BREASTFEEDING YOUR BABY WITH

PRADER-WILLI SYNDROME

PWSA
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CONGRATULATIONS ON THE BIRTH OF YOUR BABY

Receiving a diagnosis of Prader-Willi syndrome (PWS) can literally turn all your excitement and wonder you had in your pregnancy into fear and worry for your little one's future. There are many emotions that you are most likely feeling right now. Allow yourself time to process these feelings. You can be assured however, your baby is your baby, first and foremost. Your baby will amaze you and they will be a wonderful addition to your family as you embark on an incredible journey filled with love and joy.

You may have already been told that "babies with PWS can't breastfeed". That isn't entirely true and successful breastfeeding is possible with a baby who has PWS. This booklet will help to support you through your own breastfeeding journey and explain how breastfeeding can be a valuable and rewarding part of caring for your baby as well as provide you with information and techniques on how to support your baby to breastfeed effectively. Also please remember breastfeeding is not always about providing only nourishment, it also provides much needed comfort and cuddles that a baby with PWS needs just like all babies.

BENEFITS OF BREASTFEEDING AND EXPRESSED HUMAN MILK (EHM)

The benefits of breastfeeding to both mother and baby are well documented and apply to the babies who have Prader-Willi syndrome.

- Human milk provides protection from many infections such as ear infections, bronchitis and pneumonia by boosting their immune systems. This can be especially important in PWS as their respiratory system can be compromised due to their low tone.

- Human milk may reduce the risk and severity of auto-immune disorders such as coeliac disease, asthma and allergies.

- Human milk may reduce the risk of adulthood diseases such as diabetes, cholesterol and obesity. This again is very important in people with PWS due to their increased risk of developing these disorders in both childhood and adulthood.

- The sucking required for breastfeeding strengthens your baby's lips, tongue and face. This will be helpful when it comes time to learn to chew food and for speech development.

- Human milk provides a reduction in gastrointestinal illnesses and may decrease the risk of constipation. This is Important in the PWS population due to decreased gut motility.

- Breastfeeding enhances calmness in the mother due to the release of hormones (oxytocin and prolactin) which have an endorphin effect. This can create a closeness to your baby and can help to reduce anxiety as well as help with the grieving process associated with receiving a diagnosis.

- Health benefits to you such as reduced risk of breast, endometrial and cervical cancers as well as a reduced risk of heart disease and osteoporosis.

- Quicker return to your pre-pregnant state. You burn a lot of calories making milk and the hormones released during breastfeeding help to shrink your uterus.

- It is convenient. Human milk is always available and contains all the nutrients, calories and fluids your baby needs. It is amazing that it is constantly changing to suit your baby.

UNDERSTANDING BREASTFEEDING AND PWS

In order to have success at breastfeeding, any mother and baby must work together as a team to help each other out. Every baby is unique and in the early days it takes time to get acquainted with each other. Breastfeeding a baby with Prader-Willi syndrome is most likely going to take a little longer for the both of you to get the hang of it. This is because babies with PWS have some physical characteristics that can impact on the establishment of breastfeeding. Not all these challenges may be applicable for your journey but understanding your baby's particular needs, as well as the mechanisms of breastfeeding, will help to get your breastfeeding journey off to a great start.

Seven identified nutritional stages in PWS

Phase 0 - Decreased fetal movements in utero and lower birth weight than siblings
Phase 1a - Hypotonia with difficulty feeding (0-9 months)
Phase 1b - No difficulty feeding and growing appropriately on growth curve (9–25 months)
Phase 2a - Weight increase without an increase in appetite or excessive calories (2.1–4.5yrs)
Phase 2b - Weight increasing with an increase in appetite (4.5–8 yrs)
Phase 3 - Hyperphagic, rarely feels full (8 years adulthood)
Phase 4 - Appetite is no longer insatiable (adulthood, although this is a rare occurrence)

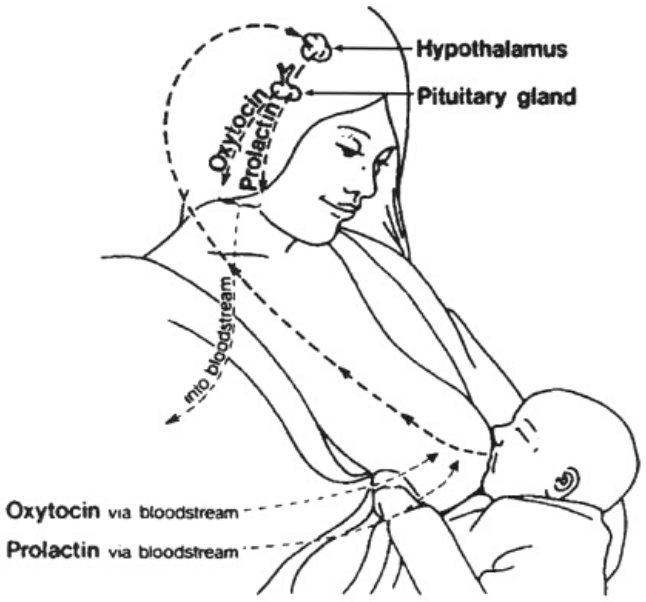
Phase 1a can be further described as;

- Weak, uncoordinated suck
- Needs assistance with feeding either through feeding tubes (nasal/oral gastric tube or gastrostomy tube) or orally with special, widened teats
- Oral feeds are very slow and baby tires easily
- Severely decreased appetite. Shows little or no evidence of being hungry
- Does not cry for food or get excited at feeding time
- Inability to rely on feeding cues to feed the baby. Puts the baby at risk of "failure-to-thrive"
- Weak cry

Due to the majority of babies with PWS entering the world with the challenges of phase 1a, patience plays a significant role in the establishment of breastfeeding. We first need the baby to be ready. Don't be disheartened as this may take quite a few months.

Breastfeeding is a feedback system and it works by supply and demand. Basically, the baby needs to stimulate the breast for your brain to keep releasing the hormones to make the milk. The milk needs to be taken out of the breast in order for the hormones to give feedback to your brain for more milk to be made. If there is a break in the system (insert sleepy baby with PWS) and your breast stays full of milk and is not stimulated to release that milk then your brain is being told we do not need to make so much milk and your supply starts to drop.

"Breastfeeding is a feedback system and it works by supply and demand."



Due to the nature of phase 1a in Prader-Willi syndrome, your baby might show little or no interest in wanting to feed to begin with. Sometimes they might latch on however, they will not suck or their suck will be too weak to stimulate the let down reflex. During this time, you will need to express breast milk to continue to stimulate your breasts for your supply to continue until your baby becomes alert enough to feed effectively. Your baby most likely will be fed either by a nasogastric tube (NGT) or gastrostomy tube (G Tube). This time is a perfect time for skin to skin cuddles with your baby. The closeness will help with your breastmilk production, not to mention it is a beautiful bonding time with your baby.

BREASTFEEDING YOUR BABY

Positioning

Positioning is important to support you baby's body whilst breastfeeding. Correct positioning will help your baby to achieve a deep latch to the breast which is important to stimulate your supply. It will also aid your baby in conserving energy that they will need for feeding and help them to obtain more milk for their efforts. Despite many babies with PWS not giving many hunger cues, it doesn't mean you cannot try a breastfeed at their feed time. It will most likely be tiny steps, but having them just lick the nipple or maybe manage to latch and have a few sucks are all steps in the right direction.

- Firstly, position yourself in a comfortable chair with good back support. Use pillows and a foot stool if you feel your muscles are straining. It is important to relax and to be calm as this will help your milk to flow.
- Have your baby unswaddled and bring them close to you. Tuck their legs around your body. Remember we face our food to eat so babies need to do the same.
- Support your baby across the shoulders and neck with your arm, so the baby's whole body can be moved not just the head.
- Line your baby up nipple to nose and make sure your baby's neck is straight not tucked into its chest.
- You may need to shape your breast to match the shape of your baby's mouth.
- Try out some of the following holds to find the one that works for you and your baby.

Cross Cradle Hold

You can hold your baby lying on her side across your lap, her chest facing yours, her lower arm around your waist, so that she does not have to turn her head to grasp the nipple. By holding your baby using the arm opposite to your breast at which they will feed from (ie. The left arm when feeding from the right breast) allows you to provide your baby with good head support.

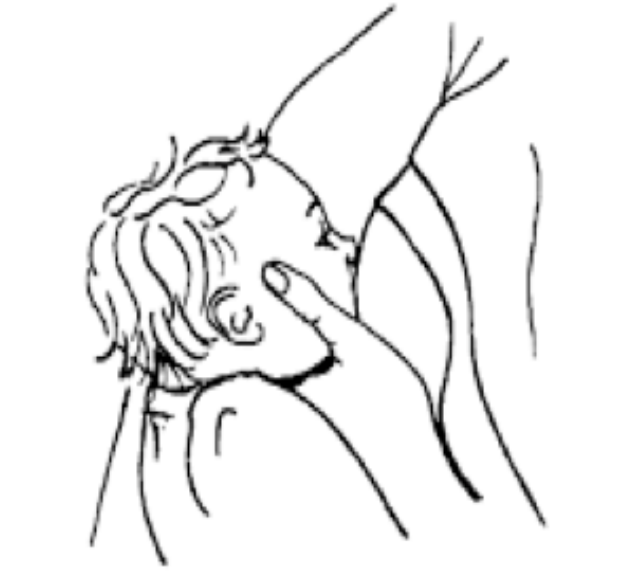
Your hand should support the neck and head and your baby's body extends along the length of your forearm. This position offers you a good view of your baby at the breast and allows you to shape your breast with your free hand. This is sometimes necessary to help support the weight of your breast.

Underarm Hold or Football Hold

The underarm or football hold allows you to support your baby's head whilst giving you a good view of their face. Put a pillow at your side and rest your baby's bottom on the pillow. Support their back on your forearm. Their torso will be under your armpit. Cradling their head in your hand and providing gentle steady support to the base of your baby's head will help them to suck effectively without tiring, which is especially helpful with babies with PWS who fatigue quickly.

Dancer Hold

The Dancer hold can be particularly helpful for a baby with PWS due to their low tone as you can physically support the baby's sucking. The "dancer hand" position helps keep the weight of the breast off the baby's chin and helps to keep their head steady. In this hold you will be supporting the breast and supporting your baby's chin whilst they feed. Cup your hand under your breast, slide it forward so that you have three fingers supporting your breast. Your index finger and your thumb form a U shape and support your baby's jaw in that U. Your thumb gently holds your baby's cheek on one side whilst your index finger holds the other.



Baby Led Attachment

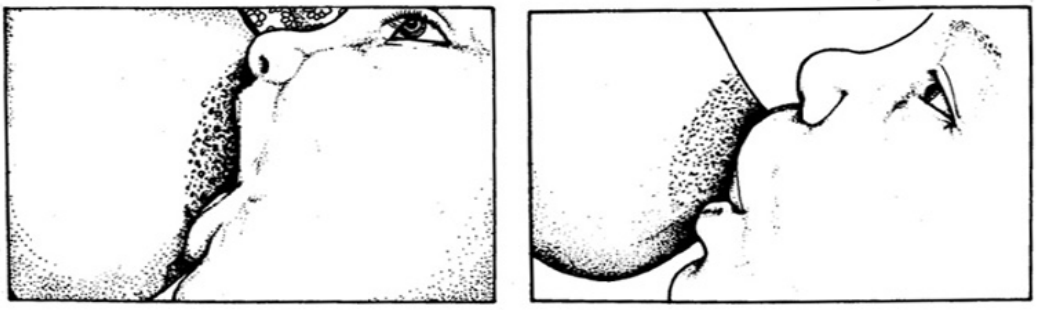
Human babies are born with the instinctive knowledge and ability to attach themselves correctly, with their mother's support. Unfortunately, this can be hindered in the beginning with a baby with Prader-Willi syndrome due to their lack of interest in feeding but as your baby begins to "wake up", they will start to be interested in suckling. Spending time with your baby skin to skin during this period will help to initiate these instincts.

A semi-reclined position works well along with holding your baby upright on your chest between the breasts, although you can choose any position that feels right for you. You might find that your baby will start to bob their head around in order to find the breast. Once there, they may start licking and pushing their hands into your breast. This is all helping to release oxytocin from your brain which helps to get breastmilk flowing. Babies who have been given opportunities to use their instincts to find the breast often will become skillful at breastfeeding. In babies with Prader-Will syndrome the only difference is the amount of time it is going to take for them to be successful.

ATTACHING YOUR BABY TO THE BREAST

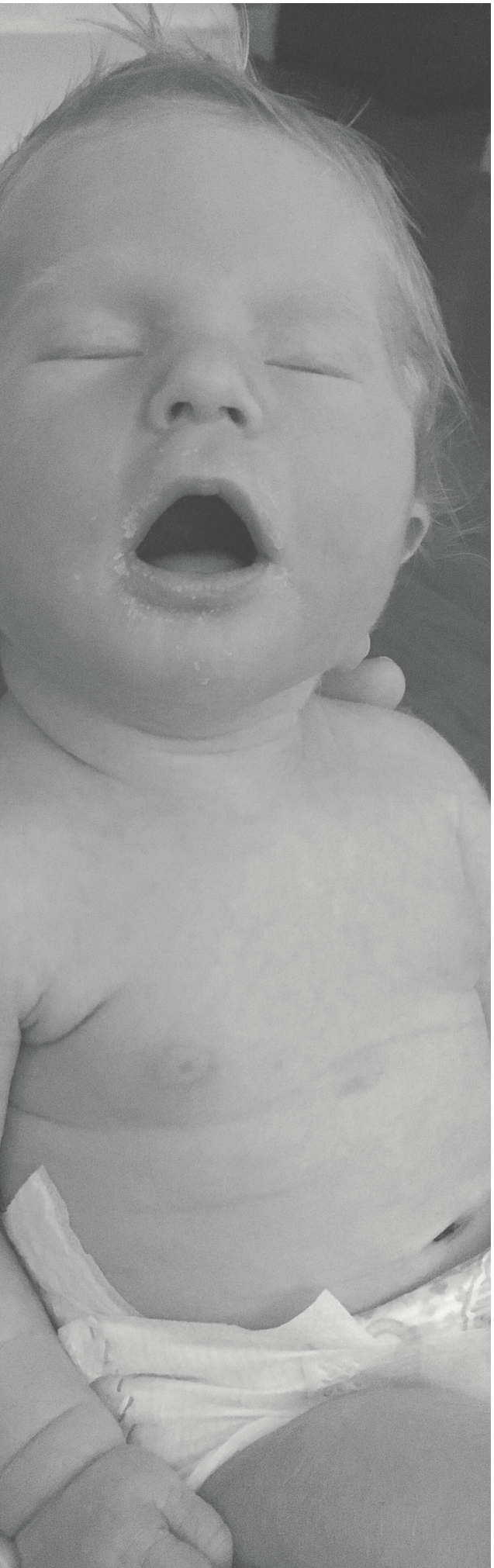
Steps to attach your baby

- Start your milk flowing before you put your baby to the breast. This will save their energy and will help them to get a result for their efforts.
- Gentle hand expressing, rolling your nipple between your fingers, gentle massage or even a warm washer or heat pack can encourage a let down.
- Line your baby up, nipple to nose making sure your baby's head is not tucked into its chest.
- Tease your baby with your nipple from nose to chin to encourage a wide gape.
- When your baby has a wide mouth, bring the baby to the breast NOT the breast to the baby, with your nipple aimed at the roof of their mouth. First point of contact will be the lower jaw or chin on the areola down from the nipple.
- Your baby's nostrils should be clear. Tuck their body closer to you if need be.
- Lower lip should be flanged out over the breast.
- The tongue should be forward over the lower gum.
- There should be much areola in your baby's mouth, more so where their chin is.
- If the latch is shallow then you will most likely experience nipple pain and the baby may not get adequate milk transfer.



Good attachment

Poor attachment



INFLUENCING FACTORS

Low Muscle Tone

Low muscle tone or hypotonia has to do with the muscle at rest. Hypotonia is a condition of diminished muscle tone and may occur with or without muscle weakness. Our muscles have the potential to move or contract and the muscles of a baby with low tone are slow to contract, do not always fully contract and have difficulty maintaining a contraction. Low tone doesn't always affect feeding skills and the symptoms of PWS are a spectrum so all babies must be treated as individuals.

As mentioned above due to the low tone in babies with PWS , they will need to be well supported whilst they are breastfeeding in order to save energy for sucking. When in position be careful not to put too much pressure on the back of their head as this can cause a poor latch. You may find that putting an extra pillow to raise their bottom to near the level of their head may help if their low tone is causing sucking problems.

It is normal for a baby to stop and start whilst breastfeeding as they are waiting for the ducts to fill with milk again. Sucking should be in a rhythmical pattern with the whole jaw moving and you should be able to hear your baby swallow after they have stimulated milk transfer. When babies have low tone, their cheek muscles may not contract as tightly causing an incoordinate suck or a weaker suck that may prevent adequate suction on the nipple. They may be slow to feed and have frequent long pauses when feeding.

Sleepiness

Newborns with Prader-Willi syndrome are usually very sleepy. Often not rousable, even for feed time. If they do wake they are often not awake enough to sustain a full feed. Generally, this overall sleepiness starts to improve around 3-4 months of age and very gradually you will see your baby be more and more alert each day. In this period, it is ok for you to take the cues from your baby. Be patient and they will start to wake up. You will be more successful with feeding if the baby is awake and willing than trying to attach a non-rousable baby.

Try these things to keep a baby awake during a feed:

- Dim the room so your baby doesn't have to close their eyes against the light.
- Remove their clothes before breastfeeding to keep them cool and aware.
- Stimulate their senses by lightly touching the edge of their outer ear, stroking their arms, and talking to them during feeding. These touches and sounds can help distract them from becoming drowsy and help him to focus on the task at hand.
- Try placing a cool, damp washer on your baby's belly, leg or forehead. The cool sensation can help to wake them up.

USEFUL TIPS

Breast compressions
Breast compressions can be used to encourage active sucking. Use one hand to squeeze the breast firmly, but not too hard, to help with the release of breast milk. Breast compressions can be done when the baby is sleepy but not actively sucking. This should help to start the baby to suck and swallow. Repeat the squeezing and releasing until it appears to be no longer working. Often, working the hands in a clock like motion around the breast will allow for greater milk flow.

Switch Feeding
Switch feeding can be beneficial if your baby is sleepy at the breast. If your baby starts to lose interest, then you can break the latch by gently slipping your little finger into the side of their mouth to break the suction then offer the other breast. They will often start to suck more vigorously again. You can continue to repeat this if needed.

Nipple shields
Nipple shields are thin silicone covers that go over your nipple. They can be useful in helping the baby to attach especially if your nipples are a little flat or inverted. If your baby has been having bottles sometimes nipple shields can make the adjustment to breastfeeding a little easier.

Bottles
For any baby learning to breastfeed, avoiding bottles during this time can be useful to achieve successful breastfeeding. Sucking at the breast is different to sucking on the bottle and exposure to a different type of teat can have an impact on a successful latch. Also, babies can become frustrated when at the breast if they have been bottle feeding because they haven't had to wait for a let down with a bottle.

Milk Flow
If you find that you have a fast or forceful let down and your baby appears to be drinking too quickly or gulping and coughing, you can try a few different positions. Try leaning back in a semi reclined position or have your baby sit up in a straddle position on your lap. Sometimes you might need to express the let down just whilst your baby is learning. If your flow is slow then massaging the breast or using a warm cloth may help.

HOW DO I KNOW MY BABY IS GETTING ENOUGH?

The million-dollar breastfeeding question! It is normal for mothers to worry if their baby is getting enough from the breast. This will be especially worrisome in babies with PWS as we can't rely on their behaviour to tell us that they have had enough due to the fact that they often will not give hunger cues or may fatigue before a feeding is finished.

Adequate weight gain is probably the most obvious sign that baby is breastfeeding effectively. However, in babies with PWS this should not be solely relied upon as babies with PWS often gain weight at a slower rate than traditional measures may suggest. Often babies who are fully tube fed are also having issues with weight gain in the beginning.

As you can't see how much milk is going into your baby there are a few things to watch out for.

Output
If it is coming out, then it must be going in. Babies should be having at least 5 heavily wet disposable nappies in 24hrs, urine should be pale in colour. Bowel motions can vary but at least 3 soft/runny bowel motions in a 24hr period (this may slow as the baby grows). Babies with PWS can have slower bowel mobility so this is also something to be aware of.

Swallowing
To stimulate the let down the baby will suck rapidly for one to two minutes. During the let down the baby may do a suck/swallow, suck/swallow or will pause every 3-4 sucks to swallow and breathe. After the let down the sucking slows and there is a pause more frequently between sucks. If you listen closely you should be able to hear the swallow. Have a professional listen and help you to hear. If you can hear the swallows, be confident your baby is transferring milk.

Skin Tone, Skin colour and Alertness
Good skin tone (if you pinch the skin then it should spring back into place). Their skin should also be pink and well perfused. Alertness is difficult to assess in the very young baby with PWS, given the nature of the excessive sleepiness they often have but as they get older and start to "wake up" you should notice that they are alert during these periods.

Test weighing
Whilst this is not an accurate measure it can be a useful tool in reassuring mothers that their baby is actually getting milk. Babies are weighed immediately before the feed on an electric scale and then immediately reweighed after the feed in the exact same circumstance (nappy/diaper, clothes etc). Intake during the breastfeed is reflected by weight gain, 1g=1ml.

WEIGHT GAIN AND SUPPLEMENTING

Typically, adequate weight gain of about 150g/ week in the 3-4mths and then it starts to slow to about 100g/week until around 6mths is acceptable. It is not unusual for babies with PWS to struggle with this even if they are being provided with enough nourishment.

High calorie milk (hind milk) is towards the end of the feed. A baby who is still learning to master breastfeeding or tires easily on the breast may be missing this higher calorie milk. You may need to give this milk as a supplement after you have finished the attempt at a breastfeed.

As mentioned above, giving bottles at this time may hinder the establishment of breastfeeding. However sometimes they are hard to avoid especially if your baby is having a hard time managing to suck at the breast and if they haven't got an NGT or a G Tube in place.

You may want to try a supply line. This is where a small tube is placed on the breast near the nipple and the expressed human milk (EHM) or formula is gravity fed down through the tube so that whilst the baby sucks at the breast they receive the extra flow of milk.

When you first start breastfeeding your baby still may require "top ups" until you are satisfied that they are taking off adequate milk from the breast.

"If you have a low supply, then this will potentially make it harder for your baby to exclusively breastfeed."

Expressing

It is important to keep your supply well maintained. If you have a low supply, then this will potentially make it harder for your baby to be exclusively breastfed.

Once your baby is having full breastfeeds it is a good idea to still keep up the pumping for a few weeks. The baby is still learning and their suck may still be a little weak to adequately stimulate enough supply.

A BREASTFEEDING JOURNEY
personal stories

A BREASTFEEDING JOURNEY | LIBBY & MABEL

Mabel is our 5th child. Following four previous spontaneous, straight forward and quick labours all before the calculated due date we assumed number 5 baby would follow suit. Mabel was born at 41+2 days gestation and after a lengthy 3 days of trying to establish labour she arrived safe and sound via a vaginal birth. Initially her Apgars were good although the midwife said she was a little “floppy”.

At birth she showed little interest in going to the breast and to be honest I was just happy she was out and assumed she just needed a little recovery time from her long birth. I expressed a little colostrum for her instead and thought she would feed when she was ready. By the next morning Mabel still wasn’t showing any signs of wanting to feed despite my offerings. She landed herself in the special care nursery (SCN) on an IV for low blood sugars and then a NGT due to the lack of feeding. We continued to attempt breastfeeds and bottle feeds.

On day three she attached to the breast and had three good suck/swallows before she was back asleep. She wasn’t much good at the bottle either only taking a few mls at a time. We were transferred to a NICU for further testing and here the nurses advised us that she wasn’t safe for oral feeds due to the risk of aspiration. She was only allowed to have 5-10mls at a time via the bottle. I informed them that my wishes were to breastfeed, and they informed me that I could continue to attempt. Most of the time she would not latch or if she did, she was too sleepy to suck, although a suck attempt to the nurses was mostly via the bottle as I felt they had very little faith in Mabel’s ability to latch and feed.

When she was three weeks old, we received the diagnosis that she had Prader-Willi syndrome. I was told by the geneticist, the neonatologist and by the lactation consultant that Mabel would most likely never breastfeed as "babies with PWS just don’t breastfeed". I was devastated on so many levels. In my heart I knew Mabel could breastfeed. I had seen her latch and suck ever so briefly on that day back in the very beginning. I felt like I just needed to wait for her to wake up.

I was crying the next morning as I sat cuddling Mabel. The speech pathologist walked past and asked how I was. I cried to her about Mabel’s diagnosis. I cried about how scared I was for her future. I cried about how none of my other children had ever had any formula and how I wanted the same for Mabel. I feared I was going to let her down as I wasn’t sure how I was going to manage expressing breastmilk and 5 children once I got home. I cried to her about how I just wanted to simply put her to the breast. She looked at me and smiled and said, "well do it then." She was the one and only health professional who gave me any encouragement to keep on trying.

We were discharged home shortly after that with a tiny, floppy, sleepy baby with a NGT and a CPAP machine. Mabel was a month old. From the moment we got home I said to my husband “Ok no more bottles. If she is having a suck attempt, then it is at the breast”. It was hopeless. She was barely awake all day and night. She didn’t cry or fuss. If she was awake, she would not latch let alone suck. In desperation I tried some bottle feeds and she was just as hopeless on them too. We started growth hormone treatment at 3.5 months of age. Within a couple of weeks, it was like we had a new baby. She was so much more alert and awake. She still did not cry or give hunger cues, but she started to latch and suck. Then one day when she was 4 months, she did four breastfeeds without needing a top up. Within 48 hours the NGT was out and Mabel was exclusively breastfeeding. She would attach and feed continuously for about 40 minutes.

Our paediatrician was sceptical that she was getting enough milk as her weight was slow to gain in the beginning. I had to really trust the process and be confident that she was getting enough milk. That was hard in a baby that still didn’t give any hunger cues. I knew my supply was adequate for her. I would watch her feed very closely to listen for milk transfer. I watched her output very closely and generally looked at her. Her skin was good, her eyes were bright, her colour was good, and she was starting to hit her milestones. After a little while her weight started to pick up as she grew stronger and stronger. Mabel continued to be exclusively breastfed until she was 2 years old, when she decided she didn’t want to anymore. Ironically, she breastfed for longer than any of my other children.

"I had to really trust the process and be confident that she was getting enough milk."

A BREASTFEEDING JOURNEY | CHRISTINA & OAKLYN

Our daughter, Oaklyn, was born full term,. She was diagnosed with PWS (UPD) and went from eating “nothing by mouth” G-tube feeding to nursing exclusively starting at eleven months.

Within an hour after birth, she was placed on my chest and I tried to nurse our sweet tiny newborn with no success. I had nursed our other children for 2+ years each so I was eagerly anticipating this moment. Unfortunately, she seemed so very tired and weak yet we were able to have a few moments together skin to skin before they whisked off to NICU.

It was almost twelve hours before I could see her again and by then, she was hooked up to oxygen, NG tube, and monitors. I was able to pump and although she was able to drink from a bottle, she made consistent stridor sounds and then failed her swallow test miserably. We found out she was silently aspirating and this led to a G-tube and a Nissen Fundoplication (stomach wrapped around esophagus), a worst case scenario.

All of a sudden, all feeding by mouth came to a screeching halt. Our NICU encouraged “kangaroo care” (skin to skin) along with “dry nursing” after pumping, which she really didn’t respond to until… One day, after pumping, SHE LATCHED! At eleven months old, it just clicked.

She had been in feeding therapy for six months and had already transitioned to oral feeds. I believe the precursor was when she skipped over bottle feeding and drank from a straw! Her therapist made sure we celebrated that victory. My excitement was infused with a bit of caution and monitoring, but it seemed she was strong enough to pull the reserve milk and she showed no signs of distress and I cried tears of joy. I cried all I had contained until then, savoring the moment, and thinking what a tremendous blessing to experience this just this one time.

Surprisingly, this was not the last time! She continued to latch, feed after feed and it helped that she didn’t have any teeth at the time. She did clinch down a few times but my reactionary "OUCH" caused her to know to try again gently. She was quick to learn and was rewarded with lots of cheers! She has nursed exclusively for eight months now and still going strong.! My hope is that knowing this CAN happen, may encourage moms to keep trying. May God bless you with hope and great success in your journey.

A BREASTFEEDING JOURNEY | KATHLENE & CHLOE

Breastfeeding Chloe was one of the most rewarding and beautiful aspects of having a newborn with PWS. Without a doubt it was a lot of work to establish breastfeeding, but they were our moments of normal, attachment, peace when we could get on with being mother and baby daughter.

Chloe was born at 11.11am on a Thursday morning via planned c-section. She was my first bub and I was surprised at how small her cry was – not like an on-screen birth, the only ones I'd ever witnessed before. Nonetheless she had apgar scores of 9. She was a quiet bub and whilst she gave suckling a try, she did not successfully attach. She was syringe- fed expressed colostrum and I was reassured that c-section bubs can be slow to start feeding. On Saturday morning she went dusky, was rushed to the attending paediatrician and was found to be hypotonic and hypoglycaemic. As testing ensued and she was largely very lethargic, I focused on expressing milk that was fed to her via bottle and naso-gastric tube.

Following transfer to NICU and extensive testing, Chloe was diagnosed with Prader-Willi syndrome at 19 days old. I was told that I could start trying to breastfeed again.
Despite slow progress, Chloe and I persisted under the care of an incredible lactation consultant. She helped me to position Chloe to support her good attachment and to be patient. Every little step forward was celebrated and by 3 months of age Chloe was breastfeeding as her primary source of nutrition.

I highly recommend using a supplemental feeder when trying to teach a baby with PWS to feed. They reward bub with a lot bigger mouthful of milk for their sucking effort – a great incentive to keep trying and less likelihood they will fatigue before getting enough milk. We used the Medela supplemental feeder and it was a game changer for us.

I continued to breastfeed Chloe for 7 months and loved every moment of bonding and achievement and simple mother - bub normality that we shared. I hope that there were other benefits for her – including sensory input and oxytocin from being held in my arms, speech (she's very articulate) and microbiome health – but we'll never really know. What I do know is that I'll never regret the time investment nor forget the moments I thought we'd never share.

A BREASTFEEDING JOURNEY | ASHLEY & ALBERT

Albert is the younger of our two boys. I exclusively breastfed his older brother for 14 months and only stopped because I experienced rough morning sickness and painful nipples while pregnant. Albert was born in an independent birth center at exactly 37 weeks. He had some breathing issues right away that were resolved onsite. But he was only 4.5 lbs, so the midwives decided to transfer him to the NICU at the hospital across the street.

He was "floppy" and extremely sleepy but pretty healthy otherwise. We got his PWS diagnosis at two weeks old. By that time we had already started working on breastfeeding, though it was slow going. We were fortunate that I had a strong, stable supply and that he did not have other medical issues preventing him from feeding by mouth. He spent four more weeks in the NICU while we worked on his feeding skills and eventually came home on a g-tube.

Our time at the hospital was essential for our breastfeeding journey. At no point did anyone tell me that he wouldn't be able to. I saw online as I researched PWS that most babies couldn't, but the medical team never said anything. His doctor, the nurses and nurse practitioners, speech pathologist, occupational therapist, and lactation consultants were all supportive and so helpful.

The lactation consultants were amazing. I first learned how to latch him on using the "teacup" hold and was given a nipple shield to help stimulate his high palate. The nipple shield would also catch my forceful letdown and make it easier for him to get milk without drowning and without having to work too hard. The lactation consultants also helped with positioning and supports to make it easier and more comfortable for me. In the beginning, I exclusively used the "football" hold with my nursing pillow; I had to support both his head and my breast as he was feeding.

When we came home, I had five more weeks of maternity leave before I had to return to work as a high school teacher. We continued practicing breastfeeding while making up the difference with tube feedings. Less than a week after coming home, he was able to get a "full feeding" from the breast, but the next couple weeks his progress slowed. He seemed to be much more interested in comfort nursing than nutritive, although we were able to lose the nipple shield. Often he would indicate he wanted to nurse just so that he could have help going to sleep.

I did some internet research about nursing babies struggling to gain weight, hypotonic babies, and sleepy babies and discovered "switch" nursing. Switch nursing made a huge difference for us. He was able to get more volume and stay awake longer. He continued to get stronger, and I was able to use a "cradle" hold but I still had to support my breast. He is now 4.5 months old and we are going strong, without using switch nursing; I think of him as a breastfed baby.

During the day, he feeds at the breast when he's with me and from a bottle at daycare. At night, he usually wakes me up once during the night to nurse, but we also run a little through the feeding tube to help him get bonus calories to gain weight. We are also having to fortify all pumped breast milk to help with weight gain. But his latch is much stronger: I only have to support my breast occasionally, and I can actually get up and walk around if I need to while he's nursing. In this whole process, I have had to celebrate the small steps, just as we do with everything for our kids with PWS. There were definitely times where I've gotten discouraged, but I've always felt like if he *could* do it, it was worth the effort in the long run. Each small success pushes me forward, knowing all the benefits he will get from breastfeeding. I plan to continue as long as possible

AND REMEMBER...

Breastfeeding is not all about nourishment. It is about closeness and bonding, spending time with your baby and most importantly, loving your baby. This is supposed to be an enjoyable experience. There will be some cases that no matter how much you try, your baby with PWS may not become exclusively breastfed and that is okay. You haven't failed your baby. The sheer fact that you tried is amazing in itself. Ask for help, find an IBCLC (International Board Certified Lactation Consultant) who can help to guide you to what works best for your baby. Your child and family health nurse and paediatrician may also be able to provide support. Breastfeeding education and experience does vary between health professionals so don't be afraid to seek out someone who is prepared to support your wishes. Further support and information can be found through breastfeeding associations and support groups in your local country, either at their local meetings, online or via their phone helplines.

FURTHER SUPPORT

Australia

Australian Breastfeeding Association
www.breastfeeding.asn.au
1800 mum 2 mum (1800 686 268)

Canada

La Leche League Canada
www.lllc.ca
1800 665 4324

La Ligue La Leche
www.allaitement.ca
514 990-8917

New Zealand

Plunket
www.plunket.org.nz
0800 933 922

La Leche League
www.lalecheleague.org.nz

Breastfeeding New Zealand
www.facebook.com/breastfeedingNZ
www.youtube.com/user/breastfeedingNZ

UK

www.nhs.uk/start4life

National Childbirth Trust
www.nct.org.uk
0300 330 0700

USA

La Leche League
www.lllusa.org

International

La Leche League International
www.llli.org

Useful Websites

Find an IBCLC www.ilca.org/why-ibclc/falc

www.kellymom.com

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I became a registered nurse in 2001 and began my nursing career as a NICU nurse. In 2006 I completed a Graduate Diploma in Midwifery and have been working as a midwife since. In 2013, I became an IBCLC (under my maiden name of Elizabeth Morgan) and in 2015, I completed a graduate certificate in Child and Family Health Nursing. I am passionate about helping new mothers navigate through the sometimes challenging journey to successful breastfeeding. Breastfeeding my own children have been one of my most cherised moments of being a mother and in 2017 when our 5th child was born with PWS, I was devastated at the thought of not being able to breastfeed her too. I wanted to write this guide to provide mothers on the PWS journey some sort of hope. With the right education and support I believe many more babies with PWS can and will breastfeed. Whilst many might not exclusively breastfeed achieving some level of breastfeeding will be a gift many mothers will be grateful for.