

Ocular Mucous Membrane Pemphigoid (OMMP)

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What causes OMMP?

We don't clearly understand what causes OMMP. Although it is known to have a genetic element, it is not an inherited disease and we don't know what triggers the start of the disease. As with other autoimmune diseases, the immune system mistakenly attacks parts of the body. With MMP, your immune system creates autoantibodies which attack the layer immediately under the mucous membranes or skin, causing inflammation and scarring. Blistering is uncommon in the eyes but occurs at other sites. OMMP is not inherited, you can't 'catch' it from someone else and it isn't due to allergies or diet. It usually affects people over 40 (both men and women) but it has been diagnosed in younger adults and, rarely, in children.

How would I know I have OMMP?

In the eyes, the disease starts as conjunctivitis (red, painful and sticky eyes) which may be mild and intermittent or severe and persistent. These symptoms do not improve with treatment by antibiotics or eye drops and can create a lot of pain and irritation. Although scarring in the conjunctiva occurs early, it can be difficult to see with the naked eye until the disease is quite advanced.

As the inflammation and scarring progresses, it can also cause the pocket between the eyelids and eyeball (the conjunctival fornix) to reduce in depth, which may show as a droopy lid or as a smaller gap between the lids.

The eyelids may turn in and the eyelashes may begin to scratch the surface of your eye. This is called trichiasis. The tear producing glands can also be affected by scarring and inflammation, causing the eyes to be dry.

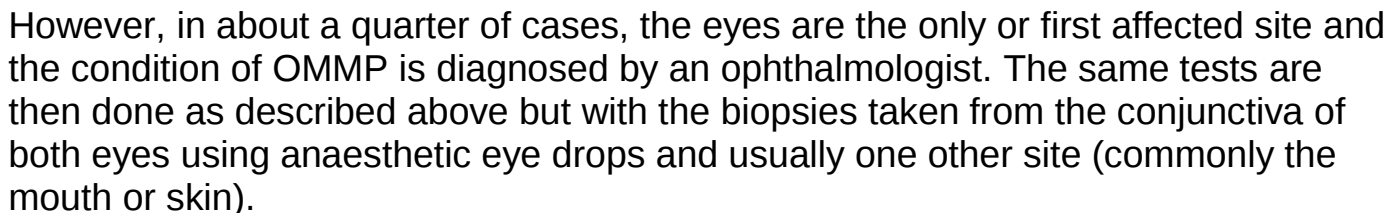
How is OMMP diagnosed and why may this be difficult to diagnose?

MMP is a rare disease and its occurrence in the eyes is, likewise, unusual. This also contributes to the difficulty of obtaining a swift and accurate diagnosis. It is thought to develop in 8 per 10 million people per year. Consequently, this disease is often not the first consideration when a doctor is trying to find a diagnosis.

To confirm a suspected diagnosis of MMP, a small piece of tissue called a biopsy, is taken from the affected mucous membrane and/or the skin under local anaesthetic and tests done to confirm the diagnosis. This test is called a direct immunofluorescence test (DIF). The blood is also tested for the presence of autoantibodies (serology testing).

MMP often starts in the other mucous membranes (most commonly the mouth) or the skin and, if you have an MMP diagnosis, you may be referred to an ophthalmologist by a specialist in oral medicine or a dermatologist. This is to ensure the eyes are monitored for the effects of the disease. If the appearances in the eyes are typical of eye involvement by MMP there is no need for any further tests to confirm the diagnosis.





Can other parts of my body be affected?

How am I going to be treated?

The immunosuppressive drugs most often used for OMMP are:

- azathioprine
- cyclophosphamide
- dapsone

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- methotrexate
 - mycophenolate
 - sulfasalazine or sulfamethoxypyridazine
 - prednisolone

If your eye disease is particularly severe, a biological treatment such as Rituximab or Truxima might be used, or intravenous immunoglobulin (IVIg) which replaces antibodies in your system.

All of these drugs can have serious side effects and you will need to be monitored while you are on them. Since this disease is chronic – which means it might last for a very long time and may require you to take medication indefinitely – you are likely to need regular check-ups.

Where the disease has also caused entropion (the eyelids turning in) and the eyelashes are scratching the cornea, then you may be recommended to have the eyelashes removed with tweezers (epilated) which some patients can do at home, or have surgery either to reposition in-turned eyelids or remove the lashes completely. Treatments to control the other side effects of OMMP may also be prescribed such as lubricating gels, drops or ointments for dry eyes and treatment for blocked eyelid margin glands (blepharitis) that can be treated with hot compresses and lid margin cleaning, as well as keeping your eyelids clean.

Can I be cured?

MMP and, specifically OMMP, are not curable, but with the right treatment at the right level, it is possible to halt the progress of the disease and 'remission' can be achieved. It is vital that there is an early diagnosis and an effective treatment can be found for severe or rapidly developing scarring. At the moment, we are not able to reverse the blindness that very bad or untreated OMMP can cause.

What can I do to manage my disease?

In addition to managing your medications as instructed (and reporting any worrying side effects), you can minimise some of the effects that OMMP has by:

1. If you can, remove any eyelashes that are turning inwards or ask someone else to do it. Partners, your hospital clinic, your optometrist and occasionally a GP practice nurse may be able to help.
2. Regular treatment of blepharitis for those affected (see the Moorfields blepharitis leaflet)
3. Do not let your eyes dry out. Ask for gels or ointments that you can use regularly to keep them moist.

4. This is a chronic severe disease which can be difficult to cope with. The complications need to be understood by your family/friends/employer and you can be helped by others in the patient support groups listed below.

Is there any support I can access?

There are several patient organisations for people with OMMP (and MMP).

In the UK there is the PEM Friends support group, found at

www.pemfriendsuk.co.uk. There is also a Facebook group, specifically run for patients with MMP. The link to this can be found on the website but we have also put it here for your information:

<https://www.facebook.com/groups/121991554546796>

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Revision number: 1

Approval date: March 2021

Review date: March 2024

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www.moorfields.nhs.uk

Moorfields Direct telephone helpline

Phone: 020 7566 2345

Monday-Friday, 8.30am-9pm

Saturday, 9am-5pm

Information and advice on eye conditions and treatments from experienced ophthalmic-trained nurses.

Patient advice and liaison service (PALS)

Phone: 020 7566 2324 or 020 7566 2325

Email: moorfields.pals@nhs.net

Moorfields' PALS team provides confidential advice and support to help you with any concerns you may have about the care we provide, guiding you through the different services available at Moorfields. The PALS team can also advise you on how to make a complaint.

