

The Canadian Pemphigus and Pemphigoid Foundation

Taking Care of You - Advice on Oral Care

For many of us living with blistering diseases such as pemphigoid or pemphigus, simple actions such as drinking, eating, and speaking can be extremely painful. Even the thought of brushing and flossing our teeth can bring tears to our eyes!

Oral care, however, is critical to our overall health. We hope this bulletin provides you with helpful information, but be sure to consult with your team of healthcare professionals to fully understand your potential challenges and special needs. Together your dermatologist and dentist should help you develop the best strategy to manage your oral health.

Coping with a Mouthful of Blisters

For pemphigus and pemphigoid patients suffering from painful blisters in the mouth, talking and eating can be excruciating. Here are a few coping strategies to discuss with your health professional team:

Topical anesthetic:

Your doctor may prescribe a 2% viscous xylocaine rinse, a topical anesthetic that comes in a 100 ml plastic bottle. It's best to rinse with 5-10ml (1 – 2 teaspoons) a few minutes before eating. This treatment, which can be used up to six times a day, will numb the entire mouth and make eating more comfortable. Note: this rinse will also numb the taste buds, so your food will not be as flavourful.

Numbing rinse:

Your doctor may recommend rinsing with a 5% benzocaine solution, which may be less numbing and may interfere less with the taste of food. If you use a numbing rinse, check the temperature of food before eating so you don't burn numb areas. It's also important to eat slowly and chew well to ensure food is swallowed easily and safely.

Diet:

Until the disease is under control, you may need a soft diet. Eat what you feel comfortable chewing and swallowing. If the gums are sensitive, it may help to drink through a straw. You can also liquify foods with a blender or try liquid meal replacements. Consult with a dietician to maintain a balanced diet.

Anti-inflammatory drugs:

For tender areas of the mouth, topical prescription drugs can help control local inflammation. Most of these drugs are steroid-based and come in various

forms such as rinses, creams (usually white), ointment (Vaseline-like) or gels. Your health care provider can also identify which topical corticosteroids for the skin can also be used in the mouth.

The use of topical steroids may result in secondary fungal infections, which are easily treated with antifungal agents. Further, a compounding pharmacy may make up special combinations. It may take several tries to determine which combination works best for you.

Place a small amount of cream, ointment or gel on a damp cotton gauze (2"X2") and apply to specific areas in the mouth. This increases the contact time of the medication. You should hold the gauze in place for about one to two minutes. (A damp gauze pad may be more soothing, especially for those suffering from dry mouth). The strength of the medication will determine how frequently it should be used (as instructed by your dermatologist or dentist). Do not eat, drink or rinse your mouth for at least 30 minutes after applying medication. It may be more effective to apply medication just before going to bed since saliva production decreases during sleep.

If only the gums are affected, you can use soft flexible guards or trays (steroid carriers) to keep the medication in contact with the gums. Prescription alcohol-free chlorhexidine 0.12% mouth rinses may also help reduce the sensitivity of oral ulcers.

In some cases, patients have found relief from inflammation with localized steroid injections just below the surface of the skin inside the mouth. This may be used for small areas of persistent disease in selected patients. (Note: no current studies support the use of steroid injections given this way).

Staying Healthy - Proper Oral Care

Pemphigoid and pemphigus do not directly cause tooth loss, but lack of brushing and flossing may lead to problems such as cavities and gum disease. Pre-existing gum (periodontal) disease and dental decay may also become worse. For all these reasons, while teeth brushing may seem impossible and is guaranteed to be painful, pemphigus and pemphigoid patients should aim to maintain above-average oral hygiene.

Use an ultra soft toothbrush softened under hot water and mild toothpaste with 1.1% sodium fluoride, or a mild children's toothpaste. Avoid whitening toothpastes and especially toothpastes for sensitive teeth.

If brushing and flossing causes too much pain and bleeding, your dermatologist or dentist can prescribe alcohol-free chlorhexidine rinses until the inflammation allows for a return to normal oral care. Continue using these rinses to supplement normal tooth brushing and flossing.

Using these rinses, however, may stain the teeth and tongue brown. The stains may require professional dental cleaning to remove. Brush teeth before rinsing to minimize staining. Some patients may also experience changed or decreased taste. In general, avoid over-the-counter mouth rinses, especially if they contain alcohol.

Impact of Medications on Oral Health

The use of immunosuppressive drugs increases the risk of oral infections, which can become life threatening. Medications may also make any existing periodontal disease more difficult to control or worsen the condition. The combination of bisphosphonates (used to prevent osteoporosis) and prednisone may slightly increase the risk of osteonecrosis (bone death resulting from poor blood supply) of the jaws.

Oral thrush (fungal infections) may also worsen oral discomfort. These fungal infections may be managed with antifungal rinses (nystatin oral suspension) or antifungal pills such as fluconazole. Cyclosporine may lead to the growth of the gum tissue.

Given these possibilities, it is extremely important to work with your team of medical professionals to monitor your oral health, and reduce the likelihood of any problems.

Monitoring Your Oral Health

Any change within your mouth should alert you to a possible problem:

- New tooth pain could be a sign of infection.
- Loosening of teeth may signal the worsening of gum disease.
- A bad taste or odour, swelling, growth, bleeding or new ulcer may signal increased disease activity or another oral problem that requires attention.

As soon as you notice any change in your oral health, contact your doctor. You may need a new oral care strategy or changes to your treatment therapy.

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Working with Dentists and Other Oral Care Specialists

You may find that you're teaching your dentist about pemphigus or pemphigoid. While all dentists learn about blistering diseases in dental school, pemphigus and pemphigoid are rare diseases. Most physicians and dentists have never even seen an actual patient with one of these conditions.

As a result, it's important to work closely with your dentist to develop the best oral care strategy for you. In some cases, your dermatologist can send a letter explaining the condition and confirming that ongoing care is being provided. If your medical team is working well together, there is no reason to postpone critical oral surgery.

You should continue to see your dentist regularly for routine dental care. If you have difficulties brushing or flossing, your dentist may suggest more frequent dental visits for cleaning and checkups—three or four times per year instead of twice a year. Any infection should be eliminated prior to immunosuppressive therapy. Pre-existing periodontal disease should be monitored closely.

Remind your dentist and dental hygienist that your oral tissues are more fragile than a normal patient's. Since you are prone to form blisters and ulcers following routine procedures, a very gentle approach is required. If necessary, break a dental cleaning into several appointments. Dental freezing, either topical or by injection, may reduce discomfort during some procedures such as a deep cleaning. Antibiotic prophylaxis (antibiotics taken before) dental procedures are not required except for patients with certain conditions such as an artificial heart valve or joint.

Inform your dentist of the diagnosis and all your medications. It is helpful to list the names and contact information of all health care workers involved in your care. In addition, document medications you have taken in the past including prednisone and bisphosphonates for osteoporosis prevention. As suggested above, encourage your dentist and dermatologist to work together. Good inter-professional communication will result in the best care for you.

When You Need More Than A Cleaning!

Don't delay emergency dental treatments. Infections and pain require prompt diagnosis and treatment. You can delay regular dental treatments, however, until the active disease has resolved or is under control.

Importance of Good Oral Care

Even for healthy individuals, good oral care is important to overall good health. For individuals living with pemphigus and pemphigoid, however, good oral care is even more important. It begins the day you are diagnosed and evolves with your condition. Rest assured, you will eat, drink and speak easily again.

The Canadian Pemphigus and Pemphigoid Foundation produces the Information Bulletin as part of its Managing Our Health Program. Expert advice was provided by Dr. Peter J. Chauvin B.Sc., D.D.S., M.Sc., F.R.C.D.(C), Associate Professor and Director of Oral Diagnostic Sciences Faculty of Dentistry, McGill University Associate member, Department of Pathology Faculty of Medicine, McGill University and member of the Canadian Pemphigus and Pemphigoid Foundation's Medical Advisory Council.

Managing Our Health Program provides information to patients on ways in which they can enhance their general health and better cope with the symptoms of their illness and/or the side effects of their treatment therapies. For more information, visit www.pemphigus.ca.

Disclaimer: The information in this Bulletin has been developed by the Canadian Pemphigus and Pemphigoid Foundation in consultation with its Medical Advisory Council and subject matter experts. The information is not intended to replace informed medical advice. You should consult your dermatologist or other healthcare professional (e.g., physician, dentist, pharmacist, etc.) for individual medical advice. While the information is presented with due care, the Canadian Pemphigus and Pemphigoid Foundation does not guarantee that it is free from all errors or omissions.