



Little Hearts Matter
*Half a heart
...not half a life*

Feeding At Home

a guide
for parents



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INTRODUCTION

As a parent, feeding your child is one of the most important elements of day-to-day care. It can be extremely distressing and demoralising to discover that your child is unable to feed as you had hoped.

If your child has been born with a complex heart condition they may find feeding difficult. Their heart condition creates a lack of energy. Feeding, especially for a newborn baby, requires the energy that we would need to run a race. The children often start a meal or milk feed with great enthusiasm because they are very hungry but gradually they become breathless and sweaty and often they are unable to complete their meal because they are so exhausted. Feeding is very hard work, and the problem is further complicated by the fact that children with heart conditions need more calories than those without.

Calories are needed to provide energy for living. If you have an inefficient heart pump you require lots of fuel/food to run your body, but children with a heart problem also need to grow so they need to take in more calories than other children of their age.

This pack has been created to help anyone involved in the feeding of children with complex heart disease. It includes information and ideas on many aspects of feeding a child, drawing on medical input and also including parents' experiences. Each topic is designed to stand alone so that different sections can be referenced as and when needed. The pack starts with general information on feeding at home, then goes on to cover specialised aspects of breastfeeding and tube feeding.

In each section we have tried to include a range of ideas - you can then choose which you would like to try, as you know your child best. Many of the ideas have been suggested by parents,



based on their own tried and tested experience. It is often helpful to try one new idea for a few days or even a week before trying something else, rather than constantly trying new techniques. It is also best to only try one new idea at a time.

If your child is experiencing difficulties with feeding or weight gain, don't despair, you are not alone. Contact Little Hearts Matter and you will be put in touch with other parents who are experiencing or have experienced feeding difficulties with their own child. The Little Hearts Matter team will also help with more information about ideas on feeding or information on specialised diets.

This information pack does not replace any individual medical advice you may receive eg from your child's cardiologist, dietician, speech and language therapist or any other health-care professional supporting your family.

PEOPLE WHO MAY HELP

Below is information about the different roles of some of the professionals who may be involved in supporting you and your child. Please be wary of non-professional advice, which although it will certainly be well intended, may not be appropriate, as children with single ventricle heart conditions often do need specialist support with feeding. Many parents report that friends and family will tell them that “babies don’t starve themselves” in trying to stop the parents from worrying about their baby’s or child’s limited food intake. Please make sure you seek professional advice from someone who understands cardiac conditions.

Dietician

Most children with single ventricle heart conditions will have a named dietician when in hospital, who will also provide follow up support after discharge either by telephone or during out-patient appointments. In some cases it may be more appropriate to request support from a community dietician based at a local hospital. Your dietician can offer help and advice on any aspect of feeding your baby or child.

Health Visitor

Every child under the age of five is allocated a health visitor, who is a regular point of contact for parents to discuss any aspect of their child’s health and development. Your health visitor will be able to visit you regularly to offer support with feeding, and will weigh your baby on a frequent basis so that you get an accurate picture of their weight gain. They will advise you on standard weaning guidelines. Regular weight checks are very important, but try not to get too obsessed by the numbers, as any child’s weight gain can be erratic. Try to focus on seeing whether your child is generally well, and whether their weight is increasing, even if it is only a slow increase.

Community Nurse

You may have contact with a community nurse, especially if your child is tube fed. They will change your child’s tube if necessary, and may teach you how to ‘pass’ the tube yourself if you wish. They may also have other useful advice relating to feeding issues based on their experience.

Speech and Language Therapist

A speech and language therapist (SALT) may be involved in your child’s care if they are tube fed and it seems likely that this might be the case for some time. Some SALTs are specially trained in oral feeding techniques, so will help you to move towards oral feeding. If your baby is referred to a SALT, please do not worry about his or her speech at this stage - the expertise relates to helping with feeding difficulties as some of the same actions and muscles are used for oral feeding and for development of speech.



BABY

During pregnancy most parents plan the way that they are going to feed their baby when he or she is born. Some plan to breastfeed and others decide that bottle feeding will fit into their lifestyle more easily. Once they have been given the news that their child has a complex heart condition, they have to take a careful look at the best ways to feed. Drinking milk, for a baby with a serious heart condition, is like running a marathon. They often become breathless and slightly blue as they come towards the end of a feed. It is however very important for them to have plenty of milk because they need lots of calories to make enough energy to run their heart with some extra energy for growth.

Parents and their medical team will need to work together to find the best way to give the baby all the calories that they need. You may need to be flexible with your ideas.

“ Thomas was breastfed for the first three months. When we moved to bottles I found I became obsessed with millilitres! While he never lost weight, his weight gain was fairly gradual and I would worry that he wasn't gaining weight fast enough. Although since his second operation, he's gained weight at a faster pace and while he can sometimes be a monkey at mealtimes (I am told this is fairly common) he's now generally eating pretty well. ”

Lindsey, Mum to Thomas

BOTTLE FEEDING

If your baby is finding it difficult to bottle feed, it may be worth experimenting with different types of teat. Premature or newborn teats often work well, as they are smaller in size. Babies who struggle to co-ordinate breathing, sucking and swallowing may find a slow flow teat the best option. On the other hand, babies who get tired whilst feeding but have a good sucking action may find fast flow teats help. Another technique can be to allow a small number of sucks, for example three, then take the bottle away to give your baby a breather.

Small frequent feeds, taking as much time as your baby needs may be the best approach.



Experiment with different teats



Preparing a special feed

If your baby isn't putting on as much weight as is needed, your dietician may prescribe a high-calorie milk such as Infatrini or SMA High Energy, or may suggest supplements to add to the milk, such as Calogen, Duocal or Maxijul. Your dietician will give you instructions on how to make these feeds, and also on how to obtain further supplies on prescription.

If you feel disheartened, small narrow bottles can make progress seem more obvious. A diary of all milk taken orally, with amounts written down in millilitres not fluid ounces can help to show when things are going well. However, please try not to get too hung up on this as all babies will take different amounts of milk on different days.



Small narrow bottles emphasise progress

If you feel that your baby may be picking up on any of your feelings of stress, you could try to feed him or her in a suitable seat eg a car seat or a bouncy chair. You may also find it helpful to ask other people to take a turn at feeding your baby, perhaps grandparents or friends could help.

BREASTFEEDING

Breastfeeding can be possible for some babies. Because of all the medical treatment that the baby needs at birth the immunity that can be gained from early breast milk may not be possible; however there are other reasons to try breastfeeding.

- ✓ Mothers produce milk that offers the baby a very good mix of the nutrients that they need for growth.
- ✓ The meal is available without needing to sterilise bottles or warm the milk.
- ✓ It is also very comforting for the baby to suckle at the breast - it has been proved that babies suck for comfort from an early age.

It is important to remember that breast milk will have started to appear just before the baby is born. The first milk will be clear and full of nutrients, it is called colostrum. After the first few days the milk will become milkier and richer in calories. Some mothers are able to put the baby to the breast straight after birth but as many babies have surgery within the first few days of life it is important to stimulate the breasts to ensure that they will continue to produce more and more milk. Mothers use an electric pump to express milk every three to four hours. The milk is then stored and used for the baby as soon as they are able to start to feed. Often the nurses are able to pass the milk into the baby's stomach via a naso-gastric tube even though the baby is not ready to feed normally.

Expressing milk allows the baby to have all the nutritional benefits of breast milk, even though they cannot currently feed for themselves. You may also find that expressing milk helps you to feel more involved in your baby's care - any contribution you

make (even if it isn't all the feeds or even if it isn't for long) will help. It is important to express frequently to keep the milk supply going, including once during the night. Some mothers find a photo of their baby helpful. All hospitals will have places where you can express milk, and will provide equipment and advice as required. Make sure you sterilise the expressing equipment properly - ask for help if you are not sure.



A hand-held breast pump

During this time it is important for mothers to look after themselves. Make sure that you see the hospital midwife regularly, and ask nursing staff on the cardiac ward to call the midwife if you have any concerns about your own health. Eat and drink well - try to have a varied diet and as much sleep as possible. Some hospitals will provide food vouchers to breastfeeding mothers. All this is very difficult because mothers are of course worried about their baby. As soon as the baby is well enough, mothers who wish to

breastfeed will be encouraged to put their baby to the breast. Most babies need to have mixed feeding until they have recovered from surgery. Some milk will be passed down a naso-gastric tube, some breast milk may be given by bottle and it may

also be necessary to add extra calories and nutrients to the feed or give them into the baby's mouth.

One of the most important things to remember, if you hope to breastfeed, is to try and stay relaxed and not to worry if it does not work the way that you hoped. Feeding can be difficult for some babies even if they don't have a heart problem. Mothers who are under stress may not be able to produce enough milk and, for some, expressing milk is impossible. Some babies are unable to breastfeed because it is too tiring and sometimes the baby needs more calories than breast milk can provide.

If you would like to find out more about breastfeeding, talk to your midwife or contact your local National Childbirth Trust group. There may be a specialist breastfeeding nurse at the children's cardiac unit where your baby is being treated. Little Hearts Matter also has a number of mothers who have successfully breastfed their babies who would be happy to talk through their experiences with you.



“ My son looked beautiful and completely normal when he was actually born, and immediately breastfed enthusiastically - in fact much better than his 'normal' sister did at first! And he stayed very fit and well-looking but the Prostin made him sleepy and after the first day he never again breastfed the way he had when he first came out. He had to start being bottle fed, and then within two days had to have a naso-gastric tube to feed at all. But I found that I could express milk - and I thought since I could do nothing else I'd do this for him - and went on doing it for five more months - looking back I can't believe it... My husband used to call me Ermyntude and offer me hay!

We didn't get out of hospital for ten weeks - and the wee man was bottle and NG fed all that time. Then the last week we were in, the consultant said we should try breastfeeding again, 'it's good for his reflexes and development'. I couldn't believe I was hearing right - after ten weeks fed by bottle and tube, I thought, you're having me on. Well one night after we'd got home, he and I were lying in bed and I just decided to try it - on a whim really, just so I could say I had tried. So I had a go at popping him on - and blow me, he latched on, and he sucked like he'd never been away from it! I was totally stunned. After ten weeks and all he'd been through, he started breastfeeding again, as if nothing had happened - he still had his NG tube even! So after that we went on with both - bottle and breast. It is worth trying again - even at ten weeks (which all the literature tells you is too late!). ”

Gill, Mum to Michael

“ I was very keen to breastfeed, but had found it hard to get relevant information before Matthew was born. When he was first born, he was very unstable so had to be taken straight to intensive care, with no chance of any feeding other than by tube. I managed to express milk for three weeks, and felt very proud of my small contribution as it went down his NG tube in ITU (the nurse let me put his first ever milk down when he was five days old). But I found the whole experience very stressful, and when it became apparent that he wasn't going to be off the ventilator for quite some time, and my milk supply was getting less and less, I had to give up. ”

Isabel, Mum to Matthew

FOR FURTHER INFORMATION

National Childbirth Trust

Breastfeeding line: 0870 444 8708

Website: www.nctpregnancyandbabycare.com

La Leche League

Tel: 0845 120 2918

Website: www.laleche.org.uk

Association of Breastfeeding Mothers

Tel: 0844 412 2949

Website: www.abm.me.uk

Breastfeeding Network

Tel: 0844 412 4664

Website: www.breastfeedingnetwork.org.uk

VOMITING/REFLUX

Many heart babies vomit frequently during or after their feeds, which can be worrying for their parents. Below are some ideas which may help.

If the problem relates to milk feeds:

- ✓ keep the baby still after a feed - sitting the baby upright in a chair might help;
- ✓ try giving smaller volumes of milk more frequently;
- ✓ your dietician may suggest you thicken the feeds (this helps the feed to stay in the stomach); if so, you will be given instructions on how to prepare the feeds.

If the problem relates to meals as the baby is being weaned onto solid food:

- ✓ keep a food diary to see if there are any links;
- ✓ offer smaller mouthfuls;
- ✓ make sure you are using weaning spoons, which are flat and small. Try different brands of spoon - some are smaller and softer than others, so may be more appropriate.

Talk to your doctor or dietician if you're really worried - they may feel anti-reflux medication could help eg Domperidone, Ranitidine, Gaviscon, Omeprazole.

TUBE FEEDING

Many babies go home from hospital still being tube fed, either for all their feeds, or for top-up feeds. Some may have overnight feeds via their tube, which leaves them free to eat during the day. It is important to remember that tube feeding will be used in your baby's best interests, in order to help with their growth and nutrition, and to try to reduce some of the stress of having a child who will not or cannot feed, despite needing a high calorie diet. It is usually a temporary measure, but timings vary from child to child.



One type of feeding pump

BABY

A secondary benefit is that medicines can be passed through the tube rather than having to be taken orally - which can be really useful for some of the cardiac medicines which don't taste too good!



Tube feeding may well satisfy your baby's hunger, but will not give them any of the pleasure of feeding for themselves. It is important to bear this in mind and try to increase positive feelings around their mouth, and link relevant sensations with feeling full, so that you can encourage normal feeding by mouth when your baby is ready. It may be that tube feeds are only required as a top-up, and that voluntary feeding should be encouraged at a rate your child can manage.

Different centres have different practices in relation to tube feeding. Some hospitals tend to use a tube passed through the nose

to the stomach, a naso-gastric tube, whilst others use a tube which goes directly to the stomach, a gastrostomy.



A naso-gastric tube (tube passing through the nose to the stomach) can usually be placed quickly and with little discomfort by a nurse. In time, you may wish to learn to 'pass' the tube yourself, if long-term tube feeds are needed.

Gastrostomies (tubes directly into the stomach through the wall of the abdomen) are inserted under general anaesthetic, but usually in conjunction with another procedure eg cardiac catheter. A gastrostomy may be useful if a child has had previous problems with naso-gastric feeds. Some families prefer them as they can be hidden under clothing. They are also often referred to as 'pegs'.



If your baby is tube fed, you may find it helpful to work out a routine for doing the feeds at home. At first you may find it difficult, but with time, you will become more practised and find a system which works for you. A special tray for all the feeding equipment can help, as can keeping plenty of packaged sterile equipment so that you can get out and about once you are more confident with the feeds.

TRANSITION FROM TUBE TO ORAL FEEDING

There are plenty of things you can do to help your baby learn to feed normally by mouth (oral feeding), but it may be a slow process, needing different ideas at different stages in your baby's development. You may be referred to a speech and language therapist - these professionals are specially trained in oral feeding techniques and will have different ideas and advice to offer.

Work closely with your dietician to ensure that your baby's calorie and nutritional needs are being met. It may be that you need to reduce or change the tube feeds in order to interest your baby in oral feeding, but this should only be done with the agreement of your dietician, who will closely monitor your baby's weight.

This transition can take a very long time (weeks, months or even over a year), so please try not to push your baby too hard, as it may be counter-productive. You will also need to make sure everyone who cares for your child adopts the same approach, so that you are all helping in the same way.

Keep oral stimulation up all the time eg use a dummy when tube feeding, try to give a bottle/breast feed first before topping up with the tube, even if the amount taken is only small. It may be that all you should be aiming for is 2-3 mls of milk, over a period of say 10 minutes, with lots of reassurance and communication with your baby. Your baby may not even really feed, but should be allowed to play with the teat, and feel drops of milk on either side of his or her mouth. If you do use a bottle or breast feed before a tube feed, stop before your baby gets too tired.

For babies who are really not interested in oral feeding, some

exercises and games can help, eg messy play (blowing bubbles around the face, playing with the face and mouth in the bath, playing with cornflour and water paste), or playing with clean toys and fingers inside and outside the mouth. It is also useful to give lots of praise and attention when touching your baby's face or mouth.

If your baby is ready to wean to solid food, very smooth purées are a good idea, perhaps using a blender followed by sieving the food also to make sure it's really smooth. There are ideas of smooth purées at the end of this section. The aim should not be to give the baby nutrition through solids at this early stage; instead it should be to interest the baby in food, through introducing a variety of tastes. Freeze purées in small ice cube trays so that you can get variety without too much wastage.

If your baby has problems co-ordinating breathing and swallowing, you may find that slightly more solid first purées are easier to manipulate.

Some parents find that moving to a cup is easier to manage than a bottle. It may be best to use a non-valved cup (ie not an 'anyway up' type cup) as using the valve needs a stronger suck. Some brands have different shaped teats, which may suit your child better. Other brands have a very slow controlled flow, which some babies find easier to manage.

Babies who are ready for finger foods sometimes make good progress as they try to learn to feed themselves. You may find it easier to try 'bite to dissolve' foods, which are much more manageable than some of the standard early finger foods suggested. Some babies react better if you introduce the food to the side of their mouth, whilst others prefer to try to feed

BABY

independently. Please see the ideas at the end of this section.

Little Hearts Matter can put you in contact with other parents whose babies have been tube fed - they may have other ideas, or simply could provide a listening ear.

“ Feeding became an all-consuming concern. Matthew was on three-hourly feeds during the day and continuous overnight feeds. Each daytime feed took an hour, followed by at least 30 minutes when we couldn't move him to try to reduce his vomiting. He had to have special feeds, which were high calorie and thickened, again to try to reduce vomiting. He also had anti-reflux medications three times a day.

I found it very difficult all the time he had his naso-gastric tube, as it gave an obvious external sign of his disability, which people would ask me about without really understanding the implications of what I was saying. But with hindsight, it made all the difference to his development, as it meant that he could gain weight at a steady rate, without tiring himself out, and without us getting too worried about his feeding problems.

We had support from a speech and language therapist with a specialism in oral feeding, both in the hospital and in the community. We started with oral de-sensitisation exercises, and then gradually tried to interest Matthew in feeding, initially with a bottle, then later with solids. We tried different bottles and teats, and eventually found a small teat which he would have a little go with. ”

Isabel, Mum to Matthew

“ Our son was NG fed for over two years. People kept telling me that he'd eventually eat, but I never really believed them. It was a long journey, with reflux and mouth aversion playing their part. When he was around 18 months old I got quite depressed about the whole feeding issue, I just felt there was no light at the end of the tunnel. Unfortunately, this rubbed off on Archie and his oral feeding got worse. I sat back and realised I was not helping the situation one bit. With a more positive approach and a New Year's resolution to eat dinner earlier and as a family, Archie gradually got the hang of it. He has now been tube free for six weeks and is doing well - even gaining weight. So for anyone out there NG feeding their child - they WILL eventually eat! ”

Andrea, Mum to Archie



Archie



Matthew

WEANING

The current Department of Health advice for any baby is to wait six months before moving away from an exclusive milk diet, but many health visitors state that it should be safe to start to wean your baby any time between four and six months of age, when they show signs of being ready. For some heart babies, weaning makes a real difference to their feeding. Using a cereal eg baby rice mixed with milk may help reduce vomiting, and may help your baby to feel more satisfied after feeding (rather than just exhausted!). It can also be easier for the baby to co-ordinate breathing and swallowing.

The standard advice about when to introduce different foods and about not adding sugar or salt to foods should be followed, unless you are advised otherwise by a health-care professional treating your baby.

Even if your baby is not ready to be weaned fully, perhaps because they are mostly or completely tube fed, it is usually still a good idea to introduce tastes of solid foods, to make sure the 'window of opportunity' of 6-12 months is not missed. This is a time when babies learn general attitudes about food and tastes, so exposing them to a variety of flavours and textures will help lay the foundations for a balanced diet later on. They do not necessarily have to swallow the food you offer.

You may find that your baby does not move to lumpy food as quickly as other babies. If possible, try not to worry about this, as they are likely to get there eventually. If they are struggling with new textures, change things slowly, and don't rush the process. You can also try to introduce a lumpier texture just for a few mouthfuls of each meal (maybe three or four mouthfuls at

the beginning of the meal), and then go back to a smoother texture which you know your baby will eat.

Finger foods can be a very useful part of weaning and encouraging a poor eater. 'Bite to dissolve' foods are good starting points, as they are easy to eat and swallow because they don't need chewing, but they do get a baby used to the idea of feeding themselves. They may then progress to foods which are easy to chew, but should still be quite manageable.

“ When we moved on to try solids, we started with quite solid baby rice, so that Matthew could control the food in his mouth, and so that it didn't cause him any further breathlessness. We then introduced tastes of a variety of flavours, with the aim being to interest him in eating, not to wean him in the traditional manner. I used to make all sorts of smooth purées, using a liquidiser, then sieving them to make sure there were absolutely no lumps. I froze them in the bottom of ice cube trays - it was ambitious to expect Matthew to eat even half a cube's worth of food! ”

Isabel, Mum to Matthew

BABY

IDEAS OF FOOD TO TRY

Bite to dissolve finger foods

Ice cream wafers
Quavers
SkiPs
Prawn crackers
Sponge finger biscuits
Rice paper
Meringues
Some cereals eg sugar puffs, cheerios, rice crispies
Chocolate buttons
Ice lollies



Smooth foods

Custard
Melted ice cream
Yoghurts
Cheese sauce
Chocolate spread
Cheese spread
Mousse eg chocolate mousse, or mint chocolate if your child likes minty toothpaste.



Bite and chew easily

Ripe peeled fruit eg pears, nectarines, peaches, banana
Cooked peeled apples
Avocado (which is also high in calories)
Well cooked vegetables eg potato, carrot, parsnip, swede
Pate
Soft fish (check carefully for bones)
Soft poultry
Cooked pasta pieces without sauce.

If you need to keep your baby's calorie intake up during the weaning process, you can add their usual milk to the foods you are offering (instead of adding water). You can also add margarine, butter or a cheese sauce to savoury purees, such as potato or chicken and vegetables.

INFATRINI RECIPES FOR WEANING

Below are some recipes which may be useful if your baby has Infatrini as their usual milk. Please always consult your dietician if you have any queries about whether a recipe is suitable for your child.

Chicken, Leek and Potato

Suitable from 4 months, 3 small servings



Ingredients

30g raw chicken breast, finely chopped

60g small peeled potato, finely chopped

30g white part of leek, finely chopped

10g butter

75-100ml Infatrini

1. Place chicken, potato and leek into a small pan, add 75ml Infatrini and simmer for 10 minutes in a covered pan.
2. Blend in a liquidiser or hand-held blender with butter and additional Infatrini to give desired consistency.

White Fish in Cheese Sauce

Suitable from 6 months, 1-2 servings



Ingredients

90g fresh or frozen portion of cod (or another white fish)

100ml Infatrini

5g (1 rounded tsp) cornflour

20g (3 heaped tsp) mild cheddar

1. Place fish portion (defrost if necessary) in a shallow dish with 20ml water. Cover and microwave on full power for approximately 2 minutes. Set aside.
2. In a 600ml jug cream together cornflour with 20ml Infatrini until smooth, then mix in remaining Infatrini.
3. Microwave on full power for 1 minute and stir. Continue to microwave on simmer/low for a further minute.
4. Stir in the grated cheese and add juices from fish, if a thinner sauce is required.
5. Pour sauce over fish and reheat in microwave on low/simmer for 30 seconds.
6. Serve with mashed potato, pasta shapes or boiled rice and a vegetable.

Microwave Infatrini Custard

Suitable from 4 months, 2 servings



Ingredients

100ml Infatrini

4g (2 rounded tsp) custard powder

1. Mix custard powder with 20ml Infatrini in a 600ml jug or bowl until well blended.
2. Mix in the remaining Infatrini and microwave on full power for 1 minute.
3. Stir and return to microwave on low for a further minute and serve.
4. For a thicker custard, use 2 1/2 rounded tsp of custard powder.

Baby Rice and Apple

Suitable from 4 months, 3 small servings



Ingredients

1/2 peeled and cored eating apple, finely chopped

10g (8 rounded tsp) baby rice

75ml Infatrini

1. Place apple and 3 tsp water in a small dish, cover and microwave on full power for 2 minutes.
2. Mash with a fork until there are no lumps, add 75ml Infatrini and baby rice and mix well.
3. For a smoother texture, blend in a liquidiser with an additional 20ml Infatrini.

Infatrini recipes reproduced with kind permission from Nutricia. Further Infatrini recipe ideas can be found in the Infatrini Recipe Book published by Nutricia Clinical Care, and available from your dietician, from the Nutricia parent/carer helpline on **08457 623653** or from the Nutricia website: www.nutricia-clinical-care.co.uk then look under 'Product Range' for 'Tasty Recipes'.



Most toddlers and young children are active and need plenty of calories - this is likely to be even more important for a child with a single ventricle heart as their body is having to work even harder.








In general terms, children should eat a healthy and varied diet, rich in fruit, vegetables and starchy foods, and they should not have too much saturated fat, sugar or salt. Government guidelines also suggest the use of a multi-vitamin tablet or drops up to the age of five. However, you may find that your child needs more 'nutrient dense' foods (such as meat, eggs, and full-fat dairy products) to keep them going than another child of their age.

Please remember that although sweet foods may be a really good way of helping your child to eat enough calories, it is also extremely important to make sure their teeth are well looked after. This is because the small bugs (bacteria) that live in everyone's mouths can cause infections if there is a problem with a tooth. For people with congenital heart disease, the infection can get into the blood stream and attach to the areas in the heart where surgery has been performed. This can be extremely serious and would require intravenous antibiotics.

Further general advice about a balanced diet for different aged children can be obtained from your health visitor or school nurse, or from your dietician.

INTERESTING A CHILD IN FOOD

If your child is not a good eater, or perhaps is tube fed, and you want to make them more interested in food, here are some ideas you could try:

-  Encourage them to join in with family meals, so that they see mealtimes as enjoyable, sociable times. If they are not yet ready to eat, suggest they bring a favourite toy to the table.
-  Use brightly coloured or character plates and bowls.
-  Have some time for playing with food and experimenting with different textures, colours and tastes.
-  Make eating fun eg traffic light pasta (Tricolore pasta), cucumber wheels (these are just normal slices of cucumber!), broccoli trees (normal small florets of broccoli).
-  Try to provide a quiet and relaxed environment for mealtimes (though this may not be possible if you have other children!).
-  Do some cooking with your child. Even quite young children can help make some things such as Angel Delight or jelly, coconut pyramids, cookies (which could also help Little Hearts Matter's cookie bake), pizzas or milkshakes made from banana, full fat milk and ice cream.
-  Offer small portions of food initially, and praise your child's efforts. Never force them to eat. Try not to show your feelings if you find you are getting annoyed with a reluctance to eat.

CHILD



Limit mealtimes to around 30 minutes.



Some heart children like stronger flavoured food than maybe you would expect for a child of their age - remember that they may have had strong tasting medicines every day since they were born. You may wish to try stronger flavours such as curry or marmite.



Do not give sweets or chocolate to your child if they refuse the main meal.



Try to make sure your child hasn't filled up on juice or other drinks just before a meal, but obviously you need to make sure they have the fluid intake they need to keep healthy.



Don't offer a choice at meal times, just offer the standard family meal for everyone.

EASY RECIPES TO MAKE WITH YOUR CHILD

Cookies

1. Mix 200g self-raising flour with 100g caster sugar.
2. Rub in 100g margarine or butter.
3. Add flavour if required eg handful of currants or chocolate chips.
4. Add 1 beaten egg, gradually, until you have a dough which can be rolled out.
5. Use shaped cutters to make cookies.
6. Bake for around 15 minutes at gas mark 4 or 180°C.



Coconut Pyramids

1. Combine 200g dessicated coconut with 100g caster sugar.
2. Add 2 beaten eggs.
3. Use egg cup to form pyramid shapes (dip egg cup in a cup of water in between pyramids to stop the mixture from sticking).
4. Place pyramids on rice paper on a tray.
5. Bake for 20 minutes at gas mark 5 or 190°C.

Milkshake

1. Use a blender to combine yoghurt (vanilla flavour is often popular), banana and apple juice, plus other fruits of your choice.

Pizza Toast

1. Toast slices of bread.
2. Spread one side with tomato ketchup or tomato pasta sauce (as desired), and sprinkle with grated cheese; heat under a grill till cheese is melted and bubbling.
3. You can also have lots of fun doing things to this; make 'smiley face' pizzas by adding a dollop more ketchup on top of the cheese for a nose and eyes (you can add various cooked veggies for 'hair' too!).

Cheesy Shortbread

1. Put into a bowl equal quantities of grated cheddar, flour and (softened) butter - say 100g of each (but could be 250g, so long as equal quantities of each, depends how many you want to make).
2. Rub together till butter lumps have disappeared, and knead into a cookie dough.
3. **EITHER** roll the dough out and cut it - in 'straws' or with cookie cutters (round or shaped - these are great party biscuits!) **OR** even easier is to make it into a thick sausage, wrap in grease-proof paper or foil, and chill in the fridge (and it also freezes very well at this point); when hard (half-an-hour to an hour), unwrap it and simply slice it, put slices on baking tray.
4. Bake in a medium hot oven, gas mark 5 or 190°C for 8-10 minutes.

EXTRA CALORIES

Children born with single ventricle heart conditions usually have higher than average calorie needs. Below are some suggestions for increasing your child's calorie intake if they are not gaining weight as well as they should be.



All children under two should have full fat milk products, not semi-skimmed or skimmed milk; children under five should not be given skimmed milk. If your child is drinking cow's milk, regardless of their age, they could always have full fat milk or they could try gold top milk. There are also some high calorie milks available on prescription eg Infatrini, Nutrini. If your child needs this type of milk, your dietician will prescribe the most suitable product. You may find that you can use high calorie milk in cooking eg to make custard or sauces.



It may be that your child needs calorie supplements eg Maxijul, Calogen, Duocal. If needed, these will be introduced gradually under the guidance of a dietician. You will be able to get the ingredients on prescription, and you will be given a recipe to make up the milk or other drinks at home.



Many children prefer to eat little and often, so make sure each meal or snack consists of small quantities of high calorie foods.



Think of snacks as being as important in your child's day as their meals. Try to offer savoury snacks such as crackers with cheese spread, as well as foods such as biscuits, yoghurts, cereal, fruit and vegetables.



Think of ways of adapting recipes to increase their calorie content. You could add milk (full fat cow's milk, or Infatrini where appropriate) when a recipe specifies water or stock. This works for savoury recipes and for puddings eg jelly. You can also add butter or cheese to savoury dishes eg cheesy mashed potato or cheesy rice.



Ideas of foods which often work well for increasing calorie intake are Greek yoghurt, high protein foods eg meat, dried fruit such as dried apricots (which are also a good source of iron), milkshakes, cheese straws or cheese on toast.



Use any combinations which work for your child - many parents have found that mixing fromage frais (eg Petits Filous) / yoghurts with other foods helps!

USEFUL RECIPES

Cheese Sauce

1. Mix 25g cornflour in a cup with small amount of milk until no lumps.
2. Heat 250ml milk in saucepan until nearly boiling (this can be high energy milk or full fat cow's milk).
3. Add cornflour/milk mixture stirring all the time, and let it bubble for a minute.
4. Add 50g grated cheese and optional 25g butter. Stir until it melts.

Basic Pasta Sauce

1. Melt a knob of butter in the pan; add a couple of large spoonfuls of soft (cream) cheese, stir in until it starts to melt; add a little milk and it will smooth out into a sauce.
2. Then add grated cheese, to taste.
3. You can also add ketchup to this, to make 'pink sauce'.

This sauce is particularly good with tuna and sweetcorn - and can also be good as a way to sneakily get a few finely chopped vegetables down...!

Ice Lollies

Combine your child's usual milk with puréed fruit and freeze it in special moulds.

Rice Pudding

1. Combine 50g flaked rice with 25g sugar and 600ml (1pt) full fat milk.
2. Bring to boil, then simmer for 10-15 minutes, stirring occasionally.
3. Add pureed or chopped fruit to serve.

This quantity should make a pudding for a family of four.

INCREASING FLUID INTAKE

You may have been advised by your child's cardiologist to ensure that they are kept well hydrated. As not all children drink well, here are some ideas which may help. These ideas may also be useful to reduce constipation.

- ✓ Many schools and playgroups have water dispensers, which can be fun for your child to learn to use.
- ✓ Try all sorts of different drinks, and maybe call them something different eg magic milk and fairy water. Drinking chocolate is often a favourite and of course pink milk - made famous by Charlie and Lola!
- ✓ Experiment with different cups and beakers. See if a favourite character cup helps.
- ✓ Ice lollies can be a good way of getting fluid into a child who doesn't drink much. Companies such as Ikea and Lakeland sell ice lolly moulds which you can fill eg with fruit juice, puréed fruit or yoghurt drinks.



Choose from a range of beakers

This section of the feeding pack gives suggestions of ways to approach other problems some of our children encounter.

Spoon phobia - try to introduce finger foods and have a complete break from meals needing a spoon, then re-introduce gradually with a soft weaning spoon or a favourite character spoon. Many foods can be eaten without a spoon, eg by dipping pasta pieces into a vegetable puree, wafers into fruit, biscuits into yoghurt, bread into soup (which can also help to get vegetables eaten), toast soldiers, etc. Another idea is to use breadsticks with something on the end to make a 'lollipop'. Cheese spread can be used either on its own or as a sticking agent, then add ham, cucumber or chicken. Other food ideas to go on the breadstick are cheese or corned beef.

Hating lumps - have a complete break from lumpy food for a short period of time, then introduce slightly lumpy foods for part of the meal only (a few mouthfuls). Or you could try a different approach such as thicker purées, finger foods, or mashed foods. With some children, changing the look of the food might be a better approach, for example put in colours, or cake sprinkles, eg pink and purple porridge with coloured sprinkles - encourage them to eat the first layer, then sprinkle again! And yes, you can even sprinkle puréed veg - and it does work...!

Taking too long over feeds - see if it's possible to change the feeding plan to include calorie supplements so that a smaller volume of milk is needed.

Reacting badly to a prescribed high energy milk - talk to your dietician who may suggest a different high calorie milk or could give you ways to increase calories in another formula milk. You could also try cooking with the prescribed milk (eg custard,

OTHER COMMON PROBLEMS

adding Infatrini to packet baby food) or adding flavours to the milk eg chocolate or strawberry milkshake mix.

Constipation - this is often reported by parents, and may be because of fluid restriction and diuretics. If your baby is old enough, you could try offering fruit purees or a few drops of freshly squeezed orange juice diluted in cooled boiled water (or one part orange juice to ten parts cooled boiled water - but no stronger than this). Older babies and young children may enjoy dried fruit eg apricots or stoned prunes, either as finger foods or cooked and pureed. Medications such as Lactulose may be prescribed, but always seek medical advice before using laxatives.

Total mouth aversion - some babies (often if they have been in intensive care for a long period of time) will not tolerate any touching near their mouth, which makes any move towards oral feeding very difficult. In these cases, you need to try to desensitise your baby's mouth area with stroking, kissing and other games. If they are very sensitive, you may even need to start with your baby's arms or legs, using a firm touch, then move gradually over time to their head/face/lips/mouth. The next step would be to play with food, for example by putting a small amount of food on a highchair tray, making sure there is no pressure at all to actually feed - the food is just there to feel and play with. Eventually, your baby/child will probably experiment by putting the spoon in his or her mouth, which should in turn lead to acceptance of the idea of spoons and food. This may take some time (in some cases it could take months, not just days or weeks), but the likelihood is that your child will one day learn to eat. Always ask for help, for example from a specialised speech and language therapist, if your baby is in this situation.

AND FINALLY...

Feeding can be a really challenging area, so we hope this booklet has given you some useful ideas. Please don't hesitate to ask for help from health-care professionals and Little Hearts Matter if you need it. Good luck!

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