



The Down Syndrome Association Gauteng

DS SUPPORT

FEEDING PROBLEMS

**Acknowledgment:
Down's Heart Group (1998-2013)**

Feeding Problems

Babies with Down syndrome have a tendency to early feeding problems possibly as a result of poor muscle tone, and babies with a heart problem also tend to have problems as they tire easily when feeding. So, babies who have a heart defect and Down syndrome have two things making it harder for them and poor feeding and slow weight gain are common causes of anxiety for parents.

If you are currently struggling with feeding your baby, perhaps the following will give you some ideas and encouragement or at the very least help relieve some stress. And whether breast or bottle fed, your baby is likely to settle and feed better with a relaxed mum rather than one who is constantly worrying about weight gain, so do try to enjoy your baby and not focus all your concentration on their weight.

Weight

Make sure their weight is being plotted on a growth chart specifically for children with Down syndrome. With a heart defect they are likely to be on a low centile (growth line) on the chart, but this will give a far more accurate picture than plotting them on a standard growth chart.

Don't expect too much, all babies lose weight after birth and those with heart problems and also those with Down syndrome tend to put on weight more slowly, so your baby is no different. The main thing is that their weight is monitored and that they continue to put on weight rather than losing it, even if the increase is very slow.

If your baby is prescribed diuretics (medicine to make them wee and get rid of excess fluid) this will cause initial weight loss and needs to be allowed for when monitoring weight. Diuretics can suppress appetite and sometimes even cause vomiting.

Adjust your expectations – if you are expecting your baby to take 30ml at a feed and they take 40ml you will be pleased. The other way you may be given an energy supplement to add to their milk. There are several different types available including Calogen, Duocal and Maxijul and you will be advised how much to use by the dietician. Supplements can be added to both formula and breast milk and may also be added to food such as yoghurts when you begin weaning.

Feeding generally

Some heart babies are very sleepy and don't automatically cry when they are hungry, so parents have to wake them for feeds. You can try changing them, rubbing or tickling their feet or perhaps bathing them, different things work for different babies. You may also need to keep them awake by stimulating them during the feed.

Babies will often fall asleep part way through feeding without taking a full feed. This may then mean that their next feed is needed earlier, and this combined with the length of time for each feed can mean that parents seem to spend virtually all their time feeding. A little and often is much better though than trying to force them to take a whole feed that they just can't manage.

Accept any offers you get to help with the housework and washing, as much of your time will be taken up with feeding in the first few months. And if you don't have helpful friends and relatives on hand to help, don't stress about a bit of dust and a few cobwebs; you will soon catch up with the housework when life settles down.

If your baby is getting too tired to feed properly, the doctors may decide to feed them via a naso-gastric tube. This is a thin tube which is fed up the nose, down the throat and directly into the stomach. It is held in place with a small piece of tape on the cheek and needs to be changed every couple of days, usually from one nostril to the other. At first the nurse will put the tube in, but many parents are quite happy to learn how to do it safely themselves.

When baby needs feeding, first of all you have to check the end of the tube is still in the stomach, (either by drawing up a small amount of fluid from the stomach and testing it with litmus paper or by listening with a stethoscope) and then a medium sized syringe is attached to the end of the tube and the milk is allowed to go down under gravity (the plunger is removed from the syringe and should not be used to force the milk down.) Parents very quickly get the hang of tube feeding if their baby needs it.

Breastfeeding

Sucking is hard work so make it as easy as possible. If you are breast feeding, try expressing a little milk to start with to get it flowing before you latch baby on, that way they get an immediate reward for their efforts and don't waste valuable energy stimulating milk production.

If you are having problems breastfeeding and have to feed breast milk from a bottle for a while, do keep putting the baby to the breast and try stimulating the baby's mouth with your finger before feeds. Stroke gently around baby's mouth and cheek, put your clean finger in their mouth to help with sucking and gently stroke downwards on their throat to encourage swallowing. Be persistent, it may take a while but eventually your baby will get the hang of feeding.

If you are expressing breast milk a hand pump can become hard work. Consider investing in an electric pump or enquire about borrowing one from your local special care unit, N.C.T. or La Leche League.

If you are breastfeeding but not producing enough milk for your baby's needs, they can still benefit from however much breast milk is available and the remainder of their feeds can be made up with formula. Breast milk can be given with a bottle or even by naso-gastric tube (a tube that goes directly into the stomach via the nose and throat), if baby tires too easily to feed on their own.

You may consider using a supplemental nurser, which is like a bottle of milk hung round mom's neck leading to a fine tube which is taped to the breast. The milk feeds by gravity so baby doesn't have to suck hard but is still latched on to the breast.

If you decide to give up breast feeding because your baby is not putting on enough weight and you have been advised to do so, it is worth continuing to express milk and freeze it for a few weeks more. That way, if the change to formula doesn't give the desired weight gain, it is possible to revert back to breast feeding if you want.

Breast feeding is recommended for babies as through it the mother passes on much of her own immunity to infection. This is of course even more important when the baby has a heart condition, particularly prior to surgery, but you should not feel bad if your baby is not breastfed or you are unable to breastfeed for very long.

Expressed breast milk can be placed in sterile bottles and stored in the freezer to be used later. This can be particularly useful if your baby is in hospital for a few days and around admission for surgery.

Bottle feeding

If you are using a bottle, either for formula or breast milk, make sure the hole in the teat is big enough to allow a good flow, but not too fast or baby will choke. You may also find using a premature teat helps as they are smaller and fit better in a tiny mouth.

Try rotating the bottle gently whilst the baby is feeding to help release the vacuum that builds up with sucking.

Experiment with teats (there are many different types available) and additives to find the combination that suits your baby. Adding calorie supplements not only helps with weight gain but can also thicken the milk and make it flow slower from a bottle. This in combination with a latex teat with a large hole can make it much easier for baby to feed and load up on those vital calories.

There are many different feeding systems on the market, many of which are designed to reduce colic etc.; but can lend themselves very well to our babies. It is worth looking into these and asking if they have samples or starter kits which may offer better value for money – examples are the Haberman Feeder and the Playtex feeding system.

Weaning

Try adding baby rice and formula milk to vegetable and fruit puree to give a milder flavour and add extra calories.

Many children can tolerate smooth foods or solid foods but can't tolerate the different textures together until they are quite a bit older. It takes a skill that they haven't acquired to cope with smooth foods with lumps in.

Later on, offer a wide variety of foods but do not force a young child to eat them, and do not assume they will dislike strong flavours – some parents have had most success with feeding where food has been covered in spicy sauces. Let them choose what to eat and give them the opportunity to feed themselves even if they get covered in food, take ages and don't eat much. It is all a valuable part of their development and if you don't make an issue of it, they won't associate eating with stress and anxiety from you.

When they get on to feeding themselves, try to find cutlery with thicker handles that are easier to hold and offer better control.

When you are trying to encourage self-feeding, try having your little one sitting in their high chair at the table with you whilst you eat. This will help develop a good attitude to eating and encourage good table manners.

Try putting your baby's hands on their bottle, cup or cutlery and holding them there before putting them to the baby's mouth to get them used to the co-ordination needed for self-feeding.

When you are trying to teach how to drink from a straw, try using a juice carton as you can gently squeeze it to make the juice come up the straw in the mouth. Or else suck a thick milk shake up a straw and quickly put your finger over the top to create a vacuum, then place in the child's mouth and slowly release the vacuum to let the milk shake out. The sucking of a straw may help with the development of the mouth muscles.

Addition sources of information

From Milk to Table Foods: A Parent's Guide to Introducing Food Textures

Moving Ahead with Food: Matching Oral Motor Skills and Food Textures

Feeding & Nutrition Overview – includes Overview, Breastfeeding, Transition to Textures and Weight Management