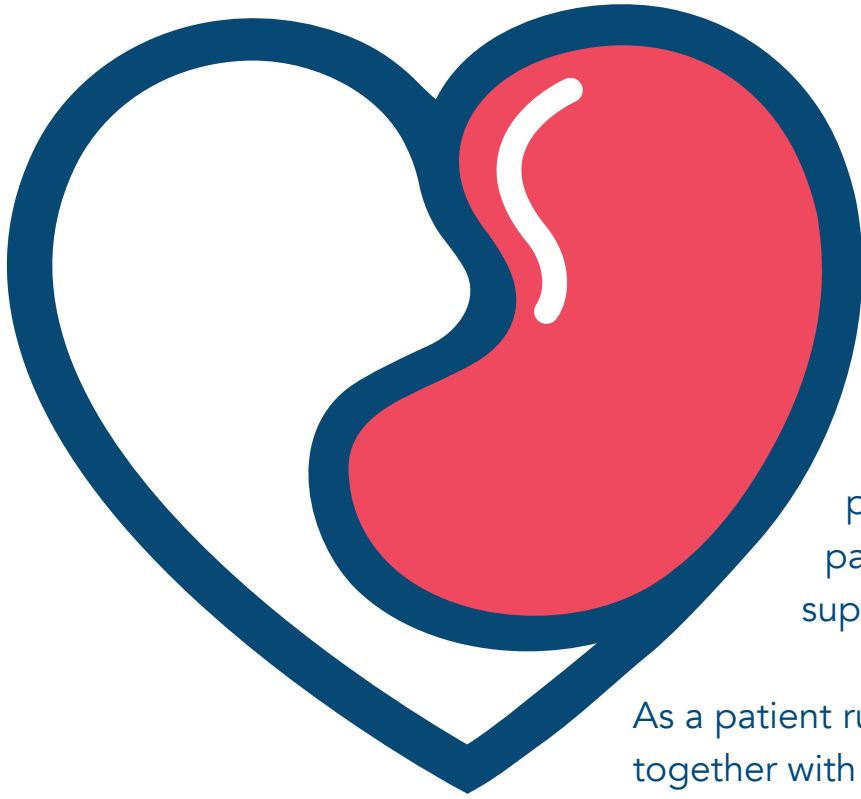




# IgA Nephropathy – What You Need to Know

## 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 ultimately, a cure.

**By patients, for patients.**

**For more information, or to get involved, visit us at [www.igan.org](http://www.igan.org).**



**IGA NEPHROPATHY  
FOUNDATION**

Dedicated to finding a cure.

# 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 to best manage your condition and slow its progression. This resource will equip you with basic information about IgA Nephropathy, what to look for and reasonably expect at different stages, helpful questions to ask, and tips for coping. It also includes worksheets to track important information, including your lab results, blood pressure readings, medications, and how you are feeling and coping in general.

## Read about:

## Starting Page:

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**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.**

**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.





# What is IgA Nephropathy?

IgA Nephropathy (pronounced “nuh-FROP-uh-thee”) happens when immunoglobulin A (IgA) travels to and 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. Some people may notice cola-colored urine or have an abnormal kidney function test after a routine health visit. For others, the first clue might be unexplained spikes in blood pressure.

As of now, a kidney biopsy is the only way to confirm you have IgA Nephropathy. 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, inflammation and scarring.

### Is your IgA Nephropathy:

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

*If you haven't had a biopsy, talk with your doctor or nurse.*

## 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, SPARK 2022



Each kidney has a million tiny filtering units called glomeruli. With IgAN, IgA deposits clog these filters, making it hard for the kidneys to do their job.

## Fear is a common first reaction

If you talk with other people living 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, as well as opportunities to join clinical trials to find new and better treatments, they felt more hopeful and empowered.

## Advocate for yourself

- 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.
- Find a kidney specialist (nephrologist) you trust, someone who is knowledgeable about IgA Nephropathy, and will work with your other providers to make sure everyone is on the same page. Remember, it’s always OK to get a second opinion.
- 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.

## 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.



Stay the same for many years

You’ll have regular check-ups to keep an eye on your kidney function



Kidneys may slowly lose function

More frequent medical appointments, labs and medications are needed



Kidneys may fail completely

Dialysis or a kidney transplant will be needed

## Things to keep in mind if you or a loved one is diagnosed with IgA Nephropathy

- **You are not alone.** The IgA Nephropathy Foundation is here for you – providing information, education, and support. We also support research to help find better treatments and ultimately a cure.
- **IgAN usually progresses slowly.** The good news is that you can take steps to help slow the kidney damage it can cause through lifestyle changes, controlling your blood pressure, and lowering the amount of protein in your urine.
- **It's hard to know how quickly IgAN might progress as everyone is different.** Talk with your kidney doctor about making a plan so that you know better what to expect by tracking your labs, blood pressure measures, and other tests.
- **IgAN remains poorly understood and is often misdiagnosed.** So it's important to learn what you can and advocate for yourself. Don't be afraid to ask questions.
- **Recently, there have been encouraging developments in the treatment of IgAN.** Be sure to check the IgA Nephropathy Foundation website for the latest information on treatments, including clinical trials.



*"I spent many sleepless nights curled up, worried about my future when I was first diagnosed. I've been living with it for [many decades] now."*

**- Leah**

*"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**



# 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.

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

- Monitor your kidney function and track changes over time (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 or blood vessel disease
  - Acidosis – a buildup of acid in the blood

## To check your kidney health, your care team will measure:

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



## Protein in the urine

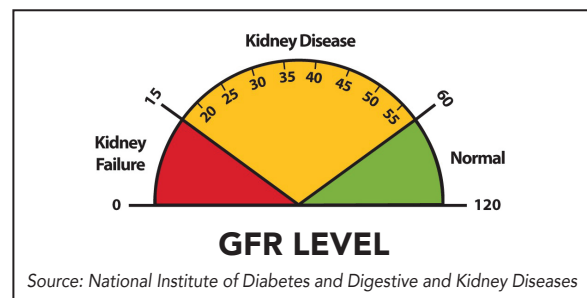
Protein circulates in your blood, but it's not usually found in the urine. Albumin is one of the most common types of protein found in blood. Having protein in the urine (called proteinuria or albuminuria if your doctor measures albumin) can be a sign of kidney damage. **With IgA Nephropathy, the less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

Urine tests may also look for blood in the urine, which can be microscopic (invisible to the eye) or visible. Many people with IgA Nephropathy notice darker, coca-cola colored or blood-tinged urine when they 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 normal, 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 7).



## More on your GFR

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.



*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.*



## Blood Pressure – another important measure for kidney health

Not only can high blood pressure damage the kidneys, but damaged kidneys can also raise blood pressure. Because the kidneys have a specific amount of blood they want to be filtering every minute. If less blood can flow through perhaps because of narrowed blood vessels, the pressure goes up to push it through faster. This can strain the heart over time too. 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. At the end of this guide, you'll find a monthly log to record your blood pressure readings.

## 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 is found.

Your care team will consider several factors. For example:

- The amount of protein in your urine – more is worse, less is better
- Your blood pressure (you should take your blood pressure at home)
- Your 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 will never need dialysis or a transplant.



## 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 more stable or early-stage disease, once or twice a year may be enough.

Ask about and write down how often you should be getting your lab 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.*

## Keep an eye on signs and symptoms

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

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

Use the **Symptom and Activity worksheet** (page 24) 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
- Recent home blood pressure readings



*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.*



# 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 feel better, help control the symptoms of IgA Nephropathy and/or slow its progression.



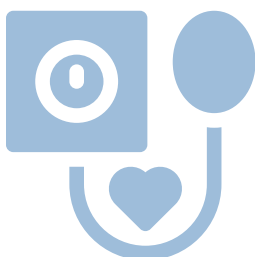
**Adopting healthy habits**



**Routine blood and urine tests**



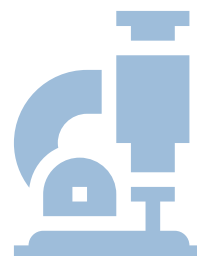
**Watching for signs and symptoms**



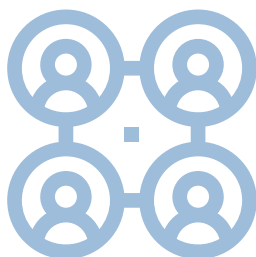
**Controlling blood pressure**



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



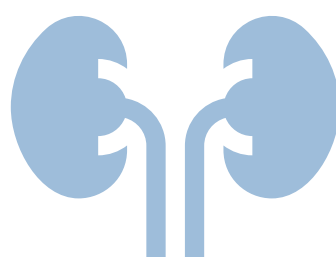
**Clinical trials**



**Emotional and peer support**



**Making sure other  
health conditions are treated**



**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 or 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 health issues. Write down your thoughts now or before your next visit.**

1. What about having IgA Nephropathy worries you most?

2. How would you define treatment success? What do you care about most when it comes to managing IgAN?

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

- 
- 
- 

## Mapping out your treatment plan

*As with anything in life, having a plan can help you stay focused and feel more in control. In this guide, 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 focus on first 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. While there is no universal guidance, eating simple, unprocessed foods can ease the workload and stress on the kidneys. Try not to make too many changes at once; doing so can feel overwhelming.

Ask your nephrologist or kidney care team to tailor recommendations that fit your goals and lifestyle. Here are some helpful tips:

- **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 what's best for you.



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 cooked from scratch are naturally lower in sodium than most packaged foods or prepared meals.
- Don't be afraid to swap the salt shaker for fresh spices and seasonings; for example, herbs, lemon, garlic, ginger, vinegar, and pepper.



Our cookbook and guide to maintaining a kidney friendly lifestyle. Order yours today at [www.igan.org](http://www.igan.org).



- **Be mindful of how much protein you eat.** A diet that is low in protein and saturated fat is generally best for adults at certain stages of kidney disease (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 are generally easier on the kidneys than animal proteins.

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

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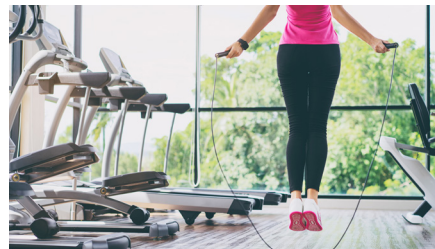
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- **Stay well hydrated.** Creatinine levels can rise if you are dehydrated. Drink plenty of water – try adding some flavor with fresh mint, cucumber, lemon, or other fresh fruits.
- **Limit alcohol.** In general, women should have no more than one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

*Based on your lab values, your provider may recommend dietary supplements (for example, iron or vitamin D) or restrictions (phosphorous). Read our IgAN cookbook and kidney health eating pages on [www.igan.org](http://www.igan.org) for more information.*

### Get regular physical activity.

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. 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. And remember that simply walking is one of the safest and best ways to stay active.

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

The types of activities I enjoy and count as exercise (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, COVID-19, 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

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

Medications can help:

- Control the symptoms of IgA Nephropathy – for example, by lowering blood pressure or reducing the amount of protein in the urine
- Slow any losses in kidney function and/or
- Manage related health problems, such as anemia, swelling (edema) or even heart disease



## Common medications used

Exactly which medications, or combination of medications, are recommended will depend on your kidney function, stage of disease and other treatments you've tried.

Most people with kidney disease are started on an angiotensin-converting enzyme (ACE) inhibitor or an angiotensin receptor blocker (ARB). But it's common to be on several medications.

Other medications are usually added over time, and as needed, to:

- 1) further slow any declines in kidney function and
- 2) lower the chance of related heart problems (for example, narrowing or hardening of the arteries, heart attack, and stroke). Keep in mind, medications will and should be adjusted over time.

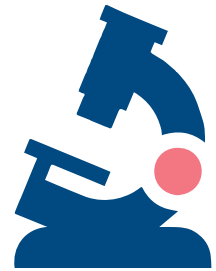
For some adults with high levels of protein in the urine and whose disease may progress quickly, there are now IgAN-specific medications that can be added to help lower the amount of protein in the urine. These are both taken once-daily by mouth and delivered by a specialty pharmacy. Ask your doctor if one could be right for you.

Medicines that may also be added include:

- **Additional blood pressure-lowering medicines**
- **A sodium-glucose cotransporter 2 (SGLT-2) inhibitor**, initially developed as a diabetes medicine, these medicines have been shown to carry heart and kidney benefits, including improved kidney outcomes overall
- **Diuretics** (called water pills), which help the body get rid of extra fluid through the urine and can help lower blood pressure too
- **Cholesterol-lowering medications** (for example, statins, ezetimibe and other non-statin therapies) that also help slow the progression of kidney damage and lower the risk of narrowed or blocked arteries, heart and blood vessel disease

## Hope on the horizon with new IgAN therapies

While there is no cure for IgAN yet, recent U.S. Food and Drug Administration (FDA) approvals of the first-ever medications designed specifically for IgAN mark an important turning point for treating IgAN.



Other promising therapies aimed at delaying or slowing the progression of the disease are being studied in clinical trials, so it's a time of great hope.

For more detailed information about some of the medications that may be recommended or that you might hear about, especially as new drugs are available, visit [www.igan.org](http://www.igan.org).

In some cases, corticosteroids like prednisone may be used. The use of high-dose, systemic steroids is controversial and current guidelines suggest but do not recommend their use. It's 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. Everyone with IgAN responds to therapies differently. The right decision is different for different people.

## Medications to manage health issues that can come from progressive loss of kidney function

Other medications or supplements may be needed to help lower inflammation or if you are anemic (low red blood cell count) or have low vitamin D levels. These may include:

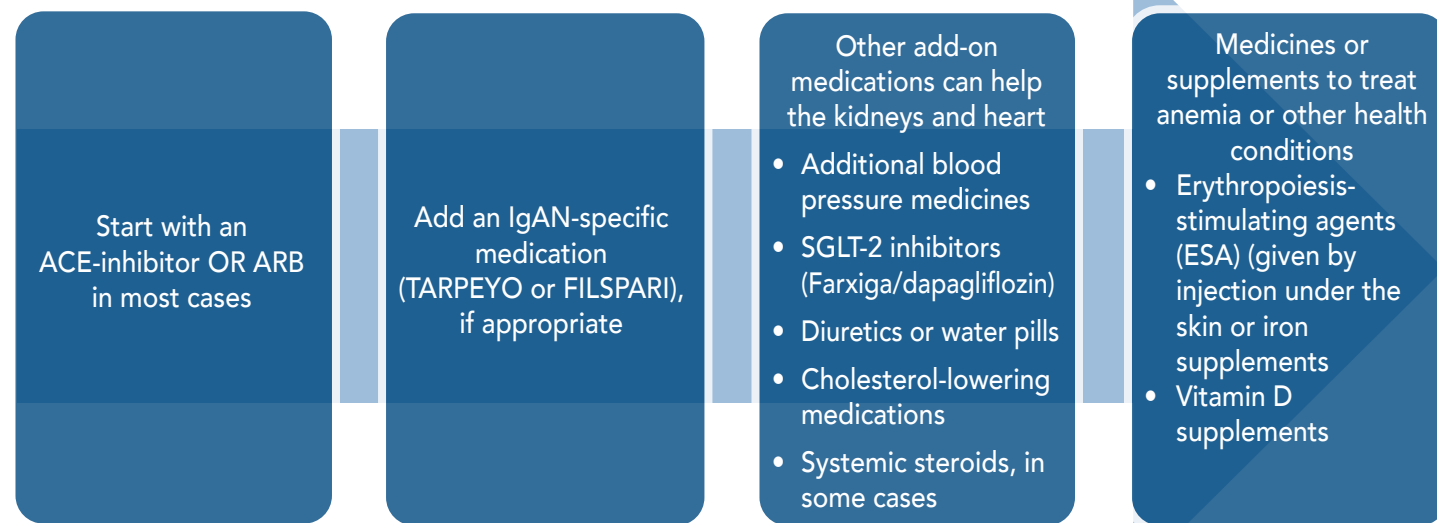
- Erythropoietin stimulating agents (given by injection under the skin)
- Iron supplements
- Vitamin D supplements

*Be sure to ask questions and learn why you are taking each medication – they often work in different ways and each may have added benefits.*

### 6 Medication Tips

- **Take your medications** as prescribed.
- **Don't make any changes** in when or how you take your medications without consulting your care team first. Find out if there are occasions when you might need to stop taking any of your medications for a period of time – if you are ill, have a procedure planned or get very dehydrated, or dry.
- **Ask before starting any new medications.** Certain vitamins, herbal remedies and over-the-counter medications, including NSAIDs (for example, aspirin or ibuprofen), can be harmful to the kidneys. Keep an updated list of everything you take and review it with your care team.
- **Talk about side effects or things that make it difficult** for you to take your medications.
- **Plan ahead** to be sure you get your medicines refilled before your supply runs out.
- **Frequent urine and blood tests** will be needed to keep a close watch on your kidney function and other numbers and see if your treatment is working.

## Quick glance of medications that may be recommended



Medications to help manage diabetes or other conditions you have that can also affect the kidneys.

## Clinical Trials

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

Most new therapies and advances in medicine are because of clinical trials. If you take part in a clinical trial, you will:

- Help other people living with IgA Nephropathy
- Help researchers gather more data to understand more about the condition and find a cure faster
- Be more closely monitored

Ask your care team if a clinical trial is an option for you, and which one 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.). **For a list of active clinical trials, visit [igan.org/clinical-trials](http://igan.org/clinical-trials).**

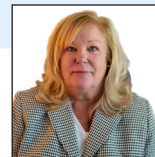
*"As a global community of patients, caregivers, doctors, and researchers, we must continue to work together to find a cure for IgA Nephropathy. We are making great strides."*

**- Professor Jonathan Barratt PhD, nephrologist**



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

**- Bonnie Schneider**



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

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 that these are options if you get to or are nearing that stage.

- **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 one-third of people after transplant.

A kidney can either come from someone who has died or a living donor — a friend, family member, neighbor, or someone else who has said they'd like to be a donor, provided they are a good match for the person who needs a kidney to survive. Talk with family and friends about your disease to help educate them and lay the foundation if you get to the stage when you might need to think about a transplant. Find ways to tell your story.





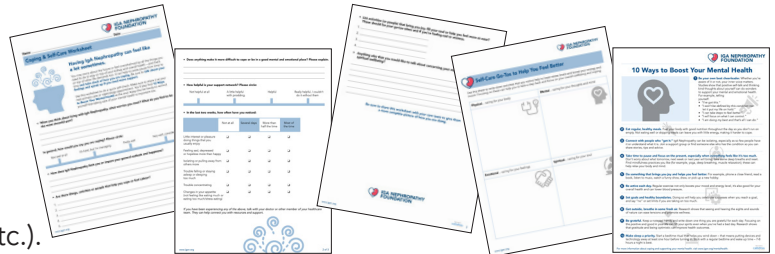
# Minding Your Emotional Health

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.
- **Find support** through family, friends, trusted online support groups, 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, meditation or yoga. Check out our meditation demos.
- **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.).
- **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.



Visit [igan.org/mental-health](http://igan.org/mental-health) and use our worksheets to check in on your mental health and how you're coping.



Use this space to write down activities, people or things that help you stay positive and/or feel better able to cope:

- 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 are new medications available to treat IgA Nephropathy specifically. What do you know about them and might I benefit from one? Can they be used together?
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 planning a family or 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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## 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.

**Blood urea nitrogen (BUN) test** – measures how much urea nitrogen is in your blood. Higher than normal BUN levels may mean your kidneys aren't working well enough to filter and remove urea nitrogen.

**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.

**Glomerular filtration rate (GFR)** – a measure of how well your kidneys are working to filter or "clean" your blood. It estimates how much blood passes through the glomeruli each minute.

**Glomeruli** – tiny filters in the kidneys that remove waste from the blood. Each kidney has a million of these tiny filtering units. With IgAN, IgA can clog and damage these filters.

**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.

**Kidney biopsy** – a procedure to remove a small piece of kidney tissue and examine it under a microscope to look for disease or damage. It is also used to confirm someone has IgAN.

**Mest-C score** – measures the degree of inflammation (M, E and C scores) and chronic scarring (S and T scores) seen on a biopsy of the kidney. These scores can help you and your nephrologist have a sense for how your IgA Nephropathy might progress and may help decide what treatments might work best.

**Nephrologist** – a doctor who specializes in treating diseases that affect the kidneys. "Nephrons" 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. It is usually measured through urinalysis.

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

**Urinalysis** – a test that can check your urine for things like color, blood, odor, sugar (glucose), bacteria, cells, and other things, all of which give a picture of how your kidneys are functioning.

**Urine protein-to-creatinine ratio** – a urine test that measures protein in the urine and monitors kidney function.



## Resources to Help

Our website, [igan.org](http://igan.org), has a growing number of resources, including:

- Up-to-date information about IgA Nephropathy, healthy living, the latest treatments, and a listing of clinical trials
- Downloadable tools and fact sheets to help manage the condition
- Opportunities to connect and share stories



**IgA Nephropathy – What You Need to Know:** A 30+ page booklet with information, tips, and worksheets to help you take an active role in your care



**Peer Support:** Join a virtual support group to connect with others on the same path



**SPARK:** a 2-day annual meeting for patients and caregivers to share stories and learn about IgAN



**Clinical Trials page:** Find opportunities to access new treatments being developed for IgAN



**IgAN Journey:** Our monthly podcast covering important topics



**The IgAN Cookbook:** A cookbook and guide to maintaining a kidney-friendly lifestyle



**Financial Aid:** Learn about grants available to help with treatment costs

*As the only organization serving patients with IgAN, and their caregivers and partners, we are steadfast in our commitment to be the go-to source for information, education, support, and hope.*

## 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 ultimately, a cure.

By patients, for patients.



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

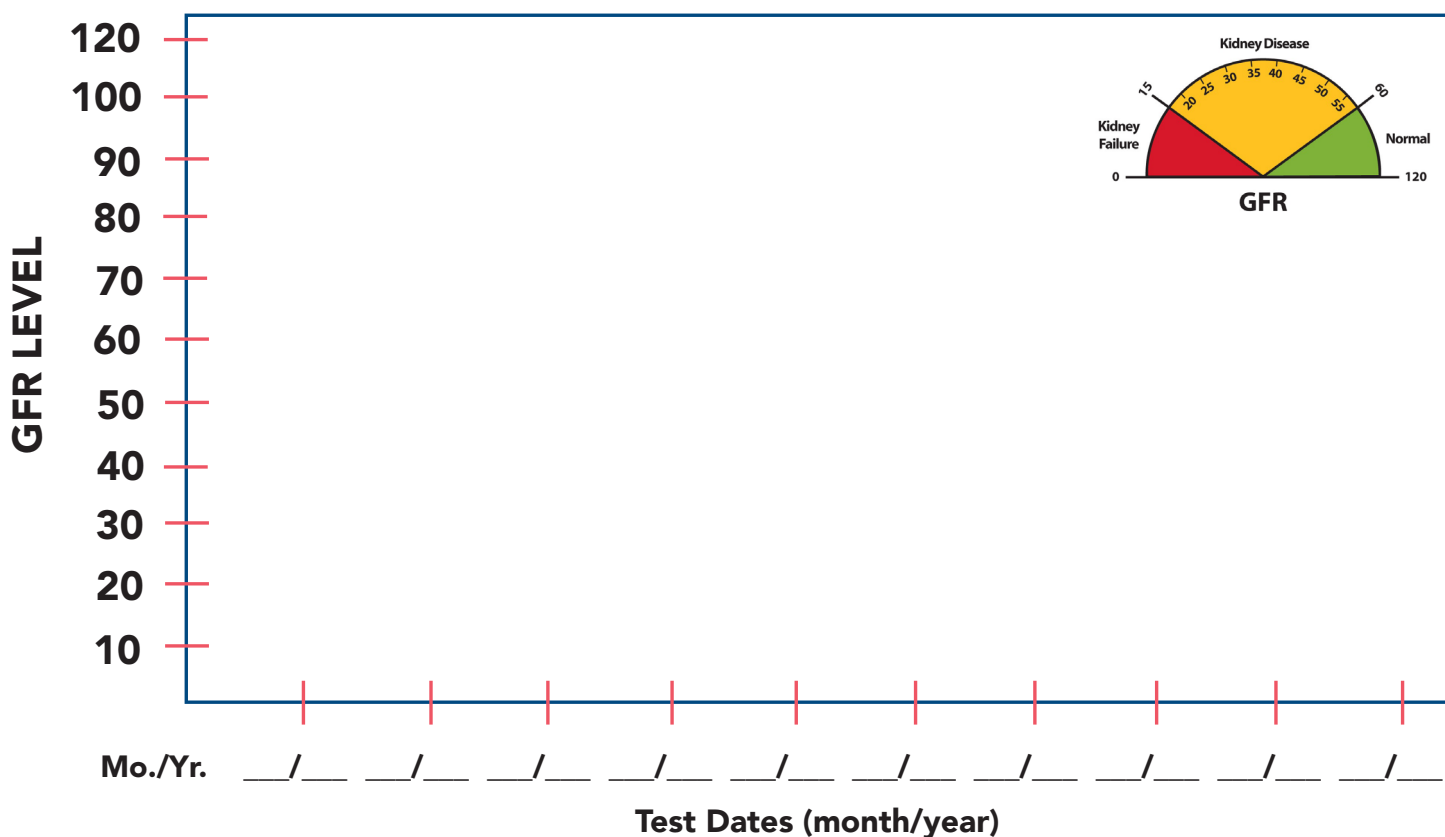


## Tracking Your Labs, Kidney Health and Blood Pressure

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. Your lab results will also help guide treatment decisions.

Use 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). Because your GFR or eGFR and the amount of protein in the urine can fluctuate, it is helpful to keep track of them over time to see whether your kidney function is staying the same or declining.

### Track Your Kidney Health Below



#### GFR

Test date:	____/____/____	____/____/____	____/____/____	____/____/____	____/____/____	____/____/____
GFR number:						

### 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 (systolic top number over diastolic bottom number) using the monthly log on the next page.

Target blood pressure is usually 130/80 mm Hg or under, 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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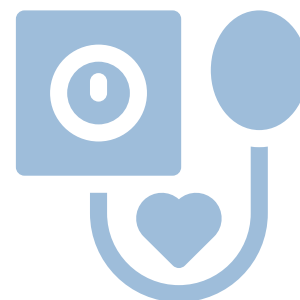
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## Monthly Blood Pressure Readings

If you have high blood pressure, be sure to check it daily. Controlling your blood pressure will also help your kidneys. In fact, it's one of the most important things people with IgAN can do.

Print this page to keep track of your blood pressure.



Month: \_\_\_\_\_

Date	Blood pressure	Date	Blood pressure
1		17	
2		18	
3		19	
4		20	
5		21	
6		22	
7		23	
8		24	
9		25	
10		26	
11		27	
12		28	
13		29	
14		30	
15		31	
16			

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



## IgA Nephropathy Symptom and Wellness 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.

### Signs & Symptoms

	Not at all	Sometimes	Often	Most of the time	All the time
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How often do you have:

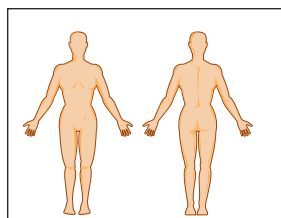
Dark urine ☐ ☐ ☐ ☐ ☐

Frothy or foamy urine ☐ ☐ ☐ ☐ ☐

Less energy/feeling overly tired ☐ ☐ ☐ ☐ ☐

Swelling in my feet, ankles or legs or face ☐ ☐ ☐ ☐ ☐

Pain or discomfort (use the illustration to mark or circle where you have pain) ☐ ☐ ☐ ☐ ☐



Poor appetite ☐ ☐ ☐ ☐ ☐

Nausea or vomiting ☐ ☐ ☐ ☐ ☐

Anxiety and/or depression ☐ ☐ ☐ ☐ ☐

Trouble sleeping, "brain fog" or difficulty concentrating ☐ ☐ ☐ ☐ ☐

High blood pressure ☐ ☐ ☐ ☐ ☐

Other symptoms:

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## How IgA Nephropathy or treatments affect your activities or coping

Have you had any trouble:	Not at All	Sometimes	Often	Most of the time	All the time
Working/being able to meet job responsibilities	<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"/>
Taking care of kids/parents	<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"/>
Intimacy/relationships	<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"/>
Participating in social activities, making plans with friends/family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling happy	<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"/>
Other:					

*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.*



## Emotional health/coping

Living with a chronic disease isn't easy. IgA Nephropathy can be isolating because so few people have it or understand what it is. 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, which could be signs of depression and anxiety, what factors do you think contribute to each?

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What might help:

- Participating in a support group
- Talking with someone else with IgA Nephropathy
- Finding ways to destress – deep breathing, daily medication, massage
- Being active each day
- Setting limits
- Talking with a counselor or mental health professional

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

Dial 988 if you or a loved one is in mental distress or thinking about suicide. Don't delay.

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



# Medication List

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	Dose	How many times a day	Special Instructions? With or w/o food?	What should I do if I miss a dose?	Are there side effects I should be looking for?

For more information about medications, refer to our IgAN patient guide or visit [www.igan.org](http://www.igan.org).

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