

Navigating IgA Nephropathy Treatment Decisions

Finding out that you or a loved one has IgA Nephropathy can be scary and overwhelming, we know. You may feel flooded with emotions and perhaps a little uncertain about the road ahead and what it might mean for you and your family.

The good news is that you're not alone and the future is bright when it comes to living with and managing IgA Nephropathy. There are more treatments being studied than ever before, including novel, targeted therapies designed to specifically treat IgA Nephropathy, one of which became the first to be approved by the U.S. Food and Drug Administration for use in certain adults.

Still, making decisions about your care isn't always easy. To help, we've compiled a basic overview of the factors that can shape treatment options, key considerations to keep in mind when making decisions, as well as tips for playing an active role in your care so you fully understand your choices and can get the care you want.

Factors that influence treatment choices

There are a number of factors that will come into play as you and your health care providers map out the best course of treatment for you both now and in the future.

In general, your treatment will depend on several factors, including:

- Your **medical history**, including other health conditions.
- Your **blood pressure**.
- How much protein is in your urine.** Protein circulates in your blood, but it's not usually found in the urine. Having protein in the urine (called proteinuria or albuminuria) can be a sign of kidney damage.
- Your estimated glomerular filtration rate (eGFR)**, a measure of how much blood your kidneys filter each minute that can help gauge how well your kidneys are working; your eGFR helps to know what **stage of kidney disease** you are in. Stages of kidney disease range from mild loss of kidney function to complete kidney failure that requires dialysis or transplant.
- Results from the biopsy** used to confirm IgA Nephropathy. This can show the extent of inflammation and scarring in your kidneys.
- Other treatments you've tried** and how you responded.
- Your goals and hopes for treatment.**

Your provider might use a risk calculator to plug in information and help determine how quickly your condition may progress. This can also help to guide treatment decisions.

Understanding all of the treatment options that can help to manage IgA Nephropathy can help you ask the right questions and advocate for yourself, especially if there are avenues that better suit your needs.

Understanding your treatment options

The ultimate goal of treatment is to help you feel better, help control the symptoms of IgA Nephropathy and/or prevent or delay end-stage kidney disease.

Treatment of IgA Nephropathy involves a combination of therapies, including health lifestyle and typically several medications that are used for other reasons. Sometimes there is a clear recommendation for treatment and in other cases you might be given a choice between different therapies.

Lifestyle changes

A healthy lifestyle can help manage IgA Nephropathy. For example:

- Eating healthy—Keep your food choices low-sodium (which can help reduce fluid retention), and focus on making plant-based foods the main feature of your meals and limit heavy meals
- Limiting alcohol
- Getting regular physical activity
- Maintaining a healthy weight
- Managing stress and getting high quality sleep
- Not using tobacco

Ask your nephrologist where to start and try not to make too many changes at once.

Medications

Medications are coupled with lifestyle changes to help protect the kidneys and help you feel better. Most people with IgA Nephropathy take several medications. They can help:

- **Reduce protein in the urine.**
- **Lower blood pressure** to help protect the kidneys. Not only can high blood pressure damage the kidneys, but the effects of IgA Nephropathy can raise blood pressure too, placing continued strain on the kidneys. Blood pressure medicines called ACE-inhibitors (medications ending in -pril) or an ARBs (medications ending in -sartan) are commonly used, ideally at the highest dose you can take.

Other medications might be added to meet your blood pressure goal, including spironolactone or aldactone. These also help to reduce the amount of protein in the urine. People with IgA Nephropathy are often asked to monitor their blood pressure daily.

- **Remove excess fluid in the body** with diuretics, also called water pills. Because the kidneys aren't working as well, your body may hold onto fluid and you may notice puffiness or swelling in your legs or ankles (called edema). Diuretics help the body excrete the fluid through the urine.
- **Lower the chance of poor outcomes, including hospitalizations or the need for advanced therapies.** SGLT2 inhibitors, which were initially developed for diabetes, are increasingly being used to slow the progression of kidney disease and protect the kidneys.
- **Reduce blood cholesterol levels** to slow the progression of kidney damage and heart or blood vessel disease. Over time, cholesterol can build up in the artery walls, making it harder for your blood to flow freely. A statin is often started first and other non-statin treatments may be added.
- **Calm the body's immune system and reduce inflammation**, generally by prescribing a corticosteroid or similar medication. The use of systemic steroids is suggested, but not recommended based on clinical guidelines, so it's important to carefully review the pros and cons of using them and the choice is very individual. Newer medicines are designed to target treatment to localized areas of the gut where the condition is thought to originate.
- **Treat complications of kidney disease**, such as anemia (low red blood cell count), bone disease, heart disease, or acidosis (a build-up of acid in the blood); erythropoietin stimulating agents or iron supplements may be used to treat anemia. Vitamin D supplements can help support immune and bone health.

If you have advanced kidney disease, you'll need to learn about and consider dialysis or kidney transplantation.

Clinical trials are also a treatment choice for many patients. Read [Considering a Clinical Trial?](#) to see whether this might be something you are interested in.

Thinking through what you want from treatment

When it comes to making treatment decision for IgA Nephropathy, focusing in on your priorities is important. Asking yourself "What do I most want to achieve from treatment?", "How will this treatment help me feel better and affect my kidney function?", and "What are the upsides and downsides of the treatment?" are all great places to start.

Making treatment decisions

Making decisions about the best treatment path can be a process. The initial step – after coming to terms with your diagnosis – is to gather as much information as you can about your treatment options. Doing so may also help you feel more in control and empowered that there are things you can do to feel better. Be sure to ask your provider how different treatments might affect your day-to-day life.

Play an active role in your care from the start. Don't be afraid to ask questions until you feel fully informed about each one – you are the most important member of your care team.

- **Make a list of the treatments** your care team is recommending—ask how to spell any words you don't know (like drug names) and be sure you understand how each treatment will work, as well as the differences between them.
- **Ask about each option.** For example:
 - **The risks of treatment** – possible short- and long-term side effects
 - **The benefits of treatment** – how will the therapy help you feel better and/or slow declines in your kidney health or function
 - **The evidence** – has the treatment been well-studied? How safe and effective is it? Are certain types of people more likely to benefit or not? Even if it's a new treatment for IgA Nephropathy, has it been used for other conditions?
 - **Costs** – How much does the treatment cost? What will be covered by your insurance? There are prescription assistance programs that can help offset some of the cost.
 - **How the treatment is administered and if you need to travel for treatment**
 - **How it might affect other medical conditions**
 - **Your goals and personal feelings about the treatment.** Write down what you most want to achieve with treatment.
- **Start a pro-con list** to write down and compare the benefits (pros) and downsides (cons) of each treatment. Sitting down and working on this list will also help take out some of the emotions around having IgA Nephropathy so you can focus on and decide which course you might like to take.
- **Talk it out.** It might be helpful to talk through your treatments with someone you trust to help you sort through your thoughts and feelings too.

Remember that even after you decide on a course of treatment, care options and needs change over time—don't be afraid to voice your changing needs to your providers. Don't forget available treatments are likely to change over time with new treatments becoming studied in clinical trials.

Use this worksheet to keep track of treatments you've been on and how they worked.

Seem like a lot? That's because it is. We understand and we're here to help. To learn more, see our *Considering Clinical Trial* page and Tip Sheet for *Doing Your Own Research*.

Considering a Clinical Trial

Clinical trials are a way to test whether a new drug, device or other type of treatment is safe for use in humans, if it has any side effects, if it works better than other treatments, and if it helps improve quality of life. While there is still no cure for IgA Nephropathy, the FDA [recently approved the first drug](#) for IgA Nephropathy based on the results of a clinical trial that found it can reduce urine protein in IgA Nephropathy in some patients.

Who can take part

If you are considering enrolling in a clinical trial, talk with your care team.

Clinical trials are designed so that participants who are included in the study are similar. This helps to ensure that the results are due to what is being studied and not to other factors or chance alone. To accomplish this, each study will outline factors that allow or prevent someone from participating (called inclusion and exclusion criteria). So in order to join a specific study, you must meet certain requirements.

Criteria may relate to:

- Age
- Stage of kidney disease
- Recent labs, for example, how much protein is in the urine, GFR levels
- Medical history and/or previous treatments someone has tried
- Current health status, fitness, and/or functional level
- Other health conditions
- Time since last treatment

Clinical trials aim to show whether a new treatment or procedure:

- Is safe
- Has side effects
- Works better than or just as well as currently available treatments
- Improves your quality of life and how you feel on a day-to-day basis
- Improves other outcomes (slows progression of kidney declines, reduces protein in the urine, improves GFR levels. etc.)

There can be some key benefits and possible risks to participating in a clinical trial.

Possible benefits

- Closer monitoring, with more frequent check-ups, lab work, and other tests
- Access to treatment that is only available as part of the trial and could be better than currently available treatments or make them more effective
- A chance to help improve treatment – and work toward a potential cure for IgA Nephropathy for patients in the future – by helping researchers gather data and better understand the disease

Possible risks

- You may get a placebo (no treatment), instead of the study therapy; the investigational drug and placebo are usually added on to standard medical care
- You may experience new side effects, even though the treatment has been carefully studied in a lab before it moves to clinical trials
- You may not respond to the new treatment
- In some cases, health insurance may not cover it
- You might need to travel and study-related appointments or additional follow up can take more your time.

While not all clinical studies result in new treatments (for example, the study drug may not be found to work or perhaps it has too many side effects when compared with existing treatments), this research invariably adds to our knowledge about IgA Nephropathy and helps build a comprehensive understanding of how to treat it. Amassing as much information as possible helps improve care overall, and having willing clinical trial participants is crucial to the process.

Getting your (informed) consent – a key first step

If you qualify for a study, one of the first things you will do is meet with the research team. They will go over the study in detail. They will also want to get written permission from you that you understand and are OK with participating in the study.

You will be given information about:

- The purpose of the study – what the researchers are hoping to test or find out
- Who is eligible to take part
- What is currently known about the treatment or intervention
- Possible side effects or benefits expected
- How it is decided which study group or treatment you will be in or receive?
- How the study will be conducted and if you will know what treatment you are getting or if that information will be kept from you until the end of the study (this is called blinded); often clinical studies are done by randomly assigning participants to one of two study groups (like drawing names out of a hat), so you won't necessarily have a choice.
- What are the expected costs?
- How will information about me be kept private?
- Your rights and how information about you is protected and that you are able to leave the trial at any time

Question to ask

Remember, it is always your choice to join a clinical trial. So take the time you need to learn about the study and ask questions.

- What are the risks? What do we already know about the drug or other treatment being tested?

- How might the study drug improve how I feel and/or my kidney function now and over time?
- Will I know if I am receiving the study drug or placebo (an inactive treatment)?
- What phase (or stage) is the clinical trial in (studies are conducted in phases that build on one another to answer certain questions). A study may be in Phase 1, 2 or 3 or even to monitor a treatment after it is more widely available to track any long-term data on outcomes or side effects.
- Will I need to plan on extra time or travel?
- Will my insurance cover the treatment?
- How does the study team coordinate with my other doctors?
- Who should I call if I have questions or concerns once the study starts?
- If the treatment works well for me – or people who are in the treatment group – can I keep taking it or ask to start it after the trial ends?

If you are thinking about enrolling in a clinical trial, we have a full list of studies looking at new treatments for IgA Nephropathy on our [Clinical Trials](#) page.

6 Tips for Doing Your Own Research

It's hard not to want to do your own research after learning you have a health condition like IgA Nephropathy. And while you should feel empowered to do your own research, it's also important to make sure the information you find is from credible sources (our website, among them!). Otherwise, you can wind up feeling even more overwhelmed and misled.

Here are some tips to keep in mind as you try to learn more about your condition and how it might impact your life.

1. **Consider where the information is coming from and if it is a reliable source or not.** There are now thousands of medical websites. Some provide reliable, up-to-date health information. Some do not. If what you're reading is from a blog, a web page with no sources credited, or something similar, it's best to do some more digging to make sure the information is accurate and not just one person's opinion.

One helpful trick is to use search terms that include reputable sources too. For example, "CDC and COVID symptoms," or "AAFP and chronic kidney disease," or "MedlinePlus and dialysis." CDC, AAFP, and Medline Plus are known to have up-to-date information that has been vetted by clinicians. As well, [MedlinePlus.gov](https://pubmed.ncbi.nlm.nih.gov/) is a website of the NIH's [National Library of Medicine](https://pubmed.ncbi.nlm.nih.gov/); it will often generate a list of information and links to other trusted sources too, so it's often a good place to start.

An important clue to know the source of the information is to look at how the Web address ends.

- **.edu** is usually published by an organization that is associated with an educational institution such as a university
 - **.gov** belongs to a governmental organization or agency
 - **.org** belongs to a nonprofit, such as the IgA Nephropathy Foundation and many professional medical societies
 - **.com** is usually a for-profit company
2. **If you come across results from what seems like an exciting new study that you think might apply to you, be sure to ask questions.** For example, how many patients were included? Were they a certain age or did they need to have a certain level of protein in the urine or stage of kidney disease to take part? While initial results of some studies are exciting (with good reason), it's important to keep them in perspective.
 3. **Don't spend too much time researching.** Read information from a few sources that seem trustworthy. Share any information you find online with your providers. They can help put the information into context and let you know if it's accurate. Also remember that what is right for one patient may not be for another.

4. **Talk with other people living with IgA Nephropathy.** Hearing first-hand accounts of what it's like to live with IgA Nephropathy or about certain treatments or side effects can help put health care choices in perspective and help answer questions only someone with IgA Nephropathy might know. It will also help you in gathering questions to ask your providers. Still, it's important to keep in mind, everyone's disease course and response to treatment is different.

5. **Be critical of information shared on social media platforms,** such as Facebook groups or other online communities where people connect with others. While some of this information may be true and can serve as a lifeline to others with IgA Nephropathy, some of it may not be. Even though a person sounds knowledgeable, it does not necessarily mean it's true or scientifically accurate. Always be wary of any treatment that claims to be a cure-all.

6. **Find a doctor you trust.** The best source of medical information that is tailored specifically to your condition and your needs should be your care team. If you don't feel as though your doctor has enough experience treating IgA Nephropathy or if you don't feel listened to, it's always OK to get a second opinion.

For more information and support, visit www.igan.org.