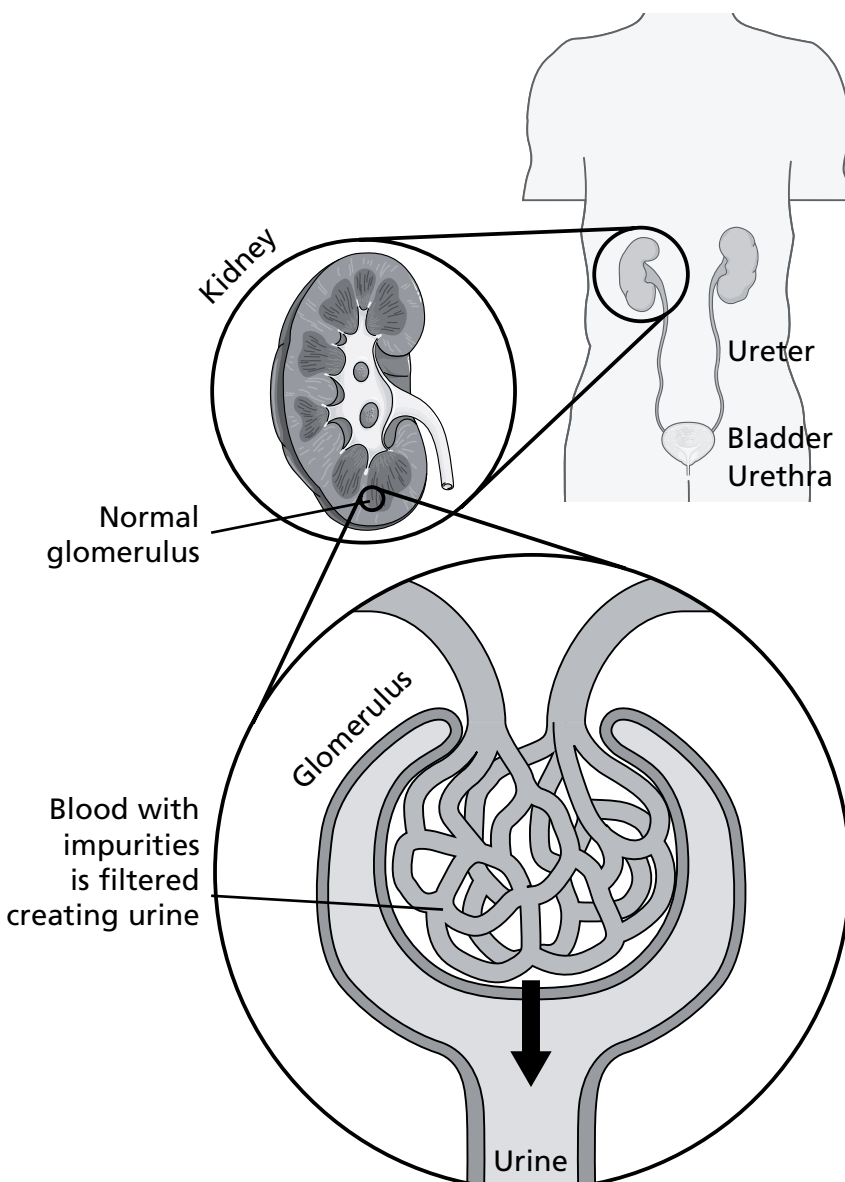




## Great Ormond Street Hospital for Children NHS Trust: Information for Families

# Lupus nephritis

**This information sheet explains about lupus nephritis, how it affects children and what treatments are available. It also explains what to expect when your child comes to Great Ormond Street Children's Hospital for assessment and treatment.**



## How does the urinary system work?

The urinary system consists of the kidneys, ureters, the bladder and urethra. The kidneys filter the blood to remove waste products and produce urine. The urine flows from the kidneys down through the ureters to the bladder, where it is stored until we go to the toilet. It passes through another tube called the urethra to the outside when urinating (peeing).

The kidneys contain around a million tiny filtering units called glomeruli. As blood passes through the tubes in the glomerulus, waste products pass through the walls of the tubes to form urine. Blood cells and other things such as protein cannot pass through the walls because they are too big.

## What is lupus nephritis?

Lupus nephritis is a specific kind of kidney inflammation (nephritis) that affects children with systemic lupus erythematosus (SLE). SLE is an autoimmune condition. Normally, the job of the immune system is to find and destroy foreign invaders, such as germs. An autoimmune condition is one where the body starts to attack itself after mistakenly recognising its cells as the 'enemy'. In lupus nephritis, the immune system attacks the kidneys, particularly the tiny filtering units within the kidneys (glomeruli), stopping them working as well as they should.



## What are the symptoms of lupus nephritis?

The symptoms of lupus nephritis are similar to other conditions affecting the glomeruli. Blood may be present in the urine, which can be discovered by test sticks. There may be swelling due to increased fluid in the body, which is not being removed by the kidneys as it should. This can cause puffiness, particularly around the eyes, tummy, feet and legs, and weight gain. The medical word for this puffiness is oedema. The urine's appearance changes so that it appears foamy, which is a sign of proteinuria. The blood pressure may rise. Other symptoms of being generally unwell are common, such as loss of appetite. These are also caused by the puffiness, which can affect internal organs, such as the digestive system, as well as the hands, feet and legs.

## How is lupus nephritis diagnosed?

Your doctor will ask you lots of questions about how your child became ill and examine your child. Various tests will be needed to confirm or rule out lupus nephritis:

- Urine tests to see if protein is present in the urine
- Blood tests to check kidney function and specific lupus tests
- Kidney biopsy to see if any areas contain inflammation

Other tests may also be needed if the results of these tests are not completely clear.

## What causes lupus nephritis?

Lupus nephritis only affects children with SLE. SLE is an autoimmune condition, caused by the body's immune system going into overdrive and attacking healthy tissue. For more information about the causes of SLE, please see our leaflet.

## How common is lupus nephritis?

SLE tends to appear around the start of puberty. Children under ten years old can develop SLE but this is less common. Over half of all children diagnosed with SLE will have some kidney involvement already. Almost all children with SLE will develop kidney problems at some point.

## How is lupus nephritis treated?

The standard treatment is steroids in combination with immunosuppressive medicines, which damp down the immune system and stop it attacking the glomeruli. We use different immunosuppressive medicines. The most common are cyclophosphamide, azathioprine and mycophenolate (MMF). The initial treatment with cyclophosphamide is often given as an intravenous infusion every four weeks or so at the start but may then change to oral tablets or medicines. This immunosuppressive treatment will need to be continued for a long time, often several years, to keep good control of the lupus. For more information about these medicines, please see our leaflets.



The amount of protein lost in your child's urine is monitored regularly. If the protein in the urine is high, medicines called ACE inhibitors are used to reduce the protein loss. For more information about ACE inhibitors, please see our information sheet. Occasionally diuretics (water tablets) are also prescribed to reduce the puffiness. Whether your child is taking steroids or immunosuppressive medicines, you may need to postpone some of your child's immunisations while taking them. You should also report to your family doctor (GP) if your child comes into contact with chicken pox unless he or she has already had it. Other precautions are included in our medicines information sheets.

## **What is the outlook for children with lupus nephritis?**

There is no cure for lupus nephritis but it can be managed well by steroids and/or immunosuppressive medicines. Without successful treatment, more areas of the glomeruli can become scarred, which affects the child's overall kidney function. Lupus nephritis can in a few cases progress to kidney failure. In the uncommon situation when your child's kidney function has dropped to a level where it is affecting his or her daily life, we will discuss dialysis and transplantation with you.

### **Notes**

## **Is there a support group for children with SLE?**

Yes, the following organisation will be able to offer advice and support:

Lupus UK  
St James House  
Eastern Road  
Romford RM1 3NH  
Tel: 01708 731251  
Website: [www.lupusuk.com](http://www.lupusuk.com)

**If you have any questions, please ask your doctor**

Compiled by the Nephrology and Rheumatology departments in collaboration with the Child and Family Information Group

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Great Ormond Street  
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[www.goshfamilies.nhs.uk](http://www.goshfamilies.nhs.uk) [www.childrenfirst.nhs.uk](http://www.childrenfirst.nhs.uk)