EXCALIBUR
MEDICAL EDUCATION



HANDLING THE HARD QUESTIONS:

WHAT OUR PATIENTS ARE ASKING US ABOUT IgA NEPHROPATHY

THE PURPOSE OF THIS DOCUMENT

Patients with newly diagnosed immunoglobulin A (IgA) nephropathy often ask questions about their disease and how it can best be managed. It is important for nephrologists and other clinicians involved in the management of IgA nephropathy to properly and effectively communicate appropriate responses to these questions. This pocket guide includes a brief summary of evidence surrounding some of the most common – and challenging – questions nephrologists and other clinicians are likely to face from their patients with IgA nephropathy. We hope you find this guide useful for your professional development.

CONTENTS

What is IgA nephropathy and how did I get it? 3
How do you know I have IgA nephropathy and not something else? 5
How will my IgA nephropathy be treated? What are my options? 8
Am I eventually going to need dialysis and/or a kidney transplant? 11
How will I know if my IgA nephropathy is getting better or worse? 13
Should I change my diet or lifestyle because I have IgA nephropathy? 16
Will IgA nephropathy affect my ability to start a family? 18
What other doctors or specialists will help manage my IgA nephropathy? 20
What are some of the long-term risks associated with IgA nephropathy? 22



WHAT OUR PATIENTS ARE ASKING US ABOUT IgA NEPHROPATHY

WHAT IS IgA NEPHROPATHY AND HOW DID I GET IT?

IgA nephropathy, also known as Berger's disease, is a kidney disease in which abnormal amounts of protein (ie, IgA) accumulate in the kidneys, causing inflammation and scarring. Over time, ongoing damage reduces the kidneys' ability to filter blood and rid the body of extra waste, salt, and water.[1] IgA nephropathy is most often diagnosed in people between ages 20 and 40 years, but it can happen at any age.[2,3]

Although we don't know exactly what causes IgA nephropathy, certain infections, gastrointestinal conditions, liver problems and/or genetics may play a role. Some patients may experience their first symptoms after a cold or upper respiratory infection. It may also be seen more often in patients with celiac disease, hepatitis B and C, liver cirrhosis, HIV, or a family history of IgA nephropathy.[3,4]

IgA nephropathy symptoms vary in different people. People with IgA nephropathy may have no or few symptoms, or their symptoms may be severe.[1,3] Some possible symptoms of IgA nephropathy include the following:[1-5]

WHAT IS IgA NEPHROPATHY AND HOW DID I GET IT?

- Dark, pink, or tea/cola-colored urine due to blood in the urine (hematuria), especially after a cold or sore throat
- Foamy urine
- Urinating infrequently
- Lower back/flank pain
- Low-grade fever
- Swelling of the hands, legs, ankles, or feet
- Fatigue
- Elevated blood pressure (hypertension)

The symptoms of IgA nephropathy often develop slowly, but they can also sometimes come on quickly. Some people with IgA nephropathy have more severe symptoms and more severe disease than others, which may mean they need more treatment than people with milder disease.[6]

It is important to know there are treatments to help manage your symptoms. Taking care of yourself and working with your healthcare provider can help manage your IgA nephropathy over time.[1,3]

REFERENCES

1. National Institute of Diabetes and Digestive and Kidney Diseases. IgA nephropathy. Available at https://www.niddk.nih.gov/health-information/kidney-disease/iga-nephropathy. Accessed September 24, 2024.
2. Yeo SC, Goh SM, Barratt J. Is immunoglobulin A nephropathy different in different ethnic populations? *Nephrology (Carlton)*. 2019;24(9):885-895.
3. Tashakkorinia N, Muco E, Tudor ME. Berger disease. StatPearls Publishing; 2021.
4. Penfold RS, Prendecki M, McAdoo S, Tam FW. Primary IgA nephropathy: current challenges and future prospects. *Int J Nephrol Renovasc Dis*. 2018;11:137-148.
5. Galla JH. IgA nephropathy. *Kidney Int.* 1995;47(2):377-387.
6. Barbour SJ, Cattran DC, Kim SJ, et al. Individuals of Pacific Asian origin with IgA nephropathy have an increased risk of progression to end-stage renal disease. *Kidney Int*. 2013;84(5):1017-1024.



HOW DO YOU KNOW I HAVE IgA NEPHROPATHY AND NOT SOMETHING ELSE?

If you have symptoms of IgA nephropathy, our team may order tests to help make the diagnosis. Other conditions that can have similar symptoms to IgA nephropathy include the following:[1-4]

- **Urinary tract infections:** People with urinary tract infections may have blood in their urine, back or flank pain, and fever. This can be detected with a routine urine sample at your doctor's office.
- **Kidney stones (urolithiasis):** Back or flank pain, and blood in the urine, may be present. Certain radiologic or imaging studies can be performed to help detect kidney stones.
- **Alport syndrome and thin basement membrane nephropathy (diseases that affect the blood vessel membranes in the kidneys):** People with either of these conditions can also have blood in their urine. A kidney biopsy is needed to tell the difference.
- **Post-streptococcal glomerulonephritis (inflammation of the blood vessels in the kidneys following a streptococcus infection):** A person usually develops symptoms later (10 days or more after an infection, as opposed to less than 5 days as seen in IgA nephropathy). Repeated episodes of blood in the urine are rare in patients with post-streptococcal glomerulonephritis.

HOW DO YOU KNOW I HAVE IgA NEPHROPATHY AND NOT SOMETHING ELSE?

- **Autoimmune diseases like IgA vasculitis/Henoch Schonlein purpura or lupus:** These conditions have specific serologic markers that can confirm/highly suggest their presence.
- **Malignancy or cancer:** Usually other blood tests and radiologic studies will be suggestive of this.

Reviewing your medical history, blood tests, urine tests, and radiologic imaging studies will help to determine if you have IgA nephropathy, but only a kidney biopsy can confirm the diagnosis:[5]

- **Blood tests:** You may have blood tests to check how well your kidneys are functioning and to check for other causes of IgA nephropathy, including liver problems, infections, or problems with your immune system.
- **Urine tests:** Testing may also be done on a urine sample to look for inflammation, blood, protein, or other abnormalities.
- **Imaging:** You may have an ultrasound or CT scan of your abdomen to get a picture of your kidneys to look for signs of damage or blockage to urine flow.
- **Kidney biopsy:** A kidney biopsy is needed to confirm a diagnosis of IgA nephropathy. This is performed by inserting a needle through your back and into your kidney to get a sample of tissue to look at underneath a microscope. You will likely lie on your stomach for this procedure and receive a sedative to help you stay comfortable throughout the process, which takes about an hour.

HOW DO YOU KNOW I HAVE IgA NEPHROPATHY AND NOT SOMETHING ELSE?

REFERENCES

1. Rout P, Limaiem F, Hashmi MF. IgA Nephropathy (Berger Disease). StatPearls Publishing; 2024.
2. Karakonstantis S, Galani D, Korela D, et al. Atypical presentation of IgA nephropathy mimicking acute pyelonephritis. *Case Rep Med*. 2018;2018:9231989.
3. van Paassen P, van Breda Vriesman PJ, van Rie H, Tervaert JW. Signs and symptoms of thin basement membrane nephropathy: a prospective regional study on primary glomerular disease-The Limburg Renal Registry. *Kidney Int*. 2004;66(3):909-913.
4. Filippone EJ, Gulati R, Farber JL. Contemporary review of IgA nephropathy. *Front Immunol*. 2024;15:1436923.
5. IgA Nephropathy. Cleveland Clinic. Available at https://my.clevelandclinic.org/health/diseases/5990-iga-nephropathy. Accessed August 31, 2024.



HOW WILL MY IgA NEPHROPATHY BE TREATED? WHAT ARE MY OPTIONS?

There is no cure for IgA nephropathy, but the symptoms can be managed so that the disease is not as severe. Some people have mild disease and some have more severe disease, which determines treatment options. Symptoms may also come and go, or get better or worse over your lifetime, causing your treatment to change over time.[1,2]

There are many types of medications that are used to treat IgA nephropathy. Most medications help to control blood pressure and/or decrease the amount of protein in the urine.[1,5,6]

- **Antihypertensives (ACE inhibitors or angiotensin receptor blockers):** These medications are used to decrease blood pressure and also help to lower the amount of protein in your urine, preventing further kidney damage. Even if you don't have high blood pressure, these medicines may be used.
- **SGLT2 inhibitors:** These medications are used to treat diabetes and also help reduce the amount of protein in the urine. Even if you don't have diabetes, these medicines may be used. One example of a recently-approved SGLT2 inhibitor is dapagliflozin.
- **Combination angiotensin receptor blocker/endothelin receptor antagonists:** This medication lowers blood pressure and reduces the amount of protein in the urine. One example of an angiotensin receptor blocker/endothelin receptor antagonist that has received increased attention in nephrology guidelines recently is sparsentan.
- **Corticosteroids (steroids):** Corticosteroids such as prednisone help to reduce inflammation that scars the kidneys. Corticosteroids cannot be continued indefinitely due to a high risk of side effects.

HOW WILL MY IgA NEPHROPATHY BE TREATED? WHAT ARE MY OPTIONS?

- **Targeted-release budesonide:** This medication, also known as nefecon, is a newer type of steroid that works in a specific portion of the intestines where the IgA protein is produced. The risk for side effects with this steroid is less than that seen with regular corticosteroids.
- **Immunosuppressants:** These medications help to reduce inflammation by suppressing the immune system and may be prescribed if you are at a higher risk for kidney damage. The most recent FDA-approved immunosuppressant used to treat IgA nephropathy is iptacopan.
- **Other medications under investigation:** Other medications are being investigated in clinical trials for IgA nephropathy, and these may be used if your healthcare provider determines that you are a suitable candidate.

In addition to these medication options, some studies have shown the benefits of tonsillectomy in patients with IgA nephropathy, and it is recommended as a treatment option in some regions around the globe. However, tonsillectomy is not routinely advised within most national guideline recommendations, including in the United States.

HOW WILL MY IgA NEPHROPATHY BE TREATED? WHAT ARE MY OPTIONS?

REFERENCES

1. KDIGO 2021 Clinical Practice Guideline for the Management of Glomerular Diseases. Available at kdigo.org/wp-content/uploads/2017/02/KDIGO-Glomerular-Diseases-Guideline-2021-English.pdf. Accessed September 24, 2024.
2. American Kidney Fund. Physical Activity and Kidney Health. Available at https://www.kidneyfund.org/living-kidney-disease/physical-activity-and-kidney-health. Accessed September 24, 2024.
3. National Kidney Foundation. How much sodium is safe for kidney patients? Available at https://www.kidney.org/news-stories/how-much-sodium-safe-kidney-patients. Accessed August 31, 2024.
4. Jarrick S, Lundberg S, Sundström J, Symreng A, Warnqvist A, Ludvigsson JF. Immunoglobulin A nephropathy and ischemic heart disease: A nationwide population-based cohort study. *BMC Nephrol*. 2021;22(1):165.
5. National Institute of Diabetes and Digestive and Kidney Diseases. IgA Nephropathy. Available at www.niddk.nih.gov/health-information/kidney-disease/iga-nephropathy#treat. Accessed September 1, 2024.
6. Wimbury D, Muto M, Bhachu JS, et al. Targeted-release budesonide modifies key pathogenic biomarkers in immunoglobulin A nephropathy: insights from the NEFIGAN trial. *Kidney Int*. 2024;105(2):381-388.



AM I EVENTUALLY GOING TO NEED DIALYSIS AND/OR A KIDNEY TRANSPLANT?

IgA nephropathy often progresses slowly, not quickly. If you don't have protein in your urine, or only small amounts (<500 mg/day), the risk of your IgA nephropathy worsening to the point of requiring dialysis or a kidney transplant is low.[1,2]

However, if the amount of protein in your urine remains high (>1 g/day), the chance(s) of requiring dialysis and/or a kidney transplant increase to about 15-25% after 10 years of having the disease and to about 20-30% after 20 years of having the disease.[1,2]

- **Dialysis:**
  - **Hemodialysis:** This is a procedure where blood and excess fluid is removed from the body through a needle and sent through a special machine to filter out harmful substances before the "cleaned" blood is returned back into your body. The dialysis needle is usually inserted into a surgically placed arteriovenous graft or surgically created fistula where an artery and vein meet (usually in the arm).[3]
  - **Peritoneal dialysis:** This is a procedure that uses the lining of the abdomen (ie, peritoneal lining) to filter waste and excess fluid from the body. During this procedure, a catheter is surgically inserted into the lower abdomen to allow access to the abdomen.
- **Kidney transplant:** This is a surgery where the healthy kidney of a living or deceased donor is used to replace the functions of the diseased kidney(s) of a patient with IgA nephropathy. The diseased kidney is normally left

AM I EVENTUALLY GOING TO NEED DIALYSIS AND/OR A KIDNEY TRANSPLANT?

in the body, and the new kidney is surgically placed in the abdomen.[4] It is important to recognize that, even after having a kidney transplant, IgA nephropathy can recur in the transplanted kidney. The risk of losing a transplanted kidney to recurrent IgA nephropathy is about 7-10% after 10 years. There are no known treatments to prevent IgA nephropathy from recurring in a transplanted kidney. If this happens, the disease is usually treated in much the same way that IgA nephropathy is treated in a non-transplanted kidney.[5,6]

REFERENCES

1. Reich HN, Troyanov S, Scholey JW, Cattran DC; Toronto Glomerulonephritis Registry. Remission of proteinuria improves prognosis in IgA nephropathy. *J Am Soc Nephrol*. 2007;18(12):3177-83.
2. Coppo R, D'Amico G. Factors predicting progression of IgA nephropathies. *J Nephrol*. 2005;18(5):503-12.
3. Mayo Clinic. Hemodialysis. Available at www.mayoclinic.org/tests-procedures/hemodialysis/about/pac-20384824. Accessed September 10, 2024.
4. National Kidney Foundation. Kidney transplant. Available at www.kidney.org/kidney-topics/kidney-transplant. Accessed September 10, 2024.
5. Frohnert PP, Donadio JV Jr, Velosa JA, Holley KE, Sterioff S. The fate of renal transplants in patients with IgA nephropathy. *Clin Transplant*. 1997;11(2):127-33.
6. Choy BY, Chan TM, Lai KN. Recurrent glomerulonephritis after kidney transplantation. *Am J Transplant*. 2006;6(11):2535-42.



HOW WILL I KNOW IF MY IgA NEPHROPATHY IS GETTING BETTER OR WORSE?

Although we can't always predict whether your IgA nephropathy will get better or worse, you can be on the lookout for "red flags" that may signal your condition is worsening. The symptoms of worsening IgA nephropathy are the same as the initial symptoms of IgA nephropathy and may include the following:[1-5]

- Dark, pink, or tea/cola-colored urine due to blood in the urine (hematuria)
- Foamy urine
- Urinating infrequently
- Back/flank pain
- Low-grade fever
- Swelling of the hands, legs, ankles, or feet
- Fatigue
- Elevated blood pressure (hypertension)

Arrangements will be made to monitor your symptoms, vital signs, and lab results at certain intervals, usually every 2-3 months, although this may be done more frequently if you are prescribed stronger medications. Tests that may be checked include the following:[1-3]

- **Blood pressure:** This may be checked in our office with a blood pressure cuff wrapped and inflated around your upper arm or at home with a blood pressure monitor. Ideally, your blood pressure is taken while you are seated and calm. The usual goal for blood pressure management in patients with IgA nephropathy is a systolic blood pressure (SBP) of <120 mmHg.
- **Blood tests**
  - ▷ **Serum creatinine (sCr):** Creatinine is a normal waste product that results from the breakdown of your muscles

HOW WILL I KNOW IF MY IgA NEPHROPATHY IS GETTING BETTER OR WORSE?

as well as from animal protein in your diet. When you have IgA nephropathy, your kidneys are unable to filter sCr out of the bloodstream, and levels rise.

- **Estimated glomerular filtration rate (eGFR):** This is a blood test that estimates how well your kidneys are working to filter the blood of waste. The lower this number is, the lower the ability of your kidneys to filter blood.

- **Urine tests**
  - **Urinalysis (U/A):** A urine sample collected at a single point in time, usually at our office, may be required to check for blood or protein in your urine. Normally, there should be no blood or protein present.
  - **Urine protein-to-creatinine ratio (Upro/Cr):** This is another urine test collected at a single point in time. The amount of protein in the urine is divided by the amount of creatinine in the urine, and a higher value may signal that your disease is worsening.
  - **24-hour urine collection:** You may be asked to collect your urine for 24 hours at home in a special container, then bring it to our office for testing to see how much protein is in it. A usual goal of IgA nephropathy treatment is to reduce this protein level to less than 1,000 mg (or 1 gram) a day.

There is no way to predict when or if your IgA nephropathy is going to worsen, and by the time you have symptoms, changes may have already been taking place in your kidneys. In other words, you can't always tell what's going on in your kidneys by how you feel. The most important thing is to call us right away if you think you are having any symptoms. We can then perform testing to determine if your IgA nephropathy is worsening. The sooner any issues are identified, the sooner you can be treated appropriately.

HOW WILL I KNOW IF MY IgA NEPHROPATHY IS GETTING BETTER OR WORSE?

REFERENCES

1. National Institute of Diabetes and Digestive and Kidney Diseases. IgA nephropathy. Available at www.niddk.nih.gov/health-information/kidney-disease/iga-nephropathy. Accessed July 31, 2024.
2. Cleveland Clinic. IgA nephropathy. Available at my.clevelandclinic.org/health/diseases/5990-iga-nephropathy. Accessed August 31, 2024.
3. National Kidney Foundation. IgA nephropathy. Available at www.kidney.org/kidney-topics/iga-nephropathy. Accessed September 1, 2024.
4. Penfold RS, Prendecki M, McAdoo S, Tam FW. Primary IgA nephropathy: Current challenges and future prospects. *Int J Nephrol Renovasc Dis*. 2018;11:137-148.
5. Galla JH. IgA nephropathy. *Kidney Int*. 1995;47(2):377-387.



SHOULD I CHANGE MY DIET OR LIFESTYLE BECAUSE I HAVE IgA NEPHROPATHY?

It is important for all patients with IgA nephropathy to adjust lifestyle practices that may affect their kidney health. Here are some diet and lifestyle issues you may want to consider:[1-4]

- **Exercising regularly:** Exercise is safe for patients with IgA nephropathy. If you are not accustomed to exercise, it's OK to start slowly. For example, taking short walks with an eventual goal of ≥150 minutes of moderate exercise weekly is great. Always check with our team when starting a new exercise routine to make sure it is safe for you.
- **Maintaining a healthy weight:** It's important to know that obesity can be associated with worse IgA nephropathy symptoms, so one goal for patients with IgA nephropathy is to maintain a healthy weight. Our team can assist you in determining a healthy target weight.
- **Limiting the amount of salt in your diet:** Our team can assist you in determining how much salt you should consume on a daily basis. Usually, around 1,500 mg (about ¾ teaspoon) a day is appropriate.

SHOULD I CHANGE MY DIET OR LIFESTYLE BECAUSE I HAVE IgA NEPHROPATHY?

- **Smoking cessation:** Since smoking can be associated with worsening kidney disease, it's best to quit smoking. Be sure to talk to us about this, since we may be able to prescribe nicotine patches or gum to help.
- **Addressing any existing heart-related conditions:** Since patients with IgA nephropathy are at an increased risk for heart disease, it's important to be screened for and address any co-existing heart-related conditions.
- **Switching to a kidney-friendly diet:** This may include a low-fat, low-protein diet that consists of 0.6-0.8 grams of protein per kilogram of body weight daily. It is also important to stay hydrated; however, high amounts of fluid intake can also overwork your kidneys. Limited alcohol use is also recommended. A dietician can help tailor the right plan for your needs.

REFERENCES

1. KDIGO 2021 Clinical Practice Guideline for the Management of Glomerular Diseases. Available at kdigo.org/wp-content/uploads/2017/02/KDIGO-Glomerular-Diseases-Guideline-2021-English.pdf. Accessed September 24, 2024.
2. American Kidney Fund. Physical Activity and Kidney Health. Available at https://www.kidneyfund.org/living-kidney-disease/physical-activity-and-kidney-health. Accessed August 31, 2024.
3. National Kidney Foundation. How much sodium is safe for kidney patients? Available at https://www.kidney.org/news-stories/how-much-sodium-safe-kidney-patients. Accessed August 31, 2024.
4. Jarrick S, Lundberg S, Sundström J, Symreng A, Warnqvist A, Ludvigsson JF. Immunoglobulin A nephropathy and ischemic heart disease: a nationwide population-based cohort study. *BMC Nephrol.* 2021;22(1):165.
5. IgA Nephropathy Foundation. IgAN nutrition. Available at www.igan.org/nutrition/. Accessed September 25, 2024.
6. Patel J, Kalantar-Zadeh K, Betz M, Joshi S. A low-protein, plant-dominant gluten-free diet for immunoglobulin A nephropathy and focal segmental glomerulosclerosis. *Adv Kidney Dis Health*. 2023;30(6):517-522.



WILL IgA NEPHROPATHY AFFECT MY ABILITY TO START A FAMILY?

Since IgA nephropathy commonly occurs in young men and women, it is important to know how your disease may affect fertility. It is also important to know how to approach pregnancy planning and how to manage pregnancy once you've been diagnosed with IgA nephropathy.

Female fertility: Women with advanced kidney disease or kidney failure may experience low fertility or infertility because of abnormal menstrual cycles. If you require dialysis, increasing or intensifying your dialysis regimen may help to normalize menstrual cycles and improve your chances of becoming pregnant. Likewise, fertility odds may also improve after a kidney transplant.[1]

Risk(s) to mother and infant: Overall, pregnant women with IgA nephropathy are at higher risk for preeclampsia (high blood pressure and protein in the urine, also known as toxemia), low birth-weight infants, and premature delivery.[2]

If your kidney function is reduced (eGFR <70 ml/min) or your blood pressures are elevated (consistently >140/90 mmHg) before pregnancy, it's more likely that you will have pregnancy-related problems as listed earlier, as well as a higher mortality risk for your baby.[3,4]

If your kidney function is normal or only slightly low, and your blood pressure remains well-controlled, you can expect few, if any, problems during pregnancy, and little to no effect on worsening of your IgA nephropathy. Likewise, the chance of having a healthy infant at delivery is excellent.[3,4]

Therefore, it's important to have discussions with our team regarding goals to normalize your blood pressure and achieve an eGFR >70 ml/min on bloodwork when deciding to attempt pregnancy.[3,4]

WILL IgA NEPHROPATHY AFFECT MY ABILITY TO START A FAMILY?

Medications during pregnancy: While you are pregnant, certain medications should be avoided while others may be started even before you become pregnant. It's important to discuss these with either a member of our team or a preconception counselor.[3,4]

- Certain medications that decrease your blood pressure, like ACE inhibitors or angiotensin II receptor blockers, must be either stopped or switched to a different medication if you have IgA nephropathy and plan to become pregnant.
- If you have been told you are at high risk for chronic kidney disease due to your IgA nephropathy, we may also prescribe new medications to suppress your immune system, and therefore improve your kidney function, before attempting pregnancy.

Male fertility: Men with IgA nephropathy who have advanced kidney disease or kidney failure may also experience low fertility or infertility. This may improve partially with kidney transplantation.[5]

REFERENCES

1. American Kidney Fund. Family planning and kidney disease: Fertility and sexual health. Available at https://www.kidneyfund.org/article/family-planning-and-kidney-disease-fertility-and-sexual-health. Accessed August 31, 2024.
2. Jarrick S, Lundberg S, Stephansson O, et al. Pregnancy outcomes in women with immunoglobulin A nephropathy: a nationwide population-based cohort study. *J Nephrol*. 2021;34(5):1591-1598.
3. Abe S. The influence of pregnancy on the long-term renal prognosis of IgA nephropathy. *Clin Nephrol*. 1994;41(2):61-4.
4. Abe S. Pregnancy in IgA nephropathy. *Kidney Int*. 1991;40(6):1098-102.
5. Lundy SD, Vij SC. Male infertility in renal failure and transplantation. *Transl Androl Urol*. 2019;8(2):173-181.



WHAT OTHER DOCTORS OR SPECIALISTS WILL HELP MANAGE MY IgA NEPHROPATHY?

Getting the best care for your IgA nephropathy may mean that you need to see a few different specialists over the years. These may include the following:[1-3]

Nephrologist: IgA nephropathy is usually managed by a nephrologist. This is a doctor who specializes in diagnosing and treating kidney conditions. Sometimes, nephrologists are also called kidney doctors. You will have regular appointments with your nephrologist to guide the medical treatment for your IgA nephropathy. Nephrologists may also have nurses, nurse practitioners, and physician assistants who work with them to help care for you.

Radiologist: Many people with IgA nephropathy require a kidney biopsy. If this is not performed by your nephrologist, you may be referred to a radiologist. A radiologist is a doctor who specializes in diagnosing diseases with imaging procedures like X-rays, CTs, or an ultrasound. A radiologist can perform your biopsy more precisely using this equipment.

Surgeon: If your IgA nephropathy worsens to the point of requiring dialysis or a kidney transplant, you will need a surgeon who performs these procedures to be a part of your care team.

Primary care provider: Even though you will have specialized doctors to treat your IgA nephropathy, it's important to still see your primary care provider. You will need vaccines and other screening tests that only your primary care provider can prescribe.

Dietician: Since treating your IgA nephropathy may involve some changes to your diet, you may meet with a dietician. Registered dieticians have special training to help you choose the best diet for maintaining your kidney health.

WHAT OTHER DOCTORS OR SPECIALISTS WILL HELP MANAGE MY IgA NEPHROPATHY?

Psychiatrist, psychologist, or other therapist/counselor, including social workers: It's common for people with IgA nephropathy to experience stress associated with their disease, especially if a kidney transplant is required. If this is an issue for you, a psychiatrist, psychologist, or therapist may be part of your healthcare team. It's important to let a member of our team know if you're experiencing feelings of anxiety or depression so we can refer you for treatment. Likewise, if you are having financial difficulties or problems affording treatment, a social worker may also prove helpful.

Other sub-specialty health care providers: You may also need to see other types of specialists depending on your specific IgA nephropathy symptoms. For example, if you have a history of heart disease, this can potentially worsen your kidney disease, and you will be encouraged to keep regular follow-up appointments with a cardiologist.

Some people also find it helpful to join a support group of others with IgA nephropathy. This allows you to meet other people with IgA nephropathy, share your experiences, and offer each other support. The IgA Nephropathy Foundation is a good place to find a local support group.[4]

REFERENCES

1. KDIGO 2021 Clinical Practice Guideline for the Management of Glomerular Diseases. Available at kdigo.org/wp-content/uploads/2017/02/KDIGO-Glomerular-Diseases-Guideline-2021-English.pdf. Accessed September 24, 2024.
2. Sharecare. Understanding and Treating IgA nephropathy – What healthcare providers treat IgA nephropathy? Available at www.sharecare.com/kidney-urinary-health/kidney-disease-failure/healthcare-providers-iga-nephropathy. Accessed August 31, 2024.
3. Bayliss EA, Bhardwaja B, Ross C, Beck A, Lanese DM. Multidisciplinary team care may slow the rate of decline in renal function. *Clin J Am Soc Nephrol*. 2011;6(4):704-10.
4. IgA Nephropathy Foundation. Latest News & Resources About IgAN. Ambassador Program. Available at igan.org/#:~:text=The%20IgA%20Nephropathy%20Foundation%27s%20mission,building%20a%20network%20of%20support. Accessed August 31, 2024.



WHAT OUR PATIENTS ARE ASKING US ABOUT IgA NEPHROPATHY

WHAT ARE SOME OF THE LONG-TERM RISKS OF IgA NEPHROPATHY?

IgA nephropathy is typically a chronic disease that affects people for the rest of their lives. Although the majority of patients have mild or moderate disease, approximately 25-30% of patients with IgA nephropathy experience **kidney failure or end-stage kidney disease (ESKD)** within 20-25 years; this typically requires dialysis or a kidney transplant. Once this occurs, there is an approximate 6-year decrease in overall life expectancy.[1,2]

Some other long-term **non-kidney-related complications** that patients with IgA nephropathy may experience include the following:[2-6]

- **Worsening hypertension (high blood pressure):** Extra buildup of fluid and waste products in the bloodstream, as seen in IgA nephropathy, can be associated with a new diagnosis of high blood pressure or worsening of a prior diagnosis.
- **Low blood counts (anemia):** When you have IgA nephropathy, you may also experience low hemoglobin levels, or anemia, since the kidneys help to regulate red blood cell production. Hemoglobin is a protein in red blood cells that helps to carry oxygen to your organs. When this is decreased, you may experience excessive tiredness or weakness.
- **Hypercholesterolemia:** When your kidneys aren't working well, the way your body handles cholesterol is also affected. High cholesterol levels are commonly seen in patients with IgA nephropathy and can raise your risk for cardiovascular disease.
- **Cardiovascular disease:** Patients with IgA nephropathy have a higher rate of cardiovascular disease, including heart attacks, strokes, and congestive heart failure, compared with the general population. Heart-related conditions

WHAT ARE SOME OF THE LONG-TERM RISKS OF IgA NEPHROPATHY?

are a leading cause of death in patients with IgA nephropathy, so it is important to be screened and treated for any co-existing heart disease.

- **Medication-related side effects:** It's important to remember that patients with IgA nephropathy who require stronger medications (such as steroids or immunosuppressants) are also at higher risk for medication side effects. Some of these side effects include infections, fluid retention, weight gain, diabetes mellitus, and osteoporosis. When discussing your treatment plan with our team, be sure to ask about both the short-term and long-term risks of any medications you plan to take.[7]

REFERENCES

1. KDIGO 2021 Clinical Practice Guideline for the Management of Glomerular Diseases. Available at kdigo.org/wp-content/uploads/2017/02/KDIGO-Glomerular-Diseases-Guideline-2021-English.pdf. Accessed September 24, 2024.
2. Jarrick S, Lundberg S, Welander A, et al. Mortality in IgA nephropathy: A nationwide population-based cohort study. *J Am Soc Nephrol*. 2019;30(5):866-876.
3. Mayo Clinic. IgA Nephropathy (Berger Disease) – Symptoms and Causes. Available at www.mayoclinic.org/diseases-conditions/iga-nephropathy/symptoms-causes/syc-20352268. Accessed August 31, 2024.
4. Rout P, Limaiem F, Hashmi MF. IgA Nephropathy (Berger Disease). In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2024.
5. Lv J, Xu D, Perkovic V, et al; TESTING Study Group. Corticosteroid therapy in IgA nephropathy. *J Am Soc Nephrol*. 2012;23(6):1108-16.
6. Zhang K, Wang MD, Jiang SS, et al. Is serum hemoglobin level an independent prognostic factor for IgA nephropathy? A systematic review and meta-analysis of observational cohort studies. *Ren Fail*. 2023;45(1):2171885.
7. Ștefan G, Zugravu A, Stancu S. Mortality in IgA nephropathy: A long-term follow-up of an Eastern European cohort. *Medicina* (Kaunas). 2024;60(2):247.

This resource is supported by an independent educational grant from
Otsuka America Pharmaceutical, Inc.

EXCALIBUR
MEDICAL EDUCATION

www.excaliburmeded.com

Excalibur Medical Education offers this resource for educational purposes only. Healthcare professionals are expected to employ their own knowledge and judgment during discussions with, or treatment of, their patients.

Copyright © 2024