Membranous nephropathy
Information for patients
The examination of your kidney biopsy has shown that your kidney problem is caused by a condition called **membranous nephropathy**.

**What is membranous nephropathy?**

Membranous nephropathy is a type of ‘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?**

Some people with membranous nephropathy have no symptoms, but have had a kidney biopsy because they have been found to have abnormal amounts of protein in their urine. Others have developed swelling (oedema), usually in their 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 stream, because lots of protein has been lost into the urine, and is known as ‘nephrotic syndrome’. Some people with nephrotic syndrome notice that their urine appears ‘foamy’ or ‘frothy’.
What causes membranous nephropathy?

**Primary membranous nephropathy**

In most people membranous nephropathy occurs for no apparent reason and develops ‘out of the blue’. We call this primary membranous nephropathy.

Recent research suggests that this can develop when part of your body’s immune system makes antibodies that attack part of the filters in the kidney. The part of the filter which is targeted by the antibody is a protein called ‘PLA2R’. The antibodies attach to the filter and damage it, making it leaky.

**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
• an increased risk of blood clots, such as deep vein thrombosis (DVT)
• an increased risk of experiencing a heart attack or a stroke.

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 about one 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 the kidney function may get worse. If this happens, your doctor may recommend medication to dampen your immune system. This helps to prevent the antibodies being made that are attacking the filters in your kidneys.

Some people with membranous nephropathy develop kidney failure. This would result in the need for dialysis or a kidney transplant. This is more likely if you:
• are male and over 50
• have a large and persisting 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?

• If you smoke then you should stop. We can give you help and advice with this.

• Our renal dietitian will recommend some dietary changes to help lower your cholesterol level and will give you advice about reducing salt in your diet.

• Have your blood pressure measured regularly, as good blood pressure control is very important in 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.

• 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?

You should speak with your kidney doctor before trying for a baby. If you are on any medications these may need to be changed. Your kidney doctor will discuss any risks of pregnancy with you.

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 will be prescribed a drug which lowers the blood pressure in the filters (an ‘ACE inhibitor’, such as ramipril or an ‘ARB’, such as valsartan).

Your kidney doctor will also do the following:
• see you in clinic regularly
• measure your 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
• may recommend for you to take blood thinning medication to help prevent blood clots forming.

If your kidney function does not improve, then your kidney doctor may recommend medication called an immunosuppressant to dampen your immune system. If this is needed, you will be offered 6 months of treatment with steroids and cyclophosphamide, known as the ‘Ponticelli Regimen’ (please see our separate leaflet on the Ponticelli treatment).

Please speak to your kidney doctor at your next clinic appointment or by contacting their secretary if you have any further questions. If you are not sure when your next appointment is or which
kidney doctor to contact please call the renal clinic.

Tel: **01865 225 356**
(Monday to Friday, 9.00am to 5.00pm, with an answerphone available)

**Further information**

**National Kidney Federation**
A UK based charity, run by kidney patients for kidney patients.
Helpline: 0845 601 02 09 (Freephone from UK landlines)

**The Renal Association – RareRenal.org**
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.
Email: admin@rarerenal.org
Website: http://rarerenal.org/patient-information/membranous-nephropathy-patient-information/

**Edinburgh Renal Unit**
Website: www.edren.org/pages/edreninfo/membranous-nephropathy.php
If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call **01865 221 473** or email **PALSJR@ouh.nhs.uk**

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