GIANT CELL ARTERITIS (GCA)

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What is Giant Cell Arteritis (GCA)?

GCA, also called "temporal arteritis", is a type of vasculitis. **Vasculitis** is a rare immune mediated condition where the body attacks its own blood vessels. This leads to disruption of blood flow, which can cause pain and infarct or necrosis (tissue death) of the affected areas.

What blood vessels are involved?

The vessels in the face are affected the most. This includes the:

- Temporal artery (temples)
- Facial artery (lower face, jaw)
- Scalp and posterior head/neck arteries
- Lingual artery (tongue)
- Ophthalmic arteries (eyes)

Less commonly, GCA can affect the main artery coming from the heart (the aorta), and the arteries inside the skull and brain.

Who is affected? What causes GCA?

GCA typically affects people aged 60 years or older and almost never occurs in people under 50 years. In Canada, it is estimated that 4-10 per 100,000 people over the age of 50 will develop GCA every year. It is more common in people of northern European descent. Women are affected overwhelmingly more than men.

The exact cause of GCA is unknown. As with most autoimmune diseases, there is usually a combination of factors including genetic predisposition, and environmental and infectious exposures.

What are the symptoms?

Depending on which vessels are affected, GCA can cause:

- New, persistent headache on one side of the head
- Tender scalp or temples
- Pain in the jaw when eating or talking (NOT jaw clicking)
- Sudden vision loss, blurred or double vision
- Fatigue, weight loss and fever
- Strokes
- Pain in the chest or abdomen (when aorta and other vessels are affected)
- Polymyalgia rheumatica (presenting as prominent symmetrical pain and stiffness of the shoulders and hips)

How is GCA diagnosed?

Blood tests are done to look for high "inflammatory markers". A **biopsy** of the temporal artery is considered the "gold standard" and can confirm the diagnosis. Sometimes, an **ultrasound, MRI or CT scan** of the arteries in the head/neck and heart may be needed and show signs suggestive of GCA.

I have all the symptoms & blood tests for GCA, but my temporal artery biopsy is normal. Do I still have GCA?

Up to 60% of temporal artery biopsies are negative in GCA because the lesions are patchy in their distribution and the artery sample taken is only up to 2 cm long.

Sometimes, the biopsy will be repeated when negative initially, on the same or opposite side. You will still receive the same treatment as patients who are "biopsy-positive" if your treating physician has accumulated enough convincing evidence for the diagnosis of GCA.

Management of GCA includes:

- **Prednisone** – a steroid medication that is highly effective at reducing inflammation. You will start on a high dose and slowly reduce the dose over time. Doctors may need to give you a form of high-dose prednisone intravenously at the very beginning of the treatment.
- Other **immune suppressing medications,** which may be used immediately in combination with prednisone, or later to help reduce the prednisone dose. Your doctor will discuss the options and prescribe these if needed.
- **"Baby Aspirin" (81 mg per day)** – This has been shown to reduce the risk of strokes in some patients with additional risk factors for stroke. Do not take this unless directed by your doctor.
- **Bone protection** medication to prevent osteoporosis caused by long-term prednisone use.
- **Stomach protection** medication to prevent ulcers caused by high-dose prednisone.

GIANT CELL ARTERITIS FAQs

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What side effects can I expect from taking prednisone?

While prednisone is extremely effective at treating GCA, it can cause significant side effects and health complications. Some are more common than others and most are dose-dependent.

- Weight gain and fluid retention
- Insomnia and increased energy
- Weakness and shakiness
- Anxiety and restlessness
- Psychiatric disturbances
- Skin changes: thinning, bruising, stretch marks
- Heartburn and stomach upset
- Delayed wound healing and increased risk of infections
- High blood pressure
- High blood sugar and diabetes
- Bone thinning (osteoporosis)
- Muscle loss
- Disruption of body's natural stress hormone response
- Cataracts, glaucoma

I'm having side effects from prednisone. Do I have to continue taking it?

Prednisone remains the 1st line medication for GCA so unfortunately, it is currently almost impossible to avoid it. The good news is that prednisone is typically reduced to a much tolerable dose by the 2nd to 3rd month. Tocilizumab or methotrexate used in combination with prednisone can help achieve faster tapering.

Aside from prednisone, what other immunosuppressive medications are used to treat GCA?

The most commonly used medications are methotrexate and tocilizumab. **Methotrexate** is taken once a week and comes in pill or injection forms. It is typically prescribed with folic acid to counteract its side effects. **Tocilizumab** comes in injections only and is taken once every 1-2 weeks subcutaneously. Rarely, GCA can cause more severe disease, eg. "intracranial" involvement, which can lead to strokes. If this happens, you may need **cyclophosphamide**.

How is my GCA monitored?

Common tests used to monitor the disease include:

- Lab tests for blood counts and inflammatory markers (ESR and/or CRP)
- Repeat CT scans or MRIs are usually not needed unless there is involvement of the aorta or the arteries inside the skull and brain
- A repeat temporal artery biopsy is not needed once the diagnosis is made.

Your rheumatologist will be the main physician helping treat and monitor your GCA. Your **family physician** also plays an important role in monitoring for hypertension, high cholesterol, diabetes and osteoporosis.

What will happen to me? How long do I need to take medications for?

GCA is treatable but not yet curable. Symptoms resolve with medication, however may return in up to 60% of the patients within the first year of diagnosis, particularly when the medication is reduced. If the disease returns, your blood tests may (or may not) show high inflammatory markers again. Symptoms must always be the indicator of disease activity along with blood tests.

Unfortunately, we do not know exactly how long we need to treat GCA for. Some patients are able to taper off their treatments by 2 years, while others need life-long medication. The decision to treat for longer typically involves balancing the risk of relapse and disease complications vs. the risk of medication side effects.

Why am I still having headaches despite my inflammation markers being normal?

There are many non-GCA causes of headaches that are way more common, including migraines and non-migraine headaches (eg. tension, cluster, sinus, hypertension-related and drug-related).

Will I ever regain the vision lost from GCA?

Unfortunately, vision loss from GCA is often permanent. Starting prompt treatment significantly reduces the risk of vision loss in the other eye.

GCA DISEASE SUMMARY TOOL

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My symptoms included:

- ☐ Headache
- ☐ Painful scalp
- ☐ Painful temple area
- ☐ Thickened temporal artery
- ☐ Jaw pain or stiffness when chewing or talking ("clicking" does not count)
- ☐ Tongue or scalp ulcers / necrosis
- ☐ Symmetrical shoulder, hip and pelvis pain and stiffness
- ☐ Vision loss
- ☐ Blurry or double vision
- ☐ Strokes (eg. facial droop, paralysis of arm or leg, unable to speak normally)
- ☐ Fever
- ☐ Weight loss
- ☐ Severe fatigue

Important medications for my GCA:

	Date started	Date stopped
Prednisone (Starting dose _____ mg)		
Bone protectant: _____		
Aspirin 81mg		
Vitamin D		
Calcium		
Methotrexate ____ mg		
Folic acid (only if taking methotrexate)		
Leflunomide ____ mg		
Tocilizumab 162 mg		
Cyclophosphamide _____ mg		
Others:		

I had the following tests done:

- ☐ Blood test checking for inflammation markers (ESR, and/or CRP)
- ☐ Temporal artery biopsy
- ☐ Temporal artery ultrasound
- ☐ Echocardiogram
- ☐ CT scan or MRI of the brain
- ☐ CT scan or MRI of the neck and heart vessels
- ☐ MRI of the scalp arteries

What do I need to do?

- ✓ Attend follow-up visits with my rheumatologist.
- ✓ Regular blood tests to monitor my inflammation markers.
- ✓ Ensure my medical team is monitoring me for diabetes, high blood pressure and high cholesterol levels.
- ✓ **Go to the hospital ER ASAP if I have sudden new vision loss, double vision, or any sign of possible strokes (better to call 911 then)!**