

Mucositis

Mucositis is a condition that affects your mucous membrane, the thin skin that covers and protects the inside surface of parts of your body.

When you have mucositis, the mucous membrane lining your gastrointestinal (GI) tract (which runs from your mouth to your anus) is inflamed and has ulcers on it.

Mucositis is usually something you get after having chemotherapy or radiotherapy. It can be a painful side effect. Mucositis is usually divided into two types. It's possible to get both types of mucositis. These are:

- › **oral mucositis** (also called **stomatitis**) – this can cause mouth ulcers (sores) and makes swallowing difficult or painful,
- › **gastrointestinal (GI) mucositis** – this happens inside your digestive system and often causes diarrhoea.

What causes mucositis?

Mucositis is a fairly common side effect of chemotherapy and sometimes radiotherapy.

It happens because your treatment targets cells that divide rapidly, such as cancer cells. However, these treatments can't tell the difference between cancer cells and healthy fast-growing cells in your body (like your hair cells, and the cells found in your GI tract). This is why chemotherapy and radiotherapy can make your hair fall out and cause mucositis.

Who gets mucositis?

Not everyone who has chemotherapy or radiotherapy gets mucositis.

About 20–40% of people who have chemotherapy and about 50% of people who have a combination of chemotherapy and radiotherapy treatment will get mucositis.

It's more severe in people who have intensive chemotherapy and high-dose chemotherapy before either a donor (autologous) or own-cell (autologous) stem cell transplant.

You can't prevent mucositis, but your symptoms may be less severe if it's recognised early, if you have treatment for mucositis, and your healthcare team monitor you regularly.

Signs and symptoms

Oral mucositis

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

Signs and 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 and not always mucositis),
- › bad breath,
- › white patches, ulcers, or blood blisters inside your mouth – you may also have these on your tongue or lips,
- › a sore or painful mouth, which may make it difficult to eat, drink or talk, and,
- › oral thrush.

Oral thrush can happen if mouth ulcers become infected. Signs and symptoms of oral thrush include:

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

Grades of oral mucositis

If you have oral mucositis, your healthcare team will use a World Health Organization (WHO) grading system to assess how serious your symptoms are.

- › Grade 1: your mouth is sore, but you don't have ulcers (sores) in your mouth.
- › Grade 2: you have ulcers in your mouth, but you can still eat solid food.
- › Grade 3: you can't eat solid food, but you can swallow liquids.
- › Grade 4: you can't swallow solid foods or liquids.

GI mucositis

If you get GI mucositis, you'll usually get symptoms 14 days after you start chemotherapy or radiotherapy. These can include:

- › diarrhoea,
- › ulcers in your anal area or in the last section of your large intestine (rectum),
- › bleeding from your back passage – you may notice blood in your poo,
- › mucus coming from your back passage,
- › finding it difficult to swallow,
- › feeling sick,
- › pain in your stomach, and,
- › bloating.

If you have mucositis, your healthcare team will work to stop you getting infections and reduce any pain you might have.

Your healthcare team will be there to help you. You should have a clinical nurse specialist (CNS) who you can talk to if you think you have mucositis. If you haven't received the details of a clinical nurse specialist or a main point of contact (a key worker), consider asking your consultant who your key worker will be.

Our fact sheets contain general information. Always listen to the advice of your specialist about your individual condition.

Oral mucositis

Oral mucositis is often painful, so your healthcare team will usually offer you painkillers (these are also known as analgesic medications).

These may be tablets, mouthwashes, gels or sprays. The strength of the painkillers will depend on how much pain you're in. If simple painkillers such as paracetamol aren't working, there are lots of other options you can try.

If your pain is severe, you may be given morphine, which you can take by mouth, or it may be infused (given into your vein). It's important to be clear with your healthcare team about your symptoms and the amount of pain you're in, so that they can give you the right care.

Medicines your healthcare team might offer you for oral mucositis include:

- › **Palifermin** This is a type of growth factor, which are medicines that encourage new cells to grow. Palifermin can repair the lining of your mucous membrane and stop sores or ulcers from forming, so it can be used to both treat and prevent oral mucositis.
- › **Benzydamine** This drug comes as a mouthwash or spray for painful throat conditions. It is an anti-inflammatory drug that contains local anaesthetic and is not a steroid. You may hear benzydamine called by its brand name Difflam® spray or oral rinse.
- › **Antifungal medicines** These are taken as a tablet if you develop oral thrush from an infected mouth ulcer.

GI mucositis

The symptoms of GI mucositis can be broad, and can be quite distressing, so your treatment for GI mucositis will depend on what symptoms you have and how severe they are.

If you're feeling sick, this can be treated with anti-sickness (anti-emetic) tablets.

There are many different types of anti-sickness medicines available for you to try if the first one doesn't work. One type you might be given is called metoclopramide, but others include ondansetron, domperidone and cyclizine.

If you have GI mucositis with diarrhoea, you'll usually be treated with a drug called loperamide. This is the ingredient used in some over-the-counter products like Imodium®.

Looking after yourself

Oral mucositis

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

- › flossing your teeth once a day,
- › using a soft bristled toothbrush,
- › getting a new soft bristled toothbrush every month, or for each treatment cycle,
- › brushing your teeth for 90 seconds, three times a day,
- › using fluoride toothpaste, and,
- › using a plain mouthwash for 30 seconds, before meals and before you go to bed.

You might find it useful to suck on ice cubes or crushed ice to soothe your symptoms, especially if you have a dry mouth. Ice creams or ice lollies may also help. If this doesn't work, your healthcare team might offer you an artificial saliva product.

Things to avoid:

- › alcohol based mouthwashes,
- › smoking,
- › rough or hard foods,
- › acidic foods, and,
- › alcohol.

If you need support stopping smoking or cutting down on alcohol, the NHS website has advice and a list of services available. [nhs.uk/Livewell/alcohol](https://www.nhs.uk/Livewell/alcohol)
[nhs.uk/smokefree](https://www.nhs.uk/smokefree)

GI mucositis

If you have diarrhoea, it's important to avoid dehydration as much as possible. Try to drink at least two litres of water a day (you can mix in cordial juice if you like).

Things to avoid include:

- › acidic foods, and,
- › spicy foods.

Recovering from mucositis

If you have oral mucositis with mild symptoms, they usually take 3–4 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 has finished.

Some people with GI mucositis may need further tests to check what is causing their symptoms. Your doctors may do this using an endoscopy and / or colonoscopy, which involve looking inside the body using a medical camera.

To read more about an endoscopy and colonoscopy, see the NHS Choices website. Go to [nhs.uk/endoscopy](https://www.nhs.uk/endoscopy) and [nhs.uk/colonoscopy](https://www.nhs.uk/colonoscopy)

Finding out more

We offer patient information on many blood cancer types and topics, online and in free printed booklets. They cover everything from symptoms and diagnosis through to treatment and living with your condition. Go to **bloodwise.org.uk/information-and-support**



We also have an online community you may like to join **bloodwise.org.uk/our-community**



Or you can call our support line on **0808 2080 888** (Mon–Fri 10am–4pm). This is a freephone number.



See our website for more details of cancer information specialists and support groups. Go to **bloodwise.org.uk/living/where-get-help-and-support**



About Bloodwise

We're the UK's specialist blood cancer charity.

We've been working to beat blood cancer since 1960.

We fund world-class research; provide practical and emotional support to patients and their loved ones; and raise awareness of blood cancer.

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

Disclaimer

We make every effort to make sure that the information in this fact sheet is accurate, but you shouldn't rely on it instead of a fully trained clinician. It's important to always listen to your specialist and seek advice if you have any concerns or questions about your health.

Bloodwise can't accept any loss or damage resulting from any inaccuracy in this information, or from external information that we link to.

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