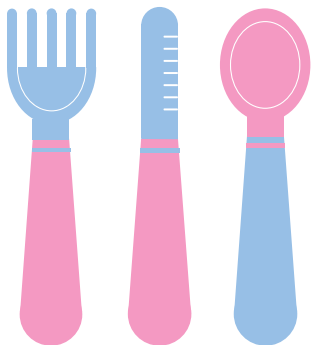


CDH and feeding



CDH UK receives regular support requests relating to feeding. We decided to carry out the first patient led survey into feeding challenges experienced by patients and their families. The results of this were published in 2019 (Power et al, 2019). Our research has shown that feeding information and support in CDH patients can be poor or inadequate and led to this resource.

This booklet has been developed by CDH UK and introduces some of the feeding challenges and treatments that can be experienced by some CDH patients. We hope it will give some guidance and reassurance with the aim of empowering patients and making feeding less stressful and more successful.



To make navigating this brochure easier we have divided the content into the following areas, using separate colour page sections to help answer any of your child's feeding issues.

4 to 7

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Diagnosed with a feeding challenge, what now?

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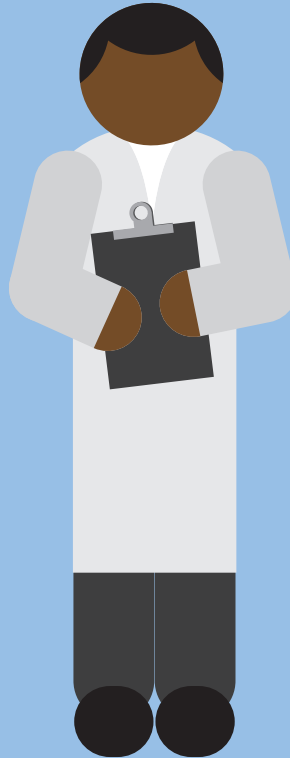
Getting help



CDH & feeding

Feeding challenges are not uncommon and are estimated to occur in around a quarter of children without any medical or additional needs (Arts-Rodas D, 1998).

If you have a medical condition, such as CDH, then it becomes more common to face some types of feeding challenge. This is particularly noticeable in childhood.



Children with CDH may require more food and more calories for example. This is probably because their body is working harder to breathe and to develop the lungs after they are born. As a parent or caregiver you may feel pressured to ensure enough calories are consumed to put weight on, which may cause stress and anxiety.

Some children with CDH also have additional medical issues and this can also affect feeding and nutrition. Problems with the mouth, teeth, throat, stomach, or bowel can cause the appetite to be affected or prevent a person from eating. That is why it is important to find out what is causing the problem.

One of the major causes of feeding challenges with CDH patients is Reflux. There are two types of reflux known as

Gastro-Oesophageal Reflux Disease (GORD or GERD) or Silent reflux and the symptoms can cause discomfort and bringing up food into the food pipe, throat, or cause vomiting. It can be treated with medication and changes in diet (such as adding thickeners to milk). These treatments need to be reviewed periodically by a Doctor and reflux should be closely monitored.

Sometimes if medication isn't working or isn't recommended, or if the reflux is severe, a surgical procedure called a Nissen's fundoplication may be recommended. This is a procedure where a portion of the stomach is wrapped around the stomach inlet valve where the food pipe ends, and the stomach begins. This is to stop acid and food from leaving the stomach.

You can find out more about Reflux and Nissen's fundoplication in our CDH and Reflux Booklet.

Most feeding challenges can be treated and improved or resolved completely with early intervention and the right support.

You should never be expected to struggle on alone with a feeding challenge, so do not be afraid to seek help or advice. Even if you have been given lots of help and advice already, finding a good group for peer support through a recognised organisation such as CDH UK can provide invaluable support at often difficult times.

If you are concerned about feeding or nutrition for you or someone you care for it is important to talk to someone about it and not to ignore it. The earlier the support, the better the outcome

The CDH Team

A good place to start is to record feeding habits, foods eaten or issues relating to feeding in a diary or notebook. This will help you and any medical professionals to see how and when things are happening, any patterns and any quantities and volumes of feeds or vomits. This can often help to identify food intolerance too.

Make an appointment to see your GP or Consultant or have an initial chat with a Midwife or Health Visitor if your child is affected. Don't leave things too long before you seek an opinion as it can be more difficult to treat or resolve and could lead to unnecessary stress.



Some feeding challenges are not unique to children with CDH and are often seen in 'healthy' infants too. Take breastfeeding for example. Many women find breastfeeding difficult, without the added challenges of a baby with CDH. There is no reason not to attempt to breastfeed a baby with CDH. With the right support from a specialist midwife or health visitor and some tips from others who have breastfed their baby, breastfeeding can be successful. If you have attempted breastfeeding and it hasn't worked out, don't feel defeated, because what matters is that your baby is nourished and thriving and mum and baby are happy.

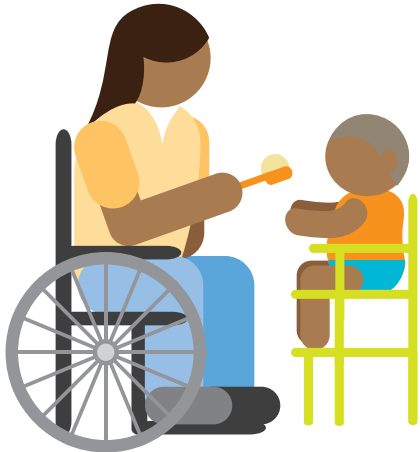
Breast milk can also be thickened naturally by extra calorie intake by mum or by adding milk thickener to breast milk and feeding by bottle or sippy cup, but you should always consult a medical professional for the best advice on thickening milk safely.

Remember you are not alone and the team at CDH UK are always here to help support you!



What is a feeding challenge?

A feeding challenge is sometimes also called a feeding problem, difficulty, issue, disorder, or aversion. It can be when you or a person you are caring for doesn't eat or digest food normally. They may behave or act strange around food and eating. They may gain or are losing weight.



Feeding challenges can be broken down into different types:

Physical - caused by something in the body; for example, a weak swallowing reflex or acid reflux, mouth, stomach or bowel problems.

Psychological - caused by something connected with the mind, such as a fear of things in the mouth or dislike the sensation of a particular food texture, emotional reasons.

Environmental - caused by something around a person, such as a busy room that causes distraction or difficulties at home or around mealtimes.



Picky eater or problem feeder?

In general, a 'picky eater' is someone who will eat fewer foods, textures or even amounts. They may only eat when food is served in a certain way. However, they usually still eat a good range of food types and though they can be reluctant to try new foods they will tolerate trying them. Most young children will show signs of picky eating at some point and so it's quite normal for children to refuse food or to eat at certain times or in a particular social setting. Picky eating can improve with time and patience.

Problem feeders usually eat less than 20 types of food. They refuse entire textures or food groups (meats, vegetables for example) often display a true melt down when new food is introduced and will refuse it completely. They eat different foods to the rest of the family and will often refuse to eat with family. This can also be called having a food aversion.

It is important to recognise the difference between a 'picky eater' and a 'problem feeder' as a problem feeder will need early

support and possibly further intervention such as referral to a specialist in feeding.

A true feeding aversion is where there is a refusal to eat any food or only very small amounts of food or a refusal to eat from feeding implements such as spoons or baby bottles.

Sometimes children born with CDH can become reluctant to touch certain textures or get mess on their hands and this can be due to a sensory problem. Sensory problems can be linked to Autistic spectrum disorders and so it is important to mention sensory problems to your Doctor or Health Visitor for example.



Children, who have feeding tubes, may also have fewer opportunities to explore foods as they may not engage in regular mealtimes when food is presented to them. Children that had a lot of medical interventions, feeding tubes, oxygen masks/nasal prongs, food allergies, gastro-oesophageal reflux or extended stays in hospital may show such "sensory aversion" to touching and exploring different textures.

Sometimes a person who has undergone any abdominal surgery like a CDH repair will choose food that they know will digest easier and sometimes this is referred to as a bland or white diet. It usually consists of things like rice, mashed potato, pasta, cheese, yoghurt, and white meat. This is in fact a similar type of diet often prescribed following gastric or bowel surgery.

Food challenges can develop at any age or stage of development. Please do not think you are overreacting if your baby or child is refusing any type of milk or food.

Either your GP, Consultant or Dietician will assess the patient for any food intolerances, food allergies and nutritional deficiencies they may have which could be causing their dislike to food. The assessment will look at the patient's nutritional intake to ensure they are receiving the energy and nutrients they need to grow and develop and a care plan with plenty of support will be made.



Our suggestions

- Keep a diary of mealtimes and foods eaten plus any events such as tummy aches, vomiting or complaining of feeling unwell.

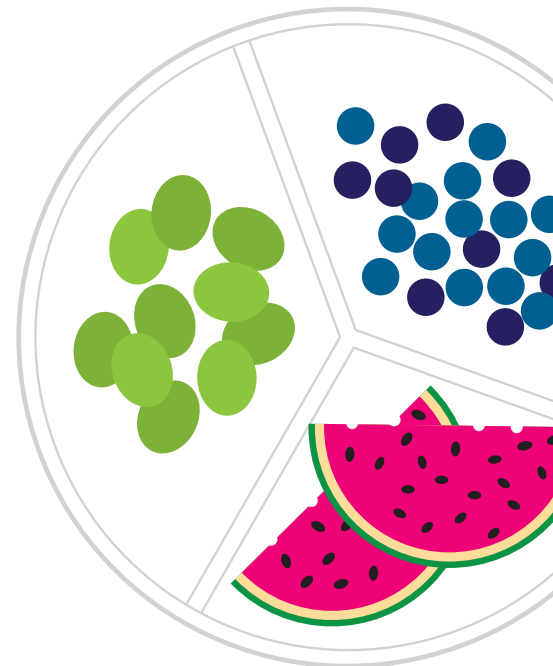
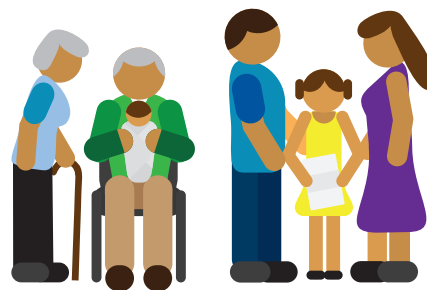


- Try and make mealtimes happy, regular, and social occasions.
- If you find yourself becoming anxious

Choose a time when there are likely to be less interruption.

- Don't force your child to try a food.
- Ignore fussy eating as lots of attention can sometimes encourage unwanted behaviours.
- Minimise distractions such as the TV, mobile phones or tablets.
- Encourage them to feed themselves so that they can control the amount of food they put into their mouth and eat at their own pace.
- Prepare for mess and don't be tempted to clean up the mess until they have finished eating.
- Try not to prevent children from using their hands or make them use a certain utensil. It is easier to pick up with hands. Remember It's normal for your child to drop or throw food on the floor and it can take lots of attempts for the child to even place the food in their mouths.

- Small bite-sized pieces that are easy to pick up, such as small pieces of bread, soft fruit and cooked vegetables are ideal.
- Some children may like to use a plate with sections. This will not only help with keeping foods types separate but support with portion sizes and can make food more fun.
- Chat with your Health Visitor, relatives, or other parents on the CDH UK forums as this can help to reassure you and to get valuable tips and advice to improve mealtimes.

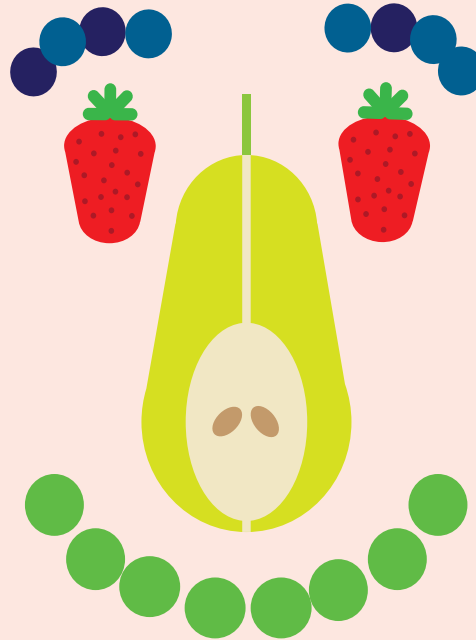


What about taste and texture?

Some children will be sensitive to tastes and textures, some may like crunchy while others like smooth textures. If a child doesn't like the smell or texture, it can be enough to make them lose their appetite, gag or be sick. Some children dislike change in their routine and new foods can be overwhelming. Some children may have a physical reason for disliking certain textures, such as sore gums, tongue tie, difficulty swallowing or reflux and so it is important to rule out any physical reason if things don't improve.

Our suggestions

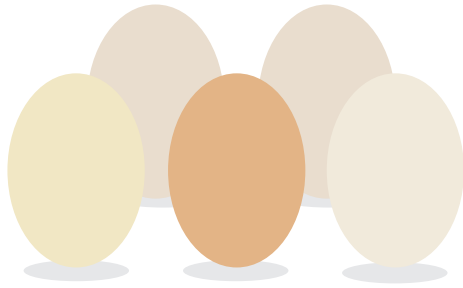
- When introducing new foods do this slowly.
- Encourage them to put the food on their plate, hold the food or even lick it. Try and offer the food many times and ask family members to show their enjoyment of eating this new item.
- Try food games such as placing different foods and textures in different bowls and encourage touch and hand immersion.
- You lead and see if they will copy you!
- Encourage food art! Show them how to pick up food pieces and make faces on plates for example.



Messy play with food is an important activity for all children in supporting their feeding skills and acceptance of different textures and foods. Messy play provides opportunities for a child to explore food (the unfamiliar) in a non-threatening way. When engaging in such play, there should be no expectation that your child will put food to their mouth, nor should they be encouraged to eat, rather a child should be left to explore the food in a way that they feel comfortable – allowing them to experience the way the food smells, looks and feels.



Food allergy or intolerance?



A food intolerance is an adverse reaction to certain foods or food types, or an allergy to them. Some of the most common intolerances involve the following foods:

- Dairy products (milk, yoghurt, cheese)
- Eggs
- Nuts (peanuts, tree nuts)
- Grains or gluten
- Soy
- Sugars

Things like oils, high starch content, and food additives can also be a problem for some people.

It is quite a common issue amongst children, particularly with dairy and lactose (a sugar found in dairy products). Symptoms can range from a skin rash to breathing difficulties and often it can cause vomiting or a change in bowel habits and swelling of the lips or face.

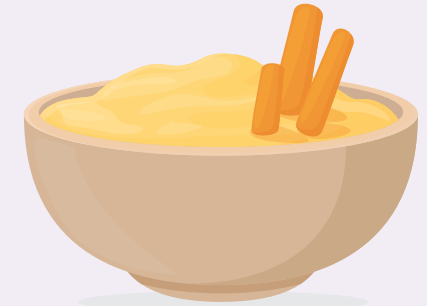
You can also purchase things like medical wristbands to alert people to a food allergy

Those who have an allergy or intolerance display symptoms soon after eating the 'trigger' food and in some cases, such as those with a nut allergy, the consequences can be life threatening. It is important to tell anyone who comes into contact with the sufferer about their food allergy and inform them of what to do should a reaction occur. You can also purchase things like medical wristbands to alert people to a food allergy.

Food allergies and intolerances are diagnosed by having what is called a patch test to identify what food causes the symptoms and treatment is to not eat the trigger food and antihistamines (where appropriate) for relief of the symptoms. In severe cases symptoms can be bought on by just touch. The sufferer must carry with them an adrenaline EpiPen, or a visit to the hospital may be needed.

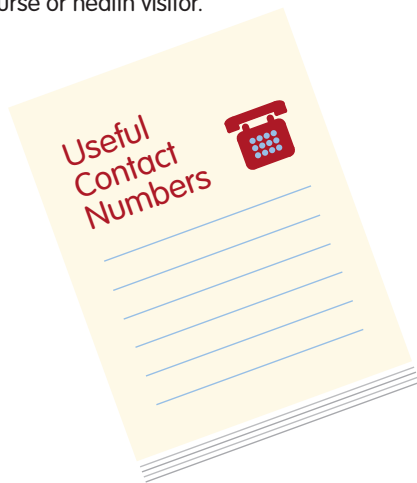
Patients who have food allergies may look at alternative foods such as:

- Soya milk
- Lactose free products
- Gluten free products
- Tofu
- Vegan cheese
- Cashew Cheese
- Tahini
- Sweet potato



Diagnosed with a feeding challenge, what now?

You may feel a bit overwhelmed to begin with. With time and experience you will settle into a routine and feel much more confident about things. Before you leave hospital or your appointments make sure you have asked all of your questions. Write things down and have a contact number for someone who can help while you are at home such as a community nurse or health visitor.



You may be referred to a speech and language therapist for swallowing therapy, they can teach different ways to help them swallow. They can work with children with sensory based feeding difficulties to help them to accept and build their food range and to identify any other underlying causes.

A dietician can help with changes to milk and food to make sure you receive a healthy balanced diet and can help with understanding calories or alternatives if needed such as dairy.

The paediatrician or consultant can support and complete referrals. They may feel a feeding tube is required. A tube implanted directly into the stomach can be used for people who have difficulty with swallowing or if there is a risk of food going "the wrong way" into the lungs.



A feeding specialist is normally someone who has lots of knowledge and experience in helping patients with a feeding difficulty. This can be a Doctor who also specialises in problems with the stomach or bowel, or a Dietician, who is qualified in nutrition and feeding or even a Speech and Language Therapist who helps with a range of problems relating to the mouth and throat. It can also be a psychologist who specialises in mental, social and behavioural problems.

A feeding clinic is a department normally within a healthcare setting such as a hospital or surgery, which specialises in feeding challenges. It is run by a team of specialist Doctors, Nurses and other Healthcare professionals to diagnose, treat and support patients and their families. Not all hospitals have this service, which is why you may have to travel out of your area to attend a clinic. Some hospitals have a feeding clinic as part of a CDH clinic.

Our suggestions

- Make sure you fully understand any medical advice or treatment. Don't be afraid to ask how to administer any medications, give feeds, supplements, or carry out cares.

- Ask if there is anything you are unsure about or don't understand. Feeling confident is the best place to start with feeling less stressful and more successful!
- Keep a diary to record events such as foods eaten, any reactions, or food that won't be eaten.
- Ensure you know who to contact for help and advice and keep names and numbers close to hand.
- Talk to family and friends and anyone else involved in their care, such as nurseries, child-minders or schools and make sure they have up to date information on your child's challenges, medications, requirements and what to do in case of a problem or emergency. Ask for a CDH UK carers pack.
- If you are feeling really anxious speak to your GP for some Mental Health support.
- Try to develop a support network of family, friends and support groups or patient organisations such as CDH UK.

What is a special diet, prescribed nutrition, or supplements?

Special diet

A specialist diet is a range of foods or type of nutrition to help with your feeding challenge. It can involve avoiding certain foods if you have a food intolerance. It can mean including more of a certain type of food for example those with lots of calories such as bread or foods high in fat.

Prescribed Nutrition

Prescribed nutrition can be things like high calorie milk feeds or milks free of dairy products such as soya based milks or lactose free products. It could even be a feed including thickeners to make the meal less likely to come back up from the stomach (like with Reflux for example).

Supplements

Supplements are things such as vitamins and minerals or extra calories in the form of drinks to add to our usual diet. These are quite common if you have difficulty absorbing nutrients, but you must always follow the advice of medical professionals when considering vitamins or supplements as they can interfere with some medications.



What is tube feeding?

Tube feeding will allow the patient to be fed without using their mouths, but will ensure that they are receiving enough nutrients to grow and thrive



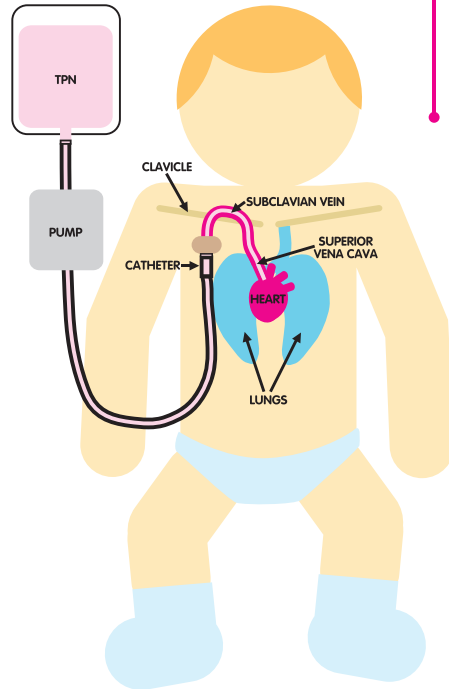
A baby born with CDH is normally tube fed until they are well enough to feed by breast or bottle. They are weaned off the tube feeding until natural feeding is established. This will be decided by your care team.

For several reasons, it may be very difficult or unsafe for a child to take enough food and fluid by mouth to keep them healthy. Tube feeding will allow the patient to be fed without using their mouths but will ensure that they are receiving enough nutrients to grow and thrive.

People born with CDH can use more energy because of their smaller lungs having to work a bit harder, so they often need to eat more food or eat foods that are higher in calories. Some babies can find the co-ordination of sucking, swallowing and breathing difficult so having a tube can help.

There are different types of tube feeding and we have provided illustrations of some of them on the next few pages.

TPN Total Parental Nutrition (Collar Bone)

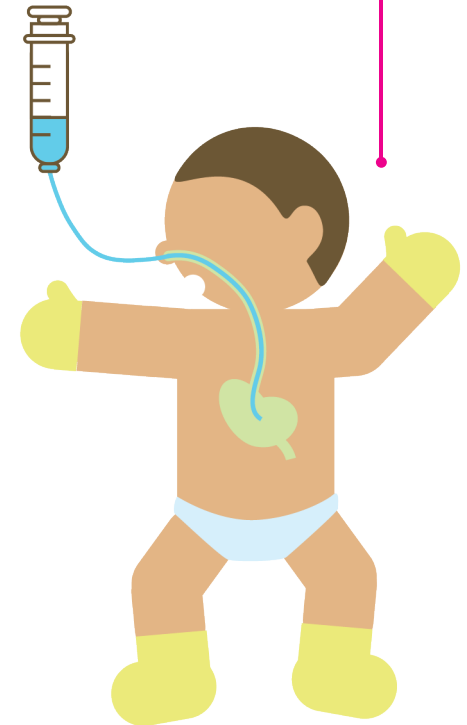


Some people will have tubes long term others will only need them for a smaller amount of time

It can be difficult to cope with feeding a baby born with CDH and it is normal to feel anxious about not breastfeeding or bottle-feeding. Most people will only need to use a feeding tube until they become strong enough or well enough to feed on their own. Ensure you talk to the doctor or nurse or CDH UK about the emotions you are feeling.

Some people will require all their food through a tube and others will be able to eat normally just needing a 'top up' of calories with more food given through a tube overnight. Overnight feeding can encourage a child to eat regular food throughout the day. However, some people may need to use the feeding tube throughout the day.

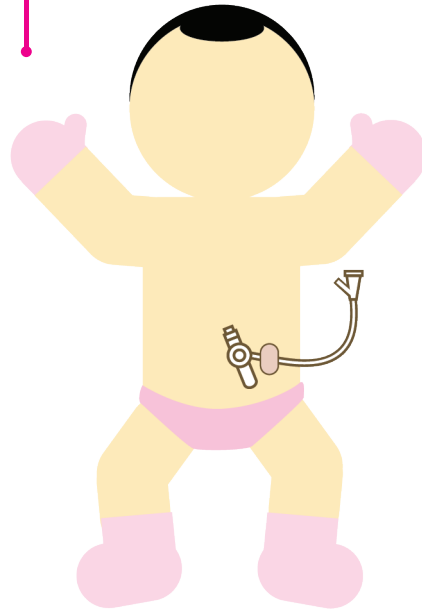
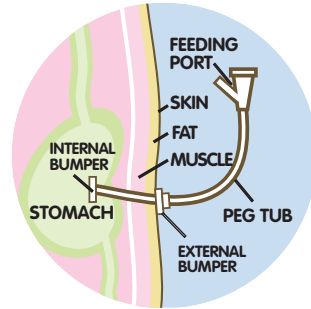
N G TUBE (Nasal)



PEG MICKEY BUTTON (Stomach)

The feeds will either be through a pump or bolus feeding (syringe). Before you leave the hospital, family or carers who will manage the tube will be shown how to care for the feeding tube and how to manage the feed. If, after you leave the hospital you are still unsure about anything you will need to contact the community nurse or dietician.

Tube feeding provides valuable access for nutrition and can be highly effective for weight gain. Tube feeding can help the body tolerate food better resulting in less sickness. Parents and carers also find by having a tube can make meal and feeding times less stressful. It can also help with reducing anxiety around feeding.



Tube feeding provides valuable access for nutrition and can be highly effective for weight gain

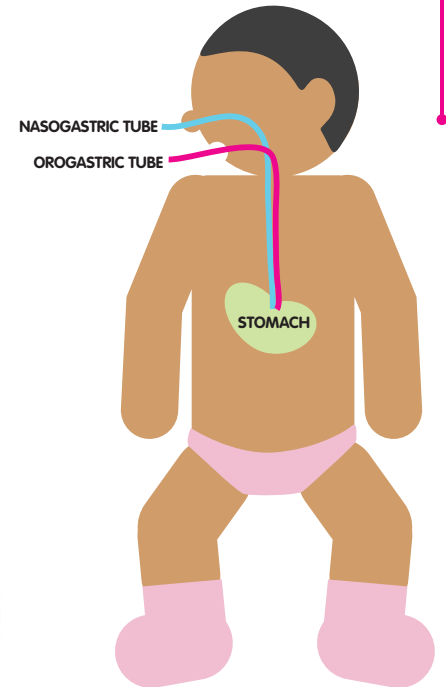
Children with a feeding tube are able to lead a normal life and can carry on taking part in usual activities.

Your doctor will explain what is the best option and you will be able to discuss the types of feeding tube available.

We have an additional information book on Tube Feeding called **CDH and Tube feeding**.

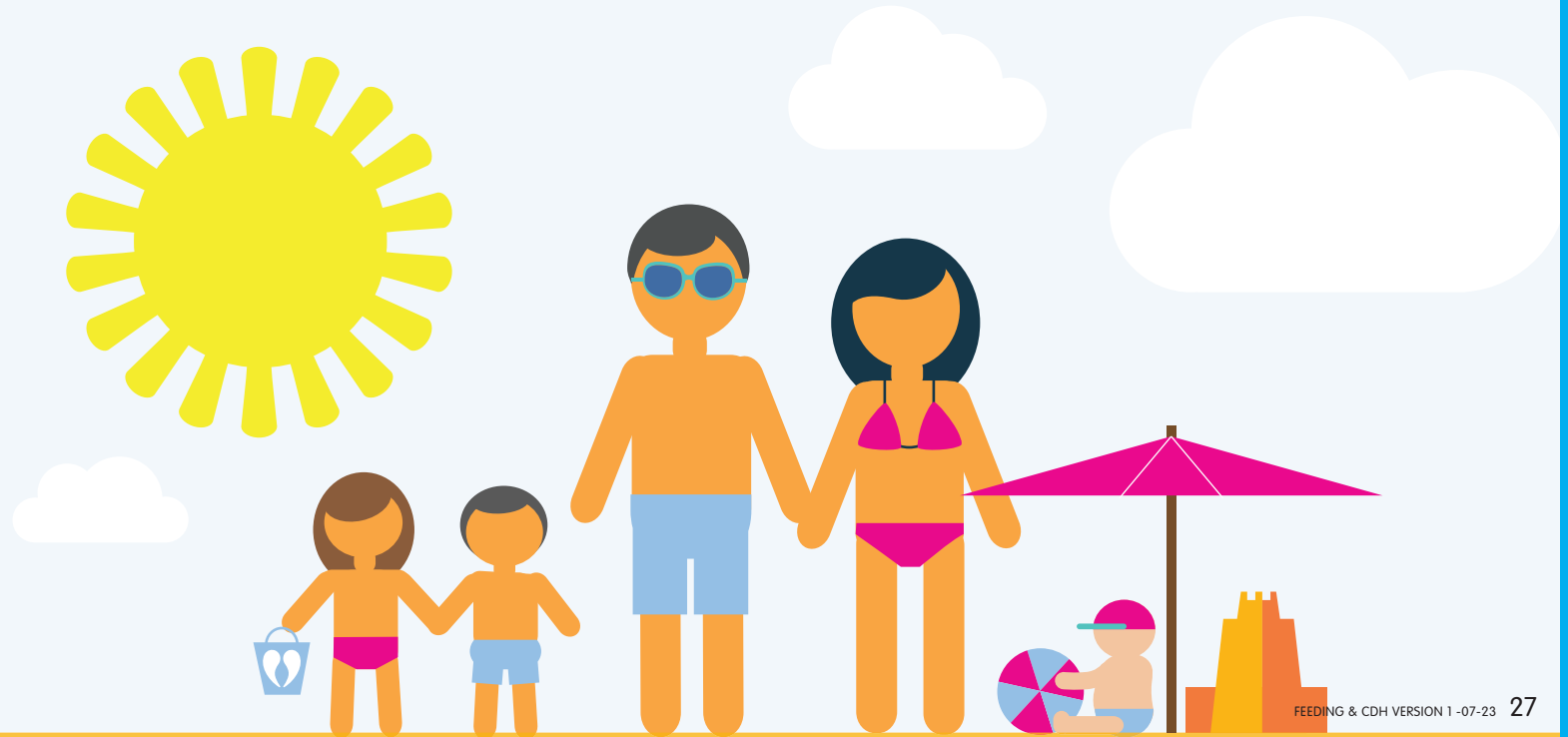


NASOGASTRIC & OROGASTRIC Feeding Tubes



Feeding away from home

Plan ahead as much as possible and start with a list of things you will need to take with you



You may be popping round to a friends or going on a day out, a weekend at the seaside, or a holiday overseas.

Whatever the reason for being away from home and your familiar surroundings, it can cause anxiety. Here are some useful tips to help:

- Plan ahead as much as possible and start with a list of things you will need to take with you.
- Find out where the nearest Pharmacy, Doctor's Surgery and hospital is to where you will be going or staying and find out contact details and addresses.
- If you use prescription nutrition and medical items make sure you have enough of what you need for the duration and a bit extra for unseen circumstances.
- Check with your GP/Doctor to make sure vaccinations and check ups are up to date if you are going overseas and that you have a fit to fly certificate if required by the airline.
- Contact the airline or travel agent in advance if you need to take specialist equipment and to notify them of any other specific requirements that you may have.
- Ensure you have with you any contact numbers in case of an emergency or hospital admission. This could be for a Consultant, Dietician, Speech & Language Therapist, or family members for instance.
- If you are using portable equipment that isn't used often, check it is in working order and that you can remember how to use it before you go.
- Remember to take out adequate travel insurance if you are going on holiday
- You can also contact CDH UK for a list of CDH specialist hospitals in the UK and overseas and for details on our financial schemes that may be helpful.

Try not to worry about being away from home and remember we are always here to help. If your time away from home is for pleasure have a great time!



Getting help

Depending on the type of challenge you are experiencing and what is causing it you will be signposted or referred to an experienced care provider or service. This could be one or more of the following:

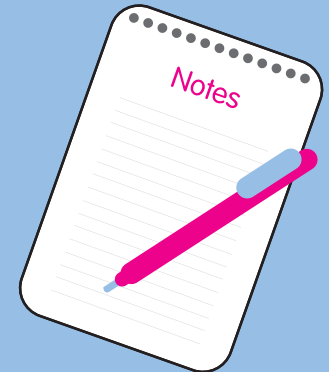
- Consultant Physician or Surgeon (paediatric for children)
- Dietician (paediatric for children)
- Specialist Feeding Clinic
- Speech and Language Therapist (SALT)
- Psychologist
- Counsellor
- Patient Organisation/Charity such as CDH UK
- Sensory Integration or Therapy
- Community nurse, midwife or Health Visitor

These specialist medical professionals or services may suggest the following:

- Therapy, for example Speech & Language
- Therapy (SALT) or counselling
- Medication
- Special diet, prescribed nutrition, or supplements
- Tube feeding
- Surgery
- Feeding aids such as special feeding utensils, teats, or cups



We highly recommend taking a record such as a diary to your appointments to give as much information as possible. This also will enable you to make any notes as it is sometimes difficult to remember everything that is said or discussed. Do not be afraid to ask questions or challenge suggestions or recommendations. Having as much information as possible is very empowering!



We're CDH UK and we're here to give help, support and advice.

We hope that this booklet has helped to answer some of your questions. Please remember that each patient is different and what works well for one patient may not work the same for another. Always consult a medical professional if you think your child is unwell or not eating normally.

For further information and support please contact support@cdhuk.org.uk

All the additional information resources mentioned in this booklet can be obtained through our website or by emailing support@cdhuk.org.uk

We would love to hear your feedback on this booklet by emailing support@cdhuk.org.uk and referencing 'Feeding and CDH' Version 1 -07-23.



CDH UK helpline
0800 731 6991

Website
www.cdhuk.org.uk

Email
support@cdhuk.org.uk

Alternatively write to us
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