

Sore mouth or gut (mucositis)

Mucositis affects the lining of your gastrointestinal (GI) tract, which includes your mouth and your gut. It's a common side effect of some blood cancer treatments. It's painful, but it can be treated and gets better with time.



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What is mucositis?

The gastrointestinal or GI tract is a long tube that runs from your mouth to your anus – it includes your mouth, oesophagus (food pipe), stomach and bowels. When you have mucositis, the lining of your GI tract becomes thin, making it sore and causing ulcers. This can happen after chemotherapy or radiotherapy.

There are two types of mucositis. It's possible to get both at the same time:

- **Oral mucositis.** This affects your mouth and tongue and can make talking, eating and swallowing difficult. It's sometimes called stomatitis.
- **GI mucositis.** This affects your digestive system and often causes diarrhoea (frequent, watery poos).

Mucositis may be less severe if it's picked up early, so do tell your healthcare team if you have any of the symptoms described in this fact sheet (see pages 4–5). There are also treatments and self-care strategies which can reduce the risk of getting mucositis and help with the symptoms.

What causes mucositis?

Cancer treatments target cells that multiply quickly. This includes cancer cells, but also fast-growing healthy cells such as hair cells, skin cells and the cells in your GI tract. That's why having chemotherapy or radiotherapy can make your hair fall out, increase your risk of sunburn and cause mouth or gut problems.

Mucositis happens when cancer treatments kill healthy cells in the GI tract. The lining of the GI tract gets thinner and becomes inflamed (sore and swollen).

How common is mucositis?

The chance of getting oral or GI mucositis varies depending on the type of treatment you have and how intensive (concentrated) it is. Your genes and your general health also affect your likelihood of getting mucositis.

Generally, mucositis affects:

- one or two out of five people (20–40%) who have standard chemotherapy
- four out of five people (80%) who have high-dose chemotherapy before a stem cell transplant, with or without total body irradiation (TBI).

Symptoms of oral mucositis

If you get oral mucositis, you'll normally get symptoms five to ten days after chemotherapy, or 14 days after radiotherapy.

Symptoms of oral mucositis include:

- a dry mouth, which can lead to mouth and gum infections (although sometimes a dry mouth on its own can just be a side effect of chemotherapy rather than mucositis)
- ulcers or blood blisters (or both) inside your mouth, and sometimes on your tongue or lips
- a sore or painful mouth, which may make it difficult to eat, drink or talk
- bad breath
- oral thrush, an infection caused by a fungus called Candida.

Oral thrush can happen if mouth ulcers become infected.

Symptoms include:

- pain in your mouth
- white patches in your mouth that may bleed
- a loss of taste
- cracks at the corner of your mouth.

Different people will experience different levels of severity, or grades, of oral mucositis. For example, we know mucositis can be severe if you have high-dose chemotherapy as preparation for a stem cell transplant. It depends how toxic your treatment is, and how it affects you personally. Your healthcare team will assess and treat your particular symptoms.

Symptoms of GI mucositis

Symptoms of GI mucositis can start up to 14 days after you begin chemotherapy or radiotherapy.

The main symptoms are:

- diarrhoea (frequent, watery poos)
- ulcers around your rectum or anus
- bleeding from your gut, which you may notice as blood in your poo
- trouble swallowing because it hurts
- feeling sick
- constipation (difficulty pooing)
- stomach cramps
- bloating.

Mucositis and infection

Normally, the lining of your gut acts as a barrier to stop germs getting into your bloodstream. If you have mucositis, the lining doesn't work properly, so you're more likely to get an infection. You're particularly at risk of infection if your condition or treatment cause a drop in your white blood cell count, so your body can't fight off germs as well as it usually does.

If you get symptoms of an infection, speak to your healthcare team straight away. Symptoms of an infection include having a high or low temperature, feeling confused, or generally not feeling well.

For more information about the symptoms of infection and when to get help, order or download our fact sheet

Understanding infection from
bloodcancer.org.uk/information

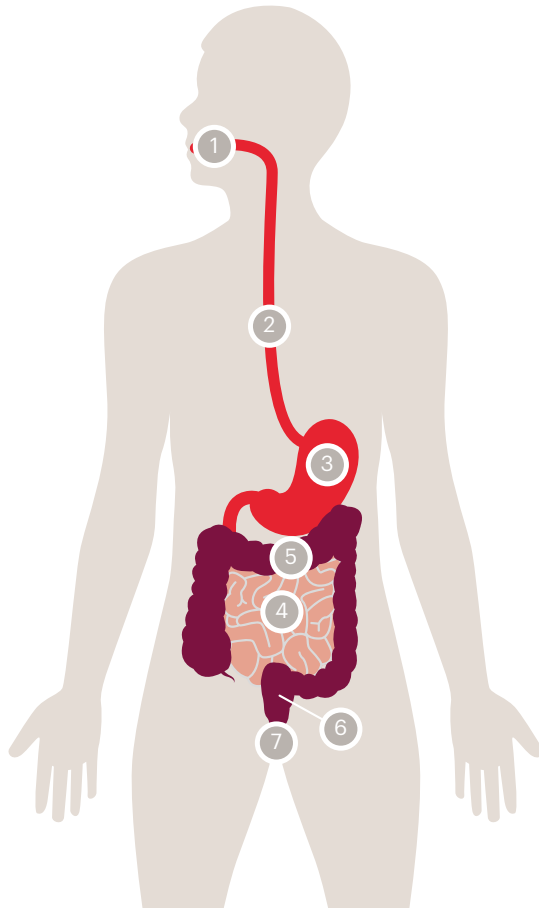
Treatment for mucositis

There are treatments that can lower the risk of getting mucositis and help with the symptoms. If you're worried about getting mucositis or think you have it, talk to your keyworker – this is usually your clinical nurse specialist (CNS). If you're not sure who your keyworker is, check with your consultant or another member of your healthcare team.

Oral mucositis treatments

Oral mucositis can be very painful, so your healthcare team will usually offer you painkillers. These might be tablets, mouthwashes, gels or sprays.

The gastrointestinal (GI) tract



- | | | |
|--------------|---------------|--------|
| 1 Mouth | 4 Small bowel | 7 Anus |
| 2 Oesophagus | 5 Large bowel | |
| 3 Stomach | 6 Rectum | |

The strength of the painkillers will depend on how much pain you're in. If you're in a lot of pain, you may be given drugs containing morphine, which you can take by mouth, as a patch on your skin, or by injection under the skin (subcutaneous injection).

Try to be clear with your healthcare team about your symptoms and the amount of pain you're feeling, so they can give you the right care. Don't be afraid to tell them if the treatment isn't working. There will be other options to try.

Treatments that can help stop you getting oral mucositis and help with symptoms include:

- **Benzydamine.** This is an anti-inflammatory drug that contains a local anaesthetic to numb the pain of oral mucositis. It comes as a mouthwash or spray. You may hear it called by its brand name Difflam®.
- **Antifungal medicines.** You may be given antifungal tablets or drops to stop oral thrush developing from an infected mouth ulcer.
- **Low level laser therapy.** This uses low-energy beams of light delivered by a hand-held device. This is placed inside the mouth or close to the outside of the cheek for around 20 to 30 minutes. The aim is to reduce pain and inflammation and encourage healing.
- **Artificial saliva products.** If you have a dry mouth, your healthcare team may offer you an artificial saliva product.

- **Caphosol®**. This is a rinse that contains calcium phosphate. It helps by cleaning and moistening the mouth and can be used several times a day.
- **Ice**. Sucking on ice lollies while you're being given high-dose chemotherapy can help to stop the chemotherapy drugs getting to the lining of your mouth. This reduces the effects of mucositis.

GI mucositis treatments

Your treatment for GI mucositis will depend on your symptoms and how severe they are.

If you're feeling sick, you'll be offered anti-sickness (anti-emetic) tablets. There are different types of anti-sickness medicines that you can try if the first one doesn't work.

If you have symptoms of indigestion, your healthcare team may recommend drugs to reduce stomach acid or numb the pain. If you have sharp stomach cramps, there are drugs that can relax your gut.

For diarrhoea caused by mucositis, you'll usually be treated with a drug called loperamide. This is the ingredient used in some over-the-counter products. If loperamide isn't effective, you may be given another anti-diarrhoea drug called octreotide. You'll usually be given octreotide in hospital.

For more information, order or download our fact sheet **Managing sickness and vomiting** from **bloodcancer.org.uk/information**

Symptoms of GI mucositis can be upsetting and hard to talk about, but do tell your healthcare team about your symptoms so that they can treat them. They can also give you things to make you feel more comfortable, such as incontinence pads or pants, or creams to soothe a sore anus.

Taking care of yourself: oral mucositis

Taking care of your mouth, teeth and gums can reduce pain, bleeding, infection and dental problems caused by oral mucositis.

Here are some simple things you can do:

- Make sure you see your dentist before you start treatment.
- Brush your teeth and gums at least twice a day using a very soft child’s toothbrush and a mild fluoride toothpaste. Ideally brush after every meal and before bed.
- Rinse your brush and store it in a cup with the head facing up.
- Change your toothbrush every month.
- If you’re used to cleaning between your teeth, carry on using floss or interdental brushes. Don’t start flossing during treatment if you haven’t been doing it before as you risk making your gums bleed.
- Rinse your mouth with a mild alcohol-free mouthwash, plain water or saltwater throughout the day. For a saltwater rinse, add a teaspoon of table salt to 900ml of cold or warm water that’s previously been boiled, and use within 24 hours.

- You might find it soothing to suck on ice cubes or crushed ice, especially if you have a dry mouth. Ice creams or ice lollies may also help.

It may also be helpful to avoid things which can irritate or damage the inside of your mouth, such as:

- smoking
- alcohol, including alcohol-based mouthwashes
- rough or hard foods such as crusty bread or crisps
- hot drinks
- spicy foods
- acidic foods like tomatoes, oranges and lemons.

If you need support to stop smoking or cut down on alcohol, the NHS has advice and a list of services. Visit: **[nhs.uk/live-well/alcohol-support/](https://www.nhs.uk/live-well/alcohol-support/)** and **[nhs.uk/smokefree/](https://www.nhs.uk/smokefree/)**

If you have dentures

Try not to wear your dentures if your mouth is sore. Brush them at least twice a day with toothpaste and rinse with water. Make sure you also brush your gums with a soft toothbrush.

If you have an oral infection such as thrush, soak your dentures in a suitable disinfectant (chlorhexidine or sodium hypochlorite) for 15 minutes twice a day.

Taking care of yourself: GI mucositis

If you have diarrhoea, it's important to avoid dehydration. Try to drink at least two litres of water a day. You can mix in cordial or squash if you like.

Things to avoid include spicy foods and acidic foods, such as tomatoes, oranges and lemons.

Recovering from mucositis

If you have oral mucositis with mild symptoms, it usually takes three to four weeks to get better after you've finished chemotherapy. More severe symptoms may take longer, and you may need to stay in hospital to be treated and monitored.

If you have GI mucositis, most of the symptoms should stop a few weeks after your treatment has finished, although occasionally diarrhoea can continue for some months after radiotherapy.

Some people with GI mucositis may need further tests to check what is causing their symptoms. Your doctors may do this by inserting an endoscope – a long, thin, flexible tube with a camera at one end – into your body through your mouth or your bottom. The endoscope takes pictures which doctors can view on a screen. This procedure is called an endoscopy, or a colonoscopy when the camera is inserted into your bottom.

To read more about endoscopy and colonoscopy, go to: **[nhs.uk/conditions/endoscopy](https://www.nhs.uk/conditions/endoscopy)** and **[nhs.uk/conditions/colonoscopy](https://www.nhs.uk/conditions/colonoscopy)**

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About this fact sheet

We have produced this fact sheet in collaboration with expert medical professionals and people affected by blood cancer. Thank you to Clinical Nurse Specialist Jodie Nightingill and Consultant Haematologist Anne Parker for their support checking the content. Thanks also to Consultant Haematologists Dragana Milojkovic and Mike Dennis for their invaluable feedback.

Our fact sheets contain general information. Always listen to the advice of your specialist about your individual condition because every person is different.

A list of references used in this fact sheet is available on request.
Please email information@bloodcancer.org.uk

Disclaimer

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