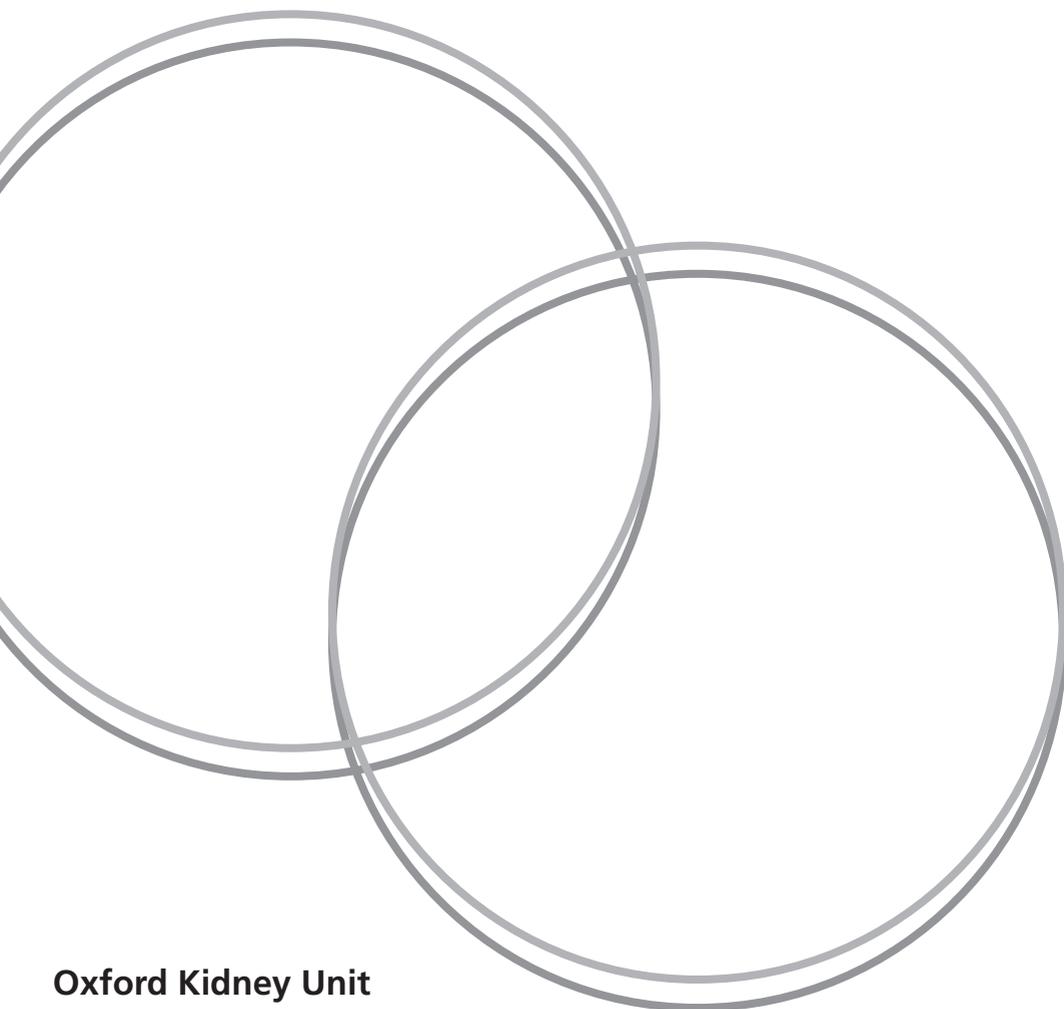




Oxford University Hospitals
NHS Foundation Trust

Tell me more about vasculitis

Information for patients



Oxford Kidney Unit

This leaflet will provide you with information about what vasculitis is and how we treat it at the Oxford Kidney Unit. If you have more questions after reading this leaflet please speak to your kidney doctor.

What is vasculitis?

Vasculitis is inflammation of blood vessels. Inflammation is your immune system's natural response to injury or infection. Vasculitis is an autoimmune condition in which the immune system attacks your healthy blood vessels, causing them to become damaged. Any type of blood vessel can be affected including capillaries, arteries or veins. Symptoms and treatment depend on which organs and tissues are affected and can vary from person to person.

Vasculitis can range from a minor problem that affects a single organ such as the skin, to a more serious illness that causes problems with the heart, lungs or kidneys.

If you have been asked to see a kidney doctor it is likely that the illness is already affecting your kidneys.

The aim of treatment is to prevent further damage to your kidney function and avoid potentially life-threatening complications.

What types of vasculitis may affect your kidneys?

The most common types of vasculitis we see include:

- **ANCA-associated vasculitis**
 - Granulomatosis with polyangiitis (also known as Wegener's granulomatosis)
 - Microscopic polyangiitis
 - Eosinophilic granulomatosis with polyangiitis (also known as Churg Strauss syndrome)
- **Anti-GBM disease (also known as Goodpasture's disease)**
- **Cryoglobulinaemia**
- **IgA vasculitis (previously known as Henoch-Schönlein purpura)**
- **Polyarteritis nodosa**
- **Giant cell (temporal) vasculitis**
- **Urticarial vasculitis**

Please talk to your renal team if you would like more information about the type of vasculitis you have.

What causes vasculitis?

We usually don't know what triggers vasculitis, although infection, medication, genetic or environmental factors have been associated.

How will I know that I have vasculitis?

Your kidney doctor will have talked to you about your health history, performed a physical examination and taken some blood and urine samples. They may have also suggested that you have a kidney biopsy (a separate leaflet is available for a kidney biopsy, please ask if you would like a copy).

When you have a blood sample taken we will look at:

- Inflammation markers, such as the erythrocyte sedimentation rate (ESR) or C-reactive protein (CRP).
- Full blood count, this will show if you are anaemic and whether you have normal levels of white blood cells (which fight infections) and platelets (which are involved in clotting).
- Anti-neutrophil cytoplasmic antibodies (ANCA), these are important in the diagnosis of some types of vasculitis.
- Kidney function (eGFR, urea and creatinine).
- Liver function.

When you provide a urine sample we look to see if there is any evidence of blood or protein suggestive of kidney inflammation.

If we think that the blood vessels in your lungs are affected, we may arrange for you to have scans and lung function tests.

What are the symptoms?

The symptoms can vary from person to person. All parts of the body can be affected, but the following are some of the most common symptoms that you may experience:

Kidneys	Vasculitis can cause damage in the small blood vessels in the kidneys. You may notice blood appearing in the urine and in severe cases it can lead to kidney failure.
Skin	Small blood vessels in the skin can become damaged causing them to burst, leaving a rash with small red blotches.
Joints	Inflammation around the joints, causing joint pain, stiffness or swelling.
Nose	The lining of the nose can become inflamed leading to nose bleeds. Nose bleeds can occur for a period of time before the kidneys are affected.
Lungs	Small blood vessels inside the lungs may bleed. If you notice that you cough up blood, you will need to seek medical attention urgently.
Other parts of body	Vasculitis may cause strokes, heart attacks and damage to the bowel. However, this is rare and the risk of these problems can usually be minimised once you start treatment.

How is vasculitis treated?

Steroids and immunosuppressant medications are used to treat vasculitis. Both of these dampen down the immune system therefore reducing the damage caused by vasculitis. You usually need these for months and sometimes years.

These medications can potentially cause some serious side effects and regular monitoring is vital. There are separate leaflets available for medications commonly used in vasculitis, please ask if you would like a copy.

Which medications you receive may depend on your health and type of vasculitis. Your kidney doctor will explain this in more detail with you.

The treatment of vasculitis involves an 'induction phase' of 3–6 months to induce a remission to rapidly reduce inflammation and hopefully improve organ function and prevent permanent damage. During the induction phase you will need to come to the Renal Day Case Unit to receive an intravenous immunosuppressive drug therapy on several occasions.

Once you have completed the induction phase of treatment this is followed by a longer 'maintenance' or 'relapse prevention' phase. You will then be regularly reviewed in the outpatient clinic by your kidney doctor. You will need to continue to take immunosuppressive medication.

There will also be other medications (tablets) that you will need to take to offset potential side-effects of the treatment.

How often and how long you need treatment for depends on how your body responds to the treatment. It is sometimes a long-term condition which can relapse. Our aim is to get the disease under control and bring you into remission and prevent flare-ups.

If vasculitis is diagnosed at an early-stage treatment is very effective.

How can I help myself?

- Take all your medications as prescribed; if you are unsure speak to your renal doctor or pharmacist.
- If you smoke, then you should stop. It increases the risk of heart attacks and strokes.
- Have your blood pressure measured regularly, as good blood pressure control is very important in protecting your kidneys (and also reduces the risks of stroke and heart attacks in the future). You should consider buying a blood pressure machine so you can monitor your blood pressure at home.
- Take regular exercise, this will help you to achieve an ideal weight, reduce blood pressure and improve mental health.
- Talking to family and friends about what is happening to you can help you to cope. Consider joining a vasculitis support group. We also have a Clinical Psychologist and Patient Support Advisor who can help you with your emotions and mental health.
- Choose a healthy diet. If you need some nutritional advice, ask to speak to one of our Renal Dietitians.
- Avoid some painkillers that can cause kidney problems such as non-steroidal anti-inflammatory tablets (e.g. Brufen, Nurofen, ibuprofen, and Voltarol, also called diclofenac).
- Sign up to the rare renal database.
- Attend all of your renal clinic and blood test appointments.

Contact details

Renal Day Case Unit

Churchill hospital

Tel: 01865 226 106

8am to 6.30pm, Monday to Friday

(Please leave non-urgent messages on the answerphone)

Renal Outpatient

Churchill Hospital

Tel: 01865 225 355

8am to 5pm, Monday to Friday

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 Ward

Churchill hospital

Tel: 01865 225 780

24 hours, including weekends and bank holidays

Useful websites

Vasculitis UK

Vasculitis UK has been a registered UK charity. It has a lot of information about vasculitis and the organisation provides information and advice to patients suffering from vasculitis and their families.

Website: www.vasculitis.org.uk

UK National Kidney Federation

The UK National Kidney Federation is a national kidney charity run by patients with kidney problems and their carers, for kidney patients. It has more information about vasculitis.

Website: www.kidney.org.uk/vasculitis

NHS website

Has lots of information about vasculitis.

Website: www.nhs.uk/conditions/vasculitis

Oxford Kidney Unit

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

Website: www.ouh.nhs.uk/oku

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

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

Heath for Me (patient portal)

'Health for Me' enables you to access to your digital health record via the OUH Patient Portal. It is an online system that allows you to easily view parts of your digital health record safely and securely from a computer or smartphone.

Please ask a member of the renal team to sign you up to the 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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