Giant cell arteritis
(temporal arteritis)

This booklet provides information and answers to your questions about this condition.
What is giant cell arteritis?

Giant cell arteritis (GCA) or temporal arteritis is an inflammatory condition that mainly affects the blood vessels of the head. In this booklet we’ll explain what causes the condition, its symptoms, and how it can be treated. We’ll also look at how you can help yourself and suggest where you can find out more about living with GCA.

At the back of this booklet you’ll find a brief glossary of medical words – we’ve underlined these when they’re first used in the booklet.
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What is GCA?
GCA, or temporal arteritis as it’s also known, is a condition that causes severe inflammation of the blood vessels – particularly the arteries of the skull.

What are the symptoms?
Symptoms commonly include:
• severe headache, pain and tenderness over the temples and scalp
• prominence or tenderness of the blood vessels at the temples
• fatigue
• flu-like symptoms
• weight loss
• loss of vision or double vision
• pain in the jaw or tongue when chewing.
Less common symptoms include:
• pain, stiffness or tenderness in the arms or legs
• occasionally, mini-strokes if other blood vessels are affected.

Although the effects of GCA are potentially serious, early treatment will usually prevent the most serious problems. For this reason, doctors will usually begin treatment as soon as GCA is suspected – even before the diagnosis is confirmed.

How is it diagnosed?
Diagnosis is usually based on your symptoms, a clinical examination and blood tests. To confirm the diagnosis, your doctor may suggest a biopsy of the temporal artery, where a small piece of the artery is removed under local anaesthetic and examined under a microscope.

What treatments are there?
Treatment is normally with steroid tablets:
• A high dose is needed at first to protect against possible loss of vision.
• This is followed by a gradually reducing dose to bring and keep the inflammation under control.
Your doctor may also suggest low-dose aspirin as extra protection against loss of vision.
Like all medicines, steroids can have side-effects. Your doctor will reduce your dose as soon as possible to reduce the risk of side-effects, and may suggest
other medicines to protect against side-effects such as osteoporosis. You mustn’t stop taking steroids or reduce the dose yourself without advice from your doctor.

**How can I help myself?**

Simple tips for self-help and daily living can help improve your long-term outcome:

- A diet that provides plenty of calcium and vitamin D will help to guard against osteoporosis.
- Keeping active will help to keep the bones strong. Gradual, well-paced exercise and careful planning of your activities can help to manage fatigue.

GCA is very rare in people under 50. It’s more common in women than men. In the UK 22 people in every 100,000 are affected.*

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What is GCA?
Giant cell arteritis, referred to as GCA, is one of a group of conditions referred to as vasculitis, meaning inflammation in the blood vessels. It’s called an arteritis because it affects the arteries rather than the veins. It commonly affects the arteries of the skull, causing pain and tenderness over the temples. Because of this, GCA is often known as temporal arteritis.

Who is affected?
GCA is very rare in people younger than 50. It’s more common in women than men, and more common in people of northern European descent than in people of other races. In the UK, 22 people in every 100,000 are affected. GCA is quite often associated with a condition called polymyalgia rheumatica (PMR), which causes severe stiffness of the muscles, particularly in the shoulders and hips. About 15% of PMR patients also develop GCA, while 40–50% of people with GCA also have symptoms of PMR.

What are the symptoms of GCA?

Although some of the effects of GCA can be serious, these can usually be avoided by prompt treatment with steroids.

People with GCA may have a number of different symptoms. Most people will experience some, but not all, of these symptoms. The most common symptoms of GCA are:

- headache, with severe pain and tenderness over the temples and the scalp – it may be painful to brush your hair or to shave
- prominence or tenderness of the blood vessels at your temples
- fatigue
- flu-like symptoms, night sweats or fever
- weight loss
- loss of vision (this may be only partial, but it can sometimes be total. It’s usually temporary in the early stages, but without treatment loss of vision can become permanent)
- double vision
- pain in the jaw or tongue when chewing (claudication).

You should see your doctor urgently if you have visual disturbance or pain in the jaw or tongue. These symptoms suggest that you may be at greater risk of visual loss unless you receive prompt treatment.

Less commonly, GCA can affect other large blood vessels that could lead to pain when using the arm muscles or in the calves when walking. Occasionally, GCA can cause strokes or mini-strokes (also known as transient ischaemic attacks or TIAs).

Patients with GCA often have symptoms of PMR, including pain, stiffness and tenderness in the muscles of the shoulders, arms, hips and legs, especially in the morning.
Patients with GCA often have symptoms of PMR, including pain, stiffness and tenderness in the muscles of the shoulders, arms, hips and legs, especially in the morning.
What causes GCA?
We don’t yet know the exact cause of GCA. However, we do know that it’s an autoimmune condition. The immune system normally helps keep us healthy by fighting infection. However, in GCA, these defence mechanisms attack the healthy artery, causing inflammation. We don’t yet know why this happens. Although GCA isn’t directly inherited, we know that genetic factors play some part.

How is GCA diagnosed?
The diagnosis is based on your symptoms, a clinical examination, blood tests, and other tests or scans.

Should I see a specialist?
It’s very important that your family doctor (GP) starts treatment straight away if GCA is suspected. However, you should also be referred to a specialist to confirm the diagnosis. Depending on your symptoms, this specialist will usually be either an ophthalmologist (an eye specialist) or a rheumatologist (a doctor who specialises in autoimmune problems, and problems with the joints and muscles).

What tests will I have?

Blood tests
These are used to check for signs of inflammation in the blood vessels. They’re useful in diagnosing GCA, but will also be repeated over time to check that the inflammation is controlled.

The key blood tests are the C-reactive protein (CRP) and the erythrocyte sedimentation rate (ESR). The levels measured by both these tests increases when there is inflammation in the body. Your doctor may do one or other of these blood tests. In most cases, ESR and CRP are high in people who have GCA.

Other blood tests may be performed to look for other possible causes for your symptoms, including tests to check for inflammation in other blood vessels.

Temporal artery biopsy
Your doctor may suggest this test to confirm the diagnosis of GCA even if you have already started on steroid treatment (see Figure 1). There are three main reasons for having the test:

• It is important to confirm the diagnosis since this means a prolonged period of steroid treatment which can have side-effects.

• If your condition doesn’t improve with steroid treatments, it may be that you don’t have GCA. If the test shows no signs of GCA and your doctor is satisfied that you don’t have GCA the steroid treatment can be stopped.

• There’s some evidence that the test can help in assessing how severe the condition is. In some cases, more powerful treatment may be needed.

The biopsy will usually be carried out by a surgical doctor, but it’s not a treatment in itself. Using local anaesthetic, a small
sample of artery from the scalp over the temple is removed and examined under a microscope. Your doctor will explain the procedure, including the risks and benefits, and you will be asked to sign a form consenting to the biopsy.

After the biopsy is carried out you’ll have a wound about 3–4 cm (1–1½ in) in length, close to the hairline. The wound will be covered with a dressing until your follow-up appointment about a week later, but you will still be able to wash your hair with care. When the anaesthetic wears off you may need painkillers such as paracetamol for a time.

As with any surgical procedure, you should look out for signs of infection – such as redness which starts to spread or a continuous discharge. Very rarely, the procedure may lead to temporary or permanent damage to the nerves, which may result in numbness or a drooping brow. In patients who have narrowing of the arteries in the neck (carotid artery disease) there may be a very small risk of a stroke. If you have any concerns about the risks you should discuss them with your doctor beforehand.
Usually, the biopsy will contain a sufficient sample to confirm the diagnosis. But sometimes, if not all of the artery is affected by GCA and the biopsy is taken from an unaffected area, it may not show evidence of GCA. In this situation your doctor will decide whether to continue treatment based on the clinical picture and blood tests.

X-rays and scans
You may be asked to have an x-ray of your chest to rule out other conditions. You may also be asked to go for a PET (positron emission tomography) scan, to see if the GCA has affected other blood vessels in the body. This test will only be requested if your doctor suspects this is happening.

Your doctor may suggest an ultrasound of the temple or an MRI (magnetic resonance imaging) scan, although these techniques are not yet widely used in diagnosing GCA.

What treatments are there for GCA?

Steroid tablets
Although there’s no cure as yet for GCA, treatment with steroid tablets is very effective, and they usually start to work within a few days. These tablets are sometimes called corticosteroids and they work by suppressing the immune system to reduce the inflammation in the blood vessels. These are not the steroids sometimes used by athletes and body builders (anabolic steroids). Prednisolone is the most commonly used steroid tablet.

Steroid treatment consists of an initial high dose, followed by a gradually reducing dose as the inflammation is brought under control.

Because there’s a serious risk of sight loss if you’re not treated, it’s important to start steroid treatment straight away. If your doctor has a strong suspicion that you have GCA, they may prescribe steroids even before the diagnosis is confirmed by a specialist.

To effectively treat GCA you’ll usually be given a high dose of between 40 mg and 60 mg of prednisolone tablets every day to begin with. This dose of steroids is usually continued for 3–4 weeks. If you’re well after that, and your blood tests have improved, then your doctor will advise you to start reducing the dose. The specialist will want to see you regularly to monitor your progress.

Corticosteroid tablets come in different strengths and different colours. Therefore, it’s very important that you know exactly what dose you’re supposed to be taking, and how many tablets of each strength you need to take every day.
Although there’s no cure as yet for GCA, treatment with steroid tablets is very effective, and they usually start to work within a few days.
Reducing the dose and coming off steroid tablets is a gradual process. If this is done too quickly, the inflammation can come back. It usually takes 1–3 years to come off steroids altogether; however, for most of this time you’ll be on a low dose. It isn’t always possible to stop taking steroids completely and some people will need to be on a low dose for a long time.

Your body makes small amounts of steroids as part of its normal function, to help maintain blood pressure and control the balance of salt and water in your body. But when you’re on steroid treatment your body stops producing its own supply. This can take a little while to start up again. It can therefore be dangerous to suddenly stop taking your steroid tablets, or to alter the dose unless advised by your doctor.

If the inflammation in the blood vessels returns this is called a relapse, and your steroid dose may have to be increased again to deal with this. Relapse is most common within the first 18 months of treatment. Your regular check-ups will include blood tests for CRP or ESR, and these will show if there are signs of the inflammation returning.

If an increased dose of steroids isn’t stopping these relapses, your doctor may suggest an additional medication, such as methotrexate, to keep the inflammation under control.

Sometimes your doctor may request other tests. Occasionally GCA can affect the large arteries of the body, and you will be assessed for this.

⚠️ It’s extremely important that you let your doctor know if you get any disturbances in your vision or jaw pain while eating, even if it’s between clinic appointments.

**What are the side-effects of steroid treatment?**

Unfortunately, there are some possible side-effects from steroid treatment. Although the side-effects can be worrying, steroids are necessary to treat GCA. Your doctor will try to keep you on the lowest dose of steroids that keeps the disease under control; however, the early high dose may cause side-effects such as:

- facial flushing
- lack of sleep
- indigestion or stomach pain

Steroids can cause high blood pressure (hypertension), or a rise in your blood sugar level. You should therefore have these tested regularly.
• dizziness or faintness
• difficulty concentrating
• mood changes including depression or elation, irritability or aggressiveness.

If you are on steroids for a long time, other side-effects may include:
• weight gain
• thinning of the bones (osteoporosis) and fractures
• easy bruising, stretch marks, and thinning of the skin
• muscle weakness
• cataracts and glaucoma – or worsening of pre-existing glaucoma
• diabetes
• high blood pressure.

Your regular check-ups will help to identify any signs of side-effects.

Because steroids work by suppressing the immune system, you may be more likely to develop infections. Chickenpox and shingles can be severe in people who are taking steroids. You should contact your doctor if you have not had chickenpox and come into contact with someone who has either chickenpox or shingles, as you may need antiviral treatment.

See Arthritis Research UK drug leaflet Steroid tablets.
What else should I know about steroids?
You should be given a **steroid card** to carry that records the dose of steroid tablets you’re on. If you need to see another doctor for any reason (such as an operation or a hospital admission) you should tell them what dose of steroids you’re on, or show them your steroid card. Depending on what the problem is, they may need to temporarily increase your steroid treatment, or give it to you by a different method; for example, into a vein if you’re not to take anything by mouth.

There are no particular foods that you should avoid, but you should make sure you eat a healthy diet, containing plenty of calcium and vitamin D.
Will I need any other treatments?
Your doctor may suggest low-strength aspirin (75 mg) as it helps to protect against loss of vision in GCA.

Because steroids have possible side-effects, your doctor may also suggest additional medications to protect you from these. You will be started on calcium and vitamin D supplements to protect your bones. Your doctor may also advise you to start another medication called a bisphosphonate to reduce the risk of developing osteoporosis. Because steroids can affect the stomach lining, you may also be given a stomach-protecting tablet (called a proton pump inhibitor, or PPI) such as omeprazole. Bisphosphonates and PPIs will usually be started at the same time as the steroids.

Self-help and daily living
Diet
There are no particular foods that you should avoid, but you should make sure you eat a healthy diet, containing plenty of calcium and vitamin D (see Figure 2).

The richest sources of calcium are dairy products (milk, cheese, yogurt), calcium-enriched soya milk, and fish that are eaten with the bones (e.g. sardines). Leafy green vegetables, beans, chick peas and some nuts and dried fruits also contain calcium. We recommend a daily intake of calcium of 1,000 milligrams (mg) or 1,500 mg if you are over 60.

Vitamin D is needed for the body to absorb calcium, and is normally produced by the body when the skin is exposed to sunlight. However, it can also be obtained from food, especially from oily fish, or supplements. Vitamin D is often added to soya milks and vegetable-based margarines.

<table>
<thead>
<tr>
<th>Food</th>
<th>Calcium</th>
</tr>
</thead>
<tbody>
<tr>
<td>115 g (4 oz) whitebait (fried in flour)</td>
<td>980 mg</td>
</tr>
<tr>
<td>60 g (2 oz) sardines (including bones)</td>
<td>260 mg</td>
</tr>
<tr>
<td>0.2 litre (1/3 pint) semi-skimmed milk</td>
<td>230 mg</td>
</tr>
<tr>
<td>0.2 litre (1/3 pint) whole milk</td>
<td>220 mg</td>
</tr>
<tr>
<td>3 large slices brown or white bread</td>
<td>215 mg</td>
</tr>
<tr>
<td>125 g (4 1/2 oz) low-fat yogurt</td>
<td>205 mg</td>
</tr>
<tr>
<td>30 g (1 oz) hard cheese</td>
<td>190 mg</td>
</tr>
<tr>
<td>0.2 litre (1/3 pint) calcium-enriched soya milk</td>
<td>180 mg</td>
</tr>
<tr>
<td>125 g (4 1/2 oz) calcium-enriched soya yogurt</td>
<td>150 mg</td>
</tr>
<tr>
<td>115 g (4 oz) cottage cheese</td>
<td>145 mg</td>
</tr>
<tr>
<td>3 large slices wholemeal bread</td>
<td>125 mg</td>
</tr>
<tr>
<td>115 g (4 oz) baked beans</td>
<td>60 mg</td>
</tr>
<tr>
<td>115 g (4 oz) boiled cabbage</td>
<td>40 mg</td>
</tr>
</tbody>
</table>

Note: measures shown in ounces or pints are approximate conversions only.
Rest and exercise
You should keep as fit and active as you can. This helps prevent osteoporosis, and may help to avoid weight gain and muscle weakness caused by the steroids.

Fatigue can be a major problem for some people even when on treatment. This can be a difficult symptom to manage, but some people find that gradual, well-paced exercise can help. Pacing and planning activities and setting realistic, achievable goals can improve your energy levels and well-being. If fatigue becomes a significant problem for you, an assessment with a specialist nurse or occupational therapist might help.

Help and support
People with GCA usually look well, even when the condition is severe (some of this may be due to the treatment with steroids). Because of this, friends and family may not understand why you feel unwell or find some things difficult. Some people also find it hard to come to terms with managing a long-term condition.

If GCA has caused partial or total loss of sight, this impairment should be registered to make sure you are offered the benefits and support you are entitled to.

Support and advice is available from a number of different organisations. There are also local self-help and patient support groups around the country. The contact details for these groups can be found at the end of this booklet.

Patient story
Lucy was diagnosed with GCA 3 years ago
It started when I was 70. For a few weeks I felt extremely tired, had no appetite, and my shoulders and hips ached. I had a terrible headache and my face was tender, especially at the temples. I noticed a flickering light in my right eye and pain in my upper jaw when I ate. Then I woke up one morning and found that half my bedroom looked black. I closed my eyes, and when I opened them, everything looked normal again.

See Arthritis Research UK booklet
Fatigue and arthritis.
I was very scared and went to see my GP immediately. He arranged a blood test and he told me my ESR was very high at 112. They took me straight in to hospital and gave me steroids into a vein for 3 days. My symptoms settled down in a few days and I had much more energy. While I was in hospital I had a biopsy, and the specialist told me this confirmed the diagnosis. Everything moved so quickly in those few days. It felt like a rollercoaster.

When I left hospital I was taking 70 mg of prednisolone tablets every day, but the doctor gradually reduced the dose over the next 2 years. I had one relapse when the symptoms came back, but they got better after the steroid dose was temporarily increased. I came off steroids completely last year.

I feel quite well now. I keep active and have lots of different interests. My ESR is now 11 and my symptoms have gone, except a slight flickering in the right eye. I still feel tired sometimes and my legs ache at times, but I know that I could have lost my eyesight, and I’m so grateful that this didn’t happen.
Glossary

Bisphosphonates – drugs used to prevent the loss of bone mass and treat bone disorders such as osteoporosis. They work by reducing high levels of calcium in the blood and by slowing down bone metabolism.

Cataracts – clouding or loss of transparency in the lens of the eye caused by changes in its protein fibres. Advanced cataracts may impair vision or cause blurred vision but do not lead to total blindness.

C-reactive protein (CRP) – a protein found in the blood. The level of C-reactive protein in the blood rises in response to inflammation and a blood test for the protein can therefore be used as a measure of inflammation or disease activity.

Diabetes – a medical condition that affects the body’s ability to use glucose (sugar) for energy. The body needs insulin, normally produced in the pancreas, in order to use glucose. In diabetes the body may produce no insulin or not enough insulin, or may become resistant to insulin. When the body is unable to use glucose obtained from foods the level of sugar in the blood increases. If untreated, raised blood sugar can cause a wide variety of symptoms.

Erythrocyte sedimentation rate (ESR) – a test that shows the level of inflammation in the body and can help in the diagnosis of rheumatoid arthritis. Blood is separated in a machine with a rapidly rotating container (a centrifuge), then left to stand in a test tube. The ESR test measures the speed at which the red blood cells (erythrocytes) settle.

Glaucoma – increased pressure in the fluid within the eye, which may compress or obstruct blood vessels in the eye and result in damage to the nerve fibres and gradual loss of vision.

Inflammation – a normal reaction to injury or infection of living tissues. The flow of blood increases, resulting in heat and redness in the affected tissues, and fluid and cells leak into the tissue, causing swelling.

Magnetic resonance imaging (MRI) – a type of scan that uses high-frequency radio waves in a strong magnetic field to build up pictures of the inside of the body. It works by detecting water molecules in the body’s tissue that give out a characteristic signal in the magnetic field. An MRI scan can show up soft-tissue structures as well as bones.

Osteoporosis – a condition where bones become less dense and more fragile, which means they break or fracture more easily.

Polymyalgia rheumatica (PMR) – a rheumatic condition in which you have many (poly) painful muscles (myalgia). It is characterised by pain and stiffness of the muscles of the neck, hips, shoulders and thighs, which is usually worse in the mornings.
Positron emission tomography – an imaging technique in which a radioactive substance is introduced into the body, for example into a vein. The substance can be tracked as it moves round the body using special scanners which pick up positively charged particles (positrons) from the substance. The images can be matched with images taken by other methods to give a clearer picture of how the body’s organs are working.

Ultrasound scan – a type of scan that uses high-frequency sound waves to examine and build up pictures of the inside of the body.

Where can I find out more?
If you’ve found this information useful you might be interested in these other titles from our range:

Conditions
• Osteoporosis
• Polymyalgia rheumatica (PMR)

Self-help and daily living
• Diet and arthritis
• Fatigue and arthritis
• Keep moving

Therapy
• Physiotherapy and arthritis

Drug leaflet
• Steroid tablets

You can download all of our booklets and leaflets from our website or order them by contacting:
Arthritis Research UK
PO Box 177
Chesterfield
Derbyshire S41 7TQ
Phone: 0300 790 0400
www.arthritisresearchuk.org

Related organisations
The following organisations may be able to provide additional advice and information:

PMR-GCA UK
Centre for Disability Studies
Rocheway, Rochford
Essex SS4 1DQ
Phone: 0300 111 5090
www.pmrcauk.com

PMR-GCA UK is a national organisation which aims to raise awareness of both polymyalgia rheumatica and giant cell arteritis. It provides information and support to people with PMR and/or GCA and their families and carers, promotes research into PMR and GCA, and encourages the setting-up of local support groups.

Arthritis Care:
‘Challenging Pain’ and ‘Challenging Your Condition’ programmes
18 Stephenson Way
London NW1 2HD
Phone: 020 7380 6500
Helpline (freephone): 0808 800 4050
Website: www.arthritiscare.org.uk
This body also produces useful resources and literature to help people manage long-term conditions and symptoms.

It also runs self-help courses designed to help people get on top of their condition.

**National Health Service (NHS):**
‘Expert Patients Programme’
For details of courses in your area, visit: www.expertpatients.nhs.uk

**Royal National Institute of Blind People**
105 Judd Street
London WC1H 9NE
Phone: 020 7388 2034
www.rnib.org.uk
Notes
We’re here to help

Arthritis Research UK is the charity leading the fight against arthritis. We’re the UK’s fourth largest medical research charity and fund scientific and medical research into all types of arthritis and musculoskeletal conditions. We’re working to take the pain away for sufferers with all forms of arthritis and helping people to remain active. We’ll do this by funding high-quality research, providing information and campaigning.

Everything we do is underpinned by research.

We publish over 60 information booklets which help people affected by arthritis to understand more about the condition, its treatment, therapies and how to help themselves.

We also produce a range of separate leaflets on many of the drugs used for arthritis and related conditions. We recommend that you read the relevant leaflet for more detailed information about your medication.

Please also let us know if you’d like to receive our quarterly magazine, Arthritis Today, which keeps you up to date with current research and education news, highlighting key projects that we’re funding and giving insight into the latest treatment and self-help available.

We often feature case studies and have regular columns for questions and answers, as well as readers’ hints and tips for managing arthritis.

Tell us what you think of our booklet

Please send your views to: feedback@arthritisresearchuk.org or write to us at: Arthritis Research UK, PO Box 177, Chesterfield, Derbyshire S41 7TQ.

A team of people contributed to this booklet. The original text was written by Prof. Bhaskar Dasgupta and Jayne Sibley, who have expertise in the subject. It was assessed at draft stage by nurses Sue Brown and Deborah Bond, and Jennifer Nott of the PMR-GCA society. An Arthritis Research UK editor revised the text to make it easy to read, and a non-medical panel, including interested societies, checked it for understanding. An Arthritis Research UK medical advisor, Dr Ben Thompson, is responsible for the content overall.
Get involved

You can help to take the pain away from millions of people in the UK by:

• Volunteering
• Supporting our campaigns
• Taking part in a fundraising event
• Making a donation
• Asking your company to support us
• Buying gifts from our catalogue

To get more actively involved, please call us 0300 790 0400 or e-mail us at enquiries@arthritisresearchuk.org

Or go to:
www.arthritisresearchuk.org