CONDITION

Mucous membrane pemphigoid

Mucous membrane pemphigoid is an autoimmune condition that causes blisters and scarring on the mouth, eyes, and other moist body linings.

WHAT IT IS
Autoimmune blistering condition affecting moist body linings

BODY SYSTEM
Mouth, eyes, throat, genitals, and skin

MAIN SYMPTOMS
Painful mouth sores, eye irritation, blisters, scarring

WHAT CAUSES IT
Immune system attacks the tissue-anchoring layer

HOW IT IS DIAGNOSED
Tissue biopsy with direct immunofluorescence and blood tests

MAIN TREATMENT
Anti-inflammatory and immune-suppressing medicines

CAN IT BE CURED?
No - treatment can control activity

IS IT AN EMERGENCY?
Sometimes - breathing trouble or sudden vision change

LONG-TERM OUTLOOK
Often controllable, but scarring may cause lasting problems

Overview

Mucous membrane pemphigoid is a long-lasting autoimmune condition. "Autoimmune" means the immune system mistakenly attacks part of the body.

The condition mainly affects mucous membranes. These are the moist linings of areas such as the mouth, eyes, nose, throat, genitals, and anus. The skin can also be affected.

The immune attack causes the upper layer of tissue to separate from the layer below it. This creates fragile blisters. In the mouth, blisters often break so quickly that you may notice only raw, painful areas.

Mucous membrane pemphigoid matters because repeated inflammation can lead to scarring. Scarring in the mouth may be uncomfortable, but scarring around the eyes, airway, or food pipe

can affect sight, breathing, or swallowing. Early treatment aims to stop inflammation before permanent damage develops.

The condition is not contagious. You cannot catch it from another person or pass it on through touching, kissing, food, or shared items.

Symptoms

Symptoms depend on which body areas are affected. More than one area may become involved over time.

The mouth is the most commonly affected area. Possible symptoms include:

Eye involvement may cause redness, burning, grittiness, watering, or sensitivity to light. The eyelids may stick to the surface of the eye as scar tissue forms. Eyelashes can turn inward and rub against the eye. Vision may become blurred if the clear front surface of the eye, called the cornea, is damaged.

Eye inflammation can sometimes progress without severe discomfort. Regular eye examinations may therefore be important even when symptoms seem mild.

Blisters and ulcers may also occur inside the nose. They can cause crusting, bleeding, blockage, or discomfort.

Throat or voice-box involvement may cause persistent hoarseness, pain, coughing, or difficulty breathing. Inflammation in the oesophagus-the tube carrying food to the stomach-can make swallowing painful or cause food to feel stuck.

Genital involvement can cause soreness, blisters, painful urination, or pain during sex. Scarring may narrow the vaginal opening or the opening of the penis. Anal involvement can make bowel movements painful.

Skin blisters are less common. They may appear on the head, neck, upper body, or limbs and can heal with scars or changes in skin colour.

- Painful ulcers or raw patches
- Blisters on the gums, cheeks, tongue, or roof of the mouth
- Red, peeling, or bleeding gums
- Pain when eating, drinking, or brushing your teeth

Causes and risk factors

Mucous membrane pemphigoid develops when the immune system produces proteins called antibodies against structures that normally hold the surface layer of tissue in place. The attack weakens this connection, allowing blisters to form.

Several different tissue proteins can be targeted. This helps explain why the pattern and severity are not the same for everyone.

The exact reason the immune reaction begins is usually unknown. It most often starts later in adulthood, although it can occur at other ages.

Mucous membrane pemphigoid is not caused by poor hygiene, stress, diet, or an infection. It is not usually passed directly from parent to child. Most people have no clear avoidable trigger.

Diagnosis

Diagnosis usually involves an examination by a dermatologist or another specialist familiar with blistering conditions. Depending on your symptoms, an ophthalmologist, dentist, oral medicine specialist, ear, nose and throat specialist, or gynaecologist may also be involved.

A biopsy is the main test used to confirm the condition. During a biopsy, a small piece of tissue is removed after the area has been numbed. The most useful sample for direct immunofluorescence is generally taken beside a fresh blister rather than from the centre of an old ulcer.

Direct immunofluorescence uses fluorescent markers to look for immune proteins along the layer where the surface tissue joins the tissue underneath. A second biopsy may be examined with routine microscopy to show how the tissue layers have separated.

Blood tests can look for circulating antibodies and may help identify the specific protein being attacked. However, blood tests can be negative even when mucous membrane pemphigoid is present.

Other assessments depend on the areas involved. An eye specialist may examine the eyelids, conjunctiva, and cornea with a microscope called a slit lamp. Throat symptoms may require a small flexible camera examination. Swallowing tests or an endoscopy may be considered if the oesophagus could be affected.

Treatment and management

Treatment aims to stop new blisters, control pain, prevent scarring, and protect sight, breathing, swallowing, and genital function. The approach is based on where the condition

occurs, how quickly it is progressing, and whether scarring is developing.

Mild disease limited to the mouth or skin may be treated with strong topical corticosteroids. These reduce inflammation and may come as gels, rinses, ointments, or preparations held against the gums with a fitted dental tray.

Careful mouth care remains important. A soft toothbrush and regular dental review can help control plaque without causing excessive injury. Treatments for oral yeast infection may be needed if it develops, particularly during corticosteroid treatment.

More extensive disease often needs medicine that works throughout the body. Options include anti-inflammatory medicines such as dapsone or certain tetracycline antibiotics, and immune-suppressing medicines such as mycophenolate, azathioprine, or methotrexate.

Systemic corticosteroids may be used when rapid control is needed. Cyclophosphamide, rituximab, or intravenous immunoglobulin may be considered for severe or treatment-resistant cases. These treatments have different risks and monitoring needs, so selection is individual.

Eye, airway, or oesophageal involvement is generally treated more actively because scarring in these areas can have serious effects. Lubricating eye drops may ease dryness and irritation, but eye drops alone may not control the deeper immune process. An eye specialist should monitor for ongoing inflammation and scarring.

Surgery can correct problems such as inward-turning eyelashes, narrowed passages, or established scar tissue. Whenever possible, surgery is planned after inflammation is controlled because active inflammation may promote further scarring.

Regular blood tests and other checks may be needed during systemic treatment. Monitoring looks for effects on blood cells, the liver, kidneys, infection risk, and other treatment-specific concerns.

Complications

Scarring is the main long-term concern. Damage that has already become scar tissue may not disappear even when the immune activity is controlled.

Possible complications include:

Medicines that reduce immune activity can also increase susceptibility to infection or affect organs and blood cells. Monitoring helps identify these problems early.

- Eyelid distortion, corneal damage, and loss of vision

- Narrowing of the airway or persistent voice changes
- Oesophageal narrowing and difficulty swallowing
- Genital or urinary narrowing
- Poor food intake because of mouth pain
- Tooth and gum problems when brushing becomes difficult
- Infection in broken skin or tissue

Prevention

There is no established way to prevent mucous membrane pemphigoid from starting. It is an autoimmune condition, not the result of a known lifestyle choice or an infection.

Once it develops, prompt treatment and follow-up can help prevent avoidable scarring. Take prescribed treatment consistently and report new symptoms in another body area rather than waiting for a routine appointment.

Gentle care may reduce irritation. Avoid rubbing affected eyes and try not to break blisters. If your mouth is sore, softer foods and avoiding sharp, very hot, spicy, or acidic foods may be more comfortable. These steps can reduce discomfort, but they do not switch off the immune process.

Living with it and what to expect

Mucous membrane pemphigoid usually lasts for years. Its activity can rise and fall, and periods without new blisters are possible. A period when the condition is inactive is called remission.

Treatment may need to continue for months or longer before it can be reduced. Relapses can happen after treatment is lowered or stopped. This does not necessarily mean that all previous treatment has failed; the plan may need to be adjusted again.

Active inflammation and permanent damage are different. Treatment can stop new injury, but established scarring may continue to affect vision, swallowing, or movement even after inflammation settles. Rehabilitation, eye care, dental care, or surgery may help manage these lasting effects.

Follow-up often involves more than one specialty. Keeping appointments matters particularly when the eyes, throat, or oesophagus have been involved. Some changes are easier to find during an examination than through symptoms alone.

Mouth pain can affect eating, sleep, speaking, and social activities. Adjusting food texture, planning dental care around symptom flares, and using prescribed pain relief or mouth treatments may make daily life easier.

Many people achieve good control with treatment, although finding an effective and tolerable plan can take time. The long-term course cannot be predicted precisely for one person.

When to get medical help

Call emergency services or go to an emergency department if you have:

Seek urgent, same-day medical advice for a new painful or very red eye, blurred vision, light sensitivity, new hoarseness, worsening swallowing difficulty, or rapidly spreading blisters. Fever or feeling significantly unwell while taking an immune-suppressing medicine also needs prompt assessment.

Arrange routine follow-up if sores are becoming more frequent, a new body area is affected, or treatment side effects are troubling you. Keep planned eye and specialist appointments even when the condition appears quiet.

- New or worsening difficulty breathing
- Noisy breathing or a feeling that your airway is closing
- Sudden major loss of vision
- An inability to swallow saliva or clear food stuck in your throat

Common questions

Is mucous membrane pemphigoid contagious?

No. It is caused by an immune system error, not bacteria, viruses, or fungi. Close contact, kissing, sex, and sharing food do not spread it.

Can mucous membrane pemphigoid be cured?

There is no treatment that permanently removes the tendency for the immune system to attack these tissues. Treatment can suppress the activity and may lead to remission, sometimes for a prolonged period.

Why do I need eye checks if only my mouth hurts?

Different areas can become involved at different times. Early eye inflammation may feel mild but can still cause scarring. An eye examination can detect changes that are difficult to notice

yourself.

What can I eat when my mouth is sore?

Soft, cool, or lukewarm foods may be easier to manage. Spicy, acidic, salty, rough, or very hot foods can irritate open areas. If pain is limiting your nutrition or fluids, tell your healthcare team.

Will the blisters leave scars?

Mouth blisters often heal without obvious scarring, but repeated inflammation can damage deeper tissue. The eyes, throat, oesophagus, and genitals are particularly vulnerable to harmful scar formation. Controlling active inflammation reduces further damage but may not reverse existing scars.

How long will I need treatment?

Treatment often continues for months or years. The length depends on the affected areas, whether new blisters or scars are forming, and how safely treatment can be reduced. Stopping medicine suddenly without a treatment plan may allow the condition to become active again.

Sources

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