# Giant Cell Arteritis –information for patients and their families

### What is giant cell arteritis?

Giant cell arteritis (GCA) is an inflammation of the lining of your arteries. Although giant cell arteritis can affect the arteries in your neck, upper body and arms, it occurs most often in the arteries in your head, especially those in your temples. For this reason, giant cell arteritis is sometimes called *temporal arteritis* or *cranial arteritis*.

The term "giant cell arteritis" is often used because when one looks at samples of inflamed temporal arteries under a microscope, one often sees large or "giant" cells.

### What are the symptoms of giant cell arteritis?

The most common symptoms of temporal arteritis are headache, pain in the shoulders and hips (called polymyalgia rheumatica or PMR), pain in the jaw after chewing (called jaw claudication), fever, and blurred or double vision. Other symptoms can include tenderness of scalp (it hurts to comb the hair), cough, throat pain, tongue pain, weight loss, depression, stroke, or pain in the arms during exercise. Some patients have many of these symptoms; others have only a few.

Blindness — the most feared complication — can develop if the disease is not treated in a timely fashion.

### Who is at risk of giant cell arteritis?

Although the exact cause of giant cell arteritis is not known, several factors can increase your risk, including:

- **Age.** The average age at onset of the disease is 70, and it rarely occurs in people younger than 50.
- **Sex.** Women are 2-3 times more likely to develop it than men are.
- Race. Although giant cell arteritis can affect people of any race, the majority of people affected are white.
- Polymyalgia rheumatica. People with the arthritic condition polymyalgia rheumatica (PMR) have an increased risk of giant cell arteritis. (15-25% of people with PMR also have giant cell arteritis)

## How is giant cell arteritis diagnosed?

Giant cell arteritis is relatively uncommon and can cause many different symptoms. Although almost all patients with giant cell arteritis have a high ESR, blood tests alone cannot diagnose the condition.

If your clinical presentation is typical and you have a high ESR, this may be sufficient for a specialist to make the diagnosis of giant cell arteritis. If your case is not typical (or you have other important medical conditions that may affect the symptoms or treatment) the diagnosis needs to be confirmed by a tissue biopsy.

Because of the concern about potential blindness, doctors will often start treatment first and then confirm the diagnosis of giant cell arteritis later.

### What is the role of temporal artery biopsy?

A biopsy of the temporal artery is performed in most cases. The biopsy result can help your specialist decide whether to continue treatment or whether it is safe to stop.

Temporal artery biopsy involves surgical removal of a small piece of the temporal artery and looking at it under a microscope for signs of inflammation. This is done at Manukau Super-clinic by a specialist surgeon.

The biopsy can be done while you are awake, using local anaesthetic to numb the skin. Dissolvable stitches are most commonly used; these will dissolve over time and do not need to be removed later (your surgeon will tell you if other stitches are used and need to be removed at a later date.)

Because there is no general anaesthetic, you do not have to starve for 6 hours beforehand like other surgical procedures.

It takes about 30 minutes to do the actual biopsy although the waiting time may vary on the day. Please arrive in plenty of time so you can complete the necessary paperwork before the biopsy.

There are very few risks involved in a temporal artery biopsy. In some cases, there can be some bruising around the wound that takes a few days to resolve. In very rare cases, the wound can get infected and has to be treated with antibiotics. Please ask your surgeon on the day if there is anything in particular that you are worried about.



A few patients with giant cell arteritis have biopsies that do not show any inflammation in the artery. This is because giant cell arteritis does not affect the entire length of the temporal artery evenly. In some cases, when one biopsy is negative, your doctor may consider biopsying the temporal artery on the other side of the head.

### How is giant cell arteritis treated?

Patients suspected of having giant cell arteritis are started on prednisone. Due to the risk of blindness, this medicine is often started before a biopsy has confirmed the presence of giant cell arteritis.

Prednisone works by "damping down" the immune system reaction that is causing the blood vessels to become inflamed. Initially, the prednisone is started at a high dose but as the patient improves, the dose can be slowly reduced down.

The rate of tapering prednisone depends on how the patient feels, what the doctor finds on examination, and the results of blood tests. Although virtually all patients are able to reduce their prednisone dose to quite a low dose, most patients require some prednisone for 2-5 years. Longer treatment periods are not uncommon.

Some patients experience side effects from prednisone. These can include bruising easily, weight gain and difficulty sleeping. It can also affect people's blood pressure or their blood sugar control.

Prednisone can affect bone strength if taken for a long time. When you start on prednisone, your doctor should talk to you about ways to protect your bones from osteoporosis.

Prednisone can interact with a small number of other medicines so it's important to tell your doctor what medicines you are already taking.

Unless contra-indicated, aspirin therapy should also be started in patients with GCA.

### Does giant cell arteritis run in families?

It is unusual for giant cell arteritis to affect more than one person in a family, so it's unlikely that it's an inherited disorder.

#### Can diet affect giant cell arteritis?

All patients want to do whatever is within their power to help treat their disease. There is presently no evidence that a person's diet makes them more at risk of developing giant cell arteritis, or that consuming or avoiding certain foods or beverages affects the course of the disease.

In general, we encourage people to eat a balanced, "heart–healthy" diet. Avoidance of excessive calories may be very important, particularly in patients on steroids who are at risk for weight gain.