

Appendix 5. Information leaflet for patients referred to TAB

What is Giant Cell Arteritis (GCA)?

Giant Cell Arteritis (GCA) belongs to a group of illnesses caused by vasculitis. Vasculitis means inflammation of the arterial blood vessels, which are those transporting blood from the heart to all the organs. The pulse your doctor feels at your wrist is an example. There are different types of vasculitis and each one tends to affect arteries of a certain size. GCA commonly affects arteries in the head and neck, but also sometimes in other parts of the body. If not treated promptly it can cause blindness (approximately 30% of patients) or stroke (this is much less common). You can find more information on this condition in the GCA leaflet from Versus Arthritis (which you can get from your doctor) or on their website (www.versusarthritis.org).

How is GCA treated?

There is effective treatment for GCA, which is initially high-dose steroid. Steroid treatment should be started immediately even before the diagnosis is confirmed to minimise risk of blindness. The steroid dose is then gradually reduced but most patients will require treatment for up to 2 years. Steroids can have side effects including, for example, mood changes, difficulty concentrating, lack of sleep, weight gain, increased risk of infection, thinning of the bones and diabetes. In time, your doctor may add in another medication to help reduce your steroid dose, especially if you have significant steroid side-effects.

Why do I need a Temporal Artery Biopsy (TAB)?

There are many other conditions that can be mistaken for GCA. If US scan does not confirm a diagnosis of GCA TAB can help confirm this. Whilst steroid therapy is a highly effective treatment it potentially has serious side effects. We need to be as certain as possible that you have GCA in order to make sure that you are offered the safest and most effective treatment.

What is a Temporal Artery Biopsy?

A Temporal Artery Biopsy involves the surgical removal of a small piece of the temporal artery from either the left or right temple. This is then sent to a pathologist to examine under a microscope. It can show inflammation of the temporal artery – this is called positive biopsy. Alternatively the temporal artery can look unremarkable under the microscope, which is called a negative biopsy. Occasionally it can demonstrate another cause for your symptoms.

What if my biopsy is positive?

A positive biopsy confirms that you have GCA and that you will need prolonged steroid therapy to control it and prevent relapses, which in the worst scenario could cause blindness.

What if my biopsy is negative?

A negative biopsy means it is less likely that you have GCA, and that there might be another cause

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for your symptoms. Your doctor may discontinue steroid treatment especially if there are no other strong clinical factors suggesting GCA. Sometimes however your doctor will recommend continuing therapy as people occasionally have GCA even if their biopsy is negative.

Are there any alternatives to temporal artery biopsy?

Ultrasound scan (US) is another method which can show inflammation of a temporal artery. It is usually performed as the first diagnostic test prior to a temporal artery biopsy. However it is not always conclusive and some patients still require a biopsy. US scan needs to be performed as soon as possible after starting steroid as signs of inflammation disappear quickly. However inflammation can often still be seen under the microscope for up to a few weeks. If you are offered TAB and have not had US it is because you have been on steroid too long to see inflammation by US. Sometimes it is possible to establish the diagnosis on specialised urgent MRI but this test is not yet widely available.

What happens if I decide not to have temporal artery biopsy?

If you decide against a biopsy then it will be more difficult for your doctor to be sure what is causing your illness and what the best treatment is. The decision to continue or stop steroid therapy would be based on clinical grounds alone without the benefit of a test which can potentially confirm the diagnosis of GCA.

What are the risks and potential complications of a temporal artery biopsy?

The procedure is usually straightforward and safe but there are some risks:

- An allergic reaction to local anaesthetic (very rare)
- Failure to find the temporal artery (occasional)
- Undue bleeding during or after the procedure (occasional)
- Nerve injury, including permanent nerve damage in the temple region or drooping of the eyebrow (very rare)
- Undue wound pain (rare)
- Wound infection (rare)
- Unsightly scarring (rare)
- Suffering a stroke (extremely rare)

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What happens on the day of surgery?

- You will be asked to sign a consent form prior to your biopsy. The procedure and the risks involved will be explained to you. By signing this you agree that the risks and benefits have been explained to you, and that you agree to the operation.
- The procedure takes place in the operating theatre.
- You will need to lie still for 30-45 minutes.
- Local anaesthetic is used to numb the area, then a small section of the artery from your temple region is removed. This is usually about 2cm in length.
- We might need to shave a small area of your hair where we will take the biopsy at the side of your head. This usually regrows very quickly.
- The wound is about 3-4 cm long and usually absorbable sutures (stitches) are used.
- No additional procedure would be anticipated.

After the procedure

- You will have a small dressing to cover the wound on your temple. This can be left in place until your follow-up appointment.
- For a short time there may be a small amount of pain after the anaesthetic wears off. Taking painkillers like paracetamol can help ease this pain.
- You will be discharged home following the operation and will need to continue taking your daily steroid dose as advised until your follow up appointment.
- You can carefully wash your hair if you wish.
- Your follow-up appointment will be with rheumatology usually within 2-4 weeks after the procedure, unless you are diagnosed with another condition. At this appointment the biopsy results are usually available and your doctor will be able to advise the best treatment for you based on all the factors including the biopsy result.

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