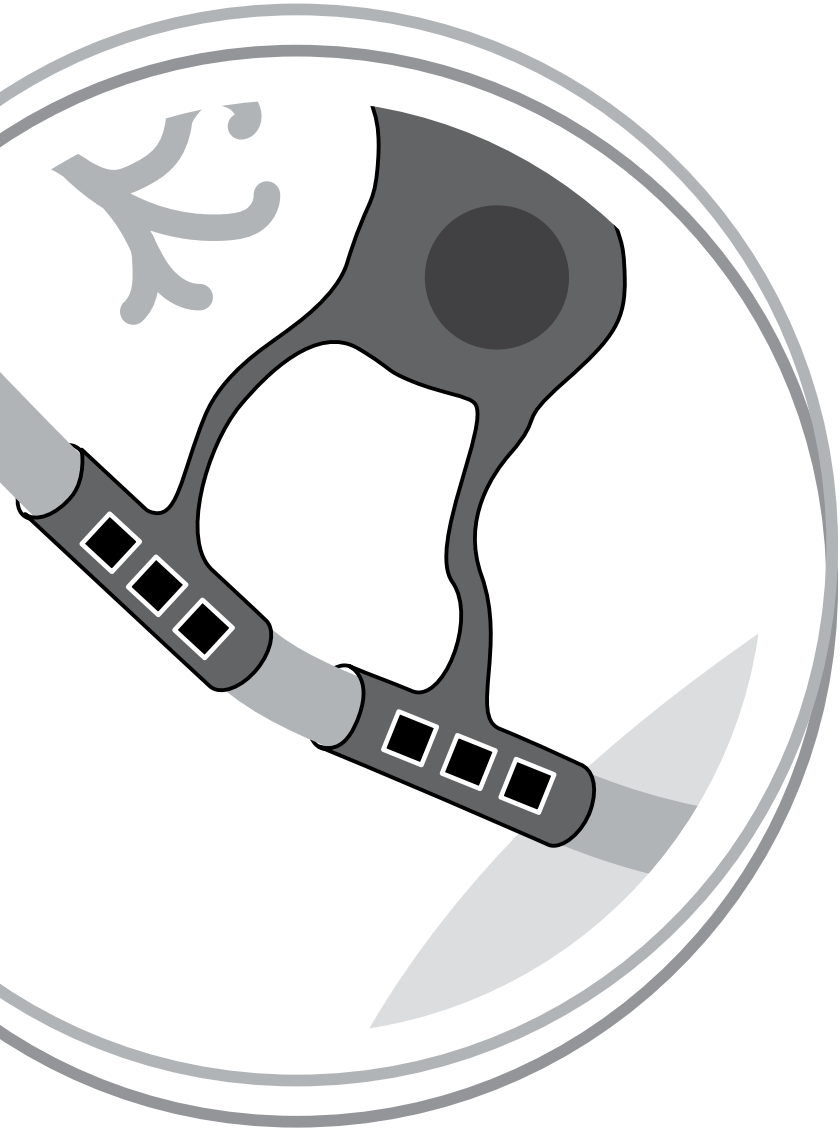
NHS
Oxford University Hospitals
NHS Foundation Trust

MOG ANTIBODY DEMYELINATION

Information for patients



MOG antibody demyelination and Neuromyelitis optica (NMO) are autoimmune neurological conditions which cause attacks of inflammation in the optic nerves and/or the spinal cord.

Most people with NMO have proteins in their blood called anti-aquaporin 4 antibodies (AQP4), which are the cause of the disease.

Recently another antibody has been identified called myelin oligodendrocyte glycoprotein (MOG). This is believed to cause similar attacks of inflammation of the optic nerve and/or spinal cord, but the disease develops differently and needs to be treated in a different way.

When AQP4 or MOG antibodies attack the optic nerves and/or the spinal cord, they also damage the myelin sheath. This is a layer that covers and protects the nerves. Damage to the myelin sheath is called demyelination.

You have been given this leaflet because you have been diagnosed as having MOG antibody demyelination. This leaflet aims to explain the differences between AQP4 antibody NMO and MOG antibody demyelination and how this affects the treatment you may be given.

What are antibodies?

The immune system has defence methods to prevent infection by bacteria and viruses. Certain types of white blood cells produce **antibodies**, which attack and destroy viruses and bacteria. These antibodies also allow our bodies to recognise and defend against infections we have already encountered.

Antibodies can be found in healthy people and do not usually cause any harm. Some antibodies are found in people with a disease, but the antibody does not usually cause the disease. Finding the antibody in the blood can help to identify the disease, if that antibody is only found when someone has that particular disease and it is not found in other diseases.

However, some antibodies are the cause of a disease. MOG antibodies are believed to fall into this category.

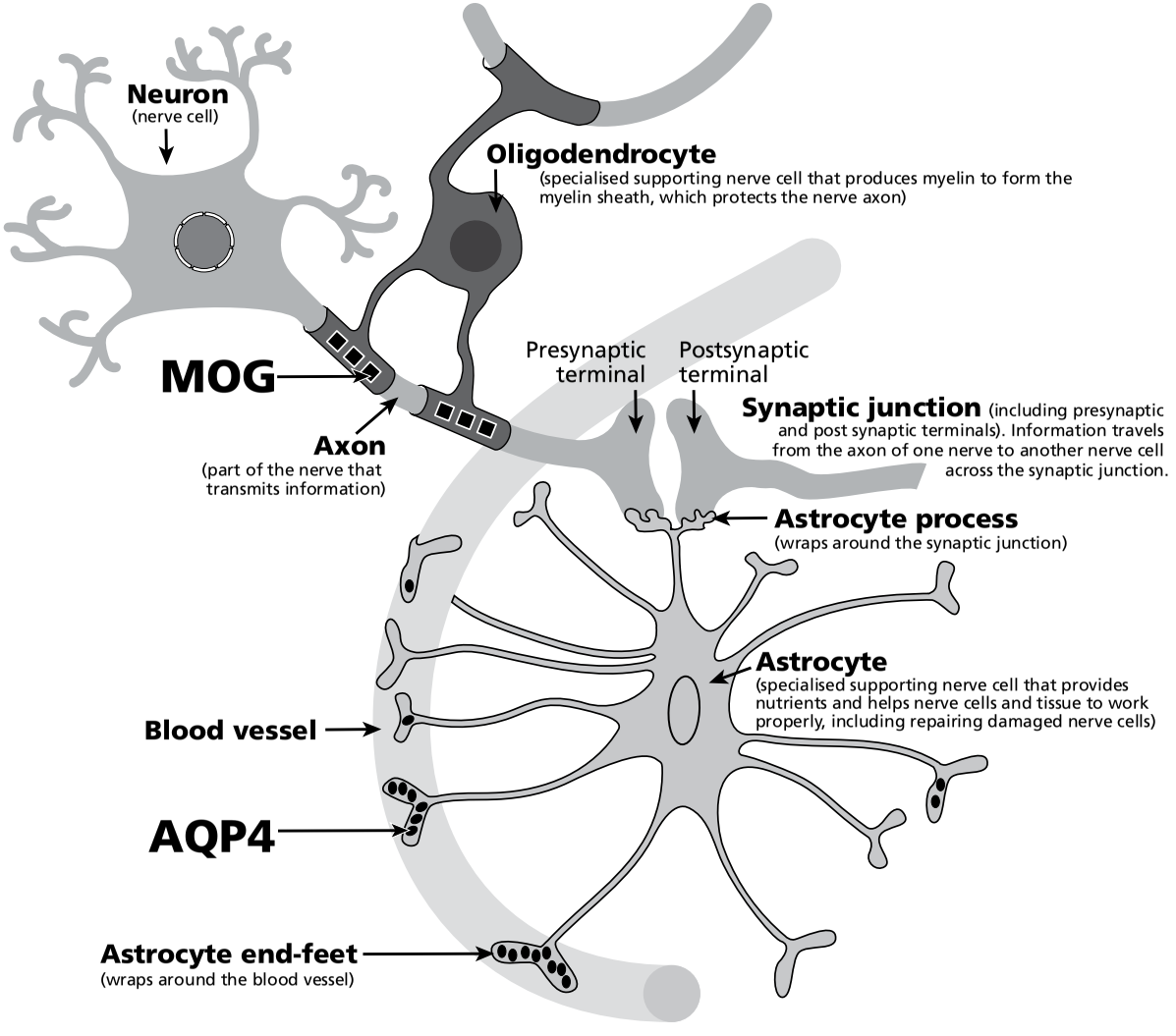
What are MOG antibodies?

MOG stands for myelin oligodendrocyte glycoprotein, which is found on the myelin sheath of nerve cells. The myelin sheath insulates and protects nerves and helps them to work effectively. It is thought that MOG helps to repair the myelin sheath when it gets damaged.

In MOG antibody demyelination, MOG antibodies attack the myelin oligodendrocyte glycoprotein, causing damage to the myelin sheath.

AQP4 antibody NMO is highly likely to cause repeated attacks, which can cause severe disability if it is not treated. MOG antibody demyelination is less likely to cause further attacks and appears to cause less severe disability in most people.

Cells of the central nervous system and MOG and AQP4 antibodies



MOG antibodies and disease

MOG antibodies have been recently found in people who have the following:

- optic neuritis (inflammation of the optic nerve)
- transverse myelitis (inflammation of the spinal cord)
- ADEM (acute disseminated encephalomyelitis). This is an inflammatory condition affecting the brain, often after an infection. It is more common in children.

Optic neuritis

When there is inflammation within a section of the optic nerve (the nerve that passes messages between the eyes and brain) it is known as 'optic neuritis'.

MOG optic neuritis usually affects one eye, but sometimes it affects both eyes at the same time.

Optic neuritis causes visual disturbances, such as blurred vision, problems seeing colours and visual field defects, where sections of the central or peripheral (side) vision are disturbed. It can sometimes cause a complete loss of vision.

It often causes pain around the eye and/or at the back of the eye, particularly when it is being moved around.

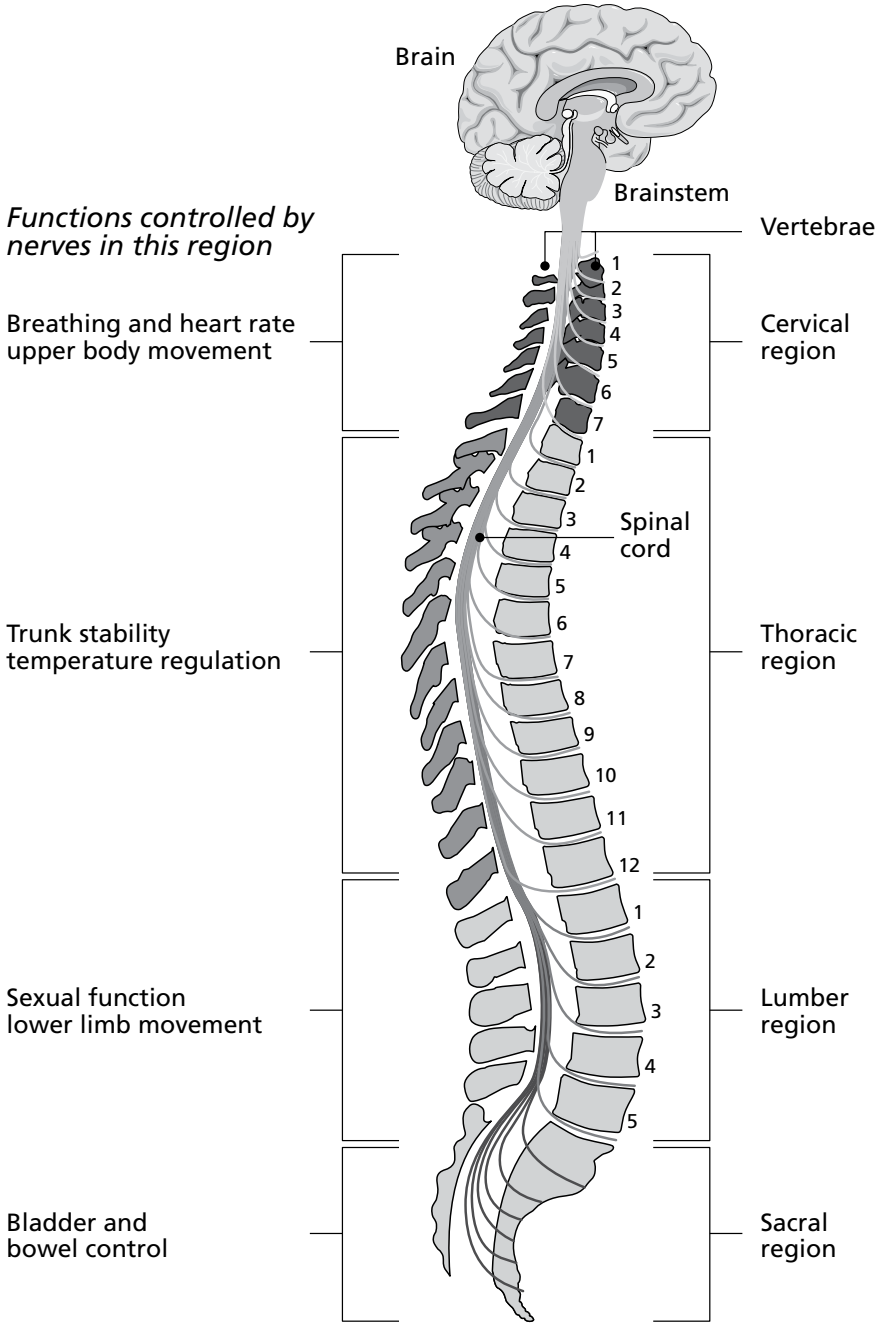
Transverse myelitis

Inflammation of the spinal cord is known as transverse myelitis.

Transverse myelitis can have a different effect on each person, depending on which area of the spinal cord has been affected. How severe the symptoms are depends on how far the inflammation has spread and how much damage has occurred.

The main symptoms of transverse myelitis are muscle weakness in the legs and/or arms, altered sensations (pins and needles, numbness), bladder and bowel problems and pain. These symptoms may develop quickly over a few hours or gradually over weeks.

The brain and spine, showing how the functions of the body relate to areas of the spinal cord



MOG antibodies and course of illness

If you have MOG antibodies you are likely to just have a 'one-off' attack and will usually recover well.

Some people do experience further attacks, but the risk of this may be reduced if you take a medication called prednisolone for 3-12 months after the original episode. If you do have a relapse, you are likely to recover well, but may be prescribed corticosteroid treatment (see 'MOG antibodies and treatment` section).

MOG antibodies and disability

Most people will recover well from relapses and many have a full recovery, but not all. If you have had optic neuritis, you may be left with some level of visual impairment. If you have had transverse myelitis, you may be left with bladder, bowel or sexual function problems.

The management of these problems will be discussed with you, your local neurology team and your GP. Further information about the management of common symptoms can be found in additional leaflets, which you can get from your NMO Specialist Nurse.

MOG antibodies: what we don't know

Although MOG antibodies have been found for many years, the previous test was unreliable and did not help us to understand the disease.

Nowadays, MOG antibodies are detected using a more reliable technique. They are thought to be relevant particularly to the symptoms of optic neuritis, transverse myelitis and ADEM.

However, this technique is recent and there is still much to be learnt. The length of prednisolone treatment that is needed following an attack is not yet fully understood. It is also not known how the length of this treatment affects long term symptoms.

MOG antibodies and treatment

Your first attack is likely to have been treated with intravenous corticosteroids (such as methylprednisolone), given through a drip into a vein in your hand or arm. This may be followed by a course of prednisolone (corticosteroid) tablets for 3-12 months.

We currently recommend that you stay on prednisolone tablets for up to a year. However, if the MOG antibodies become undetectable by six months we may stop the treatment earlier.

If you are taking prednisolone for more than 2-3 months, you will also need to take medication to help prevent side effects. This may include medicine to protect the lining of your stomach and vitamin supplements to protect your bones.

Stopping treatment

Steroids should not be stopped suddenly. Your body needs steroids to work properly and usually makes its own natural steroids. When you take steroid tablets your body stops producing its own steroids. When you stop taking steroid tablets your body needs time to start producing its own steroids again, so you will need to gradually reduce the dose before stopping.

Stopping steroids suddenly could increase the risk of having another attack. If you want to stop taking the steroids, please speak to your NMO Specialist Nurse.

Alternatives

As any further attacks (relapses) often recover well, another option is to not use regular prednisolone but to only treat attacks if they occur.

We are not currently recommending longer-term use of prednisolone (or other medications that act in a similar way) beyond one year (even if MOG antibodies are still present), unless you have multiple or severe attacks.

If you do have a further attack, we recommend quick treatment with high dose corticosteroids. These should speed up and improve your recovery from the attack.

When you have recovered from an attack, we may offer you a follow-up MRI scan. This scan can be used as a baseline, which can be looked at and compared against if new symptoms develop in the future. Any changes seen on the MRI images usually get better, as do changes seen in other tests. We will also discuss with you if we think you might need longer-term immune-suppressant medication to prevent further attacks.

Recognising a relapse

An attack of MOG antibody demyelination occurs when there is inflammation within the nervous system. This inflammation is usually within the optic nerve from the eyes (optic neuritis) or the spinal cord (transverse myelitis). The inflammation may cause you to experience new symptoms, or a recurrence of symptoms you have had previously.

Specific symptoms for optic neuritis are listed on page 5.

If you think you are having a relapse, it is important to seek medical advice promptly from your GP and your NMO Specialist Nurse.

If you experience symptoms for more than 24 hours please contact your NMO Specialist Nurse (contact details are at the end of the leaflet).

If you have problems outside of normal working hours, your GP can contact the on-call neurologist for advice at either the John Radcliffe Hospital or the Walton Centre.

MOG antibodies and research

We still have a lot to learn about this condition, so are interested in carrying out further research in this area. We are auditing how people get on during the years after their attack, as well as the treatment they have been given. This helps us to look at the effects of different treatment.

The opportunity to take part in this research is offered to every person who is referred to us with NMO-like symptoms. This is so we can compare how different types of NMO and similar conditions effect people differently, depending on what antibodies (if any) they have. This can help us to understand these conditions and provide the most appropriate treatment.

We may ask for your consent to include you in our research tissue bank. This means we can study your symptoms and the investigations you have had. If you are happy to be involved in research, we may ask for extra blood samples when you visit. We will also let you know of any other research studies you may be suitable for.

How to contact us

NHS NMO Specialised Services

This is the National Highly Specialised Service for Neuromyelitis Optica, based at the John Radcliffe Hospital, Oxford, and the Walton Centre, Liverpool. If you have any questions about MOG antibody demyelination or NMO you can contact the NMO Specialist Nurses for advice and support.

Website: **www.nmouk.nhs.uk**

John Radcliffe Hospital, Oxford

Email: **nmo.advice@ouh.nhs.uk**

Tel: **01865 231 905**
(9.00am to 4.00pm, Monday to Friday)

Walton Centre, Liverpool

Email: **nmo.advice@thewaltoncentre.nhs.uk**

Tel: **0151 529 8357**
(9.00am to 4.00pm, Monday to Friday)

If you need an interpreter or would like this information leaflet in another format, such as Easy Read, large print, Braille, audio, electronically or another language, please speak to the department where you are being seen. You will find their contact details on your appointment letter.

Authors: Dr Jacqueline Palace, NMO Consultant Neurologist
Rosie Everett, NMO Specialist Nurse

April 2019
Review: April 2022
Oxford University Hospitals NHS Foundation Trust
www.ouh.nhs.uk/information

OMI 45339P