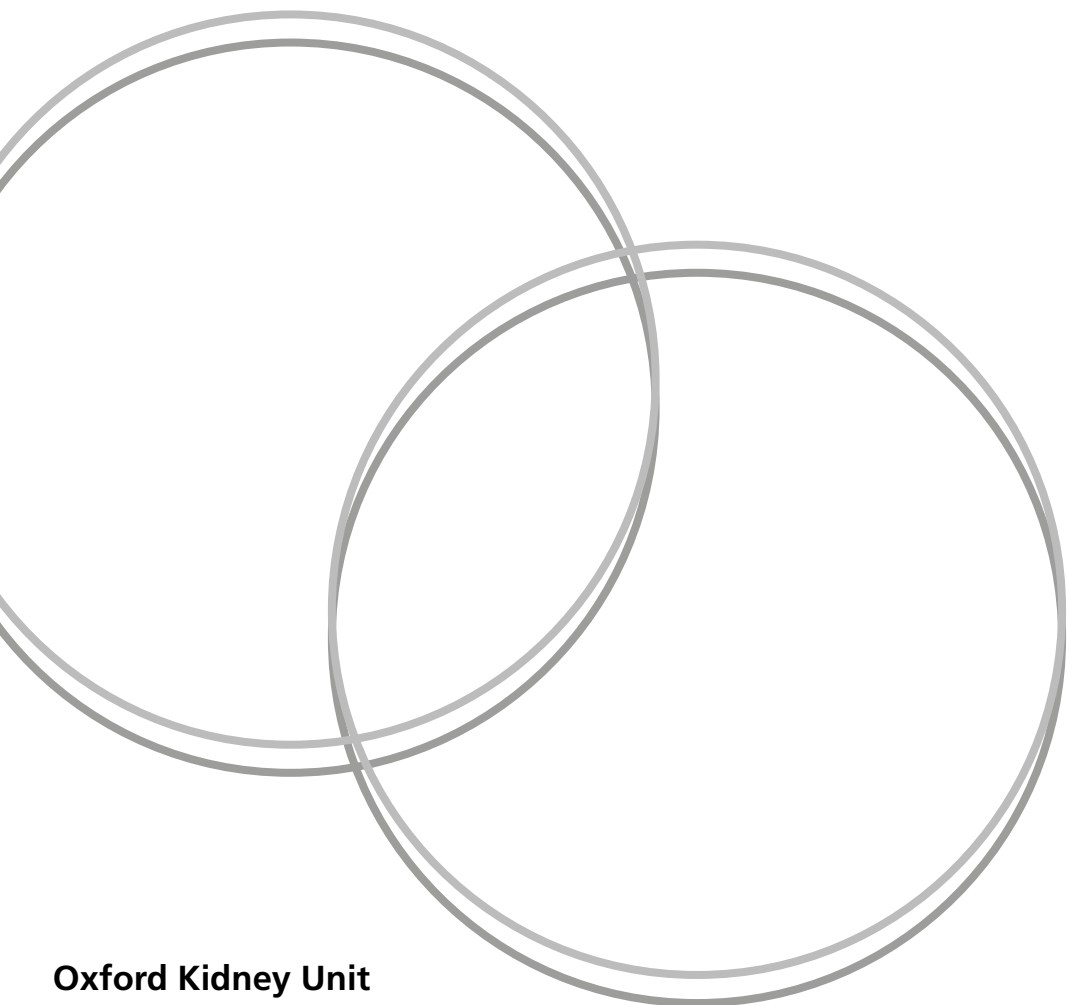




Oxford University Hospitals
NHS Foundation Trust

IgA Nephropathy

Information for patients



Oxford Kidney Unit

You've been given this leaflet as you have been told by your kidney doctor that you have IgA nephropathy. If you have any questions after reading this leaflet, please speak to your kidney doctor.

What do the kidneys do?

The kidneys are the specialised organs that filter and purify the blood, ridding the body of excess water, salts and waste products. The part of the kidney that does the filtering is called the glomerulus.

The kidneys are also responsible for healthy bones, controlling blood pressure and preventing anaemia.

What is IgA nephropathy?

IgA nephropathy is also known as IgA disease or Berger's disease (after the doctor who first discovered it). These names all describe the same condition.

IgA nephropathy is a type of glomerulonephritis (inflammation of the glomerulus; the filtering part of the kidney). We do not fully understand what causes IgA nephropathy, but it appears to relate to a type of antibody called IgA. IgA is a normal part of our natural defence against infection. In IgA nephropathy we believe this antibody behaves abnormally and collects in the glomerulus, causing it to become inflamed and scarred over time.

IgA nephropathy is more common in men. It can be diagnosed at any age, but is often found in young adults and children.

Does IgA nephropathy affect other parts of the body?

No, it does not, but there is a related condition called IgA vasculitis (formerly known as Henoch-Schönlein purpura or HSP for short) which does cause additional symptoms. People with IgA vasculitis will also have IgA antibodies in their kidneys.

People with IgA vasculitis may develop episodes of a skin rash (particularly on their legs and back), aches and pains in their joints, and pain in their abdomen. The skin, joint and abdominal effects of IgA vasculitis often disappear over weeks or months, but the kidneys continue to be damaged in the same way as in IgA nephropathy. IgA vasculitis can occur at any age but is commonest in young children.

How is it diagnosed?

IgA nephropathy may be diagnosed with a kidney biopsy. Your kidney doctor will talk to you more about this. There is no blood test that can diagnose this condition.

What are the symptoms and signs of IgA nephropathy?

You may experience episodes of visible blood in your urine, causing it to appear red or brown. This may happen around the same time as a sore throat or viral infection, or occasionally after exercise. You may experience lower back pain whilst the blood is present. Between these episodes you may have invisible blood and protein in your urine, which can be detected when it is tested by your nurse or doctor.

Some people never have visible blood in their urine. The problem may only be discovered when a urine sample is checked for another reason, for example at a routine medical examination.

You may also have high blood pressure, as well as signs of kidney damage, which would be found by doing a blood pressure check and a blood test.

IgA vasculitis may be diagnosed differently. You may have developed a rash on your legs and buttocks and pain in your joints or abdomen, as well as the other features above.

What are the complications of IgA nephropathy?

In around half of people with IgA nephropathy, kidney function will get worse over many years (called 'chronic kidney disease'). In a small number of people this can happen more quickly.

In a quarter of people, the IgA nephropathy will continue to cause a small amount of protein and blood in the urine, but the kidneys will not show other signs of damage.

In the final quarter of people, the invisible blood in the urine will slowly disappear, leaving no evidence of IgA nephropathy. The blood in the urine may come back in the future, although this is unlikely.

It is often difficult to say what will happen in the future, when you are first diagnosed. For that reason you will be kept under long term review by the Nephrology Clinic or your GP.

What happens if I have repeated attacks of visible blood in my urine?

Many people with IgA nephropathy have quite a few attacks of visible blood in their urine. These gradually become less frequent and usually stop after a few years, although the blood may still be found on 'dip-stick' testing of the urine.

The number of attacks of visible blood in the urine will not increase the risk of long-term kidney damage. Sometimes the kidneys may decrease in function at the time of visible blood in the urine, but this often recovers once the visible blood has cleared.

There is no specific treatment for visible blood in the urine and this will usually settle down on its own in a few days.

Does IgA run in families?

Relatives of someone with IgA nephropathy are more likely to have the antibodies seen in IgA nephropathy. However, only about 5% of relatives (5 in 100) with this antibody will also develop blood and protein in their urine.

It is usually only recommended that relatives of people with IgA nephropathy are investigated if they also have symptoms of IgA nephropathy.

What treatments will I be offered?

There is no specific cure for IgA nephropathy, but we can take action to slow any damage that might occur to your kidneys. The most important step is to control high blood pressure, as this increases the damage to the kidneys from IgA nephropathy.

High blood pressure is common in people with IgA nephropathy. Controlling high blood pressure also reduces the risk of heart attacks and strokes in the future.

Your kidney doctor will discuss your blood pressure with you and how this can be improved.

In some people, the kidneys will gradually stop working over many years. If this happens you may need treatment to replace your kidney function, such as dialysis or a kidney transplant. Your kidney doctor will discuss your kidney function with you at each clinic appointment.

What can I do to help my condition?

- **Diet** – there are no foods known to cause IgA nephropathy or to provoke attacks of visible blood in the urine. You do not need to change your diet unless your kidney doctor has told you otherwise.
- **Alcohol** – alcohol has no effect on IgA nephropathy, but we advise you to stick to the alcohol intake limits as recommended by the Department of Health.
- **Exercise** – in some people, vigorous exercise may produce visible blood in their urine. It is not thought that this is damaging to the kidneys in the long-term, but you may wish to avoid the exercise that causes the blood in your urine to occur. Otherwise you can continue to enjoy all physical activities.
- **Blood pressure** – it can be helpful to monitor your own blood pressure at home, to assess the effect of the blood pressure medications you have been prescribed.

Can IgA nephropathy come back after a kidney transplant?

After a kidney transplant you will still have IgA antibodies circulating in your blood. These may collect in the filtering parts of your new kidney after you have a transplant. In most people this does not cause a problem for many years, but in some people this will cause the transplant to gradually stop working.

People with IgA nephropathy do not require different treatment after their transplant.

Useful websites

Kidney Patient Guide

Information for patients with kidney failure and those who care for them.

Website: www.kidneypatientguide.org.uk

Kidney Care UK

A charity which has lots of practical support and information for people with kidney disease.

Website: www.kidneycareuk.org

Oxford Kidney Unit

The website has lots of information about the Oxford Kidney Unit for patients and carers.

Website: www.ouh.nhs.uk/oku

NHS website

Website: www.nhs.uk

PatientView

This shows your latest blood results

Website: www.patientview.org

EdRen

This website is run by the Edinburgh Renal Unit and has information on IgA nephropathy.

www.edren.org/ren/edren-info/iga-nephropathy

RareRenal (The Renal Association)

Run by UK based kidney doctors promoting research. There are links from the website to join the register and be the first to know about potential new treatments and clinical trials.

Register: www.rarerenal.org/radar-registry

If you need an interpreter or would like this information leaflet in another format, such as Easy Read, large print, Braille, audio, electronically or another language, please speak to the department where you are being seen. You will find their contact details on your appointment letter.

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