

Mouthcare and mucositis in children

An information guide for parents, carers and families

The purpose of this guide is to help explain how your child's treatment may affect them and what you should do.

Information in this guide should be used to support professional advice specific to your child's diagnosis. If you have any questions, it is important to ask your medical team.

What is mucositis?

Mucositis is the swelling or inflammation of the cells that line the mouth and gut (called mucosal cells). Chemotherapy kills cells that grow fast, like cancer cells, and as mucosal cells also grow fast some chemotherapy may harm them, causing them to become irritated and inflamed (red and sore).

Symptoms usually start 5-7 days after chemotherapy treatment and may lead to a delay in the next course of treatment. Drugs more likely to cause mucositis are daunorubicin, doxorubicin and methotrexate, including oral methotrexate in some patients.

What are the symptoms of mucositis?

Mucositis in the mouth is the easiest to identify as it is the most visible. However, the whole of the gastrointestinal tract (from your mouth to your bottom) can be affected.

Symptoms include:

- bleeding or cracked lips
- sore and/or dry mouth

- sore throat
- difficulty in swallowing (including difficulty in swallowing saliva causing lots of dribbling)
- difficulty in talking
- shedding or peeling of mucosa (moist lining of the mouth and gut)
- pain behind the big central chest bone (like heartburn)
- pain around the stomach/upper abdomen/lower ribs area (sometimes called epigastric pain)
- lower abdominal pain
- diarrhoea
- constipation
- ulcers

These symptoms can be very painful and often limit your child's ability to eat and drink fully.

How do we treat mucositis?

Regular mouthwashes can be prescribed to help keep your child's mouth clean and healthy, and hopefully prevent any further infections from occurring.

The pain from mucositis can be severe and your child may need a morphine infusion, through the central line, port or cannula, to control the pain.

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Some hospitals use laser therapy to reduce pain and encourage ulcers to heal. There may also be options to try topical solutions to help ease pain. Ask your team for information.

If your child needs help with the pain whilst at home, contact your hospital team or shared care centre.

What if my child cannot eat or drink?

If your child cannot eat well enough, they may need to be fed via a nasogastric (NG) tube. Another option is to have total parental nutrition (TPN) which is given via a central line or port. This is usually given for a minimum of 7 days so your medical team will help you to decide if this is an option. Speak to your hospital team about nutrition options that may be easier to eat, such as milkshakes, and help to boost your child's calorie intake at this time.

How can we prevent mucositis?

Mucositis during cancer treatment cannot be prevented. To help with symptoms, encourage your child to keep their mouth clean and moist to help prevent infection. Brush twice daily with a soft toothbrush and change your child's toothbrush more regularly than you would usually. If brushing is too painful to tolerate speak to your medical team about other options.

If you have any concerns about your child at any time, please contact your medical team.

USEFUL ORGANISATIONS

Children's Cancer and Leukaemia Group (CCLG) publishes a variety of free resources to order or download. www.cclg.org.uk

Young Lives vs Cancer offers practical support to children and young people with cancer and to their families www.younglivesvscancer.org.uk

Macmillan Cancer Support offers support and advice to those affected by cancer. www.macmillan.org.uk



Scan here to order or download this guide from www.cclg.org.uk



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Patient Information Forum

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Children's Cancer and Leukaemia Group (CCLG) is a leading national charity and expert voice for all childhood cancers.

Each week in the UK and Ireland, more than 30 children are diagnosed with cancer. Our network of dedicated professional members work together in treatment, care and research to help shape a future where all children with cancer survive and live happy, healthy and independent lives.

We fund and support innovative world-class research and collaborate, both nationally and internationally,to drive forward improvements in childhood cancer. Our award-winning information resources help lessen the anxiety, stress and loneliness commonly felt by families, giving support throughout the cancer journey.

Our work is funded by donations. If you would like to help, text 'CCLG' to 70085 to donate £3. You may be charged for one text message at your network's standard or charity rate. CCLG (registered charity numbers 1182637 and SC049948) will receive 100% of your donation.

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