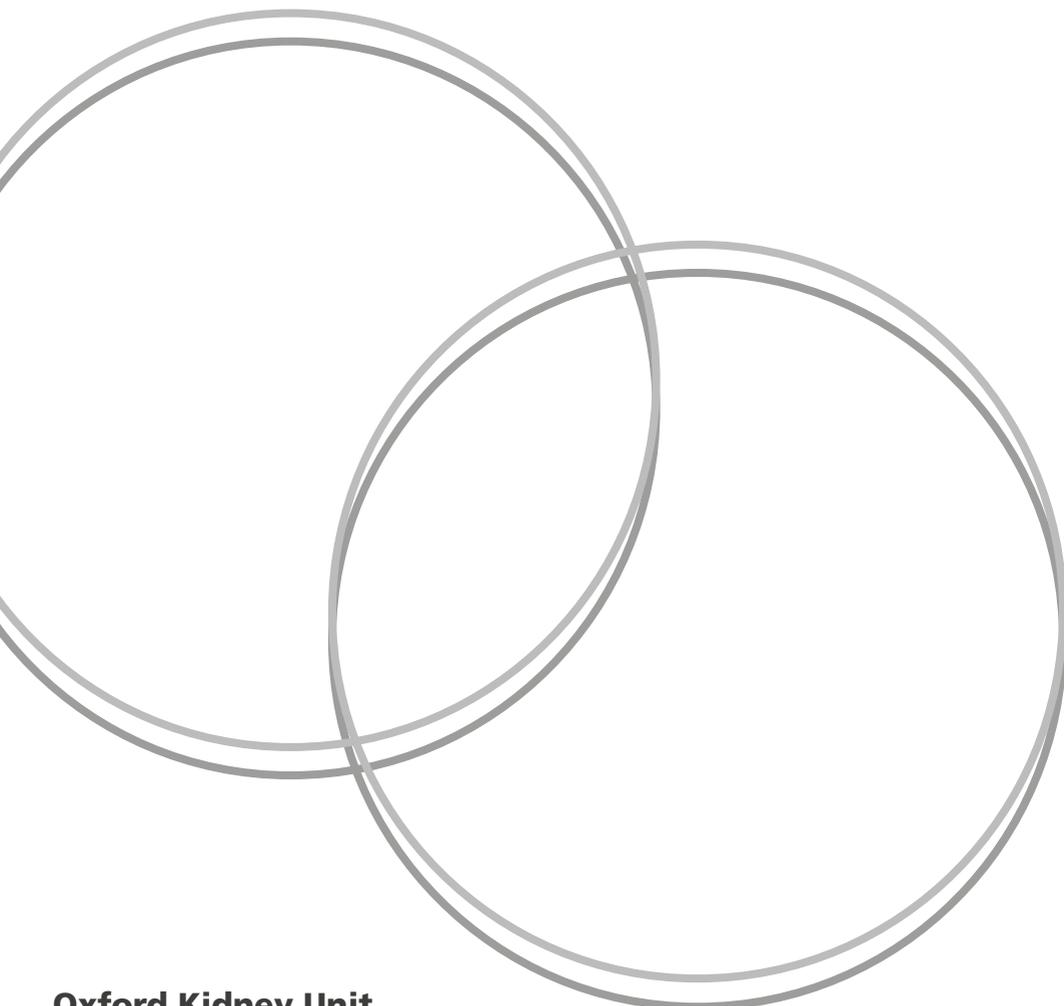


# Membranous nephropathy

Information leaflet



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?**

Membranous nephropathy develops slowly, often over years. Many people do not know they have it. Often it is found during routine urine testing, where a lot of protein is seen.

Some people may develop swelling (oedema), in the 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 3 grams per day), and is known as 'nephrotic syndrome'. Often 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 damage them, making them leak too much protein into 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 the blood, the more likely you are to have a more 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 advanced kidney disease, and need treatment with 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 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. Ask a healthcare professional if you would like help to stop smoking.
- 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 happens at the Kidney Clinic appointment?**

A kidney doctor will:

- Monitor your kidney function (blood test).
- Test your urine to measure the amount of protein loss.
- Measure your weight and blood pressure.
- Speak with you about medications that often need to be taken.
- Adjust the doses of medications if required.

# Medications for membranous nephropathy

## Water tablets (diuretics)

These help your kidneys remove excess fluid from your body. They can reduce swelling (oedema) in your legs, ankles, or around your eyes.

## Blood pressure medications

Controlling blood pressure is very important in protecting your kidneys.

You may be prescribed:

- **ACE inhibitors** (medications that often end in “-pril”), such as Ramipril
- **ARBs** (medications that often end in “-sartan”), such as Valsartan

These medications also help reduce the amount of protein leaking into your urine.

## Statins

Statins are medications that lower cholesterol levels in your blood. High cholesterol is common in people with nephrotic syndrome and treating it helps reduce long-term risk of heart disease.

## Blood-thinning (anticoagulation) treatment

People with membranous nephropathy may have a higher risk of developing blood clots, especially if protein levels in the blood are very low. If your risk is high, your kidney team may recommend anticoagulation (“blood-thinning”) treatment.

Options include:

- **Warfarin**

A long-established blood thinner that requires regular blood tests (INR monitoring) and some dietary considerations.

- **Low-molecular-weight heparin (LMWH)**

Given as an injection, usually used for short-term treatment.

- **Direct oral anticoagulants (DOACs), such as Apixaban**

These are taken as tablets and usually do not require routine blood test monitoring.

In membranous nephropathy, the use of DOACs is considered “off-label” (outside the original product licence), but this is common practice and supported by local guidance.

The choice of anticoagulant depends on several individual factors, including:

- Kidney function
- Risk of bleeding
- Other medications you are taking
- Your personal preferences

## **Immunosuppression**

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](http://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](http://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](http://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.ukkidney.org/rare-renal](http://www.ukkidney.org/rare-renal)

### **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](http://www.sixcountieskpa.org.uk)

## **OUH Patient Portal Health for Me**

Please ask a member of the kidney team to sign you up to the patient portal.

Website: [www.ouh.nhs.uk/patient-guide/patient-portal](http://www.ouh.nhs.uk/patient-guide/patient-portal)

## 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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[www.ouh.nhs.uk/information](http://www.ouh.nhs.uk/information)



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