

Dry, sore mouth (oral mucositis)

Sore or dry mouth (oral mucositis) is a side effect of some treatments for lymphoma. This information gives general suggestions to help you manage the symptoms of oral mucositis.

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We have separate information about the topics in **bold font**. Please get in touch if you'd like to request copies or if you would like further information about any aspect of lymphoma. Phone 0808 808 5555 or email information@lymphoma-action.org.uk.

Symptoms of oral mucositis

Oral mucositis is where the soft lining in the inside of your mouth (mucous membrane) is damaged. It can then become swollen, red and painful (inflamed), causing symptoms such as:

- pain when you swallow
 - **mouth ulcers** (sores), which can lead to infection
 - dry, sore mouth and lips.
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Oral mucositis as a side effect of lymphoma treatment

Chemotherapy and **radiotherapy** affect healthy cells as well as lymphoma cells. This includes cells in the lining of your mouth, which can lead to oral mucositis. Some **targeted treatments** can also cause oral mucositis.

Your medical team should talk to you about your risk of developing oral mucositis before you begin treatment for lymphoma. There are some **things you can do to help manage oral mucositis**. If it becomes problematic, you might be given **treatment for oral mucositis**.

Chemotherapy

The likelihood of developing **chemotherapy**-related oral mucositis, and how severe your symptoms are, depends on factors including:

- the type of drug or drugs you have
- the dose of **drug or drugs** you have
- how much time you have between cycles of treatment
- how many cycles of chemotherapy you have
- whether you have experienced chemotherapy-related oral mucositis already – having it once increases your risk of developing it again with your next cycle of chemotherapy.

Symptoms generally start at around 7 to 10 days after you start treatment. For most people, it lasts for around 2 to 3 weeks after completing treatment.

Radiotherapy

Radiotherapy to the head and neck can cause oral mucositis, particularly when given at high doses. The risk of sore mouth increases if you have both radiotherapy and chemotherapy (sometimes called 'chemo-radiotherapy').

Symptoms typically start between 12 and 15 days after you begin treatment. It usually clears up between 6 to 8 weeks after finishing treatment.

Stem cell transplant

Oral mucositis can also happen after a **stem cell transplant**, often starting around a week after you begin treatment. It can be caused by both the high-dose chemotherapy and immunosuppressive drugs given as part of the transplant.

How long does oral mucositis go on for?

Usually, oral mucositis gets better once you finish your treatment for lymphoma and your **blood counts** return to the levels they were at before you had treatment.

Usually, this is about 2 to 3 weeks after chemotherapy, and 6 to 8 weeks after radiotherapy.

For some people, sore mouth goes on for longer. This can happen if you have a low number of a type of white blood cell called 'neutrophils' (**neutropenia**) that continues for a while. It improves once your blood cell count returns to normal levels.

I experienced severe oral mucositis 9 months after I was deemed to be in remission mainly because my immune system was low. Once my white blood cell count went up and my immune system improved, my symptoms got better.

Teresa, diagnosed with nodal marginal zone lymphoma

What can I do to help myself if I have oral mucositis?

Speak to your medical team for advice about how to manage oral mucositis. We offer some general tips below that you might like to discuss with them:

- **Tips for your diet, nutrition and lifestyle**
- **Tips for your mouth (oral) hygiene**
- **Tips for keeping your mouth moist**
- **Tips for pain relief**

Diet, nutrition and lifestyle

If you find **eating and drinking** uncomfortable or painful, try to minimise the amount of irritation to your mouth.

- Eat soft foods such as yoghurt, mashed potato, scrambled eggs or soup – though make sure that foods are not very hot when you eat them. Likewise, avoid those with rough textures or sharp edges, such as crisps and crusty bread.
- Avoid eating and drinking things that are very hot or spicy foods, and citrus products.
- Use a straw if you find drinking painful – just make sure you keep them clean to minimise the bacteria collecting inside them. Take care not to scald your mouth when drinking hot drinks as it is more difficult to tell how hot a drink is through a straw.
- Avoid acidic products, like vinegar and uncooked onion.
- **Do not smoke.**
- Avoid alcohol, including in **mouth rinses**.

If you think you might not be getting the nutrients your body needs, and if you are losing weight, speak to your clinical nurse specialist or your GP for advice.

I think oral mucositis is a very individual side-effect, and many things other people recommended did not work for me. I was given a mouth rinse, which gave short-term relief. I tried different foods and drinks to see which were suitable for me. It took about 2 to 3 weeks for my mouth to ease after I had finished chemotherapy treatment but I still had a strange taste many, many months later. I found tomatoes particularly difficult to eat even 4 to 5 years after treatment ended.

Debbie, who was diagnosed with follicular lymphoma

Mouth (oral) hygiene

If you have oral mucositis, it is particularly important to take steps to **prevent infection**. Contact your medical team if you have any questions or concerns that involve your mouth.

- Clean your teeth twice a day, using a soft-bristled brush. You could try using a mild toothpaste, such as one designed for children.
- After eating, use an alcohol-free mouth rinse. Some people make their own at home by mixing a teaspoon of salt with boiled water. Make sure the mixture has completely cooled down before you use it. Alternatively, you could ask your medical team if they can prescribe one for you – they might be able to suggest one that contains an anaesthetic, to help reduce pain.
- Floss gently once a day if you already floss, but do not continue if you have a low platelet count (**thrombocytopenia**) or if flossing makes your mouth bleed.

If you can, visit your dentist before you start treatment for lymphoma as you might not be able to have dental work done during or soon after treatment.

Keeping your mouth moist

A dry mouth is very common when your mouth is sore. There are simple things you can try to help moisten your mouth:

- Sip fluids throughout the day.
- Eat moist foods such as mousses, jellies and fruit.
- Chew gum or suck a boiled sweet to trigger saliva production.
- Ask your medical team about artificial saliva treatments, which can come as sprays, gels, tablets or lozenges.
- Use a moisturiser or lip balm on your lips.

Pain relief

Pain can be a very distressing symptom of oral mucositis.

- **Sucking on something cold**, like an ice lolly or an ice cube, can help to sooth a sore mouth.
- Ask your medical team about suitable pain relief medication. Regular paracetamol or aspirin can be helpful, particularly in dispersible form, which can be easier to swallow and help with pain further down than just your mouth. You might also be prescribed pain relief. This might be a cream or a gel (topical treatment) to apply to the inside of your mouth to make a protective coating. You might also be given a pain relief medicine (analgesic).
- If you wear dentures, you might find it more comfortable to leave them out while you have oral mucositis. Keep them clean and moist even when you're not wearing them. The NHS website has information about **dentures and how to look after them**.

During some of my treatment, I struggled with mouth ulcers. I was given several mouthwashes, and those helped. I also ate ice-cream and yoghurt, just letting it melt in my mouth. Really cold milk helped too. I also needed to have my medication in liquid form so that I could get it down my throat, as swallowing tablets was so hard.

Jean who was diagnosed with Burkitt lymphoma

Treatment for oral mucositis

You might be prescribed medication to prevent or treat oral mucositis.

If you are at a high risk of developing oral mucositis, your **medical team** might prescribe medication to help prevent you from developing it. This is to help lower your risk of infection, which can be serious and need prompt treatment with antibiotics. **If you develop any signs or symptoms of infection, seek advice straightaway from your GP, clinical nurse specialist or other member of your medical team.**

You might be given medicines to prevent oral mucositis. An example of this might be if you have treatment with a chemotherapy drug that carries a high risk of causing oral mucositis, such as methotrexate. In such cases, you will be given folinic acid, either as an injection or through a drip (infusion) after your treatment.

Other circumstances where you might be given preventative medicines include if your immune system is lowered. For example, if you have:

- a low number of neutrophils (**neutropenia**), which is a common side effect of chemotherapy
- had a **stem cell transplant**
- have **human immunodeficiency virus (HIV)**.

Cryotherapy

Cryotherapy is a way of cooling your mouth with ice, for example by sucking on an ice cube or ice lolly, or drinking ice-cold water. It's sometimes used to help prevent oral mucositis for people having some types of chemotherapy; however, it isn't suitable in all cases.

You might be given a form of cryotherapy 5 minutes before your treatment, which you continue for around 30 minutes during treatment.

Scientists think cryotherapy works by narrowing the blood vessels in the mouth – the amount of blood that contains chemotherapy is therefore lowered, which reduces oral mucositis.

Palifermin

Palifermin is a drug that can help trigger the growth of new cells in your mouth and throat. It can therefore help in the prevention and healing of mouth sores that develop as a side effect of chemotherapy and radiotherapy. Palifermin is suitable for some people treated for blood cancers, including lymphoma. It's usually given as an injection before you have treatment for lymphoma.

Low-level laser therapy (LLLT)

With low-level laser therapy (LLLT), low energy beams of light are directed at the soft lining (mucous membrane) of your mouth. The energy beams encourage the growth of new cells, which can help to:

- reduce the severity of oral mucositis
- speed up the healing of wounds such as mouth ulcers
- bring down swelling (inflammation)
- lower pain.

LLLT is sometimes used with radiotherapy and chemotherapy. However, it needs specialist equipment and is only available in some specialist cancer centres. Your medical team can advise on whether this is a suitable treatment option for you.

References

The full list of references for this page is available on our website. Alternatively, email publications@lymphoma-action.org.uk or call 01296 619409 if you would like a copy.

Acknowledgements

- Samantha Darby, Clinical Nurse Specialist Lymphoma, Portsmouth Hospitals NHS Trust.
- We would like to thank the members of our Reader Panel who gave their time to review this information.

Content last reviewed: June 2022
Next planned review: June 2025
LYMweb0063SoreMouth2022v4

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