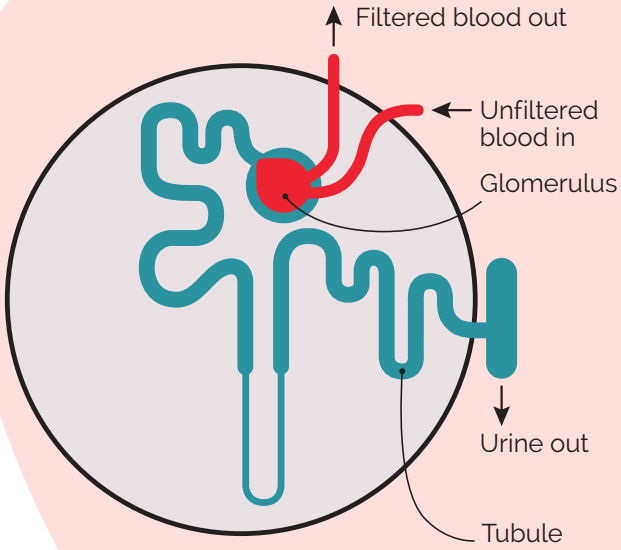
Kidney Health® Australia

IgA nephropathy

How do the kidneys work?

The kidneys are two large bean-shaped organs located in your lower back. Each kidney contains up to one million tiny filtering units, called nephrons.

Inside a nephron, there is a tiny set of blood vessels called the glomerulus. The glomeruli filter your blood, allowing extra fluid and waste to pass into your urine (wee). In a healthy kidney, this filter helps to keep blood cells and protein out of your urine.

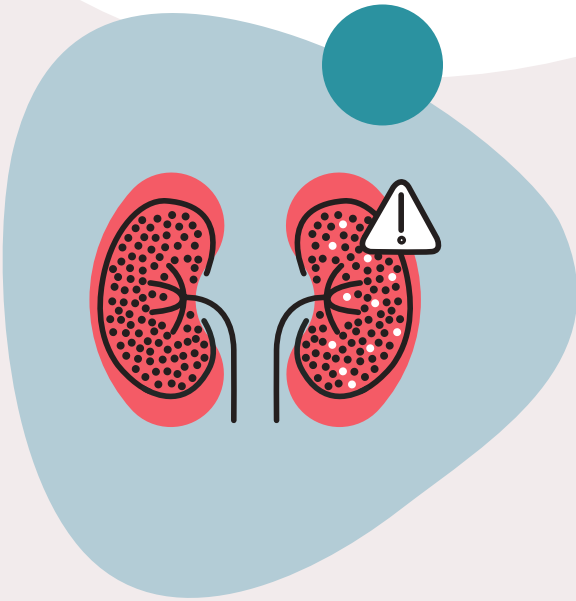


A diagram of a nephron

What is IgA nephropathy?

Although IgA nephropathy (IgAN) is one of the most common diseases that affects the filtering units (the glomeruli) of the kidney, it is not common in the general population.

IgA refers to the **immunoglobulin A (IgA)** protein. This protein is a normal part of your immune system, which helps to fight germs. In IgA nephropathy, this protein does not form properly. This IgA can get stuck in the kidney filters and cause swelling and scarring, making it harder for the kidneys to do their job.



When the filters are damaged, blood and protein can leak into the urine. IgA nephropathy is a long-term (chronic) condition.

In some people, the condition is mild. In others, the damage slowly gets worse and can lead to kidney failure. This factsheet covers IgA nephropathy, a chronic kidney disease, and its treatment and monitoring.

What causes IgA nephropathy?

Doctors do not know exactly what causes IgA nephropathy. It is likely due to a mix of:

- **Changes in the immune system.**
- **Genes (things you inherit from your parents).**
- **Triggers such as infections (for example colds or sore throats).**

Researchers now understand that IgA nephropathy involves changes in how the immune system makes IgA. Scientists found out that special cells in your body, called B cells, make this IgA. In IgA nephropathy, the B cells make abnormal IgA which clog the kidney filters, causing damage.

Certain genes may raise your chances for getting IgA nephropathy. It's more common in some families and some groups of people with East Asian or Caucasian backgrounds. However, it is not usually directly passed from a parent to a child in a simple way.

How IgA nephropathy can vary

IgA nephropathy can affect people differently. Some people have mild kidney problems and may not have symptoms for many years. Others may have clear signs, as kidney damage gets worse. Usually IgA nephropathy is progressive, meaning it worsens over time.

Signs like blood or protein in the urine or high blood pressure are common in IgA nephropathy. Your doctor will watch these signs to monitor damage to the kidneys. That's why regular check-ups to monitor your kidney health are important.

How fast the disease gets worse varies from person to person. It depends on your overall health and how much kidney damage you have.

Over a lifetime, about 4 in 10 people may develop kidney failure from IgA nephropathy. If this happens, your doctor may suggest treatments like dialysis or kidney transplant.

What are the symptoms of IgA nephropathy?

If you have IgA nephropathy, you may not have any symptoms at first. 90% of kidney function can be lost without experiencing any symptoms. Early signs are blood or protein in your urine, which are often found by chance on routine tests. This is why early testing and regular check-ups are important.

IgA nephropathy may cause symptoms in some people, which can include:

High blood pressure

Pink, reddish or brown coloured urine due to blood in your urine (haematuria)

Frothy or foamy urine (proteinuria)

The need to pass urine more often, sometimes during the night

Tiredness

Swelling of the feet, ankles, hands, or face

Shortness of breath

High blood pressure is common in IgA nephropathy. If left untreated, this can increase the risk for kidney disease, heart attacks, or stroke.

If you notice blood in your urine or any of these symptoms, especially after an illness, be sure to check with your doctor to have your kidneys checked.

IgA nephropathy in children and young people

IgA nephropathy can occur in children and young people, although it is more commonly diagnosed in early adulthood.

In younger people, blood in the urine may first appear after an illness, such as a sore throat or cold. Children may also have a red or purple rash on the legs or buttocks and/or belly pain. Let the doctor know if your child has these symptoms.

Children and young people may have mild disease, which is why continued check-ups with the doctor are important. They will continue to monitor how well the kidneys are working and for signs of damage.

Blood in the urine is common in IgA nephropathy. You may notice your urine looks brown or reddish, often during or soon after a cold, sore throat, or other infection. Sometimes the blood is too small to see. A simple urine test can check for blood even when your urine looks normal.

How is IgA nephropathy diagnosed?

IgA nephropathy is usually found during routine testing. The best way to check for problems with your kidneys is through a Kidney Health Check. A Kidney Health Check is quick and simple, involving:

A **blood pressure check** to see if you have high blood pressure. High blood pressure can damage your kidneys and kidney disease can cause your blood pressure to increase.

A **urine test** to see if any blood or albumin (protein) is present in your urine. Blood and albumin in your urine can be a sign of damage or scarring in the kidneys.

A **blood test** to check your kidney function. This test will measure how well your kidneys are filtering your blood and is called estimated glomerular filtration rate (eGFR).

Your doctor will use these tests and a physical exam to see if you have signs of IgA nephropathy. If your doctor finds blood or protein in your urine, this could be a sign of kidney damage.

The only way to be sure you have IgA nephropathy is through a test called a **kidney biopsy**. This means taking a tiny piece of kidney to look at under a microscope. It helps them see how much damage there is.

The biopsy shows what your kidneys look like right now. Your doctor will keep testing you to see if things change.

Your doctor can also use tools to work out your risk for kidney failure. Finding and treating IgA early through medicine and healthy habits can help slow down damage to your kidneys. After diagnosis, regular monitoring is important for all children and adults with IgA nephropathy.

Should my family members be tested for IgA nephropathy?

Deciding whether family members should be tested is a personal decision. IgA nephropathy is not usually directly inherited, but in some families may have a higher chance of the disease.

If you are concerned about your family members, speak to your doctor. They may recommend simple tests, such as urine and blood tests, to check for signs of kidney disease.

Your doctor can help you understand the benefits and limits of testing. They will support you in making the best decision for you and your family.

Planning for a family when you have IgA nephropathy

If you are planning a pregnancy, speak to your kidney specialist early.

Some medicines used to treat IgA nephropathy are not safe in pregnancy and may need to be stopped or changed before you become pregnant. If you are pregnant or planning a pregnancy, speak to your kidney doctor before stopping, starting, or changing any medicines.

During pregnancy you may need regular blood pressure checks, blood tests and urine tests, as well as close follow-up with your kidney doctor and obstetric team.

How is IgA nephropathy treated?

While there is currently no cure for IgA nephropathy, lifestyle changes, good blood pressure control, and medicines can help. Treatment helps slow down kidney damage. The main goals of treatment are to:

- **lower blood pressure**
- **lower protein in your urine**
- **protect kidney function**
- **manage symptoms.**

Lifestyle changes and good blood pressure control are important, and for many people this may be the main treatment required. Others need medicines to help slow down damage to kidneys, lower protein in the urine, and treat symptoms.

ACE inhibitors (medicines ending in -PRIL) or **ARBs** (medicines ending in -SARTAN) help to lower blood pressure which lessens the stress on the kidney's filters. These medicines also help to lower protein in the urine which helps to protect your kidneys.

SGLT-2 inhibitors (medicines ending in -FLOZIN) can lower the protein in your urine and may help keep your kidneys working for longer. These may be added if the protein in your urine remains high.

There are newer medicines available for IgA nephropathy that act on the immune system. Some target pathways involved in making abnormal IgA (such as BAFF and APRIL pathways), reduce swelling, and slow kidney damage. These medicines are usually considered for people at high risk of kidney failure. Talk to your doctor to see if these new treatments are right for you.

Scientists are testing new medicines and approaches for IgA nephropathy to see if they can help to slow down kidney disease. There are ongoing studies for new treatments of IgA nephropathy. Ask your kidney doctor if a clinical trial is right for you.

Do not stop, start or change your medicines without speaking to your doctor. Remember that regular visits to a doctor or kidney specialist are important for anyone with IgA nephropathy. Your kidney doctor will help decide which medicines and treatments are right for you.

When kidneys are damaged, protein can leak into your urine. Lowering protein in the urine helps protect your kidneys.

Managing the symptoms of IgA nephropathy

Lowering blood pressure and keeping a healthy weight and lifestyle are key to taking care of IgA nephropathy. Your doctor will work with you to manage these symptoms, by suggesting medicines or lifestyle changes.

- **High blood pressure:** Keeping it under control helps protect your kidneys. Medicines, less salt, and regular exercise can help.
- **Protein in your urine:** This sign of kidney damage is treated with medicines. Lowering protein leakage helps protect your kidneys.
- **Swelling:** You may notice swelling in your legs or around your eyes. Less salt and medicine can help.
- **Blood in your urine:** You may see blood, often during or after an illness. Let your doctor know if it keeps happening.
- **Tiredness:** You may feel very tired if your kidneys are not working well. Sometimes, this could be caused by anaemia, a condition where your blood cells are low or not working properly. Your doctor can prescribe medicines to help.

Chronic kidney disease (CKD): Kidney function may get worse over time. Medicines and a healthy lifestyle can help slow this. If kidney failure develops, you may need treatments like dialysis or kidney transplant. Our **'My Kidneys, My Choice'** resource can help you and your doctor choose the best treatment for you.

Support is available

Being diagnosed with IgA nephropathy can feel overwhelming. You may feel worried, stressed, or uncertain about the future. Speak to your doctor, a family member, or a social worker if you are having trouble coping.

Know that you are not alone. It may help to speak with someone who understands kidney disease from a lived experience. Our **Kidney Health 4 Life** Community Hub can connect you with peer support, linking you with those facing similar challenges. Visit **kidneyhealth4life.org.au** to learn more.

If you feel overwhelmed and need professional mental health support, you can call the **Beyond Blue** support line at **1300 224 636** or visit **beyondblue.org.au**. For crisis support, call **Lifeline** at **13 11 14** or visit **lifeline.org.au**.

There are also support organisations and patient groups for people living with IgA nephropathy. To learn and connect with others in a similar situation, you can visit the **IgA Nephropathy Foundation** at **igan.org/go-global/australia**.

KIDNEY HEALTH 4 LIFE®

Healthy habits to support your kidneys

Going to your doctor appointments and taking your medicine help keep your kidneys healthy for many years. Healthy eating, exercise, and not smoking all help protect your kidneys. These healthy habits work together with your medicine to help keep you well.

Maintain a **healthy diet** full of wholegrains, fruits, and vegetables.

Reduce salt in your diet. Avoid adding salt at the table. Use other herbs and spices to flavour your foods.

Keep a **healthy weight**.

Get enough **exercise**. Aim for 150 - 300 minutes of moderate-intensity exercise per week.

Quit smoking or vaping. Call the **Quitline** at **13 78 48** for free support to stop smoking or vaping.

While there is no specific diet for IgA nephropathy, you may be advised to reduce salt intake and follow a balanced, healthy diet.

If you need help with your diet, talk to an Accredited Practising Dietitian with special training in kidney disease. They can tailor a meal plan to your needs, including any limits on certain nutrients and your stage of kidney disease.

To better support your kidney health and wellbeing, check out **Kidney Health 4 Life**, where you can access guidance on kidney disease management, practical diet and lifestyle resources, plus connection to others in the kidney community. Visit **kidneyhealth4life.org.au** to learn more.

Things to remember:

- ✓ IgA nephropathy is a common kidney condition that **affects the filtering units** of the kidneys.
- ✓ It's a chronic condition that slowly worsens over many years. **Early detection is important**, as treatments can help slow down damage to the kidneys.
- ✓ Blood in the urine, protein in the urine and high blood pressure are common signs.
- ✓ **Regular check-ups**, good blood pressure control and medicines to reduce protein in the urine help protect your kidneys.
- ✓ Scientists are studying **new treatments** to slow down IgA nephropathy and improve the condition.

What does that word mean?

Albuminuria – Occurs when albumin is present in the urine. There are filters in the kidneys that prevent large molecules, such as albumin, from passing through. If these filters are damaged, albumin passes from the blood into the urine.

Anaemia – When there are only a small number of red blood cells in your blood, or your blood cells are not working properly. Red blood cells carry oxygen, so if you have anaemia, you can feel weak, tired, and short of breath.

Antibody – A protein molecule made by your immune system to attack tissue that is not normally part of your body (e.g. viruses and bacteria).

Chronic kidney disease (CKD) – Progressive reduction in kidney function or kidney damage which is present for at least three months. A term used widely to describe kidney damage or reduced kidney function (irrespective of the cause) that persists for more than three months.

(continued) Sometimes CKD leads to kidney failure, which requires dialysis or kidney transplant to keep you alive.

Dialysis – A treatment for end stage kidney disease that removes waste products and excess fluid from your blood by filtering your blood through a special membrane. There are two types of dialysis: haemodialysis and peritoneal dialysis.

Estimated glomerular filtration rate (eGFR) – An estimation of glomerular filtration rate (GFR). GFR is the best measure of kidney function and helps to determine the stage of kidney disease. It shows how well your kidneys are cleaning your blood.

Glomerulus – One of the key structures that make up the nephron which is the filtering unit of the kidney.

Haematuria – Blood in your urine. It can turn urine a red or dark 'cola' colour, which is visible to the eye **OR** may only be found by a urine test (microscopic haematuria).

(continued) Blood in the urine is a common sign of urinary tract infections but can be the first sign of a problem with the kidneys or the bladder.

IgA nephropathy – A common type of glomerulonephritis where the build-up of the IgA antibody damages the kidney filters, allowing protein and blood to leak into the urine.

Kidney biopsy – A small piece of kidney tissue is removed for testing and examined under a microscope.

Kidney transplantation – A treatment for end stage kidney disease where a kidney is removed from the body of one person (the donor) and put into the body of the person with end stage kidney disease.

Nephrologist – A doctor who specialises in treating conditions of the kidney.

Nephron – The tiny parts of the kidney that filter blood to make urine. There are over one million filters in each kidney.

Special Thanks! **This educational resource is supported by a sponsorship provided by Novartis**