How often should I be getting my labs tests done:

- Once a month
- Every 2-3 months
- Every 6 months
- Once a year
- Other: \_\_\_\_\_

Use the worksheet at the end to keep track of your GFR, protein levels in the urine and blood pressure numbers over time. There is also room for notes and questions to help you prepare for follow up visits.



*You know your body best, so speak up if you are feeling worse. The body can do a lot to compensate for kidney damage, so be sure to report how you are feeling in general.*

### Keeping an eye on symptoms, changes in what you're able to do

In addition to lab work, be sure to watch for and report signs that kidney function may be changing or getting worse. For example:

- Consistently red or tea colored urine
- Swelling in your face, legs or feet
- Feeling even more tired than usual
- Severe headaches
- Uncontrolled blood pressure
- Low back (flank) or bone pain
- Getting sick more often or for longer periods
- Metallic taste
- Sudden changes to your appetite
- Generally not healing as quickly as normal

Staying in tune with how you're feeling and managing in your everyday life at work and/or home is important. Also be sure to pay attention to and talk about your emotions and how you are coping.

Use the **Symptom and Activity worksheet** (page 22) at the end of this guide to keep track of:

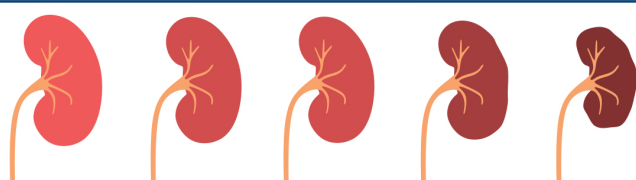
- Any symptoms you've been having, including how often they occur and what seems to make them better or worse
- How IgA Nephropathy or related treatments are impacting different parts of your life, including your emotional wellbeing, quality of sleep, ability to work or care for others, etc.
- Recent home blood pressure readings



## The 5 Stages of Kidney Disease

There are 5 stages of kidney disease. How quickly declines in kidney function will happen varies from one person to another. It usually happens slowly. Certain factors play a role, such as when you were diagnosed, if you have protein in your urine and how much, and if you have diabetes or other health conditions also known to harm the kidneys.

	Stage 1	Stage 2	Stage 3	Stage 4	Stage 5
<b>Kidney function</b>	Slight kidney damage with normal kidney function	Mild loss of kidney function	3a – mild to moderate loss of kidney function 3b – moderate to severe loss of function	Severe kidney damage, loss of function	Advanced kidney disease or end-stage disease
<b>% of normal kidney function</b> (based on your GFR)	90% or higher	60-89%	30-59%	15-29%	Less than 15%
<b>Possible signs and symptoms</b>	Usually none	Some people don't have any, but you may notice a loss of appetite, feeling overly tired	Same as in stage 2 plus possible changes in urine, swelling in hands and feet, back (flank) pain, itching, feeling weak.  High blood pressure or anemia may develop.	Same as in stages 2 and 3, plus possible chest pain, difficulty concentrating, nausea or vomiting	Earlier symptoms plus possible shortness of breath, difficulty breathing or sleeping, feeling very weak
<b>Potential treatment(s)</b>	Healthy lifestyle and controlling blood pressure, cholesterol and blood sugar levels if you have diabetes	Healthy lifestyle and managing high blood pressure, cholesterol and diabetes	Healthy lifestyle and addition of medications Manage any complications (anemia, high blood pressure, bone problems)	Same as stage 3 but start discussions about dialysis and kidney replacement as options in case of further declines in kidney function Manage complications	Need kidney replacement either through dialysis or a new, transplanted kidney to survive  Continuing medical therapy and not doing either is also an option depending on a person's preferences



Stage 1	Stage 2	Stage 3	Stage 4	Stage 5
Normal function	Mild loss of function	Moderate loss of function	Severe loss of function	Kidney failure



## Tools for Managing IgA Nephropathy

There are things you can do to stay on top of this condition and help to slow its progression.



**Adopting healthy habits**



**Routine blood and urine tests**



**Watching for and reporting signs and symptoms**



**Controlling blood pressure**



**Medications to ease symptoms or slow the progression of the disease**



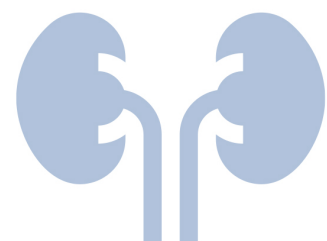
**Clinical trials**



**Emotional and peer support**



**Optimally managing other health conditions**



**Dialysis or kidney transplant for advanced disease**

### **Your treatment plan will depend on:**

- Your current stage of kidney disease or how much kidney damage you have
- Any complications from the disease, including anemia or inflammation (swelling)
- Other health conditions you have, such as diabetes, high cholesterol
- Personal goals and preferences – your care team needs to know what's most important to you in managing your IgA Nephropathy, so speak up and advocate for yourself

*The ultimate goal of treatment is to prevent or delay end-stage kidney failure at which point someone would need dialysis or kidney transplantation. But easing symptoms and making sure you can have a good quality of life matters too.*



## Your Goals for Managing IGA Nephropathy

**Think about your goals for managing IgA Nephropathy and any related complications. Write down your thoughts now or before your next visit.**

1. What about having IgA Nephropathy worries you most?

2. What do you care about most when it comes to managing your IgA Nephropathy?

3. A good day with IgA Nephropathy means that I am able to:

- 
- 
- 

*Even if you feel well and your kidney function is stable (sometimes called remission), it's important to keep up with a healthy lifestyle and take any medications that have been prescribed. IgA Nephropathy is a lifelong condition that requires ongoing management.*

## Mapping out your treatment plan

As with anything in life, having a plan can help you stay focused and feel more in control. Here we review treatment options and provide opportunities for you to personalize recommendations you discuss with your care team, take notes, and prioritize next steps.

### Lifestyle Changes

Taking care of yourself and making changes to how you live your life – for example, eating healthy, staying physically active and shedding any extra weight – can help protect the kidneys, control blood pressure, and prevent or manage other health problems.

Talk with your care team about what changes to make. Decide which ones to start to avoid feeling overwhelmed and set realistic goals.

*“If you eat right and take care of your body, you can extend the life of your kidneys.”*

**- Bonnie Schneider**



## Switch to a kidney-friendly diet as best you can.

What you eat plays a role in your kidney and overall health. But what works for one person may not work for another. There is no universal guidance. In general, eating simple, unprocessed foods can ease the workload and stress on the kidneys. Ask your nephrologist or kidney care team for recommendations.

- **Choose mostly plant-based foods**, including fruits, vegetables, beans, and whole grains rich in fiber. The Mediterranean or DASH eating plans may be a good place to start.
- **Limit salt (sodium)**. Remember that many sauces, soups, prepared foods, cold cuts, breads, and other processed foods are high in sodium. Limiting sodium can help prevent swelling and excess fluid in the body (edema) and lower blood pressure.
  - Try to consume no more than \_\_\_\_\_ mg of sodium a day. (While current U.S. Dietary Guidelines for Americans recommend less than 2,300 mg of sodium a day, this recommendation is often much lower for people with chronic kidney disease. Ask your doctor.)



3/4 teaspoon salt = 1,500 mg sodium,  
which is often what is recommended with kidney disease

- If you don't already, read food labels. Look for words like: sodium-free, low salt/low sodium, no sodium added, unsalted.
- Remember that foods you cook from scratch are naturally lower in sodium than most packaged foods or prepared meals or soups.
- Don't be afraid to swap the salt shaker for fresh spices and seasonings; for example, herbs, lemon, garlic, ginger, vinegar and pepper.

- **Be mindful of how much protein you eat.** A diet that is low in protein and saturated fat is generally best at certain stages of kidney disease and for adults (children need a certain amount of protein for healthy development). Some common examples of proteins include lean meats, poultry, fish, eggs, many dairy products, nuts, lentils, and tofu. Other foods, such as smoothies, granola or energy bars may have protein too. Not all protein is the same either; plant-based proteins may be easier on the kidneys.

Write down the amount of protein you should stick to each day (for example, one serving of lean meat or fish, no more than the size of your fist):

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- **Stay well hydrated.** Creatinine levels can rise if you are dehydrated. Drink plenty of water – try adding some flavor with fresh mint, cucumber, lemon, or other fresh fruits.
- **Limit alcohol.** In general women should have no more than one alcoholic drink per day and men should have no more than two, but this may be too much depending on your kidney disease.
- **Ask your provider if a referral to a registered dietitian is appropriate.** If you need more guidance, a dietitian or nutritionist can help you come up with a kidney friendly eating plan. Not all insurance plans will cover a nutrition consult. It is often covered with more advanced disease, diabetes and other health conditions.

Based on your lab values, your provider may recommend dietary supplementation (for example, iron or vitamin D) or restrictions (phosphorous).

**Get regular physical activity.**

Exercise is good for your heart, your kidneys and your overall health. It also promotes better sleep and can boost your mood and energy level. Because you lose muscle mass with kidney disease, it is very important to stay active. Certain types of exercise can help to increase muscle mass, which can improve strength, balance and coordination too.



Exercise as much as is appropriate for you. Always check with your care team before beginning any new exercise program.

- Be physically active for \_\_\_\_ minutes \_\_\_\_ days a week. Listen to your body and ease up if needed.

The types of activities I enjoy and are OK for me to do (circle all):

- |                  |  |
|------------------|--|
| - Walking        | - Water aerobics                                     |
| - Swimming       | - Climbing stairs                                    |
| - Bicycling      | - Group fitness classes that allow for modifications |
| - Hiking         | - Resistance bands or strengthening activities       |
| - Playing tennis |  |

Other activities that I do or might try: \_\_\_\_\_

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What might make it difficult for you to be physically active? Share this information with your provider.

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### Stay at a healthy body weight.



- Current body weight – \_\_\_\_ pounds.  
In talking with my clinician, I should [ ] maintain or [ ] try to lose \_\_\_\_ pounds in the next \_\_\_\_ months.
- Current waist circumference – \_\_\_\_ inches. For good health, women’s waist should measure less than 35 inches, and men’s should be less than 40 inches.

### Commit to getting on a regular sleep cycle.



- Aim to get 8-9 hours of sleep a night by adopting healthy sleep habits.

### Avoid tobacco use.

- If you smoke, make a date to quit: \_\_\_\_\_
- Ask about smoking cessation programs, medications or nicotine replacement therapies.

**Carefully follow your treatment plan.** Ask questions if you are unsure of what is being recommended, or if you have concerns about treatment costs or side effects. Use the extra pages at the end of this booklet to jot down questions in between your visits.

**Get an annual flu shot and stay current with other vaccinations.** Many people with IgA Nephropathy tend to feel worse after being sick, so take steps to stay as healthy as possible.

- Last flu shot received: \_\_\_\_\_ (date)
- Other vaccinations (against pneumonia, shingles, tetanus, etc.) that are due soon:

*You may have heard that exercise may raise creatinine levels. This does NOT mean exercise is hurting your kidneys. It just means that your exercise habits should be considered when your care team looks at your labs.*

“IgA Nephropathy is a chronic disease. You need to learn about it, but not be consumed by it. There are things you can do to slow down the disease, many of which are in your hands already by making different choices and changing your lifestyle.”

*Dr. Dana Rizk, nephrologist*

## Medications

There are currently no medications available to specifically to treat IgA Nephropathy. But there are medications that may be recommended to help treat your symptoms, slow any losses to your kidney function, or manage complications. Again, it will depend on your kidney function and what other treatments have been tried.



Medications	Things to Consider	Ask About Side Effects
<b>Medicines to lower blood pressure and reduce protein loss to help slow kidney disease</b>		
Angiotensin-converting enzyme (ACE) inhibitors (these <b>medicines end in-pril</b> )	<p>ACE-inhibitors and ARBs are first-line therapies for people with IgA Nephropathy; the goal is to have you take the highest dose or amount you can tolerate.</p> <p>Let your provider know if you have any dizziness while on these medications.</p>	
Angiotensin receptor blockers (ARBs) (these <b>medicines end in-sartan</b> )	<p>Additional therapies may be added, including:</p> <ul style="list-style-type: none"> <li>• Other blood pressure medicines to help meet blood pressure goals</li> <li>• Spironolactone or aldactone (mineralocorticoid-receptor antagonist) to try to further reduce high amounts of protein in the urine above and beyond what is achieved with ACE-inhibitors or ARBs</li> </ul>	
<b>Medicines to lower cholesterol, slow the progression of kidney damage and heart or blood vessel disease</b>		
Statins	There are many types of statins, so if the first one doesn't work there are other options.	
Ezetimibe, PCSK9-inhibitors or other non-statin therapies may be added depending on your numbers	These are usually added if your LDL or "bad" cholesterol is not lowered enough with statins alone.	
<b>Medicines to help the body get rid of extra fluid through the urine, which can also improve blood pressure</b>		
Diuretics or water pills	Although these may be needed if your body is holding onto extra fluid and have noticeable swelling in your legs and ankles, for example, they can raise creatinine levels, so you will need to be watched carefully	

**It's common to be on more than one medicine as each works in different ways or have additive benefits. Note that certain vitamins, herbal remedies and over-the-counter medications, including NSAIDs, can be harmful to the kidneys. Always ask your doctor before taking any over-the-counter drugs or supplements.**

## Medications

## Things to Consider

## Ask About Side Effects

Medicines that help reduce inflammation or suppress the immune system may be used		
Fish oil, omega-3 fatty acids	<p>Some people may respond to fish oil, while others do not.</p> <p>You need to take a high amount or dose, usually around 3 grams a day, but ask your provider.</p> <p>Fish oil capsules are available by prescription and over-the-counter. Over-the-counter fish oil omega-3 fatty acid supplements are not regulated, so ask your provider or pharmacist what they recommend.</p>	
Corticosteroids, including prednisone	<p>The use of high-dose, systemic steroids such as prednisone is controversial.</p> <p>It is important to discuss the pros and cons, as well as potential side effects (for example, weight gain, damage to muscles, joints and bones, irritability, moodiness). Your priorities and other health conditions should also factor into your decision too. The right decision is different for different people.</p>	
Supplements or medicines to treat anemia, low red blood cell count, or weakening bones		
Erythropoietin stimulating agents -or- Iron supplements	<p>These may be recommended if you are anemia or are iron deficient</p> <p>ESAs are given by injection under the skin</p>	
Vitamin D supplements	<p>This may be recommended if you have low levels of vitamin D, which is fairly common even without kidney disease</p> <p>Vitamin D plays an important role in supporting the immune system, vascular (blood vessel) and bone health.</p>	
Other medications discussed:		

**Use the medication list at the end to write down the name of all of the medications you are taking, including any over-the-counter medications. It's important to keep this list up-to-date and to review it at each medical visit. Make sure you understand how each medication works and when to take it.**



## Clinical trials

To date, there is no FDA-approved medication specifically for IgA Nephropathy. However, there are a number of promising clinical trials underway to test the effectiveness and safety of new drugs that specifically treat IgA Nephropathy. Most of these trials involve people who are at high risk of disease progression, including those with high levels of protein in the urine.

Ask your care team if a clinical trial is an option for you, and which might be a good fit. You need to meet the study criteria to be able to participate (for example, a GFR within a certain range, not being on steroids for a period of time, etc.).

There are now many clinical trials underway to find better and more targeted treatment for people living with IgA Nephropathy. Most new therapies and advances in medicine are a product of clinical trials. If you take part in a clinical trial, you will be helping other people with the disease. For a list of active clinical trials, visit [igan.org/clinical-trials](http://igan.org/clinical-trials).

*"As a global community of patients, caregivers, doctors and researchers, we must continue to work together to find a cure for IgA Nephropathy. We are making great strides."*

*- Professor Jonathan Barratt PhD,  
nephrologist*

## Dialysis or kidney transplant for end-stage kidney disease

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

- **Dialysis** – removes wastes and excess fluid from your blood
- **Kidney transplantation** – replaces the damaged kidneys with a donated kidney. In the U.S., patients can be evaluated to get on the transplant list when their GFR is less than 20. But transplantation doesn't happen until it is much lower.

It's important to remember that 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 can recur in about half of people after transplant.

A kidney can either come from:

- A living donor – a friend, family member, neighbor, or someone else who has said they'd like to be a donor, but they don't yet know to whom they will be giving it to. Talk with family and friends about your disease to help educate them and also lay the foundation if you get to the stage when you might need to think about a transplant. Find ways to tell your story.
- A deceased person



## Minding Your Emotional Health

It's normal to feel overwhelmed by a new diagnosis. If you're like many people who have IgA Nephropathy, you may worry about how the condition may affect your ability to work or fulfill life dreams, as well as the toll it may take on your family or relationships. Share your concerns and feelings with your care team so that they can help you. Remember that your emotional and mental health can affect your physical health too.

### Tips for coping:

- **Learn how to advocate for yourself**, which includes making sure you have the right care team behind you, and that you know about all of the options for managing the disease and improving your quality of life.
- **Play an active role in your care** (use the worksheets in this guide to help). Keep track of how IgA Nephropathy impacts your daily life.
- **Find support** through family, friends, and the IgA Nephropathy Foundation, which offers many ways to connect with other people living with the disease.
- **Use relaxation techniques** such as deep breathing or yoga.
- **Ask about seeing a mental health professional**, if needed, to talk through your feelings.
- **Try to stay positive** and don't let the disease define you. But remember that it's OK to have bad days.
- **Be thoughtful about nurturing your mental, social and spiritual health**, which affects your physical health too.
- **Surround yourself with positive, supportive people** who you trust.
- **Pick up a new hobby** (photography, art, yoga, etc.).



Use this space to write down activities, people or things that can help you stay positive:

- 1.
- 2.
- 3.
- 4.
- 5.

**Having personal goals can help too**, giving you a feeling of accomplishment and that you are in charge of the disease, and not the other way around.

List a few things you can do to better manage your IgA Nephropathy and your overall wellbeing:

- 1.
- 2.
- 3.
- 4.
- 5.

*"It's overwhelming to know you have a chronic disease that's going to take over one of your organs. That's why it is so important to meet other people who have IgA Nephropathy and know that you can live a happy, productive and good life with it."*

**- Bonnie, caregiver**

*"Many people worry about when their kidneys are going to give out. It's a pretty normal reaction. It helps to take a deep breath and understand that you can live with this disease. If you focus on your health and your diet, in combination with medications, you can slow the progress of the disease."*

**- Judy, person living with IgA Nephropathy**



### **We're Here for You**

The IgA Nephropathy Foundation offers online support communities and a monthly support group. Become a member today by going to [igan.org/membership](http://igan.org/membership). You'll also find credible resources and information to help manage your disease and feel more empowered in your journey.



## Questions to Ask

Sometimes it's hard to know what questions to ask. Here are some questions that people living with IgA Nephropathy have found helpful:

### Lab work and assessing kidney health

1. How often should I have blood and urine tests done?
2. What do my latest lab results mean?
3. Are there certain things that can affect my labs (for example, being dehydrated, eating a lot of protein beforehand, etc.)?
4. How likely do you think it is that I will need dialysis or a new kidney based on my current GFR and biopsy results and when?
5. Can you explain the MEST-C score and any other relevant findings from my kidney biopsy and what they mean?
6. Will I ever need a repeat biopsy?
7. Should I be taking my blood pressure at home? If so, how often?

### Treatments

1. What steps can I take to protect my kidneys and slow declines in kidney function?
2. Why are you recommending this particular medication? How will it help? Are there side effects I should watch for?
3. I've heard there may be new medications that will be approved to treat IgA Nephropathy soon. What do you know about them and could I benefit from trying it when it's available?
4. What should I be eating (or staying away from) to prolong the health of my kidneys?
5. Can you refer me to a dietitian who specializes in kidney disease?
6. What about restricting fluids?
7. How much exercise should I be getting, and which activities are best?

### Other questions

1. I've been gaining weight. Could it be related to my kidneys not working as well?
2. When should I call your office in between appointments (for example, changes in urine color or frequency, higher blood pressure readings, noticeable swelling, etc.)?
3. What complications should I be worried about (anemia, bone health)?
4. How can I best manage IgA Nephropathy while also living my life?
5. How do I best make decisions about pregnancy?
6. What clinical trials are available, and which might be a good fit for me?
7. I know many people never progress to end stage kidney disease, but when would we know if I need to put my name on a transplant list?

Use the space below to write down other questions you have or would like to talk about at your next visit:

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## 10 Terms to Know

**Albuminuria** – specific kind of protein that leaks in the urine when the filtering units of the kidneys (the glomeruli) are sick.

**Berger's disease** – another name for IgA Nephropathy. Jean Berger was a French pathologist who first recognized IgA Nephropathy. IgA Nephropathy is a type of kidney disease that happens when too much IgA protein accumulates in and causes damage to the tiny filters of the kidneys.

**Creatinine** – a marker of kidney function. Creatinine is a waste product from normal wear and tear of our muscles. Normally, the kidneys filter creatinine from the blood and secrete it through the urine. If the kidneys aren't working as well as they should, creatinine levels can build up in the blood.

**Edema** – swelling caused by too much fluid in your body's tissues. It usually occurs in the feet, ankles and legs.

**Glomerulonephritis** – inflammation of the tiny filters in your kidneys called glomeruli. IgA Nephropathy is one type of glomerulonephritis and is the most common.

**Hematuria** – blood in the urine. This is often the first sign of IgA Nephropathy, but it can happen later too. Most people with IgA Nephropathy have some amount of blood in the urine whether it is visible or not.

**Immunoglobulin A (IgA)** – is a type of antibody that is usually part of the immune system. It usually helps fight infections.

**Nephrologist** – a doctor who specializes in treating diseases that affect the kidneys. "Nephron"s are the filtering units in the kidneys. There are a million of these in each kidney.

**Proteinuria** – excess protein in the urine, which happens when the kidneys are not working as well as they should; albumin is one type of protein that is commonly measured.

**Renal** – of or relating to the kidneys.



## Resources to Help

If you or a caregiver is in need of support, education, and connection, the IgA Nephropathy Foundation is here for you!



### We offer:

- A wealth of resources, including credible information about IgA Nephropathy, the latest treatments, and a listing of open clinical trials.
- Opportunities to connect with other people living with IgA Nephropathy and share stories.
- Compassionate support and care management tools.
- An annual conference called SPARK that brings patients, caregivers, clinicians, and industry partners together to share advances in IgA Nephropathy treatments, best practices, and key challenges to optimally manage the condition. It's also a great way to meet other people living with the disease.

### Our mission:

The IgA Nephropathy Foundation's mission is to be a patient-centric organization focused on finding a cure for IgA Nephropathy. Using the power of the patient community we are focused on funding research, using patient advocacy to empower our patients, and building a network of support.

As a patient run organization, we will work together with the hope of finding better treatment options and the ultimate cure.

By patients, for patients.

Name: \_\_\_\_\_ Date: \_\_\_\_\_



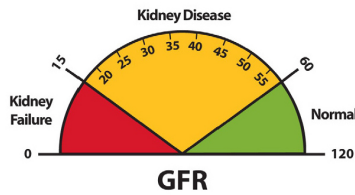
## Tracking Your Kidney Health

If you have IgA Nephropathy, routine blood and urine tests can help you and your care team see how well your kidneys are working and whether your kidney function is staying the same or getting worse. The results can also help guide treatment decisions.

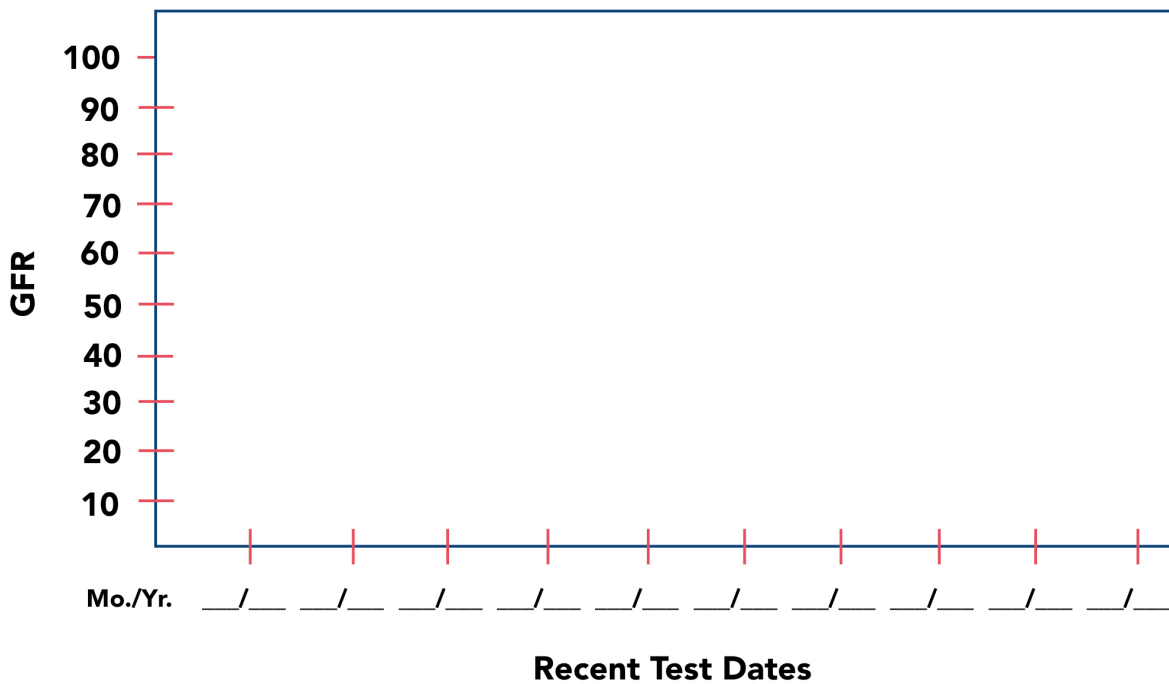
Print this worksheet to write down your lab results, including your GFR or creatinine level, urine protein, and red blood cell count (to check for anemia) and keep track of them over time. Your GFR and the amount of protein in the urine can fluctuate. You and your care team are looking for trends over time to see whether your kidney function is staying the same or declining.

### GFR

Test date:	___/___/___	___/___/___	___/___/___	___/___/___	___/___/___
GFR number:	___/___/___	___/___/___	___/___/___	___/___/___	___/___/___



### Track Your Kidney Health Below



### Protein in the urine

Test date:	___/___/___	___/___/___	___/___/___	___/___/___
Protein in the urine?	Yes/No	Yes/No	Yes/No	Yes/No
How much?				

Albumin is a type of protein that is often measured.

### Red blood cell count

Test date:	___/___/___	___/___/___	___/___/___	___/___/___
Hemoglobin or hematocrit				

### Blood pressure readings

If you are taking your blood pressure at home, write down your most recent measures here:

Date Taken:	___/___/___	___/___/___	___/___/___	___/___/___	___/___/___
Systolic (top number)					
Diastolic (bottom number)					

Target blood pressure is usually 130/80 mm Hg, and lower if you have other conditions or depending on the amount of protein in your urine. Ask your care team what your target goal should be based on your condition and other health issues.

My goal is to keep my blood pressure at or below \_\_\_\_\_ mm Hg.

### Notes & Questions

Use this space below to write down any notes or questions that you want to remember to mention at your next visit.

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Name: \_\_\_\_\_ Date: \_\_\_\_\_



## IgA Nephropathy Symptom and Activity Log

You will have regular health visits and bloodwork to assess your kidneys and determine whether your treatments are working or if they need to be changed in any way. Use this worksheet to take note of how you are feeling and the ways the condition might be limiting your ability to do certain activities. Be sure to review this information with your care team at each visit.

**Overall, have you been feeling:**

Better The same Worse

If worse, explain? \_\_\_\_\_

	Not at All		Often		All the time
Dark urine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Frothy or foamy urine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Less energy/feeling overly tired	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Swelling in my feet, ankles or legs or face	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain or discomfort (use the illustration to mark or circle where you've pain)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poor appetite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nausea or vomiting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety and/or depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Trouble sleeping, "Brain fog" or difficulty concentrating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other symptoms:

\_\_\_\_\_

\_\_\_\_\_

### Blood pressure readings

If you are taking your blood pressure at home, write down your most recent measures here:

<b>Date Taken:</b>	___/___/___	___/___/___	___/___/___	___/___/___	___/___/___
Systolic (top number)					
Diastolic (bottom number)					

Target blood pressure is usually 130/80 mm Hg, and lower if you have other conditions or depending on the amount of protein in your urine. Ask your care team what your target goal should be based on your condition and other health issues.

My goal is to keep my blood pressure at or below \_\_\_\_\_ mm Hg.

### How IgA Nephropathy or related treatments might be limiting your activities

How often have you had:	Not at All	Sometimes	Often	Most of the time	All the time	Not Applicable
Working/being able to meet job responsibilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participating in school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Taking care of kids/parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Staying physically active	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Intimacy/relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sleeping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participating in social activities, making plans with friends/family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Traveling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other: \_\_\_\_\_

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## Emotional health/coping

Living with a chronic disease isn't easy. Be sure to talk about your feelings. Speak up if you need more support.

### Generally, how would you say you are coping with IgA Nephropathy?

Over the last two weeks, how often have you noticed:

	Not at all	Several days	More than half the time	Most of the time
Little interest or pleasure in doing things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling sad, depressed or hopeless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Trouble falling or staying asleep or sleeping too much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Trouble concentrating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you are experiencing any of the above, what factors do you think contribute to your depression/anxiety:

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**Be sure to share this worksheet with your care team so they have a more complete picture of how you are doing.**

*Don't delay calling your doctor if you see blood in your urine or notice sudden swelling in your legs or feet. Urine can be darker if you have a cold or infection. Talk with your care team in advance about when to call in between appointments.*

Name: \_\_\_\_\_ Date: \_\_\_\_\_



## Making Treatment Decisions

It's really important to understand the benefits and risk of each treatment that you talk about and consider with your doctor. Weighing the pros and cons will help you make an informed choice that's right for you. Use this form to write down notes and questions and share it with your treatment team. Make sure to discuss your preferences, previous treatments tried, and anything else that's important to you.

Option:	
+ Pros	- Cons
Questions or other things that matter:	

Option:	
+ Pros	- Cons
Questions or other things that matter:	

Name: \_\_\_\_\_ Date: \_\_\_\_\_



## Medications

Keep this list updated and handy at all of your medical visits. Be sure to add any over-the-counter medications or supplements you take too.

Name	Reason for taking	Amount (dose)	How many times a day?	Special Instructions? With or without food?	What should I do if I miss a dose?	Are there side effects I should be looking for?

- Always take your medications as prescribed.
- Don't make any changes in when or how you take your medications without consulting your care team first. Ask before starting any new medications, including over-the-counter drugs, herbal remedies or supplements, as some can be hard on the kidneys.
- Talk about any side effects or things that make it difficult for you to take your medications.
- Plan ahead to be sure you get refills of your medicines before your supply runs out.

## Notes:

## Notes:



**IGA NEPHROPATHY  
FOUNDATION**

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