

Mucous membrane pemphigoid (affecting the mouth)

This leaflet explains more about having mucous membrane pemphigoid in your mouth. If you have any further questions, please speak to a doctor or nurse caring for you.

What is pemphigoid?

Pemphigoid (or mucous membrane pemphigoid) is an autoimmune disease caused by an overactive immune system which reacts against parts of the body such as the mouth, nose, throat, skin and sometimes the eyes.

The condition is not contagious and cannot be passed onto another person. It is not hereditary so is not be passed on to your children.

What are the signs and symptoms?

Pemphigoid causes soreness, blisters or ulcers in the mouth and sometimes affects the skin of the body or scalp, the eyes, throat or genital area.

Pemphigoid can come and go over the years. In some patients the disease may be very mild but in others it may be more troublesome. Some patients are very fortunate and the disease goes away after a while, but unfortunately this happens in only a few cases. Most patients need medicines for quite some time (from months to years) to control it.

Do I need any tests to confirm the diagnosis?

A biopsy and blood tests are needed to confirm the diagnosis. A biopsy involves taking a small sample of tissue from inside your mouth under local anaesthetic (so that the area we take tissue from is numb). The sample is sent to pathology for examination under a microscope and special tests.

What treatments are available?

It is not possible to cure pemphigoid but there are a number of treatments that can be used to control it. They all work by dampening down the inflammation in the affected areas. Different treatments suit different individuals so it may be necessary to try several treatments before the best one is chosen. We often start with 'topical' treatments which are applied directly to the affected areas.

For symptoms in the mouth we use mouthwashes and sprays, and for the skin we use creams and ointments. If the soreness and ulcers persist, then it will probably be necessary to start oral medicines (those given by mouth) in addition to topical treatments. This may only be necessary for a few weeks in some patients. However, others may need to take oral treatment for many months or years.

What happens if I do not get treatment?

If no treatment is received, the condition will often become worse. In some rare cases, the condition may then become very serious and result in significant scarring of the affected sites. It is rarely life threatening.

Is there anything I can do to help?

The gums are sometimes sore, which makes brushing teeth painful and it may cause bleeding of the gums. However, it is very important to try and continue tooth brushing because if plaque is allowed to build up, not only can the teeth decay, but also the gums may pull away and the teeth may eventually become loose.

To help with tooth brushing, anaesthetic mouthwashes can be used to numb the gums and a soft toothbrush can be used with toothpaste for sensitive teeth. In addition, regular treatment from a dental hygienist is recommended to help keep the teeth clean.

Further information

Patient information leaflets can also be obtained from:

- 1) the British Society of Oral Medicine website
www.bsom.org.uk
- 2) the British Association of Dermatologists website
www.bad.org.uk/for-the-public/patient-information-leaflets

Contact us

If you have any questions or concerns about pemphigoid, please contact the Oral Medicine department on 020 7188 4399, Monday – Friday 9am–5pm.

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk

t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch:

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

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t: 0800 731 0319 **e:** members@gstt.nhs.uk **w:** www.guysandstthomas.nhs.uk/membership

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