



Southampton
Hospital Charity

PARENT INFO

Information on feeding for infants
with congenital heart disease



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Introduction

Congenital heart disease (CHD) is one of the most common birth problems in babies. For lots of different reasons, your child may have problems with weight gain and feeding.

We have written this booklet with the help of parents, and the information is based on what they have told us would have been reassuring to know as well as what to expect in terms of feeding and growth.

What should you do if there is a problem?

If you are ever worried about your baby's health contact their health care team as soon as you can, using the contact numbers you have been given.

Your baby may need an urgent medical review if they have any of the following;

- Does not want to breastfeed or is drinking less than half of their bottle of milk
- Has fewer wet nappies than usual
- Has a temperature of 38.5°C or more
- Is quieter or sleepier than usual
- Increased sweating during feeds
- Increased vomiting
- Not gaining weight or is losing weight
- Is a different colour or has a slower or faster breathing rate
- Or you are in anyway worried

In an Emergency always dial 999

What to expect – in the first few weeks

What is congenital heart disease?

Congenital heart disease is the name that doctors use to describe heart defects babies have been born with. Congenital heart disease may be caused by holes between chambers of the heart, or a change in one or more of the heart vessels or valves.

What is likely to happen in the first few days or weeks of life?

Some babies will only have one heart surgery during the first few days of life, whereas others may need several during the first year of life and later on in life.

What can you do during this time to help with bonding and feeding?

Babies enjoy skin to skin contact

There are a number of things you can do with your baby to help with bonding, as well as feeding. Where possible – try to have skin to skin contact with your baby, especially in the first few weeks, as this can be comforting for you both;

- Skin to skin contact is where your baby is naked – except for a nappy
- When you are sitting in a comfortable chair, lay your baby on your partially exposed chest
- You can cover your baby with a light blanket to keep you both warm
- Skin to skin contact has been shown to relax babies, helping them feel calmer
- Dads can do this too!

Sometimes babies are too poorly and skin to skin contact is not possible

- If you are not able to hold your baby during this time, you will be able to stroke their cheeks and do other forms of positive touch such as massaging their feet and hands
- Sing or talk to them at the same time, as they will already know the sound of your voice
- Put a muslin cloth or toy that you have been holding near them as it will have your smell on it

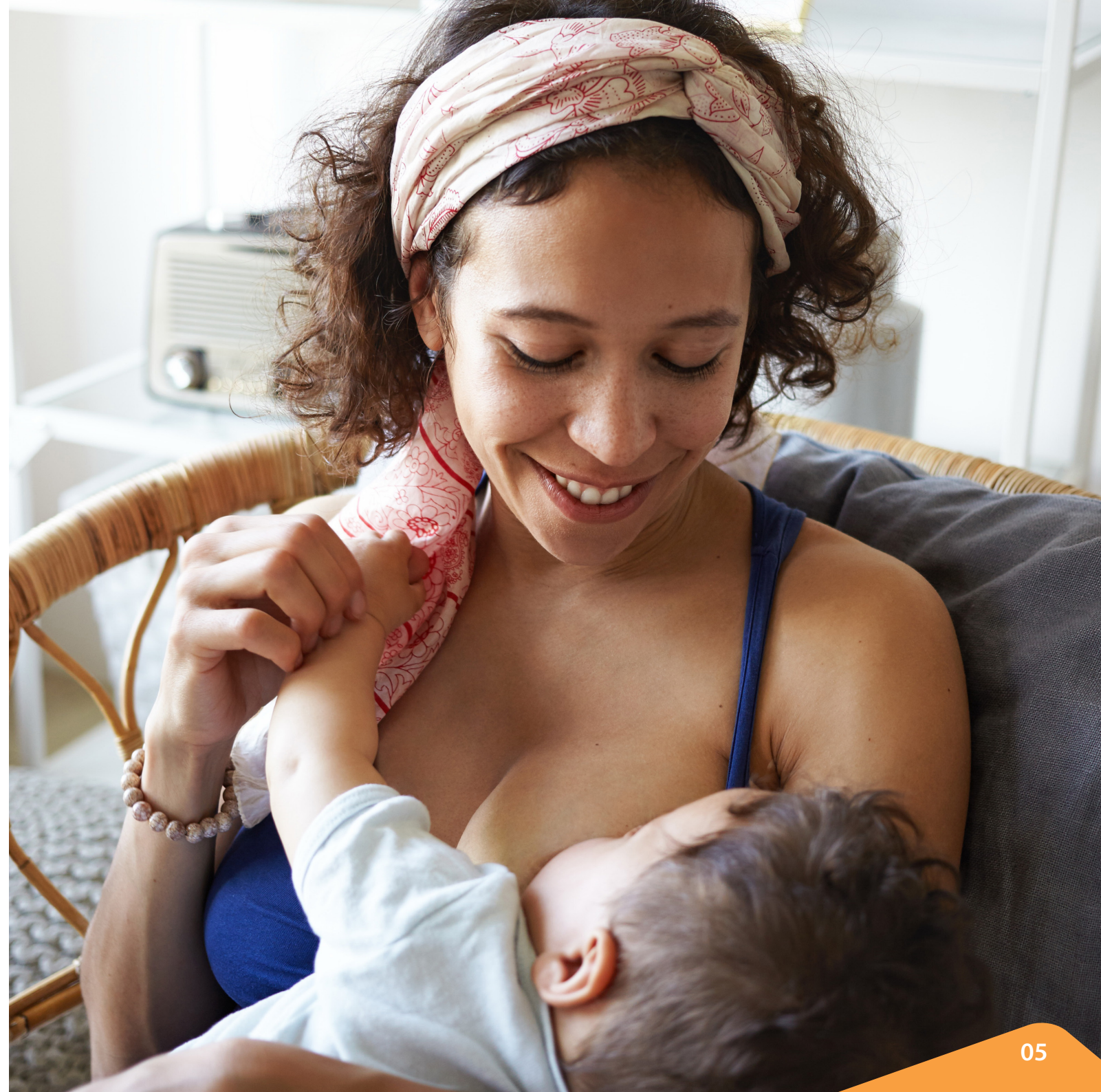
PATIENT STORY:

My baby didn't have anything by mouth for over a month as he had a feeding tube into his stomach. During this time we were able to use a dummy, which really helped his sucking. Even when he was in paediatric intensive care unit and ventilated (on the breathing machine) he sucked a dummy.

Before he had his surgery, I was really worried he was never going to drink by mouth again and that he would have forgotten how to drink. He kept vomiting before his operation and needed lots of suctioning in his mouth which made him cry.

After his surgery, we were warned it might take weeks for him to learn how to suck again. But by the 2nd day of being back on the ward he began to take 5ml by a bottle and by the end of the first week was managing most of the milk in his bottle. What he didn't manage to drink was put down his feeding tube.

It was good to know at the beginning why he might find it difficult to drink as it made me relax a bit more about feeding times.





What to expect – weight gain & feeding

Babies who have their heart surgery during the first year may not gain enough weight on breast milk or standard infant formula and often need a high energy infant formula as well, shown in the table below. Your baby’s health care team will work with you to come up with a feeding plan that suits your baby.

Name	Uses
Breast milk & infant formula	Breast milk is best for at least the first 6 months of life. If your baby is not able to breastfeed then expressing breast milk is an option. Where it is not possible to breastfeed or express breast milk babies should have infant formula
High energy infant formula: SMA Pro High, Energy Similac High Energy, Infatrini	These high energy feeds may be used in combination e.g. every other feed is a high energy milk or as a top up following their usual milk
High energy Infant formula – hydrolysed: Infatrini Peptisorb	This high energy feed is partially digested and may be easier to tolerate, easing symptoms of reflux or vomiting

How much weight should my baby gain?

Being a good weight will help prepare your baby for surgery and help your baby recover more quickly.

- Your baby should gain around 200g per week for the first 6 months
- Each baby’s journey is unique and some babies gain weight as expected but for others weight gain is slower
- A high energy feed may help your baby gain weight

What are common feeding concerns?

Babies with CHD are more likely to have feeding problems and many parents find feeding very stressful; as they feel that every drop of milk counts.

- Heart defects increases the chance of your baby having symptoms of reflux or vomiting
- This is because their tummy empties more slowly following a milk feed
- Both of which increase their discomfort when feeding – your baby may squirm and wriggle a lot during a feed
- Some babies with CHD may also have a syndrome e.g. Di-George which can impact on feeding

Your baby’s team or GP may be able to prescribe some medicines to help with some of the symptoms of reflux.

What can you do if there are feeding problems?

If your baby is developing feeding difficulties such as retching or gagging with feeds, the following might help.

Feeding tips

- Although your baby will still need to drink a certain amount each day demand feeding can sometimes be better – offering your baby milk when they seem hungry
- Stop feeding when your baby has had enough – often babies vomit if they are too full
- Offer a high energy infant formula as they will need to drink less to get the same energy

Babies also pick up on how you are feeling

- Try to relax at feeding times, using mindfulness techniques can be helpful
- It can be helpful to ask someone else to help with feeding times

Positive touch and massage is a good way to bond with your baby, as well as overcoming feeding problems

- Try to do baby massage 3 – 4 times per day
- Gently stroke your baby's face for as long as they seem to enjoy it
- If your baby doesn't enjoy having their face stroked, start by massaging their hands or feet
- Talk to your baby whilst you do baby massage

Reduced feeding

- If your baby has not been able to finish the usual amount of milk for more than 2 days in a row, get in touch with your baby's health care team, as your baby may require an urgent cardiac review.

Even if your baby drinks a high energy feed, they may not drink enough to gain weight and need a feeding tube

Before and after surgery some babies may need a small tube down their nose into their tummy. The tube is used to give medicines as well as their usual feed. Some babies need a feeding tube for a few days and others will need them for months.

The most common reasons babies need feeding tubes are:

- Getting tired when feeding
- Using all of their energy on feeding
- Getting full quickly, so they are not able to finish all of their bottle feeds
- Coughing or choking when drinking
- Following a surgical procedure, as they might be sedated or drowsy
- Vomiting
- Severe reflux and discomfort on feeding

For babies who have their usual milk through a feeding tube

- Many will still be able to breastfeed or bottle feed as well
- If they are having their usual feed via a feeding tube, make eye contact, smile and talk to them and where possible cuddle them as they are being fed
- Some babies may have all of their usual milk through the feeding tube and have very little by mouth
- If this is the case using a dummy may help your baby maintain some of these skills
- Babies can learn about the taste of milk through dummy dips

- When able to, offer your baby your clean little finger to suck on, which can be dipped in your baby's usual milk
- Your finger or dummy should be coated in milk, but not dripping
- During the day you can do this every 2 - 3 hours
- If possible give your baby dummy dips at the same time as your baby is having a feed through the tube

Longer term feeding tubes

Some babies who have a feeding tube for many months may need to have a gastrostomy. A gastrostomy is a surgical opening through the abdomen into the stomach. A feeding tube is inserted through this opening which allows children to be fed directly into their stomach. This will mean the feeding tube from their nose to their tummy can be removed.





PATIENT STORY:

We found out about our baby's heart condition at our 20 week scan. Our baby girl would be born with a hole in the heart called an atrioventricular septal defect (AVSD) and Down's syndrome. She was born early at 35 weeks, and we spent time in a Special Care Baby Unit, before being transferred to our local hospital. She had to be fed with a feeding tube when she was born and we went home with this, which was daunting.

She needed a feeding tube which was really difficult, and we spent a lot of time trying to breastfeed our little girl. However, in the first couple of months she struggled to gain weight – which was really stressful, as it was so disheartening every time she was weighed. We ended up having to have a high energy infant formula 4 times per day as well as expressed breast milk. It was really hard to know that even though we were trying with breast milk, she needed formula as well. She also needed extra vitamins because she was born early. Having a baby with a heart condition and Down's syndrome is so different – we have older children but found we had to forget everything we ever learned about being parents and start from scratch again! We learnt instead to go at our little girl's pace and stopped trying to rush things, and I am so glad we did, as looking back now things slowly but surely got better with time.

Our little girl is now growing really well. She is a very smiley, playful little girl and is really enjoying all the tastes and textures that weaning can offer! We are still waiting for her surgery, but as she is now gaining weight well it worries us less and feeding is getting less stressful every day. The most important thing for us was that we were listened to when we had worries about our little girl's growth and feeding – we got lots of help.

It was good to know at the beginning why she might find it difficult to drink as it made me relax a bit more about feeding times.

How will I know what and how much milk to feed when I go home?

Your baby's team will give you a 24 hour feeding plan which may include

- A set number of breastfeeds or bottles per day with a fixed amount of milk per bottle e.g. 50mls of milk every 3 hours, which may help if your baby never seems hungry

Or

- A total amount of milk for the day which you can give on demand when your baby is hungry
- Before your baby goes home, they will need to be gaining weight. If this is not happening your baby may go home with a feeding tube, (a small tube down their nose into their tummy).



What to expect – after surgery

What is likely to happen with weight gain and feeding after surgery?

Following surgery your baby will go to the paediatric intensive care unit and will be ventilated (on the breathing machine) for a few hours or days. Having a breathing tube causes a sore throat and as a result some babies do not drink their usual milk or eat quite as well as they normal would for number of days following surgery.

What can I do about it?

After surgery, some babies may take a few days to drink from a bottle or breastfeeding and might need a feeding tube for a bit longer.

Once your baby is off the breathing machine, they are likely to have a feeding tube for a few days, which is used to give medicines and their usual milk

- If you are able to start oral feeding; offer your baby 5 – 10 ml of your baby's usual milk 1 – 3 times a day
- As your baby is able, increase the amount per feed and number of feeds until they are back to their usual feeding pattern

For babies who have started solids

- You may find they don't want to eat anything for a few days, this is quite normal and when they do they may only want to only eat smooth foods
- Even in hospital babies learn by example, so eat with them or in front of them
- Keep calm at feeding and mealtimes – some days will be better than others
- Ask other family members to help with feeding

- Keep trying with 3 small meals a day – a meal may just be a taste of puree on their lips or 1 – 2 teaspoons
- If they signal they have had enough stop offering food or milk

How can I help my baby gain weight?

Following surgery your baby should start to gain weight. The aim would be to help them gain weight back towards the growth line (centile) they were born on.

The speed at which catch up growth happens varies, but the ideal is around 12 weeks after surgery. Trying to achieve catch up growth often happens around the same time as you have started weaning your baby onto food. We have developed high calorie recipe books to guide you through the weaning process for babies and toddlers.

This book can be used alongside our 3 recipe books:

- **For babies who need to make the most out of every mouthful**
- **For toddlers who need to make the most of every mouthful**
- **For young people who need to make the most of every mouthful**



There are lots of different recipes and suggestions, but our top tips are as follows;

Breakfast:

- Add ½ – 1 teaspoon of smooth nut butter (almond, cashew, peanut) to warm baby porridge or
- Add 1 tablespoon smooth fruit puree
- To make the puree to the right consistency for your baby use your baby's usual milk instead of water

Lunch & supper:

- Offer protein at both main meals such as meat, fish, chicken or beans/lentils with a starch (rice/potatoes/pasta) and vegetables – add ½ – 1 teaspoon of a smooth nut butter
- As your baby gets older e.g. > 9 months of age and their portion size increases, increase the amount of nut butter to 1 – 2 teaspoons per meal
- Following a meal offer a fruit or full cream yogurt based dessert or custard or rice pudding or mashed avocado
- For older babies e.g. > 10 months, a teaspoon of grated cheese or cream cheese can be added to mashed potato or meat dishes, instead of a nut butter



PATIENT STORY:

I thought the day would never come when my little girl would eat or drink. Food for us has been such a difficult journey. When I look back now, there are times when I felt quite low about it all. If I could go back and tell myself then what I know now, I would say "don't worry so much – she will gain weight and eat eventually". I tried breastfeeding in the beginning but had to stop as all the stress of her being so little and poorly made my milk dry up. As she wasn't growing she had to have a feeding tube, which was really stressful in the beginning as she was vomiting ALL the time. She ended up having a gastrostomy (a feeding tube directly into the stomach) – which did help but she would still be sick after some feeds.

When I went home I felt alone, as going out was such an effort and when we did people just stared and some made horrible comments – there were some kind people who had been through the same thing and gave advice of social media groups to join, which was a lifeline.

She eventually started to gain weight... but by the time she was 1 year old she wouldn't eat or put anything in her mouth. We worked with a dietitian and speech & language therapist to come up with a feeding and eating plan and slowly she became a bit more interested in food. It took ages – at least 9 months before I could think of not giving her a feed down her gastrostomy.

Now – she is just turning 2 years of age and has had her final surgery. She no longer uses the gastrostomy and we are planning to have that taken out soon. Mealtimes are so much better. Don't get me wrong, not all of them are good – but they are so much easier than they used to be. Although she is still little for her age, she is catching up quickly. I am glad we are out of the other side and each day is easier than the one before.





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