

# IgA nephropathy

This infoKID topic is for parents and carers about children's kidney conditions. Visit [www.infoKID.org.uk](http://www.infoKID.org.uk) to find more topics about conditions, tests & diagnosis, treatments and supporting information.

Each topic starts with an overview followed by several sections with more information.

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IgA nephropathy, or Berger disease, causes inflammation (swelling) in the kidneys. Children with IgA nephropathy have blood and protein in their urine, and may have swelling in their body. IgA nephropathy may lead to other complications, including high blood pressure (**hypertension**).

All children with this disease are carefully monitored by a team of healthcare professionals. Some need to stay in hospital for a few days, but most of the time they will need to visit the hospital during the day only. Children may need to make changes to what they eat and drink, and take medicines.

For many children, IgA nephropathy is quite mild and they will get better.

About 3 or 4 out of 10 children with this disease will have long-term problems with their kidneys, and will need to be monitored and have specialist treatment when it is needed.



## Overview

### About the urinary system

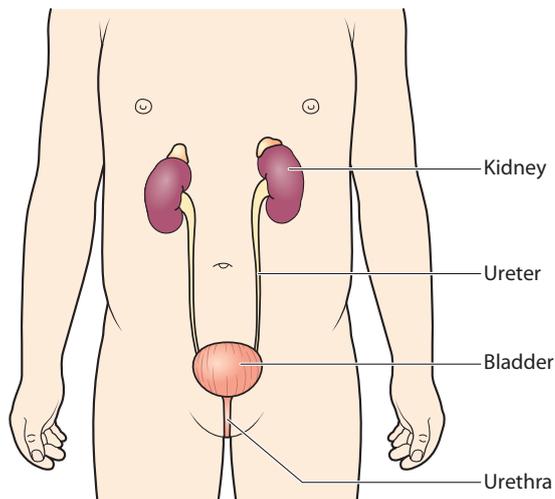
The **urinary system** gets rid of things that the body no longer needs, so that we can grow and stay healthy.

The **kidneys** are bean-shaped organs. They filter blood to remove extra water, salt and waste in urine (wee). Most of us have two kidneys. They are at the back on either side of our spine (backbone), near the bottom edge of our ribs.

The two **ureters** are long tubes that carry urine from the kidneys to the bladder.

The **bladder** is a bag that stores urine until we are ready to urinate (have a wee). It sits low down in the pelvis.

The **urethra** is a tube that carries urine from the bladder to the outside of the body.



# About IgA nephropathy

## About glomerulonephritis

**IgA nephropathy** is a type of **glomerulonephritis**, a group of conditions that affect the kidneys. Inside the kidneys, there are many tiny filters called glomeruli. They help to remove extra water, salt and waste, which are passed out of the body as urine. They also make sure the body keeps what it needs, such as blood cells, protein and other important chemicals.

In glomerulonephritis, the glomeruli become inflamed (swollen) or damaged. This causes both blood and protein to leak into the urine.

## About IgA nephropathy

Although it is rare and does not affect many people, IgA nephropathy is the most common type of glomerulonephritis in developed countries such as the UK. It happens in people of all ages, though it is most often diagnosed (identified) in people under 30 years of age, especially older children and teenagers. IgA, a protein made by the body, gets 'trapped' in the glomeruli, causing damage.

IgA nephropathy is sometimes called Berger disease. This is because a doctor called Berger first described the disease in the 1960s.

## Henoch-Schönlein purpura

Children with **Henoch-Schönlein purpura (HSP)** may have IgA nephropathy as well as other symptoms, often including a rash on the skin, pains in their tummy and pains in their arm and leg joints.

# Symptoms and complications

## Symptoms and signs

Some children with IgA nephropathy do not have any symptoms and signs, especially in the early stages of the disease. Common symptoms and signs of IgA nephropathy include:

- blood in the urine (**haematuria**) – you cannot always see the blood, but if there is a lot, the urine may be coloured red or dark brown (like a cola drink)
- protein in the urine (**proteinuria**) – you cannot usually see the protein, but sometimes it can make the urine look frothy. It can be found on a simple urine test
- urinating (weeing) less often or smaller amounts
- swelling or puffiness in different parts of the body, especially around the eyes, legs and feet – this is called **oedema**.

## Complications

Some children have complications – health problems that happen because of the condition or its treatment.

- IgA nephropathy may lead to blood pressure that is too high (**hypertension**).

- Occasionally, the condition gets worse quickly and the kidneys work less well than normal – this is called **rapidly progressive glomerulonephritis (RPGN)**.
- RPGN is one cause of **acute kidney injury (AKI)** – when the kidneys quickly stop working as well as they should, over a short time.

» [More about symptoms and complications](#)

## Causes

IgA nephropathy is usually caused by problems with the immune system, which normally protects the body against disease and infection. The body makes proteins called immunoglobulins that help to kill germs. In IgA nephropathy, one of these proteins, immunoglobulin A (IgA), gets trapped in the glomeruli.

Doctors do not fully understand why this happens in some children. It cannot be passed on to other children or adults. It does not usually run in families.

» [More about causes](#)

# Tests and diagnosis

## Diagnosing glomerulonephritis

Your child's doctor can diagnose (identify) glomerulonephritis with a **urine test**. It is often picked up during a urine test for another reason – such as red or brown urine or a **urinary tract infection (UTI)**. Your doctor will speak with you and your child about the symptoms and do a physical examination. Your child may also need other tests, such as **blood tests** and an **ultrasound scan**.

## Diagnosing IgA nephropathy

Your doctor can diagnose IgA nephropathy with a **kidney biopsy**, and may recommend this test. A tiny piece of one kidney is removed from the body with a needle, and examined under microscopes. Special medicines are used so your child does not feel any pain or can sleep through the procedure.

» [More about tests and diagnosis](#)

# Treatment

## Where will my child be treated?

Your child will probably be referred to a **paediatric renal unit**, a special unit for children with kidney problems, which may be in a different hospital from your own. Your child will be looked after by a paediatric nephrologist, a doctor who treats children with kidney problems.

Your child may need to stay in hospital for a few days or longer. Most of the time, children with IgA nephropathy have their care as **outpatients**. This means that your child will visit the hospital during the day and go home.

## About treatment

Your child may need to make changes to what he or she eats or drinks. Many children need to take medicines that aim to reduce the amount of protein lost in their urine. Occasionally, other medicines are needed.

» [More about treatment](#)

## About the future

### Follow up

It is very important that your child goes back to the hospital or clinic for follow-up appointments, especially to check for proteinuria (protein in the urine). You may also need to test your child's urine at home.

## Long-term effects

Your healthcare team will speak with you and your child about any long-term effects your child might have with IgA nephropathy. IgA nephropathy can be a chronic condition, which means that it does not go away and may get worse over time.

- For most children with IgA nephropathy, the disease is quite mild and will not affect how their kidneys work.
- About three or four children in 10 with IgA nephropathy have long-term problems with their kidneys. Their kidneys stop working as well as they should – this happens slowly and there may not be any problems until adulthood. This is called **chronic kidney disease (CKD)**. If your child has CKD, you will learn more over time about how to help manage the condition and what to expect.

» [More about the future](#)

## Your notes

# Symptoms and complications

## Symptoms and signs

Some children with IgA nephropathy do not have any symptoms and signs, especially in the early stages of the disease. Symptoms and signs may include the following.

### Blood in the urine

When **red blood cells** leak through the kidney's filters into the urine, this causes **haematuria** (blood in the urine). Sometimes you cannot see the blood, but if there is a lot, the urine may be coloured red or dark brown (like blackcurrant squash or a cola drink).

### Protein in the urine

When **proteins** leak through the kidney's filters into the urine, this causes **proteinuria** (more protein in the urine than normal). You cannot usually see the protein, but occasionally it can make the urine look frothy. Protein is an important part of our diet and is in most foods. When we eat protein, it is digested (broken down) in the stomach and gut and taken into the blood.

### Problems urinating

Some children urinate less often or pass smaller amounts.

### Swelling

Some children have swelling or puffiness in different parts of their body, especially around their eyes, legs and feet (**oedema**).



A child with swelling around her eyes

### Swelling in the tummy and breathlessness

- A few children get a large swelling around their tummy (ascites). It happens when fluid builds up in the peritoneal cavity, which is the area around the organs in the abdomen (tummy).
  - A very small number of children feel breathless. This happens when fluid builds up around their lungs.
- If your child has IgA nephropathy and a very swollen tummy or feels breathless, contact your doctor as soon as possible.

## Other symptoms and signs

The below are occasionally found in children with IgA nephropathy:

- feeling tired, low energy or difficulty concentrating
- decreased appetite (not wanting to eat)
- nausea (feeling sick) or vomiting (being sick), or diarrhoea
- pain in the tummy
- headaches that keep coming back or that do not go away.
- pain, stiffness or swelling of the joints.

## Complications

Some children have more **complications** – health problems that happen because of the condition or its treatment. These are more rare. Your child's healthcare team will carefully check for these, and speak with you about any treatment that your child may need.

### High blood pressure

IgA nephropathy can cause blood pressure that is too high (**hypertension**). In some children, this causes headaches, vomiting or blurred (fuzzy) vision. Hypertension that lasts a long time can also increase the risk of getting other diseases in adulthood.

### Rapidly progressive glomerulonephritis

Occasionally, IgA nephropathy gets worse quickly – this is called **rapidly progressive glomerulonephritis (RPGN)** or **crescentic glomerulonephritis**. If this happens, your child will need to take medicines and may need more intensive treatment, such as dialysis. Some children with RPGN will get better, but a few will need long-term dialysis before they can have a kidney transplant.

This is one cause of **acute kidney injury** – when the kidneys quickly stop working as well as they should, over a short time.

## Symptoms and complications: Read more about why swelling happens

There are two reasons why children with IgA nephropathy get oedema.

- Sometimes, the damaged kidney filters (glomeruli) are not able to filter enough salt and water out of the blood into urine. After a while, there is too much salt and water in the body, which causes the swelling.
- Sometimes, the kidneys leak a large amount of protein, especially a type called **albumin**, into the urine. This leads to **nephrotic syndrome**. Fluid moves in and out of the bloodstream to nourish (feed) the body's cells. Albumin helps keep fluid in the bloodstream – if there is not enough albumin, fluid stays outside the bloodstream and in parts of the body. This causes the swelling.

# Causes

## What happens in the kidneys

In IgA nephropathy, a protein called **immunoglobulin A (IgA)** gets trapped in the tiny filters (glomeruli) in the kidneys. This causes the kidneys to leak blood and protein into the urine.

**IgA** refers to the protein. **Nephropathy** means kidney disease.

## After infection

Many children with IgA nephropathy first get symptoms with an infection – this is not in the kidney, but usually in the throat, tonsils, lungs or gut. Most children recover from these infections. But, in a few children, the infection seems to trigger IgA nephropathy.

## The immune system

Many germs – including **bacteria** and **viruses** – can make us sick if they get into the body. The immune system can kill these germs. However, if the immune system is not working properly, it can start to cause problems.

## Will it affect other family members?

Doctors do not think that IgA nephropathy runs in families. If one of your children has this type of glomerulonephritis, it is unlikely that another of your children or another family member will get it.

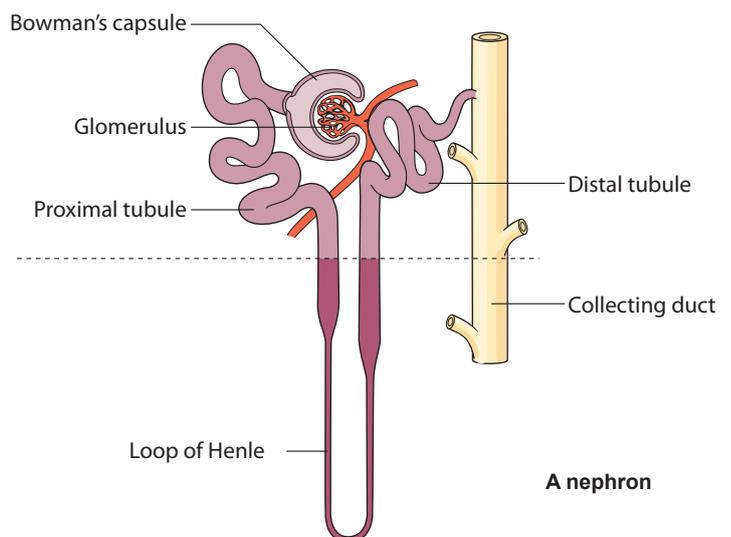
## Causes: Read more about how the kidney works and IgA nephropathy

### How the kidney works

Inside each kidney, there are about one million **nephrons**. Each nephron is made up of a **glomerulus** (when we talk about more than one glomerulus, we say glomeruli), and a **renal tubule**.

- Each glomerulus acts like a sieve, helping to remove extra water and waste from the body, and holding on to blood cells and protein, which the body needs.
- Blood flows into the kidneys and to each glomerulus.
- Most of the water and some other substances in the blood pass through the glomeruli.
- This liquid flows into the renal tubule. Most of this liquid moves back into the bloodstream. The rest of it becomes urine.
- The urine leaves the kidney by the ureters and goes into the bladder, where it is stored until we are ready to go to the toilet.

» [More about what the kidney does](#)

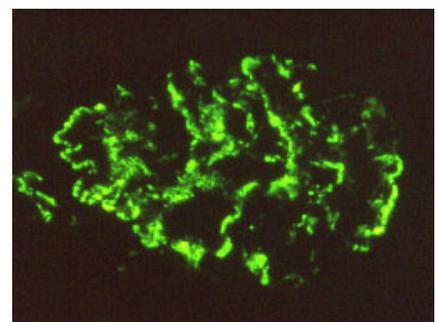


### What happens in IgA nephropathy

A protein called **immunoglobulin A (IgA)** gets trapped in the glomeruli. This causes the glomeruli to become inflamed (swollen) or damaged. The damaged glomeruli can let blood cells and protein through, which means they go into the urine.

When a tiny sample of kidney is taken in a **kidney biopsy**, it can be examined under special microscopes. Dyes can be added to show up specific proteins.

The image to the right is of a glomerulus under a microscope. The green colour shows areas where there are IgA.



A glomerulus under a microscope. The green colour shows areas where there are IgA.

### Germs

The immune system protects the body against germs such as bacteria and viruses that can cause illness. These germs can enter the body in lots of ways, such as by the nose and throat or the urinary system. If we get a cold or flu, this means that a virus germ has got into the body and started to infect some of our body's cells.

Germs have special 'markers' that are different from the markers on our own body's cells. This means that the immune system can recognise that they are germs and kill them. We often feel sick for a few days or a few weeks while this is happening.

### Parts of the immune system

The immune system has many different ways to protect the body against disease. Some of the parts include those listed below.

- **White blood cells** are living cells in the blood. Often, the number of white blood cells found in a **blood test** can give information about someone's immune system. The two main types of white blood cells in the immune system are neutrophils and lymphocytes.
- **Antibodies** or **immunoglobulins** recognise the germs that have come into the body, and can bind (stick) to them. There are five types: immunoglobulin A (IgA), immunoglobulin D (IgD), immunoglobulin E (IgE), immunoglobulin G (IgG) and immunoglobulin M (IgM).
- The **complement system** is made up of other proteins that float in the blood. These proteins work with (complement) other parts of the immune system to help kill germs or cells infected by germs. Normally, the body controls when complement is activated, so it does not attack the body itself.

### When the immune system does not work properly

Sometimes the immune system does not work as expected and can cause problems. For example, sometimes the immune system cannot recognise the body's own cells and may attack them as if they were invaders like germs.

## Tests and diagnosis

Your child will need some tests to diagnose (identify) IgA nephropathy, find out more about how it is affecting him or her and whether any treatment is needed. Your child may need an examination, urine tests, blood tests, imaging tests and a kidney biopsy.

### Examination

Your doctor will talk to you and your child about his or her symptoms and any medicines that he or she takes. The doctor will examine your child – for example, to see whether there is **oedema** (swelling in his or her body).

Your doctor or nurse will check your child's **blood pressure**. This is because IgA nephropathy may cause high blood pressure (**hypertension**).

### Urine tests

You, or a nurse, will need to collect some of your child's urine in a small, clean container for a **urine test**. A dipstick will be dipped into the urine – this is a strip with chemical pads that change colour depending on what substances are in the urine. This shows whether there are blood cells and/or protein, which are signs of IgA nephropathy.

The sample may also be sent to a laboratory for more accurate tests.

### Blood tests

A small amount of blood will be taken from a vein, with a needle and syringe, for a **blood test**. A special gel or cream can be used to help your child stop feeling any pain.

The blood test results can give the doctor more information, about:

- the immune system, and whether there has been a recent infection
- how well his or her kidneys are working – this is called the kidney function
- the amount of protein in your child's blood – in IgA nephropathy, the kidneys leak protein into urine and this is sometimes enough to affect how much is in the blood
- the amount of other chemicals.

» [Read more about blood tests on the next page](#)

## Imaging tests

Some children need **imaging tests** (scans). These use special equipment to get images (pictures) of the inside of their body.

- **Ultrasound scan** – looks at the shape and size of kidneys and other parts of the urinary system. A small handheld device is moved around your child's skin and uses sound waves to create an image on a screen.
- **Chest x-ray** – for children with breathing problems, this test checks for any fluid (liquid) around the lungs. Your child sits or lies still for a few seconds while a machine takes x-ray images.

Occasionally, other imaging tests are needed.

## Kidney biopsy

Your doctor can diagnose IgA nephropathy with a **kidney biopsy**, and may recommend this test. A tiny piece of one kidney is removed from the body with a needle, and examined under microscopes. Special medicines are used so your child does not feel any pain or can sleep through the procedure.

A kidney biopsy can give more information about how much damage there is in your child's kidney, and confirm whether he or she has IgA nephropathy or another type of glomerulonephritis. It can take a few weeks to get the results.

### Tests and diagnosis: Read more about blood tests

#### How well the kidneys are working

A blood test can find out the **estimated glomerular filtration rate (eGFR)**, the amount of fluid that the kidneys filter each minute. A low eGFR means that the kidneys cannot filter as quickly, and so are not working as well as normal.

#### Infection and immune system

A blood test can check whether there are any **immunoglobulins** or **antibodies** – the body's immune system makes these unique proteins to identify and kill specific germs. This gives information about whether there has been an infection, and sometimes which germ caused it.

Some children with IgA nephropathy have high levels of immunoglobulin A (IgA) in their blood.

#### Protein in the blood

Some children with IgA nephropathy lose a lot of protein in their urine, when it is leaked through the glomeruli. This means there is less protein in their blood, especially a type of protein called **albumin**. Because albumin is smaller than other proteins, it is more likely to leak through the glomeruli.

#### Electrolytes

**Electrolytes** are important chemicals in the body. We need the right balance of these to stay healthy. Some important electrolytes include the following:

- **sodium** helps balance the amount of water in the body
- **potassium** is needed for the muscles, including the heart muscle, to work properly
- **bicarbonate** balances the amount of acid in our body, or the pH balance (also called the acid–base balance)
- **phosphate** is important for bones, teeth and muscles
- **calcium** is important for bones and teeth, helps blood to clot and also helps the muscles, including the heart muscle, to work.

#### Full blood count and blood clotting test

A **full blood count (FBC)** counts the numbers of different types of blood cells – a higher or lower level of these may be a sign of infections or other health problems.

A **blood clotting test** looks at how the blood forms clots, when the blood clumps together – for example, when we have a cut, to stop the body losing too much blood.

# Treatment

Children with IgA nephropathy may not need any treatment, but will be monitored by a healthcare team.

Your child may need to make temporary changes to what he or she eats or drinks. Your child may need to take medicines to reduce the amount of protein lost in the urine and/or treat high blood pressure. Other medicines may be needed – for example, to treat swelling of the body, or treat infections.

A small number of children will need further treatment if their kidney function gets worse, such as medicines or dialysis, which uses special equipment to remove waste from the body.

→ It is important that your child follows any treatment plan outlined by your doctor.

→ Do *not* give your child ibuprofen (e.g. Brufen) – this medicine may cause further damage to kidneys that are affected by IgA nephropathy.

## Where will my child be treated?

Your child will probably be referred to a **paediatric renal unit**, a specialised unit that treats babies, children and young people with kidney conditions and may be in a different hospital from your own. He or she will be looked after by a team, including a **paediatric nephrologist**, a doctor who treats children with kidney problems.

### Visiting or staying in hospital

Most of the time, children with IgA nephropathy have their care as outpatients. This means that they visit the hospital during the day and go home.

Your child may need to stay in hospital for a few days or longer. Your child can go home when the doctor thinks that his or her health is stable.

## Changes to eating and drinking

Your child may need to make temporary changes to what he or she eats – for example, less salt and less of certain foods. He or she may also need to drink less fluid, such as water, squash and soft drinks.

Your doctor, nurse or a **paediatric dietitian** will help you and your child make these changes.

## Reducing protein loss in urine and controlling blood pressure

Some children need to take medicines to reduce the amount of protein lost in their urine.

These are usually medicines called **ACE inhibitors (angiotensin-converting enzyme inhibitors)** or

## Treatment: Read more about hospital visits and the healthcare team

### Hospital visits

A team of healthcare professionals will:

- check your child's **kidney function** (how well his or her kidneys are working)
- measure how much your child is drinking and how much urine he or she is passing
- test your child's **urine** with a dipstick
- check your child's **blood pressure**.

### Healthcare team

Your child's healthcare team may include a:

- **paediatrician** – a doctor who treats babies, children and young people
- **paediatric nephrologist** – a doctor who treats children with kidney problems
- **radiologist** – a healthcare professional who uses **imaging tests** (scans) to help identify a condition
- **renal nurse** – a nurse who cares for children with kidney problems
- **renal dietitian** – a healthcare professional who advises what your child should eat and drink during different stages of a kidney condition
- **renal social worker** – a professional who supports you and your family, especially with any concerns about money, travel and housing related to looking after your child with kidney disease
- **renal psychologist** – a healthcare professional who supports your child and family, especially with emotional stresses and strains from having to look after a child with kidney disease
- **play specialist** – a professional who uses dolls and other toys to help your child prepare for procedures, such as blood tests and dialysis

**angiotensin-II reception blockers (ARBs)**. These may also be used to control blood pressure. Common medicines are: **captopril**, **enalapril** and **lisinopril**.

Doctors understand that, in some children, these medicines will reduce the risk of long-term kidney problems.

→ It is important that you follow your doctor's instructions about when and how much to give. Do not stop the medicine suddenly.

## Treating infections – antibiotics

If your child has an infection, such as a throat infection, he or she may need to take an **antibiotic**, a medicine that kills bacteria. One infection is **tonsillitis**, when the tonsils in the back of the throat become inflamed (swollen).

In some children, throat infections that keep coming back may trigger **haematuria** (blood in the urine). If your child has throat infections and urine that is coloured red or brown (like a cola drink), discuss this with your doctor at the next outpatient appointment. Your child may need to be referred to an **ear, nose and throat (ENT)** healthcare professional for further tests and treatment.

→ It is important that your child completes the course of antibiotic. This means that he or she must take the medicine for the number of days that the doctor has told you to, or until all of the medicine has been taken.

## Reducing swelling in the body – diuretics

Occasionally, children with IgA nephropathy need to take **diuretics**, medicines that help reduce oedema (swelling in the body). Diuretics work on the kidneys to increase the amount of water and salt they remove from the body in urine.

If your child is taking diuretics, he or she will need to go to follow-up appointments. Your doctor will examine your child for oedema and measure his or her weight. This helps find out how well the medicine is working.

Common diuretics are: furosemide, **spironolactone** and metolazone. Some of the other diuretics that may be used are: amiloride, bendroflumethiazide and chlorothiazide.

## Managing reduced kidney function

For some children, the kidneys do not work as well as normal during this illness – they have reduced kidney function. The severity of this varies, but most do not need any special treatment and their kidney function will return to normal.

A very small number will have more serious kidney problems and will need further treatment. This may include:

- taking medicines called **immunosuppressants**, which stop the immune system from working properly, to try to stop it from harming the kidneys
- **dialysis**, which uses special equipment or a machine to 'clean' the blood, removing waste products and extra water and salts.

## Questions to ask the doctor or nurse

- What treatment does my child need?
- How will the treatment help my child?
- How can I help my child prepare for procedures and treatments?
- If the first treatment does not work in my child, what happens next?
- How will I know if we need to go back to the hospital or see the doctor?
- Will the IgA nephropathy come back? How will I know?

# About the future

Your healthcare team will speak with you and your child about any long-term effects your child might have with IgA nephropathy.

## Urine testing at home

You may need to do urine tests at home to check for protein and blood in the urine. Your child's healthcare team will show you how to do this.

## Follow up

All children who have been treated for IgA nephropathy need follow-up appointments at the hospital or clinic, to check for any health problems. These may continue throughout childhood and sometimes adulthood.

It is important to go to these appointments, even if your child seems well – remember to bring the results from your home urine testing. You will also have the opportunity to ask any questions. At these appointments, your child may have:

- his or her height and weight checked
- a physical examination
- **urine tests** – to check for blood, protein and other substances in his or her urine
- **blood tests** – to check for the amount of protein and other substances in his or her blood, and measure his or her kidney function
- his or her **blood pressure** measured.

## Will my child get better?

IgA nephropathy is a progressive disease, which means that it does not go away and may get worse over time. The impact on your child's kidney function (how well the kidneys work) depend on how severe the IgA nephropathy is, and how well it can be controlled by medicines.

### Mild disease

For most children with IgA nephropathy, the disease is quite mild. Many children get haematuria (blood in the urine) when they have infections, but this is usually of no real significance and does not require any special treatment. Encourage your child to drink plenty of water until the blood disappears.

### Acute kidney injury

Children with IgA nephropathy are at risk for **acute kidney injury (AKI)** – when the kidneys suddenly stop working. Some children with AKI get better after a few weeks, and some need to take medicines or have more intensive treatment.

### Long-term problems

About 3 or 4 out of 10 children with IgA nephropathy will have long-term problems with their kidneys. Their kidneys stop working as well as they should – this happens slowly, often over many years. This is called **chronic kidney disease (CKD)**. These children may need further care. They will need to go back to the hospital or clinic for regular follow-up appointments.

If this happens to your child, you will learn more over time about how to help manage the condition, and what to expect.

## Impact on your child and your family

Children who have IgA nephropathy can usually do the things that other children their age do. They should be able to continue going to school or nursery. They can play with other children and stay active.

### Living healthily

Your child can help protect his or her kidneys by leading a healthy lifestyle through their child and adult years. This includes:

- eating a healthy diet – with at least five servings of fruit and vegetables a day, taking care not to eat too much salt, sugar and fats (especially saturated fats)
- getting plenty of exercise
- not smoking.

### Further support

This can be a difficult and stressful experience for your child and the whole family, including other children.

**If you have any concerns or need additional support, speak with your doctor or nurse.**

## Further information

This is the end of the information on IgA nephropathy. If you would like to read more about other kidney conditions, tests and diagnosis, treatment or supporting information, you can find a list of topics covered on the infoKID website at [www.infoKID.org.uk](http://www.infoKID.org.uk).

# Your notes and contact information

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[www.infoKID.org.uk](http://www.infoKID.org.uk)



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For details on any sources of information used in this topic, please contact us through our website [www.infoKID.org.uk](http://www.infoKID.org.uk).

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