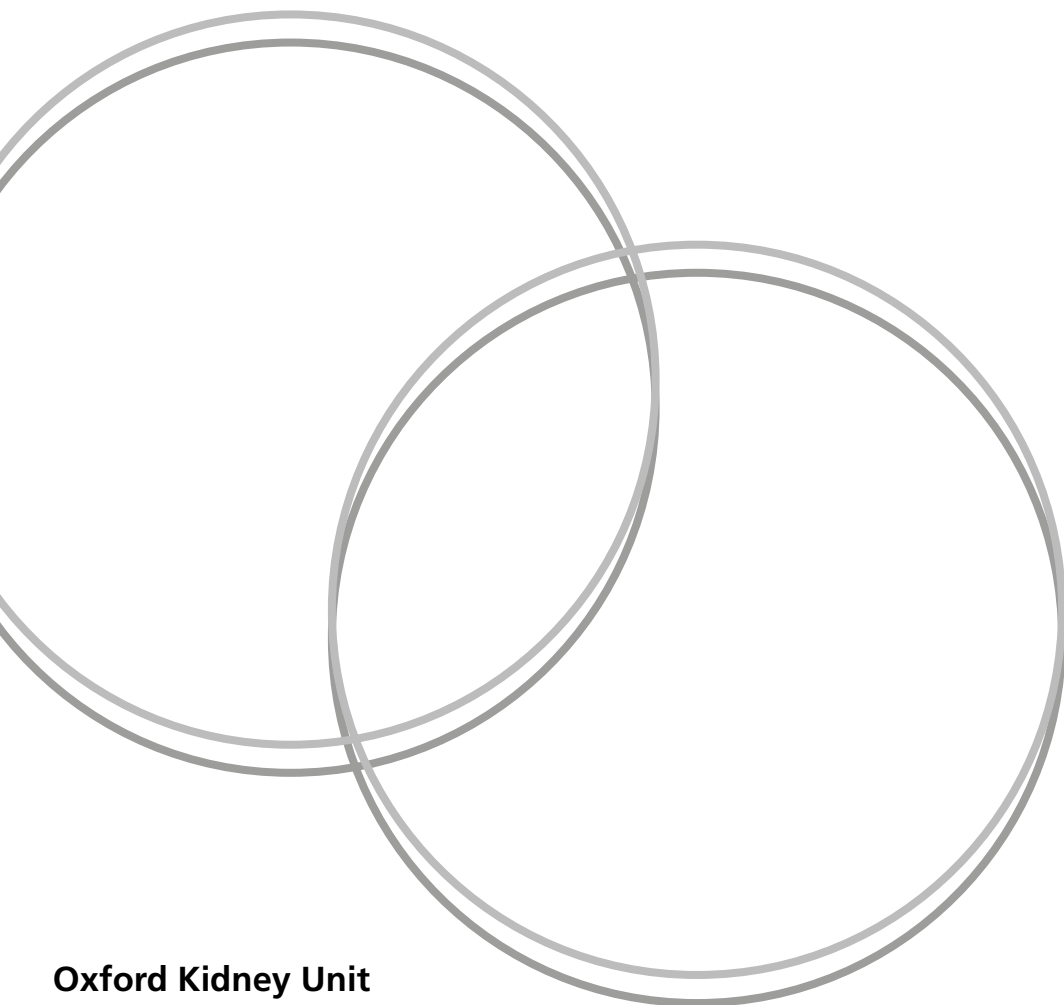




Oxford University Hospitals
NHS Foundation Trust

Membranous nephropathy

Information for patients



Oxford Kidney Unit

If you have been told you have membranous nephropathy, this leaflet is for you. If you have more questions after reading this leaflet, please speak to your kidney doctor.

What is membranous nephropathy?

Membranous nephropathy is also called membranous glomerulonephritis. Glomerulonephritis means inflammation of the filters of the kidney (which are called glomeruli). Nephropathy means a disease of the kidneys.

In membranous nephropathy, damage to the kidney's filters allows protein in the blood circulating through the kidneys to leak into your urine. It is called membranous nephropathy because the membranes of the filters look thickened when examined under a microscope.

What are the symptoms of membranous nephropathy?

You may have had no symptoms, but have had a kidney biopsy because you have been found to have abnormal amounts of protein in your urine.

You may also have developed swelling (oedema), in your lower legs and ankles. This is caused by excess fluid which has been retained by the body and then leaked into the tissues. This happens when there is less protein in the blood, because excessive protein has been lost into the urine (more than 3grams per day), and is known as 'nephrotic syndrome'. You may notice that your urine appears 'foamy' or 'frothy'.

What causes membranous nephropathy?

Auto-immune membranous nephropathy

Research suggests that auto-immune membranous nephropathy can develop when your body's immune system makes autoantibodies that specifically attack the filters in your kidneys. The autoantibodies stick to the kidneys' small filters and damages them, making them leak too much protein into the urine.

The filters are usually targeted by autoantibodies called 'PLA2R' (Phospholipase-A2-Receptor antibody). Levels of PLA2R can be measured in your blood and can show up on the kidney biopsy.

The higher the levels of PLA2R in your blood, the more likely you are to have increased active disease, which is why the levels in your blood are measured.

Other much rarer antibodies are now being discovered, but are not currently normally measured.

Idiopathic membranous nephropathy

In some people, membranous nephropathy occurs for no apparent reason and develops 'out of the blue' without evidence of any of the autoantibodies (in the blood or kidney biopsy). If no secondary cause is identified then this is called idiopathic membranous nephropathy.

Secondary membranous nephropathy

In a small number of people, membranous nephropathy is associated with other illnesses. These include:

- disease caused by an overactive immune system (such as SLE [systemic lupus erythematosus], sometimes referred to just as 'lupus')
- certain medications
- certain cancers (such as those affecting the bowel, stomach, breast and the kidney itself)
- chronic infections (for example, viral hepatitis, malaria)
- a build-up of certain toxins (such as mercury, which is sometimes used in face creams).

What are the complications of membranous nephropathy?

Some people with membranous nephropathy develop:

- high blood pressure (hypertension)
- high cholesterol
- fluid around and/or on the lungs and in the lower legs
- a puffy face, particularly with swelling of the eyelids first thing in the morning
- an increased risk of blood clots, such as deep vein thrombosis (DVT)
- an increased risk of experiencing a heart attack or a stroke
- progressive worsening of kidney function.

What will happen to my kidneys?

- In about one third of people the leakage of protein into the urine goes away by itself. This is called 'remission'.
- In another third of people the amount of protein leaking into the urine reduces, but doesn't go away altogether. This is called 'partial remission'.
- In the remaining third of people the amount of protein leaking into the urine continues and kidney function may get worse. If this happens, your doctor may recommend medication to dampen your immune system. This helps to prevent the autoantibodies that are attacking the filters in your kidneys from being made.

Some people with membranous nephropathy develop kidney failure, which would lead to dialysis or a kidney transplant. This is more likely if you:

- are male and over 50
- have a large and ongoing amount of protein in your urine
- have reduced kidney function when you are first diagnosed
- have persistently high blood pressure
- have a lot of damage seen on your kidney biopsy
- have a known cause of membranous nephropathy (such as hepatitis B or C infection) which cannot be cured.

What can I do to help my condition?

- Follow the advice from the renal dietitian, who will recommend some dietary changes to help lower your cholesterol level. They will also give you advice about reducing salt in your diet and how much fluid you should drink.

Renal Dietitians, Churchill Hospital

Tel: **01865 225 061**

- Have your blood pressure measured regularly, as good blood pressure control is very important for protecting the kidneys. Your kidney doctor will give you a blood pressure target and will review your blood pressure at each appointment. If your blood pressure is above the target, your doctor will recommend ways to reduce it (such as achieving an ideal body weight, reducing salt in your diet, adjusting your medication).
- Weigh yourself regularly, especially if you are taking water tablets (diuretics). Water tablets help your body to get rid of excess fluid. One litre of fluid weighs 1kg, therefore your weight will go down by 1kg for every litre of excess fluid your body gets rid of. Your weight may also change if you alter your diet or the amount of exercise you do, but this usually takes weeks. Changes in your weight over a few days are more likely to be related to the amount of fluid in your body.
- Your kidney doctor will advise you how often you should weigh yourself, how much excess fluid you should lose each week (and therefore how much your weight should go down each week) and what to do if this does not happen.
- If you smoke then you should stop. We can give you help and advice with this.
- Speak with your kidney doctor if you are planning a long-haul flight. Some people with nephrotic syndrome are at increased risk of developing a blood clot (deep vein thrombosis or DVT) during a long-haul flight. Your kidney doctor will advise you if you need any extra treatment before you fly.

What if I am planning a family?

If you are female, you should speak with your kidney doctor before trying to conceive, as some of your medications may need to be changed. Your kidney doctor will discuss any risks of pregnancy with you, as well as changes to your medication and how well controlled your kidney function is.

What will my kidney doctor do?

If you are retaining fluid you will be prescribed water tablets (such as furosemide), which will allow your kidneys to rid your body of the excessive water. You may also be prescribed a drug which lowers blood pressure (an 'ACE inhibitor', such as ramipril, or an 'ARB', such as valsartan), which can also reduce the amount of protein being lost in your urine. You may also need a statin to lower your cholesterol level.

Your kidney doctor will also do the following:

- see you in clinic regularly
- measure your weight and blood pressure
- monitor your blood and urine tests
- adjust your medications to minimise the protein leaking from your kidneys
- adjust the dose of water tablets if you have lots of swelling and fluid retention
- may recommend for you to take blood thinning medication to help prevent blood clots forming.

If your kidney function does not improve, or you have high levels of antibodies in your blood, your kidney doctor may recommend an immunosuppressant medication. These dampen your immune system; with the aim of reducing the amount of protein you are leaking in your urine and preserving your kidney function.

There are various forms of immunosuppressants that are used. These will be discussed with you if your kidney doctor thinks they will benefit you.

Useful websites

Oxford Kidney Unit

This website has information about the Oxford Kidney Unit for patients and carers.

Website: www.ouh.nhs.uk/oku

Kidney Care UK

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

Website: www.kidneycare.org

National Kidney Federation

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

Website: www.kidney.org.uk

RareRenal (The Renal Association)

Run by UK based kidney doctors promoting research into membranous nephropathy. There are links from the website to join a patient register and be the first to hear about potential new treatments and clinical trials.

Register: www.rarerenal.org/radar-registry

Six Counties Kidney Patients Association

The SCKPA is run for patients by patients or family members.

They offer support to people suffering from kidney disease or who are on dialysis. They work closely with the Oxford Kidney Unit and have branches in Oxfordshire, Northamptonshire, Buckinghamshire, and Milton Keynes, and parts of Wiltshire, Gloucestershire and Berkshire.

Website: www.sixcountieskpa.org.uk

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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Oxford University Hospitals NHS Foundation Trust
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