PEM Friends

Enables patients and their loved ones to share information and advice on how to manage their symptoms and to get emotional support.

We also raise awareness of PEM in the medical and research community and can help Health Care Professionals access information and support.

Enquiries and requests are all welcome and PEM Friends would be delighted to hear from anyone willing to provide support and share their experiences.



GETTING IN TOUCH

Read more in our magazine PEM Lives, available on our website: <u>https://www.pemfriends.org.uk/pem-lives</u> <u>-magazine</u>

We welcome any contacts via our website, our Facebook page or by e-mail at: <u>mail@pemfriends.org.uk</u>







https://www.bad.org.uk



PEM Friends is a registered charity; Number 1207029

Mucous Membrane Pemphigoid



Patient Information Leaflet



What is Mucous Membrane Pemphigoid?

Mucous Membrane Pemphigoid (MMP) can affect the skin, but more commonly it causes blisters in the mucous membranes (mouth, nose, throat, genital areas and anus). MMP also affects the eyes and, in serious and untreated cases, can result in blindness. The blisters can leave scars which causes longer term damage. When the eyes are involved, it is usually called Ocular MMP or OCP (Ocular Cicatricial Pemphigoid).

MMP can involve one or more of the sites mentioned above, but often starts in the mouth with painful ulceration. Scarring may continue undetected by the patient and consequently, regular monitoring is important. Long term, the scarring in the nose and larynx can create problems with crusting and a hoarse voice.



How long will my Mucous Membrane Pemphigoid last?

MMP is a chronic disease. There is no cure but remission is possible. However, MMP is difficult to treat successfully and the effects of the scarring can yield long term damage.

How is Mucous Membrane Pemphigoid treated?

Due to the range of sites which can be affected by MMP, a multidisciplinary approach is essential to manage the disease. Early recognition and treatment may decrease disease related complications. Any patient who has involvement in one site, should be checked for symptoms in other potential areas of involvement.

The choice of treatment for MMP is based upon the sites of involved, clinical severity, and disease progression. In 2002, the First International Consensus on MMP recommended dividing patients into "lowrisk" and "high-risk" groups based upon the site(s) of involvement, with "low-risk" patients defined as having only oral mucosal or oral and skin involvement. "High -risk" patients were defined as having involvement of the ocular, genital, oesophageal, nasopharyngeal, and/or laryngeal mucosae, and require more

What treatments might I be offered to reduce the impact of Mucous Membrane Pemphigoid?

In moderate to severe cases, **steroids** are usually prescribed to stop the blistering, scarring and reduce inflammation. Once the disease is under control, then an alternative drug will be used to replace the steroids, which have less severe long term. It may take a while to find an appropriate treatment. A biologic treatment called Rituximab has also been shown to be effective in bringing MMP into remission.

