

Pemphigus (affecting the mouth)

The aim of this information sheet is to answer some of the questions you may have about pemphigus. If you have any further questions or concerns, please speak to a doctor or nurse caring for you.

What is pemphigus?

Pemphigus is an autoimmune disease caused by an overactive immune system which reacts against the body. This means that your immune system attacks healthy cells in your body by mistake.

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

What are the signs and symptoms?

Pemphigus causes soreness, blisters and ulcers of the mouth and sometimes the skin of the body or genital area.

Pemphigus can come and go over the years. In some patients, the disease may be very mild and in others it may be more troublesome. Some patients are very lucky and the disease goes away after a while, but unfortunately this is rare and happens in only a few cases.

Do I need any tests to confirm the diagnosis?

Many people have blood tests to confirm the diagnosis. Sometimes a biopsy is needed. This involves taking a small sample of tissue, but you will be given a local anaesthetic so that the area we take tissue from is numb. The sample is then sent to pathology for examination under a microscope and special tests.

What treatments are available?

It is not possible to cure pemphigus, 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 for each patient it may be necessary to try several different treatments before the best one is chosen. We often start with topical treatments – medicines 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 treatments (those taken by mouth) in addition to topical treatments. This may only be necessary for a few weeks in some patients. Others, however, 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 become worse. In some rare cases, the condition may become very serious and even life-threatening (due to infections in open areas of the skin).

Is there anything I can do to help?

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

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

Further information

Contact us

If you have any questions or concerns about pemphigus, 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

Patient Advice and Liaison Service (PALS)

To make comments or raise concerns about the Trust's services, please contact PALS. Ask a member of staff to direct you to the PALS office or:

t: 020 7188 8801 at St Thomas' **t:** 020 7188 8803 at Guy's **e:** pals@gstt.nhs.uk

Knowledge & Information Centre (KIC)

For more information about health conditions, support groups and local services, or to search the internet and send emails, please visit the KIC on the Ground Floor, North Wing, St Thomas' Hospital.

t: 020 7188 3416

Language support services

If you need an interpreter or information about your care in a different language or format, please get in touch using the following contact details.

t: 020 7188 8815 **fax:** 020 7188 5953

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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