# **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: <a href="https://www.pemfriends.org.uk/pem-lives-magazine">https://www.pemfriends.org.uk/pem-lives-magazine</a>

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

Scan QR code for PEM Friends website:





https://www.bad.org.uk



PEM Friends is a registered charity; Number 1207029

# Pemphigus & Pemphigoid in the mouth



Patient Information Leaflet



# What is Pemphigus & Pemphigoid in the mouth?

Pemphigus and Pemphigoid often appear in the mouth. This can also be one of the body sites that is the most resistant to treatment. It is very frequently reported as the location of most frequent pain and can result in difficulties in eating.

# **Treating mouth erosions?**

<u>Topical steroids</u> such as betamethasone or flixonase nasules mixed in a little water are often prescribed. Steroid ointments can be applied to particular areas inside the mouth after gently drying the area to be treated with a clean tissue.

Anaesthetic (analgesic) mouthwashes are also available over the counter or by prescription. Many people find that rinsing their mouth with hydrogen peroxide can help. Difflam is most frequently recommended by clinicians or Gengigel or Gelclair can help.



### **Cleaning teeth**

It is vital to keep your mouth and teeth clean, even if it is painful.

Antiseptic mouthwash or gel may be recommended to help with plaque control when your gums are sore. Peroxyl mouthwash daily is useful or chlorhexidine twice weekly. Some people have reported good results from Pulling Oil. Oil pulling or oil swishing, involves swishing of oil in the mouth in the same way as mouthwashes and oral rinses. Avoid products containing Sodium Lauryl Sulphate (SLS) or Sodium Laureth Sulphate (SLES). SLS is a chemical that is a known skin irritant and commonly used in many products.

## Will my dentist understand?

Many dentists have a knowledge of Pemphigus and Pemphigoid and, in our experience, are often the first to diagnose your disease.

However, if your mouth is seriously affected, dental treatment can be a problem and you may be referred to a dental expert. Dental Hospitals will usually recommend someone with appropriate expertise.

Many dentists are also reluctant to treat patients who are taking bisphosphonate drugs, such as Alendronic Acid. These are used to build bone density in patients who have developed osteoporosis or osteopaenia (softening of the bone structures). Do talk to your dentist if you are taking these drugs.

You can hear more in the <u>talk</u> by Dr Roddy McMillan, of the Eastman Dental Hospital and the British and Irish Society for Oral Medicine, on our website.

