

FEEDING

What can go wrong and how can I help?

<u>Problem</u>	<u>Possible Solutions</u>
Poor sucking	Try using non-standard utensils (e.g. Haberman Feeder, spoon-feeding, Doidy cup. Adapting use of a normal bottle (e.g. enlarges the hole. Apply pressure to cheeks while feeding).
Delayed repair of cleft Palate	Try solutions above or bottle and prosthesis.
Swallowing problems	Mad as it may seem, it is often easier to swallow thickened liquids. There are commercially available products which your GP can prescribe. Do avoid runny liquids with small lumps!
Poor chewing	Although it sounds obvious, you can only chew if you have a solid diet. Salty or tart food may help. Place food on teeth or gums at the side of the mouth. Hold the lips together and rub the cheeks. Support the jaw with your thumb under the chin and guide a chewing movement. Try to stimulate the transverse tongue reflex.
Bite reflex	Never try to prise or pull the mouth open. Avoid using metal spoons which may cause pain. Wait for the child to relax and then remove what is being bitten. Pushing

the chin up slightly may assist release.

Quantity of milk

Present little and often. Don't make it a battle. If your child is small size a full feed may not be necessary, but check with a dietician. Ask your GP.

What if my child is tube fed!

Tube feeding can lead to various problems when introducing normal feeds. When a naso-gastric tube is in place, the normal process of swallowing may be affected making the child more likely to be sick during normal feeding. Therefore try to introduce oral feeds when the tube has been removed (e.g. for cleaning).

Children who have overnight feeds miss the social aspect of regular mealtimes. Do try to involve your child in family mealtimes.

What next?

Always introduce changes when both you and your child are well. All changes will take time; don't be put off if you have a bad day.

These are only guidelines and suggestions. Every child is different and what works for one may not work for another. You may refer yourself to a Speech and Language Therapist at any time. Your Health Visitor will tell you where to find one.

If you think you have found a good solution for any difficulty, share those findings with your Speech and Language Therapist who can then let you know whether there are any reasons why you should not solve the problem in this way.

Have the courage of your own convictions. "Experts" are not always right and anyway, in dealing with your own child, you are also an expert - you know them better than anyone else!

Feeding - parent's views and experiences.

Right from the start my child was a terrible feeder. I think I tried every brand of baby milk on the market, but every feed was the same, half an hour to get 100 mls down and about half a minute to get a lapful back! When she started on solids, there had only to be a tiny lump in it to get it all back.

As for feeding herself, she just didn't want to know. She was nearly five years old before she would feed herself and, even then, she was very reluctant and wouldn't eat anything that needed chewing. I was still using jars of baby food until she was seven or eight as it was the only thing that she would actually eat.

I can remember when she started school and they tried giving her the ordinary dinners, she used to hold food up in the roof of her mouth and they would try to hook it out with the end of a spoon. Eventually, she was cured of that by not being allowed to go in the hydro pool unless she had got rid of it all, as bits of food used to come out in the water!

Even now, aged 13 years, she doesn't really chew properly and prefers food that just slips down, although I think living in a boarding house during the week has improved her eating, they seem to have had more success with her than I ever have.

After struggling with various eating programmes for almost 13 years, we realise that our daughter is never going to be overweight! She has now reached the grand target of 2 $\frac{1}{2}$ stone.

When she was feeding from a bottle (which she did for about 3 years), her main problem seemed to be the copious amount of mucus she produced through her nose which prevented her breathing and sucking. Feed times seemed to go on forever - one running into the next. We tried suction before meals but this was never very successful. Once she started on solids things did get easier.

She has a varied diet at the moment; she has a really good appetite and eats four meals a day. She drinks lots of milk for which I am grateful when she doesn't want to eat.

School think that she should be able to chew and have things like sandwiches. While I think that this would be good, I feel the she wouldn't eat enough to get nourishment.

The anxiety we went through when she wouldn't eat the required daily intake slowly became less when we came to terms with the fact that, no matter how much she eats, she will never weigh the same as her peers. Now we offer our daughter dinner and pudding in whatever order she wants it and don't worry if she refuses, as she will make up for it at the next meal and as long as the drinks are going well that's fine by us.

My advice would be - if in doubt mash or liquidise it.

As a baby, my son showed no interest in food and was unable to suck. He was tube fed for some time. At four years old eating is now one of his favourite pastimes. He enjoys almost anything that is served up to him, especially chocolate bar ice cream.

My son was born with a cleft lip and palate. We were given a Haberman feeder bottle to use. This took some time to get used to but worked well. After his repair operation, I was advised that he should use a normal bottle. After 10 days of sitting in tears trying to feed my baby with all sorts of bottles which flooded milk out, I gave up and sat with an egg cup and a syringe all day and all night to get the milk down. After a few weeks I tried the normal bottle again. He sucked and sucked but the milk didn't go down. I changed to different teats, made splits and holes, without any improvement. Then I found a miracle cure - a cheap soft-bodied bottle that you could squeeze a little as the baby sucked. Well, these bottles saved my life! They are not a special make, just cheap and soft. I passed this idea on to another mum in the group and she found that they worked for her too.

I was given vitamins to add to his milk feeds but found that, if I added too much at once, he would vomit. So I started to put some in milk feeds, adding the rest to milk used for breakfast and milk puddings.

My son would cough sometimes when being fed and vomit the whole feed up. He was sent for an x-ray to see if he had reflux but he didn't. I was told little and often as his insides were still very small at 8 $\frac{1}{2}$ months. While waiting for the x-ray, I was given infant indigestion medicine to add to the feeds. This seemed to stop the coughing and vomiting. I am continuing to give the vitamins and medicine with feeds and, although he occasionally coughs and vomits, it is nowhere near as often as it was.

He doesn't drink 5 ozs down straight away; it still takes time with a break in between. I tend to change his nappy or try to do some work!

He didn't like baby food in jars or tins. I use powdered foods. He wasn't keen on my liquidised dinners, so I gradually added mine to the powdered foods until now he just has my dinners. I bought things like baby rice to add to peaches or bananas, which all said, "Just add water" but I added baby milk - anything to add the odd calories.

I found it helpful to freeze dinners in ice cube trays then transfer to freezer labelled bags. Later, with larger amounts, I used yoghurt pots. I found that sweet corn and baked beans did not

suit him, the shells would go round and round in his mouth until they came out of the sides in the end.

It is so frustrating because, before my little girl's operation, she ate well. After her operation she was tube fed and still is.

My daughter was a healthy birth weight of 7 lbs 4 ozs. She was born with a cleft soft-palate and this was thought to be the cause of her feeding difficulties: she had an extremely poor 'suck' and was in special care for five days due to her 'failure to thrive'. Once at home she was continually sick - often bringing up the entire feed (30 mls) that had taken at least one hour to give her (this was a distressing time for us all, not only was she sick but the sickness used to pass up through her nose due to her cleft palate thereby increasing her discomfort). It took her six weeks to regain her birth weight.

A Haberman teat allowed us to feed her more easily although the process resembled force-feeding. By six months she had a very negative response towards feeding and it was decided that she should have her soft-palate repaired, however, 30 minutes before the operation was due to be performed, it was cancelled as the anaesthetist decided that she was too frail to be administered anaesthetic - she was by now just under 10 lbs. It was decided, at this point, that she should be fed by us overnight using a Kangaroo pump and a naso-gastric tube. The Consultant made it clear to us that this was a long-term commitment on our part. The tube feeding involved passing a tube every night and attaching this to a pump and feeding bag.

This was the turning point in our relationship with our daughter as the crushing pressure to try to feed her was reduced. We felt more relaxed and positive in our attitude towards her and, for the first time, she began to gain weight (even if only in increments of 10 ozs per week!). Over a period of months she began to exhibit signs of wanting her feeds.

While taking much of the pressure off us, the naso-gastric tube did have it's problems. These included our daughter pulling the tube up during the night causing her to choke and vomit. It also involved us in a lot of work as we were frequently up changing her bedclothes and nightwear.

After two interminable years of this type of feeding it was decided, in an effort to reduce her dependence on it, to attempt to reduce it gradually and we began the process of supplementing her oral feeds with two bolus feeds: one in the morning and one at night - this involved passing the tube twice a day. She tolerated this process despite it's unpleasant

nature (she didn't have much choice!). This continued for about a year. Eventually we cut out one of the feeds and she continued with this type of feeding for 12 months until she was 4 ½ years old - she then weighed 30 lbs. All the time that she was on this type of feeding, she was encouraged to eat and drink normally during the day and eventually the tube feed was just used as a supplement to her normal oral intake.

Our daughter is now five years old, weighing 33 lbs and the great benefit is that now she is keen to eat and is feeding herself. This is messy but she really enjoys it! She drinks considerable quantities of water which reduces the possibility of constipation. Her diet is 'normal' and she constantly asks for biscuits and drinks and, since she began chewing about 18 months ago, she will eat most foods.

It is hard to imagine what our daughter would have been like, with regard to feeding, if she had not been tube-fed. We believe that, without that process, she would not be feeding as well as she is today. In retrospect, all the stress was worth it.

A Haberman feeder is a specialised bottle designed to help babies with sucking problems. Other special teats and bottles are available.

Because of the amount of mucus my son produced it was suggested that perhaps he was allergic to cow's milk. I will do anything to improve feeding and possibly alleviate his almost constantly running nose. For about six months I tried using powdered soya milk. I didn't feel that it made any difference and returned to cow's milk.

Feeding during the first year was the worst part. The first few weeks seemed to be devoted to feeding my daughter by bottle and expressing milk in between! Hours were spent trying to feed her a miserable 60 mls, however, the weeks went by and she gradually took 100 mls or more per feed. She was so slow and difficult to feed and yet we were told that she must put on more weight or she may not withstand her first winter (in fact she had less colds that winter than most babies her age and seemed quite robust). It used to take about 1 ½ hours for her to take only 3 ozs of milk and then ages to bring up her wind. In fact, her inability to bring up her wind was probably one of the major barriers to her feeding unsuccessfully. We tried everything in fact; gripe water and medicine prescribed by the GP - none of these really helped.

At 21 months she is having pureed food in a bottle, which has a teat with an enormous hole in it (designed by ourselves), and this is the only way

that we can get her to take solids. It seems to be working as her weight has increased from 9 lbs 12 ozs to almost 11 lbs over the last two months. Great progress for our daughter whose weight had remained static at around 9 lbs for more than six months. She seems to thoroughly enjoy her pureed food and eats (or should I say `sucks` from a bottle) almost anything. It's amazing what you can do with a food processor. For example Weetabix can be reduced down to powder which we mix with milk and liquidised banana so she can drink her breakfast rather than eat it.

We would love it if our daughter could take food off a spoon and have tried for a year without success. She totally rejects anything given off a spoon, whatever its taste or consistency. She doesn't seem to know what to do with the food, except to push it out again. It often dribbles out of the corners of her mouth, however, she goes through the motions of chewing sometimes and will put a spoon to her own mouth occasionally but this gets very messy!

She is not distressed anymore by me trying to spoon feed her, in fact, she quite often finds it a huge joke and smiles sweetly with food all over her face, bib, hands and sometimes me. I'm sure we will get there in the end but it does seem to be a long, slow process.

My daughter didn't seem to like or enjoy her milk for the first year of her life. It took an hour to get 2 ozs into her. We tried everything from spooning the milk into her mouth to cutting a cross-split into the teat and a squeezey feeding bottle so that we could squeeze it into her mouth. Looking back now it was an endless job of feeding, which was all we seemed to do. She didn't wake to be fed so we used to have to wake her every three hours, spend an hour trying to get her to feed, until she eventually fell asleep exhausted - and so did we!

The turning point came at a year old, when we put her onto the feeding cup - we haven't looked back since. I think that she just didn't know how to suck and putting her on the cup meant she didn't have to suck, just let the liquid run into her mouth. We started spoon-feeding at 4 months and she took to it very well.

Now, at 10 years old, she can hold her cup and drink unaided, she can eat certain textured food but doesn't chew, so we lightly liquidise her food. She can hold a spoon for a couple of mouthfuls, but it's still very clumsy and as she really enjoys her food she wants it there and then and prefers you to feed her. She will eat almost anything and enjoys mealtime immensely. She must have hollow legs as the amount she eats outweighs her size.

When our son was born (3lbs 7ozs) he was tube and bottle-fed. Over a period of days more bottles were introduced. He was unable to suck and still cannot. Mucus from his nose and in his throat complicated matters. Feeding, therefore, took a long time and virtually meant shaking milk out of the bottle into his mouth. When we brought him home we were advised to feed him the same amount as a normal baby. After about a week, I went back to the hospital with my son because I was finding feeding him so difficult and I was sure that he wasn't taking enough milk. I was told that he was not dehydrated, that handicapped babies were often difficult to feed and to keep trying. Being my first child and so small, I felt he needed every ounce of milk to build him up. I tried altering holes in many different teats, thickening the milk and putting it on a spoon, I tried just about everything I could think of. He seemed to be sick after most feeds, in short, feeding time was awful.

I had been told that children with Wolf Hirsch horn Syndrome were small, however, I did think that by persevering with what seemed to be never ending feeds that his weight gain would be more than it was.

Introducing food wasn't any easier. No matter how many people told me to slowly introduce graduated sized lumps into food, nobody had told him that he had to swallow it. He stored it in his cheeks and gave it back to me in no uncertain terms.

After about nine months, I tried him with a cup with a spout, without success. It was then recommended that I try a "Doody" cup which has an open top and sloping edge, enabling the person holding it to see into the cup and control the drink. After many wet clothes he began to drink from the cup. He did not drink the amount recommended for his age and still does not but he kept it down, small amounts quite often. He wasn't so sick and still gained a little weight, slowly.

Perhaps if he hadn't been my first child, I would have realised sooner that possibly he was being sick because he did not need as much milk as other babies, that small amounts more often, might cut down the sickness. Then feeding might not have seemed to dominate each day. Also if I had known that "weight gain would be slow" really meant "weight gain would be hardly anything", I would not have worried so much.

Fifteen years on and I know that persevering does pay off. I will never forget feeling that I could not feed him again, but I did. When I bring his meals in now he giggles. He still cannot chew but I simply mash his food up and he enjoys it. He is learning to load a spoon and can put the food into

his mouth with supervision. He holds his cup and puts it to his mouth, however, most of the contents end up down his jumper - but he is trying and improving all the time. I would never have believed that he would get this far. Little steps, but for our son, real achievements.

My daughter's cleft lip was sewn up at seven days old. Cleft palate at five months and cleft fistula (which developed) at 6 $\frac{1}{2}$ months, up until then she fed with a bottle designed for babies with these problems. She fed fairly well, gaining weight on my breast milk which I was expressing in the hope that I could eventually breast feed, but I was discouraged by doctors who said her suck would not be strong enough. I stopped expressing then the round of different milks started as she began vomiting. Her weight went down, tube feeds were introduced and her weight slowly climbed 100gms per month.

Finally, a stomach reflux was diagnosed as causing the vomiting coupled with colic. When she was a year old, we went to Great Ormond Street about the feeding problem. Various medications for reflux, wind and colic were tried. Operating on her was out of the question due to the colic which would worsen post-operatively.

The vomiting has almost subsided now although wind is a force to be reckoned with. She has an orthodontic teat on her bottles with a hole large enough to sink the Titanic. She has solids and powdered milk due to a mild allergy to cow's milk. Solids take a long time to get into her; she just holds it in her mouth for ages before swallowing. Lunch can take 1 $\frac{1}{2}$ hours, small and often does not work as she is on such small amounts anyway - half a tin of savoury and half a tin of dessert.

I think that I might have to succumb to the suggestion of a Gastrostomy as suggested by her Speech Therapist. If I can get the feeding licked and the colicky wind pains obliterated, life would be easy.

During a stay in hospital for a routine assessment of my daughter, I saw the Dietician who suggested a supplement to give her extra calories because she hadn't put on weight for a few months. We mentioned the sickness and were given an appointment to see a gastric Specialist.

In the meantime, on the advice of the Dietician, we started making her milk strong and using milkshake powder to flavour it, as she seemed to be going off it. For a few days she was fine but, as the week went on, she couldn't keep anything down at all. We went to our General Practitioner who ended up sending us to hospital; by then the only thing that she could keep down was juice. At the hospital we gradually started giving her solids - no

milk - and she got better. Within two days she came home and was eating like a horse, her whole personality was different, she was so much happier and wasn't sick at all.

A week later we had our appointment with the Gastric Specialist. My daughter had a Barium Meal and probe put into her gullet for 24 hours to measure acidity. These tests showed she was suffering from reflux and luckily it wasn't too severe and could be treated with medicine. The Specialist said that he had seen all too many children like my daughter with various syndromes and handicaps who had reflux and were very slow to gain weight and parents and doctors had put it down to the Syndrome and done nothing about it. He said that it may well be part of the Syndrome but that doesn't mean it can't be treated. I just wish that we had done something about it sooner and then my daughter wouldn't have had so much upset being sick all the time.

Unfortunately, my daughter's sickness hasn't stopped completely as we had hoped. I am going to find out if there are different medicines we can try. Breakfast is a major problem; she sucks her thumb a lot through the night and seems to take in a lot of air.

If you are concerned about your child's feeding, please ask your Doctor, Health Visitor or Speech Therapist for advice. Parents are sometimes told, "this is all part of the Syndrome". This may be the case, however, as a parent you need to feel that everything possible has been looked into.

Not drinking and eating enough can cause problems with constipation; sometimes talking to a Dietician is suggested.

Constant sickness can be caused by a "reflux" and often a test for this is offered. It is sometimes recommended that various medicines to stop sickness, vitamins or flavourings could be beneficial. You must seek medical advice before introducing these.

As you will no doubt have been advised that children with Wolf Hirsch horn Syndrome vary considerably in their capabilities, this also applies to feeding. Many people find their child difficult to feed but some do not have any major problems at all.

USEFUL ADDRESSES

Cleft Lip and Palate Association
1st Floor
Green Man Tower
332 Goswell Road
London EC1V 7LQ

Tel: 02078 334883
Fax: 02078 335999
E-mail: info@clapa.com

Advice for parents of children on tube or nasogastric feeding

Half PINNT
(Patients on Intravenous & Nasogastric Nutrition
Therapy)
P O Box 3126
Christchurch
Dorset BH23 2XS

Tel: 01202 481625
Fax: 01202 481625
E-mail: PINNT@dial.pipex.com
Web: www.pinnt.co

(Best time to telephone between 9.30 am & 4.30
pm)