The Lived Experience:
NG Tube Feeding

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The Lived Experience: NG Tube Feeding

When you meet your extra special baby for the first time whether you already knew prenatally about Down syndrome, or it was a birth diagnosis, the thought of your baby having problems with feeding and needing to be tube fed (either short or long term) probably never entered your mind.

However, some babies who have Down syndrome may struggle to breast or bottle feed due to low muscle tone in the mouth, worries about a safe swallow, cardiac problems, and/or prematurity.

Often tube feeding is used in the SCBU if babies struggle to feed, and you may be able to take your baby home whilst still tube feeding if that is the only thing keeping them in hospital.

One important point to note is that it is perfectly possible to continue expressing milk (EBM) which can be given down the tube with the hope that you can establish breast feeding further down the line. Even if your baby needs high calorie milk this can be mixed with EBM so don't be afraid to ask to do this if that is your preference.

Ultimately the important thing to remember is that although it may not be what you had planned, fed is always best even if that needs to involve a tube.

Many parents have found themselves in this position so please don't feel that you are alone!

Here we have provided parents top tips and lived experience stories. These stories provide different experiences of the tube feeding journey to give you an insight into the journey you might find yourself on.

Although it might feel daunting at first and "just one more thing to deal with" you can and will get through it and enjoy those first months with your little one.

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★ Top Tips ★

Tip 1 - Oral skills

Tube feeding does not mean that your baby cannot continue to develop oral skills either through some bottle feeding, dummy dips and sensory play. Always be guided by the Speech and Language Therapy team to ensure they are happy baby has a safe swallow, but this may be something you need to push for and continue to ask for reviews when baby is in hospital or at home.

Tip 2 - Support at home

If your child is discharged from hospital whilst still tube feeding, ask for a plan to be put in place to support you to either develop oral skills or move to having the tube removed if this becomes possible. Ask for timescales and review dates to be confirmed and a referral to community Speech and Language to be made.

Tip 3 - Open access

Request open access to your local Children's Ward as you can guarantee your child will pull their tube out overnight at least once! If you do not have open access this may mean a long wait in A&E. Most tube fed babies are offered this as standard so again don't be afraid to push for this.

Tip 4 - Training

Request to be trained to pass the tube yourself to avoid needing to call out the Community Nurses or attend hospital. It is a completely terrifying thought when first suggested, but something you may decide you would like to do to make life easier. Don't worry if you feel that you don't want to do this but ask to be shown the procedure a couple of times before you make up your mind.

Tip 5 - Aspirate

Not able to get an aspirate?- Don't worry, slow down, take a breath. Roll your child onto their left side and attempt again, if not roll to the right and try and if they still aren't sharing try sitting them up. If this fails, start again. If still no joy, try giving a bit orally (if safe to do so) but be warned you may get a "milky 6" but you will know the tube is in the right place!

Tip 6 - Skin care

There are many creams available if your little one's skin gets sore. Some of our favourites are Medi Honey, QV Cream, Cavilon and even good old Vaseline. Community Nurses can be helpful in advising which product might be best.

NG Tube Feeding

Top Tips

Tip 7 - Going out

When out and about always remember to pack spare tubes, tape, and stickers so you don't have to go home before replacing the tube. You can guarantee the time you forget will be the time a little finger will hook that tube out!

Tip 8 - Prescription products

Familiarise yourself with the various products available to make tube life easier. Cavilon "lolly pops" can be used to act as a barrier before applying Duoderm. Appeel or Zoff wipes can be requested to help remove tape easily and there are many websites which offer different novelty tapes to match outfits and individualise.

Tip 9 - Further investigations

Trust your parent instincts and always push for further investigations if it's unclear why your child has the tube and what the plan is moving forward. Some of these investigations include video fluoroscopy, barium swallow, impedance study and CT scans.

Tip 10 - Different bottles

Many parents have found it makes a massive difference to try different bottles when attempting to introduce some oral feeding. Popular makes that have worked include Mam and NUK but each baby is different. It may be worth seeing if a different bottle does the trick. Don't be disheartened if this doesn't work immediately or at all. The low muscle tone makes the art of feeding very hard work and often babies just need time to grow stronger.

Sophie's Story

Sophie was born with a partial AVSD and needed heart surgery. We established breastfeeding but she tired easily so the feeds were always time limited and topped up with a bottle of either expressed milk or formula. On the advice of her dietician, she moved to high calorie formula for her top ups at 7 weeks as it was taking her such a long time to complete each feed.

A few weeks later, we met with the cardiac dietician who was keen to move Sophie on to a feeding tube to increase weight gain. I was reluctant to move on to a feeding tube unless completely necessary, so I took my first go at being assertive (not something I'm very good at!) on Sophie's behalf and pushed for more time on the high calorie formula first. I'm glad I did as she managed to gain weight on that for another month or so.

She started on diuretics to help her heart and was clearly starting to struggle more due to her heart condition. When the dietician and her nurse specialist broached the subject of a feeding tube again a month later, I was more comfortable that we had fully tried all alternatives and so we agreed to go for it.

Due to being in the first Covid lockdown, they took a speedy approach to training me to tube feed Sophie – usually it would be an overnight stay on the ward at our local hospital, but we just had a day trip to the hospital. Sophie was quite unimpressed with having the tube fitted – they rolled her up in a blanket and I held her head still while they inserted it through her nose. The nurse did the first feed, showing me how to test the aspirate and then how to put the milk down the tube. I did the next two feeds under supervision and was then signed off to do them alone.

Keeping Sophie from pulling at the tube was the main challenge we encountered! We found that trimming the corners off the stickers by her nose helped to keep it stuck down despite her fiddling with it. I continued to give her a short breastfeed before every tube feed which meant getting aspirate was always easy. We found she preferred the milk warm as she could feel it going down the back of her throat.

Sophie pulled the tube out several times – we had a great community nursing team who would pop round and put the tube back in. We did find that she completely rejected bottles, so we had to give her top-ups by syringe when waiting for the nurse to come by. Once she had the tube, Sophie's weight increased much more quickly, and she was just shy of her target weight ahead of her heart surgery at 5 months.

I'm glad she had the tube as she was clearly struggling in the run up to her heart surgery although I found it oddly disconnected to feed her that way – she was always lying in her pram rather than being cuddled up with a bottle or breastfeed.

Once Sophie had had her surgery, she was fed by tube in the hospital initially. She tried breastfeeding with no problems on day 5 post surgery but getting her back on the bottles took a bit more perseverance and we ended up changing bottles in the end.

She managed small amounts initially – we'd try for 10 minutes or so and then feed her the rest through the tube. On the first day that she managed all her feeds by bottle (about 2 weeks after surgery), she pulled the tube out herself that evening and that was that!

CeCe’s Story

CeCe had an NG tube from birth until 10 months. As I write this, she is now 2 weeks tube-free.

CeCe had an operation on her bum very soon after birth which meant she wasn´t able to feed for the first week of life. She also had a heart condition that was operated on at 6 months. This affected her breathing and though medical professionals were very positive about us establishing feeding, my feeling is that she knew she couldn’t manage the suck, swallow, breath pattern because she did not have the space in each breath. With hindsight I can see how the tube was essential for CeCe whilst she had her health conditions sorted out. It meant she gained weight nicely, slept nicely, and was as well as she could be. However, I did find it hard to deal with at times.

It was hard trying to establish breastfeeding in the early days and continually thinking we nearly had it but never managing to get there. It was also very logistically tricky trying to gravity feed and breastfeed at the same time and express and recover from a c-section. By 5 weeks old CeCe would gag when liquids went in her mouth and as time went on, she´d gag pretty much when anything went near her mouth. So, we worried a lot that she would never be willing or able to eat. There wasn´t anything that could reassure me that things would change. It was hard nearer CeCe´s operation when she would be sick during or after every meal unless she was asleep. Sometimes the milk would take an hour and a half to go in and then come quickly back out. We got a pump at about 9 months which helped us a lot at that stage because she was more active and started pushing milk back up the tube. CeCe did not like the tubes being changed and we didn´t much like going to A&E in the middle of the night to get it done, learning to do this myself was definitely better. Not being able to see how things could improve was one of the hardest things about tube feeding for me.

So, let me tell you. Things did improve.

At around 7 months (after her heart

operation) we got a supportive highchair from the Occupational Therapist and started the weaning process with help from the Speech and Language Therapist. First just letting CeCe explore with her hands, then giving her tiny bits off my finger. She had stopped gagging after her surgery (I think because she could now breath normally) and was generally keen to explore the world with her mouth. It still felt like we´d never get there (this has been a theme throughout our journey!) Then she discovered she quite liked food. The first big success was cream cheese mixed with prune puree and baby formula, it tasted a bit like cheesecake topping, and she wanted it! The Speech and Language Therapist said to introduce an open cup, she didn´t think we´d have much success getting her on a bottle this late on. However, we found that Sterifeed, who make the pots for expressed milk, did a teat that fitted on the top of the pots we were using for tube feeding. So, we started giving CeCe the pot to play with, with the teat on the top and she started chewing it and then gradually experimented with sucking from it. And thank goodness she did as this has meant she has worked her way up to getting about 400ml a day of formula from the bottle plus her meals which is enough to keep her fit and healthy without a tube. Honestly 4 weeks ago I still thought we´d never get there!

A few more thoughts that might help others....

I did a lot of worrying! And where did it really get me? (when will we ever learn this lesson!)

We had quite a few professional services involved with us but sometimes their ideas didn´t work for us! So, I recommend speaking to different people to find things that work for you and your situation.

The tube is probably your friend whilst your baby needs it, keeping that beautiful kid going until they can do it themselves. Don´t hate on it too hard.
If you can, make the most of the fact that you can share the feeding duties with your partner (or someone else), I was always relieved if it wasn´t my turn!
Make the most of the time. It made me feel a bit better if I felt me and CeCe had spent some nice time together singing or playing with something whilst tube feeding. The silver foil often saved the day when no one had any energy for anything else!

CeCe is a good little communicator. She babbles nicely and chews away on pitta bread without any problem so I´m hopeful that the months spent not using her mouth haven´t had too much of an impact. This was one of my many unhelpful worries!

Fraser's Story

Fraser was tube fed at birth until 3 weeks old, he was fed mostly sugar water due to being in intensive care. He was then slowly taught how to breastfeed (yay!), and we exclusively breastfed for 5 days. I was very proud of him.

I couldn't continue to breastfeed due to Fraser's heart condition and low muscle tone making him too tired to have a full feed; it was becoming impossible for me to constantly feed him very small amounts, on and off, just for him to become exhausted.

We then moved onto bottle feeding, this is where I found that Fraser was having quite serious feeding difficulties. He never latched well, and one bottle would take 90 minutes to drink due to the number of rests he needed and just generally drank very slowly with lots of coughing and dribbling.

At eight weeks, Fraser contracted Sepsis from a UTI. Unfortunately, this really impacted Fraser's health and put his already struggling heart under significant stress. He began to really withdraw from food and became very weak, this is when the NG tube was re-introduced.

Fraser was eventually allowed home with a PICC line for antibiotics and an NG tube for feeding. Due to constantly pulling it out and trauma from intensive care/ hospitals, Fraser grew a very strong oral aversion. This was so much that he didn't like anything on or near his face: bottles, fabric, dummies, stroking his face and even face kisses. Fraser had a huge amount of patience and Speech Language Therapy to help overcome this as much as possible.

The NG tube also worsened his already severe reflux and vomiting after feeding became the norm, as did sleeping propped up, hiccups, coughing, strange swallowing sounds and constant pain.

At 4.5 months old, Fraser had open heart surgery and after was given the all clear to start weaning. He was assessed beforehand, and we found that Fraser had an unsafe swallow which made a sense! This means that when Fraser drinks liquid his muscles in his throat are very floppy and weak and they let some of the liquid into his lungs. He would need thickener in his drinks and only pureed food.

Fraser then graduated from an NG tube to a G tube (button), within two weeks Fraser was eating one small meal a day. By 6 weeks he has been eating (on a good day) two meals a day and snacks. Fraser will have his Button for as long as he needs it, he's getting the hang of food now. Drinking is more difficult; he doesn't know how to suck and finds open cups very confusing which I can't say I blame him!

Either way, I am immensely proud of his and his Tube journey and can't wait to see what he will do next. We are forever grateful of every kind of feeding tube he has had at the end of the day remember fed is best.

Ishmael’s Story

When Ishmael was born at 37+3 weeks via c-section I nursed him as soon as I was able to when in recovery. He latched beautifully but as the days went by his nappies were dry and he was falling asleep during feeds and was diagnosed with jaundice and treated under lights. We were discharged when he was 8 days old under the guidance to top his feeds with formula or expressed milk, he was too sleepy to feed effectively so ended up readmitted a few days later as the bilirubin levels had crept back up. An NG tube was inserted with the aim of working on feeding but told he may struggle to sustain full breastfeeds due to low muscle tone and being born with an ASD, VSD and a PDA in his heart. I was told to nurse him for no longer than 30minutes as he would burn calories and then top him up via a bottle and whatever was left in the bottle had to go down his tube. I always had a feeling something wasn’t right when he drank bottles as he would choke and gasp at least once or twice during a feed although no one else was concerned at this time. He pulled out the tube after one month and under the dietician’s guidance it was left out and continued to work on oral feeds. He only gained tiny amounts of weight and it felt an endless, stressful cycle of nursing, expressing, and giving bottles to try and get more into him. I gave exclusive breastfeeding my best shot, but it just didn’t work out how I planned. He had to be weighed each week by his dietician to monitor his growth and was put on a high calorie formula for top ups to try and boost his weight gain which proved fruitless as he would vomit it back up. He continued to cough during bottle feeds and sometimes choke on the milk leaving him struggling to catch his breath. I brought it to the attention of his paediatrician and dietician and pushed for SALT assessment but there was going to be a wait.

Ishmael had multiple bouts of chest infections and by 6 months old he ended up in the hospital high dependency unit with aspiration pneumonia and a collapsed lung (which was initially thought to be bronchiolitis). He was given an NG tube again at this admission as he was too weak to orally feed, and we have continued combination feeding since (boobin' and tubin' as I call it). The speech and language therapist came to see him when we got home and she listened to Ishmael's swallow and said he couldn't coordinate the movements in time to swallow so was essentially breathing milk into his lungs at times, but he had no issues while nursing. I was so disappointed I was unable to exclusively breastfeed him knowing that he didn't aspirate feeding from me. A later video fluoroscopy confirmed that he does aspirate on thin fluids but when using a thickener, it gives him time to coordinate the swallow.

Ishmael started weaning at 6 months old but showed little interest due to a combination of the NG tube, reflux and his PDA causing high pressures in his heart and lungs resulting in breathlessness. He developed an oral aversion; we tried our best to keep him interested in tasting food, but he was reliant on calories from NG feeds. After having his PDA closed at 11 months old, he has made great progress with weaning and overcome his oral aversion and his reflux has improved with more solids in his diet. He now eats three meals a day plus snacks and sips of thickened drinks. The tube allows him to have his full fluid requirements safely while he works on his eating skills and hopefully get better at drinking in the future.

I was so sad for a long time about Ishmael needing an NG tube but now I am so thankful for it, it has helped him grow strong by getting all the nutrition he needs meanwhile protecting his lungs from long term damage. We buy funky tapes that match his outfits, and they help take away the medical feel. Next on his tube journey will be to decide if he needs a gastrostomy for fluids which would be a surgical procedure to put a tube directly into his stomach therefore freeing up his face, improving reflux and making oral feeding more comfortable with no tube down his throat. Here are some pictures of Ishmael rocking his NG tube.

Lexi's Story

Lexi was born at 33+6 by C-Section, weighing 1.92kgs (4lb 4oz), and after a quick cuddle taken off to SCBU. The policy at our hospital is that any baby under 34 weeks has an NG tube as too young to orally feed!

Premature babies need a set amount of milk each day depending on weight to grow properly so an NGT assists that process! They can still orally feed but can have top ups to fulfil the right volume. I was encouraged wholeheartedly to express and try to breast feed to top her up.
Based on Lexi's 'suspected' DS diagnosis, the Dr's decided to do an echocardiogram just to be safe. During this scan they discovered Lexi had a large complete AVSD and would need surgery in the future. Then the bombshell was dropped, due to her heart condition Lexi would have to keep her NGT but would need a mixture of breast milk and High calorie formula as they didn't want her burning calories trying to take feeds orally, yes, she could still have the odd top up but that was it. She needed to grow to meet the weight criteria Great Ormond Street had set for surgery.

As time ticked on Great Ormond Street requested, we go for a CT scan before they would commit to surgery. The CT scan showed what they needed to see, and they gave the go ahead for the Open-Heart Surgery. However, at an MDT (multi-disciplinary team) meeting, someone then asked if the lungs had been fully investigated.

It turned out they could see micro aspirations in the lungs on the CT. So, without any further investigation it was decided to swap the NG tube to an NJ tube. This was because they decided the micro aspiration was being caused by reflux. Swapping to an NJT bypasses the stomach and puts the feed straight into the small intestine. Lexi got to her weight and had successful Open-heart surgery to correct the AVSD and close the PDA.

We were discharged back to our local and eventually home.

Whilst in GOSH they used a different high calorie milk (Similac high energy) rather than the one she'd been on which was infatrini. We got back to our local and they put her back on infatrini. Lexi started vomiting and the 4 days we were home from hospital it just carried on and got worse.

4 days after discharge we ended up back in hospital with increased work of breathing and a very poorly Lexi being blue lighted back to Cardiac intensive care at GOSH. Lexi was suffering with Aspiration pneumonia, now the job was to find out why!

Finally, they tested her to see if she did indeed suffer with reflux... she didn't!

To do this they first carried out an Impedance study. This is a 24-hour study, where they pass a tube to the top of the stomach and the other end is attached to a box which has several buttons on it. It records data over the 24 hours and then they get a report regarding the levels of acid in the stomach.

Then she had a barium swallow, for this they track a dye through the digestive system again to see if any refluxing is occurring. She also had a video fluoroscopy to check the other end of the process. This is done by giving oral food and/or water with a dye in it and watching the swallowing process under X-ray. This also showed Lexi has a safe swallow.

Finally, after lots of discussion with us, the medical team, and the surgeon it was decided to go for a gastrostomy, in Lexi's case this was to be a mic-key button as a primary device (This can be dependent on the surgeon's preference but saves swapping from a PEG to a mic-key button 6 months post PEG).

We've not had any bouts of Aspiration pneumonia since having the gastrostomy. Having this freed her face of the tube. Means not having to check an aspirate every feed and is safe to feed from overnight.

I know it can seem scary if this is being suggested for your baby, but honestly if your child needs to be tube fed for a longer period gastrostomy is by far the best thing. Fast forward to now at age....... Lexi is orally eating and is still under S&LT but is doing brilliantly with weaning.

Polly Blossom's Story

Polly Blossom was born full term at 39 weeks but with a complete AVSD she needed some help with breathing and eating so spent 24 days in NICU with an NG Tube for feeding.

Polly came home tube free, but after a few weeks of sleeping through her night feeds we were told she had to have a temporary NG tube fitted again. Being very poorly until she had her heart repaired meant that we spent 4 months in hospital, once the repair was done, we weren't sure whether Polly's swallow was safe or not. Unfortunately, the wait time is long, and we didn't find out until over a year old that she had a safe swallow.

Polly has recently been discharged from her dietician and SALT (feeding) team.

This time last year we were well on our tube weaning journey. We started in Feb/March 2020, and it consumed our everyday lives. Lockdown was a positive for us because it meant we could solely focus on getting Polly off the tube. So, every day at home helped keeping the same routine, albeit extremely tedious and mundane, but it helped. Polly was tube fed via an NG tube for 20 months.

Then after many months, Polly pulled her tube out one day (as she did most days at this point), and it hasn't gone back since. We had the go ahead from her Dietician the minimum amount of milk she could have morning & night then in between allow her to eat foods.

She never took to a bottle and spits milk out a lot now, but from allowing the tube out overnight for the first time ever she ate her breakfast the next day for the first time ever. She realised what hunger was!

We worked so hard, and our days revolved around getting her tube free, just to make life easier.

The last time we took the tube out was 31st October 2020. I'll never forget that day also because it was Halloween so not easy to forget! We decided to have it out all day and even the night-time, something I have never done before, mostly for the fear of her waking up hungry. Which really won't have been any more stressful than life was anyway as I would have just inserted the tube again.

So, Polly not having any milk down the tube before bed meant that morning, she felt hungry, and she ate the most amount of breakfast I have seen her eat ever. She was clearly hungry and following her cues.
If your child has a safe swallow which in our case Polly did then speak to your feeding team and see if you can restrict milk feeds and up the food (once at weaning age). Once we knew that it was safe, we pushed her that bit more with more food rather than relying on our tube and pump.
This was a turning point for us and then Polly started nursery. It was like a lightbulb went off and she was ready. She watched the other children eat and she wanted to do it too. I'm just so proud of her and when she's throwing her food all over the carpet, refusing some days, and asking for more on others I forget just how far we have come.

It seems she followed her own cues when we let her, and with guidance from her dietician she was still getting the calories she needed. We are nearly a year on being tube free and I still can't quite believe how much she eats now and how much we worked to get here!

For anyone on a similar journey there is no magic wand, its hardcore, its tiring and its relentless especially when they pull it out every other day. I get asked for advice and the one thing I would say is 100% learn how to pass the tube yourself, it avoids trips to the hospital and nurse visits, it also gives you a bit of freedom as you can pass it whenever.

Don't give up, if you have the right guidance and especially if your child's swallow is safe then they may just surprise you!

Sophie's Story

Sophie was born at 43 weeks in December 2020 with a prenatal diagnosis of Down syndrome. It became clear that Sophie did not have the sucking reflex needed to bottle feed and due to a cardiac condition identified on day two, she was quickly placed on a feeding tube with high calorie milk.

Sophie spent 6 weeks in SCBU as her oxygen saturations kept dropping. Throughout that time some nurses tried to help Sophie to bottle feed, but the majority just tube fed her as the communication wasn't clear as to whether she could attempt some feeds orally. Also, to be perfectly honest I think it was easier for nurses who were run off their feet and didn't have enough hours in the day.

During her time in SCBU Sophie was seen only three times by the hospital feeding team and each time they said Sophie wasn't ready and wasn't interested I did not feel that I got a lot of support in hospital. It became apparent that the only thing keeping Sophie in hospital was her feeding so we agreed to bring her home tube feeding with the promise that we would be given support to transition on to bottles in the community. We ensured we were trained to do the tube feeds and change the tube before leaving something I never thought I would be able to do.

When Sophie came home, I decided to start trying her with bottles at every feed that she was awake. At first Sophie wouldn't open her mouth and more was dribbling out than went in. I tried lots of different bottles with her and she seemed to prefer the MAM brand. Over time we have worked up to trying a bottle for all her daytime feeds and Sophie will take between 20 and 30 mls most times with the rest going down her tube. Whilst this doesn't seem like a lot it means that she has continued to maintain the skills of taking liquids orally and has not developed a food aversion which was one of my biggest fears.

Sophie is now seven months old, and we have been weaning on purees for about a month, this seems to be going well and I am hopeful that she may find food easier to manage than milk. One of the big problems for Sophie is she has a delayed swallow, so we manage this by using a slow teat and going very slowly timing the length of her bottle feeds as she is more likely to struggle when she is tired. With weaning the SALT suggested offering her an empty spoon every couple of mouthfuls to trigger the swallow reflex.

I don't know what the future holds for Sophie on our tube feeding journey and I hope one day to update this story with a positive ending but for now it is about patience and baby steps. Looking back, I wish I had pushed for more support we now have a wonderful community SALT lady also called Sophie and are having some investigations done to check that it is safe to continue with what we are doing but at the start of my journey I trusted that the professionals would give me the support they had promised.

My advice would be to push for that support, don't expect it to just be offered in a timely manner. Also, within reason trust your instincts as a mum unless it is not safe to do so try to encourage the development of oral skills as described in the tips above. Even little and often will make a massive difference over time.

Samuel’s Story

Samuel was born at 35 weeks. He had a lot of issues so had to be NG tube fed from birth. While at the NICU I tried breastfeeding him and bottle feed, but due to his low tone and heart issues, he was easily tired and would only manage 10 mls per feed through the bottle. The rest went down through the NG tube. He was discharged a month later with the Tube. He slowly progressed to having larger quantities with the bottle. But then he got a nasty cold, and his nose was blocked for 2 months which totally put him off feeding. Then the reflux started so again we were nowhere near the end of his NG tube journey again. In the meantime, we were taking PADS physiotherapy sessions with Donna Murphy. Which helped Samuel getting much stronger. When we started the weaning with solids, I was hopeful this would help him move further to his independence from the tube. Good thing was the reflux was gone. And he was doing better taking more with the spoon every day. Until the point when I encouraged him to take the rougher textures - stage 2 jars. Soon he has had enough and rejected everything apart from smooth purees. And restricted his diet to only fruit and yogurts. Regarding the drinking since he never managed the sucking part with the bottle, he wasn’t able to learn to drink and had all his liquids through the tube. So, we were nowhere again.

Then one day on PADS Facebook group I saw a video from the feeding consultant Jill Rabin about her method of adapted baby led weaning. I was very impressed and started following her Instagram Where she regularly shows videos of Down syndrome babies successfully self-feeding with various foods from the table. I saw one of her training zoom sessions and bought her book. We started in October 2022. As suggested in the book I got Samuel a highchair with straight back support and additional food rest. And after having been fed put him in his highchair on the table with us. Giving him tastes of our food. We started with harder bigger pieces - steak strips, chicken drumstick. And offer a smoothie consistent drink in an open cut cup after the meal. I think Samuel had a food aversion due to the unpleasant experiences with the insertion and removal of the Tube, as he was very sensitive in the mouth and nose area not allowing me to touch it or put anything in his mouth. With the adapted baby led weaning he found he had control what he would put in his mouth. In the beginning I would put the piece of food in his mouth and lift his hand to help him feed.

In November Samuel had a very bad teething period when he would refuse any food and was mainly tube fed. He had lost weight and the dietitian was talking a Pegs was needed. As soon as teething was settled, I was back with the baby led weaning. And giving him his formula with the 1st stage Tomy Tippee beaker cup. I started offering Samuel milk thickened with fruit puree and he was drinking more until In December 2023 he suddenly started drinking his whole bottle at all his feeds. In January 2023 the dietitian authorised the NG Tube removal. Today he can manage successfully chewing softer foods. Self-feeding with finger foods. Eats all food groups. Loves his food. Drinks formula and squash with the beaker cup. We are still waiting for more teeth to come to move on to hardee foods.

I think Donna Murphy's physio exercises and Jill Rabin's method were main factors in Samuel's progress.

Resources

Websites

www.feedingtubeawareness.org

www.bliss.org.uk/parents/about-your-baby/feeding/tube-feeding

www.carersuk.org

www.tubiecheeks.co.uk

www.nice.org.uk/guidance/ng154/chapter/Rationale-and-impact

Join DSUK's online community

Join our online support community, a group where parents can share their own experiences, ask advice and share concerns around NG tube feeding.

www.downsyndromeuk.co.uk
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