



## PATIENT INFORMATION SHEET

# Oral Chronic Graft-Versus-Host Disease

Chronic graft-versus-host disease (cGVHD) is a frequent and serious complication following allogeneic Hematopoietic Stem Cell Transplantation (HSCT), also known as Bone Marrow Transplantation (BMT) (for explanation of these terms see sidebar). It usually develops within the first 1-2 years following transplantation. The skin, liver, and gastro-intestinal tract (including the mouth) are the most commonly affected parts of the body. Some degree of cGVHD is likely a good thing as it is a sign of successful acceptance of the graft and may help keep the underlying disease in long-term remission (the so called graft-versus-leukemia effect). Oral cGVHD is very common and in some cases, the mouth may be the only area affected. The symptoms associated with oral cGVHD are variable and range from not being painful at all, to being so painful as to make it difficult to eat and speak.

### What causes oral cGVHD?

The engrafted donor immune cells recognize parts of the patient's body as "foreign" and mount an immune attack. The risk of developing cGVHD is greatly dependent on how well "matched" the donor was to the recipient. While oral cGVHD is seen to a greater degree in poorly matched transplants, it can still develop even in ideally matched situations.

### Appearance in the mouth

Several forms of oral cGVHD are recognized. The most common form is the *reticular* form (below Left) that looks like lacy white lines – usually on the inner cheek or the sides or top of the tongue. These are usually not painful and may be present for a long time before being noticed. A second form is the *erosive* form. These look like raw, scraped, red areas that are often painful and sore, particularly when contacted by food. Faint subtle white lines may be seen at the edges of the red areas. A third form is the *ulcerative* form (below Right). This form probably overlaps with the erosive form and is generally painful. These lesions may look like canker sores and can be quite large.

### Allogeneic Bone Marrow Transplantation

Bone marrow transplantation is most commonly used to replace the blood forming elements of a patient who develops a malignancy within the blood forming system. In preparation for this procedure the patient is treated with high doses of chemotherapy, often combined with total body irradiation to destroy their existing blood forming cells. Donor cells for replacement can be either autologous (from the same patient being treated), syngeneic (from genetically identical twins), or most commonly allogeneic (from another donor who is matched as close as possible to the recipient patient).

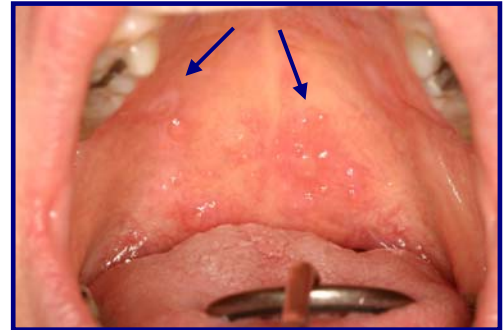




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Oral cGVHD may also affect the salivary glands, resulting in dry mouth and/or the development of small blisters (superficial mucoceles, or mucous cysts) on the inside of the lips and the palate (see Right). Mucoceles are typically more of a nuisance than actually painful.



Patients with dry mouth may have difficulty chewing and swallowing foods, may notice changes in taste, and are at very high risk for developing dental caries, especially along the gum line and between teeth (see Left). In patients who develop thickening and hardening of the skin due to cGVHD, the same process may affect the skin of the face and in some cases, the soft tissues inside of the mouth. When this happens the mouth may feel “tight” and it may be difficult to open widely.

### QUESTIONS AND ANSWERS ABOUT ORAL CHRONIC GRAFT-VERSUS-HOST DISEASE

**Q: How do I know if I have oral cGVHD?**

A: Usually your oncologist or an experienced oral medicine specialist can diagnose oral cGVHD by correlating the lesions appearance and symptoms with the medical history. In some circumstances however, a biopsy may be necessary.

**Q: What should I expect once I have been diagnosed with oral cGVHD?**

A: Oral cGVHD tends to come and go. Some days it will feel better, and other days it may feel worse. It tends to get worse if your body is stressed, both physically (such as having a cold) and emotionally. It is usually best to avoid spicy and acidic foods, as they will generally aggravate your mouth. However there are no specific foods that actually make the condition get worse. Oral cGVHD can persist for many years, although it tends to burn out after the first couple of years. If you have a dry mouth, this may further worsen the condition and put you at high risk for developing dental decay.

**Q: Is oral cGVHD contagious?**

A: No. Oral cGVHD is not an infection and you cannot spread it to family members and friends.



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### **Q: How do I treat my oral cGVHD mucosal lesions?**

A: There is no cure for oral cGVHD. However, your doctor can prescribe therapies to alleviate pain and reduce inflammation. For acute pain relief, your doctor may prescribe a topical anesthetic such as viscous lidocaine to be applied to the lesions. To reduce the inflammation, your doctor will usually prescribe an anti-inflammatory agent, such as a steroid, to be applied topically. A new non-steroidal anti-inflammatory ointment called Protopic<sup>®</sup> may also be prescribed.

If the lesions are extensive or difficult to reach, the most effective approach is to rinse with a steroid liquid (dexamethasone or another potent steroid) for 5 minutes prior to spitting out, 2-3 times each day. Gels or ointments, such as fluocinonide or clobetasol, can be used to treat localized problem areas. After cleaning your mouth, dry the area with some cotton gauze, place a small amount of gel or ointment on a clean finger, and dab it onto the painful areas. To maximize the effectiveness of any topical steroid, you should not eat or drink for 30 minutes after application. There is no harm in swallowing the small amount of residual steroid that may wash away from the lesion. When using a steroid preparation, your risk of developing an oral yeast infection is increased. Thus, your doctor may prescribe an antifungal medication to either prevent, or if necessary, treat the yeast infection.

After the symptoms have been brought under control, it is a good idea to let the mouth rest rather than use the steroid continuously when not experiencing pain. When a flare-up occurs, the prescribed medications can be used as previously instructed. However, if improvement is not noted within one week, you should see your doctor.

### **Q: What can I do to treat my mouth dryness?**

A: If your mouth feels dry, avoid caffeinated and alcoholic beverages and drink plenty of water throughout the day. There are specific “dry mouth” products that are available over the counter such as the Biotene<sup>®</sup> and Oasis<sup>®</sup> line of products that may help relieve the symptoms to some degree. In more severe cases, medications such as Salagen<sup>®</sup> and Evoxac<sup>®</sup> may be prescribed to actually help stimulate the salivary glands to produce more saliva, and these can be extremely effective. The daily application of a prescription strength home fluoride gel such as Prevident 5000<sup>®</sup> is essential to prevent dental caries. Your dentist may also recommend more frequent check-ups. For more information on this topic see the separate sheet on xerostomia.

### **Q: Is oral cGVHD a risk factor for oral cancer?**

A: Patients with cGVHD are at a significantly increased risk for developing oral cancer and should undergo an oral cancer screening at least once a year. Since, oral cGVHD can look similar to early oral cancer, it is best to be seen by a specialist who is familiar with these conditions. Periodic biopsies of suspicious lesions may be necessary.



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### Recommended Links:

The American Society for Blood and Marrow Transplantation

<http://asbmt.org/>

Chronic GVHD Response Assessment

<http://www.asbmt.org/GVHD/index.htm>

Measurement of Therapeutic Response in Chronic GVHD

<http://www.asbmt.org/GVHDForms.htm>

Chronic GVHD Oral Care Dispensary Guidelines

<http://www.asbmt.org/NR/rdonlyres/C9C3DD76-1B18-406B-8F57-578654D48E22/0/DispensaryGuidelines.pdf>

National Cancer Institute Oral Complications (PDQ®)

<http://www.cancer.gov/cancertopics/pdq/supportivecare/oralcomplications/healthprofessional>

NIH GVHD Patient Information Publication

[http://clinicalcenter.nih.gov/ccc/patient\\_education/pepubs/gvh.pdf](http://clinicalcenter.nih.gov/ccc/patient_education/pepubs/gvh.pdf)

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