

PATIENT INFORMATION

**Giant Cell Arteritis (GCA) Affecting Vision
– Information for Patients Attending the
Acute Eye Clinic at Kidderminster
Treatment Centre**



What is Giant Cell Arteritis (GCA)?

GCA is an inflammation of the arteries. If a small piece of artery is taken from a patient with GCA and examined with a microscope, some unusual 'giant cells' may be seen. It is common for the arteries in the temples (sides of the head) to be affected, so GCA is sometimes called 'Temporal Arteritis'. GCA is an 'autoimmune' disease. Our immune system is supposed to fight infections. However, in GCA, the immune system attacks healthy arteries by mistake. We do not yet know why this happens.

Why does GCA Matter?

If GCA is not treated, there is a serious risk that poor blood supply may damage different parts of the body, particularly the eye - causing blindness, or the brain - causing a stroke.

Why does the doctor think I have GCA?

The diagnosis of GCA will be based on your symptoms, on the examination by the doctor, and on the results of urgent blood tests. Treatment is urgent, so it is usually started before any further tests are done. Doctors often request an ultrasound test of the temporal arteries. This test provides pictures of the arteries and may show signs of inflammation. Doctors occasionally recommend a Temporal Artery Biopsy test. This is a small operation to remove a piece of one of the arteries in the temple so that it can be examined. These tests do not always give definite answers, so the results may need careful interpretation.

What is the main treatment?

The main treatment is with steroids. These are needed in a high dose until the disease is under control. The dose is then reduced.

If the eye doctor thinks *your vision is affected by GCA (or may have been)*, the steroids may be given intravenously (into a vein in your arm). This intravenous treatment is usually given once each day for three days. From the fourth day onwards you will continue the treatment with steroid tablets by mouth.

If the eye doctor thinks *your vision has not been affected by GCA*, you may be started on steroid tablets and referred to your GP or a rheumatology doctor for further care.

What other treatments might I need?

Steroids can cause irritation to the stomach and we usually give a tablet to reduce the risk of this. When steroids are given for more than a few weeks they may cause thinning of the bones, so you will need a treatment to protect your bones. Occasionally a specialist may advise an additional or alternative drug to suppress the immune system.

How is the steroid treatment started?

Before starting steroids, please tell the doctor if you have an infection, or have recently been in contact with an infectious disease, such as chicken pox, shingles or measles. Please also tell the doctor if you have had tuberculosis, stomach ulcer, epilepsy, severe depression or bipolar disorder.

If the eye doctor prescribes intravenous steroids for you, then normally, the nurses in the Eye Department will give you the first treatment as an outpatient on the same day. The nurses will monitor your blood pressure before you go home. Please allow 1 to 2 hours for the treatment. You must then return to hospital for two further treatments, on the second and third days. (If you need treatment during a weekend, you will be told where to go.) You will be given steroid tablets (prednisolone 5mg) for you to start taking on the fourth day.

When taking steroid tablets, you will start with a lot of tablets each day, usually all together, after breakfast. It is very important that you get further supplies from your GP on repeat prescription.

What about side effects of steroids?

Steroids are powerful drugs with a large number of possible side effects, but GCA is a very serious disease. Doctors aim to use the smallest amount of steroid that gives adequate control of the GCA. Please read the Patient Leaflet, which is inside the packet of prednisolone tablets that will be given to you.

Some side effects can occur early in the course of treatment, for example, some people have a change in mood. A possible serious side effect is damage to a hip joint, but this is rare.

If I get side effects, should I stop the steroids?

Tell the doctor if you think you are having side effects from the steroids, but keep taking the dose of steroids recommended by the doctor. After you have been on steroids for two weeks, it is dangerous to stop steroids suddenly. If the doctor wants to reduce the dose of steroids, this will be done slowly.

What if I get ill on whilst taking steroids?

Your body produces natural steroids to help it deal with stress, such as illness, surgery or injury. The gland that makes natural steroids is 'switched off' when you take steroid drugs. If you are ill, you may need a higher dose of steroid drug during the illness. We will give you a Steroid Treatment Card, which you should show to any doctor or nurse that you see.

How long does GCA last?

In many cases, GCA lasts 2 or 3 years. During this period, the dose of steroids is adjusted according to the activity of the GCA. The disease activity is monitored using repeated blood tests. Rarely, patients need to take a small dose of steroids for the rest of their lives.

Who will be looking after me?

The eye department will look after your eyes as needed. While you are being treated with intravenous steroids by the nurses in the Eye Department, the Resident Medical Officer for Kidderminster Hospital is available to help if there are any problems. When this treatment has finished you will either need urgent follow-up with your GP or we will request an urgent appointment with a rheumatology doctor. Please make sure you can be contacted by phone for any urgent appointments. Your GP will be informed of your progress and your GP will provide the long-term follow-up care.

What if I still have some questions?

Please ask one of the nurses looking after you, or telephone the Acute Clinic at Kidderminster Treatment Centre on (01562) 512382

Further information is also available in a Patient Information Booklet about GCA that is produced by Arthritis Research UK, telephone 0300 790 0400. It may be downloaded from their website at:

<http://www.arthritisresearchuk.org/~media/Files/Arthritis-information/Conditions/Giant%20Cell%20Arteritis%202061%2014-1.ashx>

Contact Details

Acute Eye Clinic, Kidderminster Treatment Centre, DY11 6RJ
Tel 01562 512382

If your symptoms or condition worsens, or if you are concerned about anything, please call your GP, 111, or 999.

Patient Experience

We know that being admitted to hospital can be a difficult and unsettling time for you and your loved ones. If you have any questions or concerns, please do speak with a member of staff on the ward or in the relevant department who will do their best to answer your questions and reassure you.

Feedback

Feedback is really important and useful to us – it can tell us where we are working well and where improvements can be made. There are lots of ways you can share your experience with us including completing our Friends and Family Test – cards are available and can be posted on all wards, departments and clinics at our hospitals. We value your comments and feedback and thank you for taking the time to share this with us.

Patient Advice and Liaison Service (PALS)

If you have any concerns or questions about your care, we advise you to talk with the nurse in charge or the department manager in the first instance as they are best placed to answer any questions or resolve concerns quickly. If the relevant member of staff is unable to help resolve your concern, you can contact the PALS Team. We offer informal help, advice or support about any aspect of hospital services & experiences.

Our PALS team will liaise with the various departments in our hospitals on your behalf, if you feel unable to do so, to resolve your problems and where appropriate refer to outside help.

If you are still unhappy you can contact the Complaints Department, who can investigate your concerns. You can make a complaint orally, electronically or in writing and we can advise and guide you through the complaints procedure.

How to contact PALS:

Telephone Patient Services: 0300 123 1732 or via email at: wah-tr.PALS@nhs.net

Opening times:

The PALS telephone lines are open Monday to Thursday from 8.30am to 4.30pm and Friday: 8.30am to 4.00pm. Please be aware that a voicemail service is in use at busy times, but messages will be returned as quickly as possible.

If you are unable to understand this leaflet, please communicate with a member of staff.