

The ROYAL MARSDEN
NHS Foundation Trust

Eating and drinking safely



NHS

**Information for children, young
people and their families**

Oak Centre for Children and Young People

Eating and drinking safely

This leaflet provides an overview of professionals that may be involved in your child's care, should chewing and swallowing food and

fluids become unsafe for your child due to their underlying cancer. It also gives information on how best to support your child at home, hospital or hospice.

Speech and Language Therapists (SALTs)

Some cancers, such as those that affect the central nervous system (brain tumours) can physically affect your child's ability to communicate with people and to physically chew and swallow food and fluids safely, over time. For example, your child's speech may sound slurred and unclear, or their voice may sound weak or hoarse.

After assessing your child's speech, chewing skills and swallow, SALTs can offer you practical advice and information. This will help to support your child to communicate with family and friends and to eat and drink safely.

Dietitians

Dietitians are trained to treat a wide range of nutritional concerns that can develop due to cancer and its treatment. If your child's appetite is poor, or they are having difficulty eating, you may wish to speak to a

dietitian who can review whether they are eating a balanced diet or not. Dietitians also help in trying to prevent and treat nutritional symptoms by advising what to eat and drink.

Some problems that dietitians may be able to help with include:

- Loss of appetite
- Taste changes
- Constipation or diarrhoea
- Weight loss
- Weight gain due to increase in appetite (if steroids being taken)
- Nausea (feeling sick)
- Vomiting.

How to support your child

Chewing and swallowing

Some children find it difficult to chew and swallow food and drink safely due to physical changes, for example, their tongue is not moving correctly to allow them to chew food properly. You may observe that when eating and drinking, your child is coughing and spluttering and may hold food in their mouth as they are unable to physically swallow it. This is the body's way of telling you that the food and drink may be going down 'the wrong way' and into your child's airway to their lungs, which could lead to a chest infection. Excess salivation with drooling may also indicate that your child is not swallowing safely.

Signs that food or fluids may be going the wrong way (aspiration) when eating and drinking:

- Coughing or choking
- Noisy breathing
- Eye reddening or tearing
- A wet or gurgly voice
- Change in colour of face (dusky, white or blue around lips).

Safe practice to improve your child's ability to safely eat and drink

- Muscle weakness may interfere with your child's ability to sit up and hold their head upright. Do not try to give your child food and fluids whilst they are lying down. Your child's head should be physically supported while they are eating and drinking. An occupational therapist can offer some practical equipment and safe seating to achieve this, if needed.
- Thickened drinks may reduce coughing and spluttering as water (thin fluid) makes coughing worse. A thickening agent is a flavourless powder that can be added to food and fluids. Your healthcare team can provide this.
- If your child is coughing and spluttering when food and fluids are taken but they would still like to taste food for comfort, it may still be possible to do so, knowing the risk of aspiration. Please discuss this with your healthcare team.
- Offering your child tastes of yoghurt, puréed food or smoothies from a spoon may be comforting for them, as they do not need to be chewed.
- Always check your child is not holding a bolus of food in their mouth before offering more food.

Hunger and thirst

Most children with advanced cancer naturally have reduced appetites and therefore do not feel as hungry and thirsty. This is a natural process which can occur because the body does not need the same nutritional intake, as they tire more easily and/or do not move around as much as they did before their diagnosis. When hunger is not reported as a symptom, comfort feeds

are offered orally without invasive interventions, such as an NGT (see page 7).

However, hunger may be a symptom if your child is taking dexamethasone (steroid) for symptom relief over a long-time period as steroids promote appetite.

It is important that we can meet your child's reported hunger and thirst needs (signs and symptoms below).

Signs and symptoms of **hunger:**

- Feeling of emptiness in the stomach
- Gurgling, rumbling, grumbling in stomach
- Nausea
- Irritability, easily agitated
- Dizziness, headache
- Lack of concentration.

Signs and symptoms of **thirst:**

- Dry mouth
- Dry lips
- Sore, cracked lips
- Minimal urine output.

An alternative way of managing your child's hunger

This needs to be done in a safe way, especially if your child has other adverse symptoms such as not being able to sit up without physical support.

If your child has an unsafe swallow and is at risk of aspiration, a safe way of giving your child feeds/fluids to satisfy their expressed hunger and thirst is for a nurse to insert a naso-gastric

tube (NGT). This goes up through your child's nostril and down into their stomach. This can be inserted by your Community Children's Nurse (CCN) at home or if you prefer, at the hospital. A plan of milk feeds for your child will take place with support from the dietitian to satisfy hunger. We will teach you to use the NGT. Medicines can also be given by NGT.

Chest infections

Your child is at risk of developing a chest infection if they have an unsafe swallow and a trickle of food or fluid goes down the wrong way.

This may present as noisy breathing (this is called aspiration), a temperature or yellow/green phlegm on coughing. If this occurs, or you are concerned, please

contact your local CCN or speak to your Children and Young Peoples Oncology Outreach Nurse Specialist (CYPOONS).

We may ask your family GP to visit to review your child's chest and consider oral antibiotics. We can provide powdered oral antibiotics to have at home in this event.

Mouth care

Your child's mouth and/or lips may become dry. We encourage you to maintain their comfort by cleaning your child's mouth with a moistened sponge and/or soft baby toothbrush and offer small sips of fluids at frequent intervals, if able. Vaseline or lip balm can soothe dry lips.

Contact details



If you have any concerns or would like further advice, then please contact the team.

The Royal Marsden CYP Outreach and symptom care team (CYPOONS)

020 8661 3625

(Monday to Friday, 9am – 5pm)

Out of hours, please call:

The Royal Marsden switchboard

020 8642 6011

Follow the electronic message to the operator, then ask for the **PATCH** team.

My notes

A large white rounded rectangle with a thin blue border, containing 20 horizontal blue lines for writing notes. The lines are evenly spaced and extend across the width of the rectangle.

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This booklet is evidence based wherever the appropriate evidence is available, and represents an accumulation of expert opinion and professional interpretation.

Details of the references used in writing this booklet are available on request from:

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Should you require information in an alternative format, please contact The Royal Marsden Help Centre.

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Thanks to supporters of The Royal Marsden Cancer Charity, we raised £16 million to build the Oak Centre for Children and Young People. Opened in September 2011 by TRH The Duke and Duchess of Cambridge, it is one of the largest comprehensive children and young people's cancer centres in Europe.

The Royal Marsden is a world leading cancer centre, pioneering new treatments that save lives. To find out more on how you can get involved please visit royalmarsden.org

The Royal Marsden Cancer Charity
For a future beyond cancer





Radiotherapy and
Chemotherapy Services
F538021 & F538022

