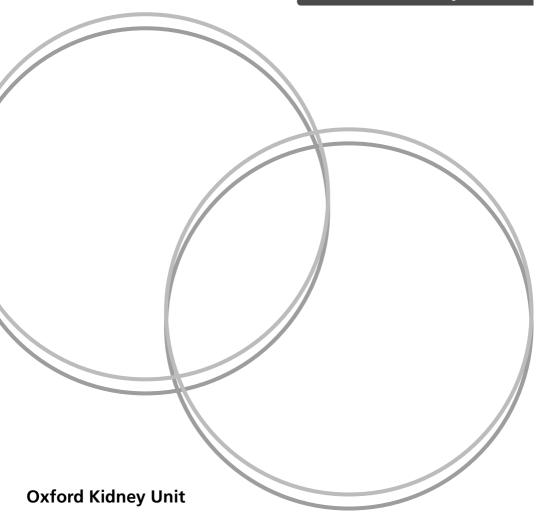


Renal: Ponticelli regimen for the treatment of Membranous Nephropathy

Information for patients



This leaflet will provide you with information about the Ponticelli regimen. If there is anything else you feel you need to know after reading the leaflet, please speak to your kidney doctor. This leaflet should be read alongside the Oxford Kidney Unit information leaflet on membranous nephropathy.

What is the Ponticelli regimen?

The Ponticelli regimen is a combination of drug treatments which is used to treat a kidney disease called membranous nephropathy. The Ponticelli regimen is named after Professor Claudio Ponticelli, an Italian doctor, who first demonstrated that it was effective in treating some people with membranous nephropathy. It is a 6 month treatment to dampen (or lower) your immune system.

In the Ponticelli regimen, you will be given the following treatments:

- a steroid called methylprednisolone (as a liquid infusion)
- steroid tablets (called prednisolone)
- cyclophosphamide tablets (a type of chemotherapy medication).

More details about these treatments are given in later sections of this leaflet.

Why has my doctor recommended this treatment?

The Ponticelli regimen is given to people with membranous nephropathy whose condition is unlikely to get better without medication. The decision to start this treatment will be made by your kidney doctor after discussion with you.

What does the Ponticelli regimen involve?

Your treatment will be given to you over a six month period. In the first month you will be given the steroids and in the second month you will be given the cyclophosphamide. This two month cycle will then be repeated twice more for a total of **six months**.

At the start of each of the months of steroid treatment (months one, three, and five) you will need to come to the Renal Day Case Unit every day for three days. You will have the steroid infusion through a cannula (small plastic tube) into a vein in your hand or arm on each of these days.

When you have each steroid infusion you will need to stay in the Renal Day Case Unit for about an hour. If you would like to, you can have a friend or relative stay with you to keep you company while you are being treated.

On the third day, you will be given a supply of the steroid tablet, to take for the rest of the month, starting from the next day. We will also give you the cyclophosphamide tablets. You will start these when you have completed the steroid tablets.

Month 1, 3 and 5: Steroids

Days one, two and three come to the Renal Day Case unit for the steroid infusion. Day 4 onwards for the rest of the calendar month take steroid tablets.

You should take your steroid tablets with food, as this helps to prevent them irritating the lining of your stomach.

Month 2, 4 and 6: Cyclophosphamide

Tablets to be taken for the full calendar month.

Cyclophosphamide should be taken in the morning, so that your body processes it throughout the day. It is best taken on an empty stomach, but can be taken with food if you find it makes you feel sick.

You will also be given the following medications to take for the whole six months of treatment:

- Antibiotics, such as co-trimoxazole. These help to protect against certain lung infections.
- **Omeprazole** or other medication to reduce the amount of acid in your stomach and protect your stomach lining.
- Some tablets to protect your bones, such as risedronate, calcium and vitamin D supplements.

What are the benefits of the treatment?

In research studies, people with membranous nephropathy who are treated with the Ponticelli regimen have less protein in their urine at the end of the 6 month treatment.

The Ponticelli regimen has been shown to reduce the risk of people developing advanced long-term kidney damage due to the reduction of protein in their urine.

Your doctor will measure your protein leak in your urine. This is a test called protein: creatinine ratio (PCR).

If your PCR level is less than 30mg/mmol your membranous nephropathy is under control (in remission).

If your PCR is greater than 30 but less than 300mg/mmol you will have partial remission. This means there is a chance the disease will start to get worse.

9 out of 10 people (90%) will achieve complete remission from having the Ponticelli regime treatment.

1 in 4 people (25%) will experience a relapse in their condition within 30 months of completing the Ponticelli regime treatment.

Tell me more about steroids

We will give you a separate leaflet on steroids that gives you more information about side effects and how to care for yourself when taking these medications.

Tell me more about cyclophosphamide

We will give you a separate leaflet on cyclophosphamide that gives you more information about side effects and how to care for yourself when taking these medications.

If you develop a **high temperature** whilst on the Ponticelli regimen please contact:

Oxford University Hospitals switchboard:

0300 304 7777

ask for the Churchill Hospital and then to speak to the renal registrar on-call.

How will I be monitored during the course of treatment?

You will be seen every month in the kidney clinic during the treatment. During month 2, whilst you are taking cyclophosphamide you will need weekly blood tests to monitor your blood count. Your blood test can be done either at your GP surgery or at the Kidney Unit. Please plan with your kidney doctor where these blood test will be done, so they know where to look for the results.

What happens after my treatment?

After you have finished the treatment, your kidney doctor will see you in the kidney clinic. They will measure your blood pressure, the amount of protein in your urine and will take a blood test to check on your kidney function. They will discuss your response to the treatment with you.

Useful websites

Oxford Kidney Unit

Lots of information about the Oxford Kidney Unit for patients and carers.

Website: www.ouh.nhs.uk/oku

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

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

Contacts

Renal Pharmacists

Churchill Hospital

Tel: **01865 226 105**

Email: orh-tr.oxfordrenalpharmacy@nhs.net

9am to 5pm, Monday to Friday

(Please leave a message on the answerphone)

Renal Day Case Unit

Tel: **01865 226 106**

8am to 6.30pm, Monday to Friday

(Please leave non-urgent messages on the answerphone)

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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