Cyclophosphamide treatment in the Oxford Kidney Unit
Information for patients
You have been given this leaflet as your doctor has prescribed you cyclophosphamide to treat your kidney condition.

### Why do I need take cyclophosphamide?

Cyclophosphamide is a medicine which dampens your immune system (an ‘immunosuppressant’). In the Oxford Kidney Unit, cyclophosphamide is used to treat certain kidney conditions which are caused by an overactive immune system or ‘autoimmune disease’, such as:

- **vasculitis** (inflammation of the blood vessels)
- **systemic lupus erythematosus** (lupus) which is affecting your kidneys.

In other areas of the hospital, cyclophosphamide is also used to treat some cancers; it is sometimes called a chemotherapy drug. This does not mean you have cancer or are having chemotherapy.

Your Kidney Doctor will give you information about your kidney condition, how this could affect you in the future and what the likely benefit of cyclophosphamide would be for you.
What are the risks and side effects of taking cyclophosphamide?

Common short-term side effects of cyclophosphamide include:
- low white blood cell count (this can increase your risk of developing infections). Your white blood cell count is measured using a blood test.
- nausea and/or vomiting
- irritation of your bladder lining, which can cause blood in your urine, stinging when you pass urine and may make you want to urinate more frequently.

Occasional side effects include:
- hair loss (hair usually grows back after stopping the drug)
- diarrhoea
- mouth ulcers
- skin changes – your skin may darken, but this is rare
- low platelet count (this can cause unexplained bruising or bleeding that won’t stop easily).

Cyclophosphamide can also cause:
- **infertility** – you should discuss this further with your Kidney Doctor.
- **damage to an unborn child** – you should not try for a baby while you are taking cyclophosphamide (whether you are a woman or a man) and for three months after stopping the treatment.
- **cancer** – cyclophosphamide causes a small increase in the risk of bladder and some other cancers. Your Kidney Doctor will give you more information about this.

Cyclophosphamide is often prescribed along with steroid tablets. Steroids are an essential part of the treatment for many kidney conditions. They work by helping to reduce inflammation in the kidneys. The length of time you need to take steroids for will depend on your kidney condition. If your doctor prescribes you steroids, they will talk to you about why you need them and how long you will need to take them for. You will also be given separate information about the side effects and what to look out for when taking them.
How will the cyclophosphamide be given?

The two main ways of taking cyclophosphamide are:
- intravenous infusion
- tablets (usually taken once a day).

Usually cyclophosphamide is given as an infusion (liquid mixture) into a vein in your hand (intravenously). The dose of cyclophosphamide (either in the infusion or the tablets) will depend on your body weight and may also change depending on how you respond to the treatment.

The cyclophosphamide infusions are usually given every two weeks to start with, and then once every three weeks. You are likely to need a total of six infusions. Before you come for each cyclophosphamide infusion you will need to have a blood test, to monitor your kidney and liver function as well as your white blood cell count (the cells which fight infection).

If you are having the cyclophosphamide infusion

**What happens on the day of the cyclophosphamide infusion?**

You will need to come to the Renal Day Case Unit at the Churchill Hospital. On the day of the infusion, it may be better to have a small, light breakfast, as you may feel nauseated during the treatment. Please bring a list of your usual medications with you, including any over the counter medication or herbal remedies.

When you arrive you will be seen by a doctor to check you are fit to go ahead with the treatment. They will examine you and check your recent medical history. Before you start the treatment, your doctor will explain the risks and benefits to you and will ask you to sign a consent form. When you are ready to have the treatment, a cannula (small plastic tube) will be inserted into a vein in your hand. The cyclophosphamide infusion is given through the cannula into your vein; this is sometimes called a ‘drip’. This takes about an hour.

Before you have the cyclophosphamide you will be given an injection of a medicine called mesna, which helps to protect your bladder lining. We can also give you a tablet called ondansetron, which can help stop you from feeling sick.
Although the treatment only takes an hour, you are likely to be in the Renal Day Case Unit for 3-4 hours. This is so that the doctor can assess you and explain the treatment; we can carry out any tests that are needed; and we can arrange any further medications or appointments you might need. If you would like to, you can bring a friend or relative to stay with you to keep you company.

What happens after the cyclophosphamide infusion?

You will be given the following medicines to take home with you.

- **ondansetron** (two tablets) – You can take one 12 hours after the infusion if you still feel sick. You can take another one 24 hours after the infusion, if needed.

- **mesna** (two tablets) – You should take one tablet 4 hours after the infusion and another tablet 8 hours after the infusion.

It is really important that you drink plenty of fluids during the next 24 hours after your cyclophosphamide infusion. Your Kidney Doctor will tell you how much fluid to drink. This helps to flush out the cyclophosphamide and protect your bladder. It is also important to empty your bladder regularly and to try to pass urine as soon as you feel the need to go.

You do not need to take your temperature unless you feel hot, shivery and unwell. If it is between 37.5°C and 38°C, repeat the reading in four hours. If it remains the same, contact your GP or Kidney Doctor and tell them you are on cyclophosphamide medication and have a high temperature.

If your temperature is greater than 38°C contact the Renal Registrar On-call immediately, on the telephone number below:

Churchill Hospital switchboard – ask to speak to the Renal Registrar On-call 01865 741 841 (24 hours)

Before you leave you will be given an appointment to have the next infusion.
If you are having the cyclophosphamide tablets

Cyclophosphamide tablets
If your Kidney Doctor decides you need cyclophosphamide tablets, they will give you a prescription. The tablets will be dispensed from the hospital pharmacy. It will say on the packaging how many tablets you need to take each day.

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

You will need weekly blood tests during your treatment, to monitor your white blood cell and platelets (blood count). This blood test can be done either at your GP surgery or at the Kidney Unit. Please plan with your Kidney Doctor where these blood tests will be done, so that they know where to look for the results.

Do I need to take anything else during the course of cyclophosphamide treatment?

Whether you are having cyclophosphamide as tablets or by infusion, there are some other medicines you will need to take to help protect against side effects. These include:

- a **co-trimoxazole** tablet to take every day. This helps to protect against certain lung infections.
- **ranitidine** or another medication to reduce the amount of acid in your stomach (if you are also being treated with steroids)
- **calcium, vitamin D** and, depending on your kidney function, a tablet called **risedronate** to help protect your bones (if you are also being treated with steroids).

You should also continue your usual medications during the course of cyclophosphamide. Your Kidney Doctor will advise you if any changes to your usual medication are needed.
How will I know if the treatment has worked?

Your Kidney Doctor may not know how well the treatment has worked until you have completed the course. They will arrange to see you at a clinic appointment to discuss how effective the treatment has been.

Is there anything else I need to know?

**Alcohol** – there is no particular reason to avoid alcohol while on cyclophosphamide.

**Breastfeeding** – you should not breastfeed if you are on cyclophosphamide, as the drug may pass into the breast milk and could be harmful to your baby.

**Immunisation** – you should not be immunised with live vaccines (such as the chickenpox or shingles vaccine) while receiving cyclophosphamide. Please speak to your Kidney Doctor about possible risks and which vaccinations are safe to have.
Where can I get more information?

If you would like more information about cyclophosphamide, or if you have any concerns about your treatment, you should discuss this with your Kidney Doctor, the Renal Pharmacist or the Day Case Unit nurses.

**Useful information is also available online:**

**Vasculitis UK**
Information for people with vasculitis and their relatives.
Website: www.vasculitis.org.uk

**NHS Choices**
NHS website which provides information on specific conditions.
Website: www.nhs.uk/conditions/vasculitis/pages/introduction.aspx
Website: www.nhs.uk/conditions/Lupus/Pages/Introduction.aspx

**Oxford Kidney Unit**
Useful information about the Oxford Kidney Unit for patients and their relatives.
Website: www.ouh.nhs.uk/oku

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**