

Feeding during cancer treatment for infants under one: information for families

It is very common for babies to face challenges with their feeding when they are going through treatment for childhood cancer and this is something that most families experience. This information sheet from Great Ormond Street Hospital (GOSH) aims to provide you with some strategies to help support your child with their feeding, alongside the specialist advice that you receive from your clinical team.

Feeding difficulties can often develop as a result of your child's illness and the side effects of cancer treatment, which can include:

- Nausea or vomiting
- Sore mouth or throat (including mucositis)
- Taste changes
- Diarrhoea
- Constipation
- Difficulty swallowing

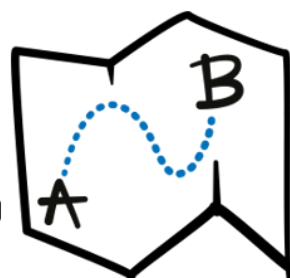
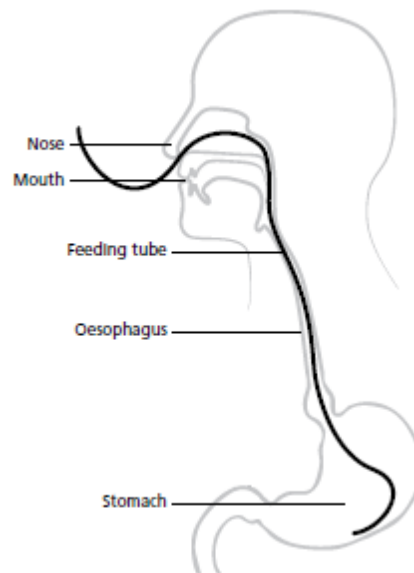
These issues can 'come and go' at different phases throughout treatment, but it is important that they are managed as well as possible to help your baby continue to feed as well as they can. Talk to your clinical team if you feel that any of these issues are a problem for your child, to see what treatment options may be available.

What is a nasogastric (NG) tube and when might it be helpful?

It is very common for babies to require a NG tube at some point during their treatment. This may be recommended if your baby is not taking their usual amount of formula or feed, if they are having

difficulty swallowing safely, or if they do not want to feed at all.

A NG tube is a flexible plastic tube which is passed through the nose and into the stomach. This can then be used to give your baby their usual formula milk, expressed breast milk or a different liquid feed, until your baby is able to manage to take the amounts that they need by mouth (orally) again.



It might also be the case that your child is recommended to have a NG tube to receive their medications. Most babies who have a NG tube will still be able to feed orally but may have 'top ups' of feed through the NG tube. A Dietitian would be able to work with you to develop a feeding plan that helps to prioritise oral feeding as much as possible to help your child continue to use their feeding skills.

NG tubes are often not required long term and difficulties with feeding do usually improve. However, in the meantime, having the option of being able to give top ups of feed through a NG tube can help to give your baby all of the nutrition that they need to cope with their treatment and continue to grow and develop, to reach their full potential. Further information about NG tubes is available from your clinical team.

When should I start weaning?

Weaning is usually recommended at the age of six months, but it is important that your baby is developmentally ready first. A Dietitian or Speech and Language Therapist can help to guide you on this if you are unsure.

For babies going through treatment, there are likely to be some extra obstacles to their weaning journey. This makes it especially important to prioritise opportunities for weaning whenever your baby is able to do this and is feeling well. Whilst your baby may take some extra time to develop their weaning skills, any practise that they are able to get will help to build their feeding skills for the future.

At the end of this information sheet, there are some links to useful sources of general information about weaning.

Helping your baby to keep up their feeding skills

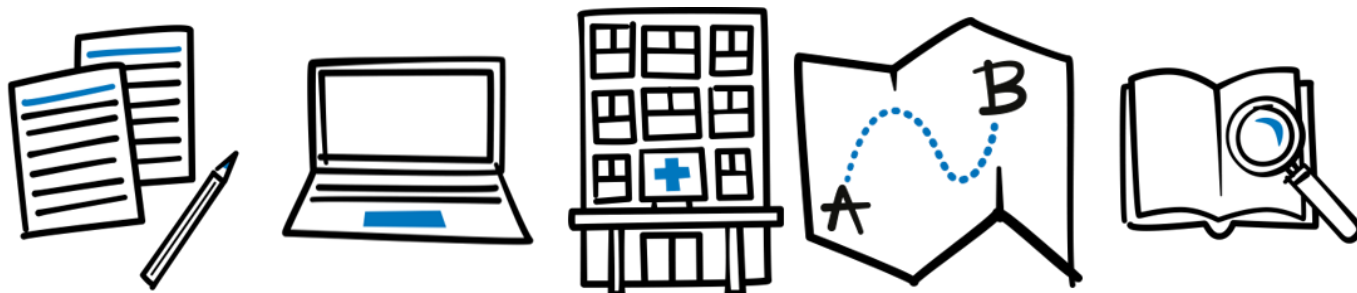
There are a number of ways that you can support your baby with their development of their oral

feeding skills, even if they are receiving 'top ups' or full feeds from a NG tube.

Some suggestions are provided below on how to help develop positive oral experiences around your baby's face and mouth, and also some ideas for how to explore food with them in a positive way once they are able to start weaning.

Positive oral experiences (useful for babies of any age)

- Use a dummy, or your finger, to help your baby learn to suck (or to help them keep practising their sucking skills) even if they are not breast or bottle feeding. If your baby is prone to gagging when you put something in their mouth, you could try gently stroking or massaging their lips or face instead.
- If you have been breastfeeding, you could continue putting your baby to your breast even if they do not want to feed. There are huge benefits from them spending time close to you with opportunities to smell, touch and maybe suck at the breast even if they are not taking much milk.
- Even if your baby is not taking from your breast or their bottle and is being fed using a tube, you can offer tastes of your breast milk or formula from the tip of a dummy or your finger. If possible, it is good to do this when a milk feed is being given via their feeding tube (and when your baby is awake and alert) so that your baby makes an association between sucking and a feeling of becoming full from the tube feed.
- It is common for babies in hospital to experience repeated uncomfortable touches to their face, such as, tape being removed or applied or the NG tube being changed. To help balance this with more positive touch experiences, you can focus on gently stroking, massaging and kissing around your baby's face.



Opportunities for positive food exploration (for older babies who are at an appropriate stage to start weaning)

- Some babies may take longer to become interested in solid foods. Even if your baby is not at the stage of wanting to be involved with food very much, or is receiving most of their feed through a NG tube, there are still ways that you can help them to explore food in a positive way.
- Encourage your baby to get messy with food. Babies learn a lot about food from touch and smell. From a sensory point of view, this is as important to their feeding development as them actually eating the food. If you find that you are struggling with messy food play, you could ask to speak to a Play Specialist who may be able to support you with different ideas.
- Placing your baby in a highchair will be helpful to allow them to have the space to explore the food in front of them. If it is difficult for your baby to stay seated in an upright position, ask if you can speak to an Occupational Therapist, who will be able to help you find the right type of support.
- Try to only wipe your baby's hands and mouth once they have finished playing with the food. This is because the sensation of their face being touched can be off-putting for them.
- Even if your baby is not feeding orally, they can still benefit from exploring utensils such as spoons and beakers if they have the motor skills to manage this. You could try to give them opportunities to practice guiding a spoon or beaker to their mouth, as this will be a useful skill for them in the future.
- Play activities can be helpful for your baby to learn about using utensils and have fun with food, for example feeding a doll or teddy (or feeding you!).
- Often babies prefer to feed themselves rather than being fed by an adult. For babies who are going through treatment, this may have also

developed from a distrust of medicine spoons and syringes. Allowing your baby to have plenty of opportunities to feed themselves with 'finger foods' can help them to feel in control and progress with feeding.

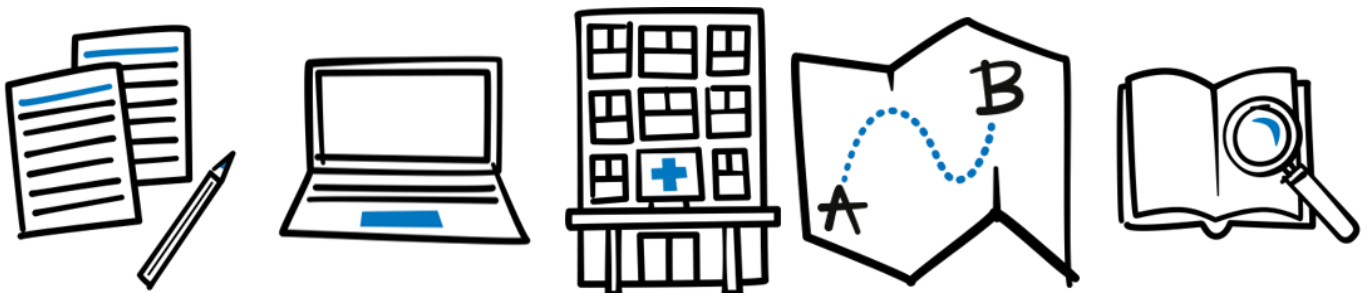
- Try to build opportunities for food play and exploration into your baby's daily routine, particularly on days when they are feeling well (and not feeling very nauseous or vomiting, for example). Repeated exposure to food will help to increase the likelihood that your baby will be more willing to accept it as time goes on.

Keeping feeding experiences positive and relaxed

It is completely understandable to feel stressed and frustrated about your baby's feeding progress and naturally this can be an ongoing source of worry for some parents. It can be difficult to feel positive if you feel that your baby is not feeding as well as they should be, or if they are rejecting food or milk that is offered to them. Quite often, babies are able to pick up on signs of stress at feeding times and any extra encouragement that might be used in an effort to help your baby to feed more may have the opposite effect and increase their reluctance to feed.

There are some steps that you can take to help your baby to learn that feeding can be an enjoyable experience and overcome negative associations that they may have with food, with some suggestions below:

- Use exaggerated positive facial expressions when your child is playing with or eating food (even if on the inside you are feeling stressed or anxious!)
- Give your baby lots of attention and praise for any positive behaviour around food (this includes them touching or playing with food and not only putting it in their mouth or eating it)
- Try not to pressurise your baby to eat if they are giving you signs that they have had



enough (for example if they have clamped their mouth shut or are turning their head away)

- Avoid syringing milk into your baby's mouth as this gives them a lack of control and can be very unpleasant for them

It is also important to think about ways that you can support your own wellbeing if feeding difficulties are ongoing. This may include asking family members to support you with managing worries, or doing activities that you find relaxing. Some people find positive coping statements or 'self-talk' useful (for example "I am doing the best that I can and that is enough").

Your team at GOSH

The team of healthcare professionals who can help to support you with your child's feeding includes:

Dietitians can give advice on how to meet your child's nutritional requirements and develop a plan to support them with their feeding.

Speech and Language Therapists (SLT) can help to assess your child's feeding and swallowing skills to make sure your child is able to feed safely and give ideas on how to support your child to explore and enjoy food.

Occupational Therapists (OT) can assess your child's skills in relation to motor, cognitive, sensory and emotional areas of eating and drinking development, as well as the environmental factors surrounding mealtimes. A plan can then be developed to support them with their independence and feeding skills, to reach their full potential.

Play Specialists may be able to support you with ideas for food based play, to help your child become more comfortable with touching and experimenting with different foods.

Further information and support

If your child is already known to the team of Dietitians at GOSH and you have a non-urgent query, you can email bccdietitians@gosh.nhs.uk or send a message via MyGOSH once you have registered. More information about MyGOSH is available at www.gosh.nhs.uk/your-hospital-visit/mygosh. For any urgent concerns about your child's feeding, please speak to a member of the clinical team.

If you would like your child to be referred to a Dietitian or a different healthcare professional, please contact your Clinical Nurse Specialist or Key Worker who will be able to arrange this for you.

For information on feeding difficulties specific to cancer treatment, visit the Children's Cancer and Leukaemia Group website at www.cclg.org.uk/

For general guidance on weaning visit the NHS website at www.nhs.uk/livewell/ or the British Dietetic Association website – in particular, their food fact sheet on weaning available to download at www.bda.uk.com/resource/complementary-feeding-weaning.html

