

Feeding and weaning your child Birth to 2 years



Using this guide

This information is intended to advise parents, dietitians and speech therapists on the best ways of helping an infant with PWS to feed.

Various methods, techniques and equipment are mentioned, but parents are advised to consult with their child's dietitian, speech therapist, health visitor or

pediatrician before trying any of these for themselves.

The importance of good early feeding patterns

Good early feeding patterns are not only important for adequate nutrition, but to establish a pleasant feeding experience.

This might seem ironic when we know that later the desire to eat can become a problem, but a bad start will give everyone negative feelings, and can lead to great stress for parents and other family members.

Good oral muscle movement patterns will help later with speech development.

Sucking movements contribute to flattening the palate so, if this is possible for your child, it could help prevent the high palatal arch shown by some children with PWS.



PLEASE NOTE!

This information

does not replace guidance from any health professionals in individual cases.

The “floppy baby”

Babies with Prader-Willi syndrome (PWS) have varying degrees of hypotonia (low muscle tone).

This makes them appear ‘floppy’ and it is difficult for them to maintain a good position for feeding.

Their suck is usually weak, because of lack of tone in the facial muscles.

They can become exhausted from the effort of maintaining the sucking action long enough to take in sufficient milk.

Also, because of low muscle tone, babies with PWS have a weak cry or cry very little, so they can't always let you know when they are hungry.



Breast feeding/bottle feeding

The first nutritional choice for a family of any child is the source of milk. Breast feeding has wide and long lasting health benefits for any child and is encouraged. However, either method of feeding (bottle or breast) can present difficulties for the child with PWS due to weak suck strength and sleepiness. Breast feeding can be very difficult, although breast milk can be expressed for use in a bottle.

Many different support options exist, ranging from specialized teats to tube feeding. In some cases, specialized formulas may be required to help your baby gain weight. Getting health professional support to make the right choice for your baby and to get the right start in life is essential, as all babies vary in their individual needs.



For ease of reading, babies are referred to as “her” but the information applies equally to baby boys.

Tube-feeding and oral feeding

Many babies with PWS will require tube-feeding in the early days and weeks, but this should be discontinued as soon as your dietitian or medical team considers it possible.

In some PWS babies their swallow can be too uncoordinated or their suck too weak to feed sufficiently. In this case tube feeding allows for the safe delivery of appropriate nutrition to support optimal growth and development.

Unless there is a medical reason, oral feeding should still continue alongside tube-feeding in order to stimulate the oral muscles and allow your baby to experience the taste and touch aspects of feeding.

If no oral feeding is possible, oral play should take place where baby is introduced to a dummy and her own fingers placed into her mouth. This is especially beneficial during tube feeding so that oral sensation will be associated with food and the satiation of hunger, although this sensation does not always appear in individuals with PWS.

If your baby is coping with swallowing saliva without choking, even if she cannot be fed orally, it is safe to introduce small tastes of pureed food by placing a tiny amount (teaspoon) on the tip of her tongue.

For some babies it is not clear whether their swallow is safe. A speech and language therapist (SLT) with a specialist feeding qualification can assess this. Occasionally the SLT will arrange a video fleuroscopy test to check that the baby is not aspirating before the tube feeding is stopped. (Aspiration is when food enters the lungs, which can cause chest infections).



Good feeding practice: breast and/or bottle feeding



Position

Hold your baby on your lap so that you have your hands free, one to hold the teat, nipple or bottle, and the other to stimulate your baby's face, or assist with lip closure or swallowing.

You can achieve this position using a pillow, or by resting your arm on a chair arm. There are also special feeding support pillows available to rest your baby on so that she is facing you. An occupational therapist should be able to help you obtain one of these, or try searching on the internet for "feeding support pillow" for suppliers.

Preparation

Before introducing the nipple or bottle teat into your baby's mouth, it may help to stimulate her lips and tongue. Use your finger to gently tap or stroke your baby's tongue, stroke, then tap her cheeks and then around the lips. Use firm but gentle pressure, rather than too soft, as it may tickle rather than stimulate sucking!

Use a spoon handle or soft toothbrush to introduce different sensations. Finally, stroke your baby's tongue from back to front with gentle, rhythmic strokes - this may help to establish the rhythm for sucking. At the very least, baby should be well awake by now!

Techniques

Lip closure

Try placing a soft bottle teat over your nipple, if breast-feeding. This means that you can help your baby to suck by pressing on the teat, and it may help her to latch on. If the seal is very poor you can help by placing two fingers, one above the top lip, and one below the bottom lip, to help to keep her lips close together.

Sucking

Your baby's suck can be supported by placing your fingers on her mid-cheeks and gently applying pressure, stroking from mid-cheeks to her lips. Once she is sucking, gently tug on the bottle or pull back the nipple to stimulate her to hold on. If your baby tires easily, it may help to increase the flow of milk slightly by cutting a cross shape on the top of the teat. This is less likely to cause choking than just making the hole larger.

Continued...

Feeding and weaning your child

Equipment

There are several specialist bottles on the market. These include:

The MAM teat - A soft orthodontic shaped teat vented to assist the elimination of air.

Mead-Johnson bottle - a soft bottle that can be gently squeezed to help the baby to suck.

Medela Haberman Feeder - A specialised bottle designed to help babies with sucking problems. It has a valve in the neck to prevent milk flowing back into the bottle so that the baby need not suck so hard to get the next mouthful.

NUK bottles - used at many hospitals and can sometimes be provided by them, or by a speech and language therapist. See <http://www.nuk.co.uk/>

Most bottles usually have to be ordered specially. Some of these bottles, and more, can be viewed and ordered on the CLAPA (Cleft Lip & Palate Association) website at <https://www.clapa.com/shop/>



Techniques (continued)

Swallowing

If your baby sucks but does not swallow, stroke gently from just under her chin to the top of the breastbone with a one-way, downward movement. If her head is very 'floppy', you may need to establish jaw support by placing one finger under her chin, or using the thumb and one finger, one each side of her face. With practice, this can be combined with stimulating the suck by cheek pressure, as above.

Vitamin drops

The Department of Health recommends vitamin drops for all infants under the age of five years. These will be required from 6 months if you are breastfeeding or using expressed breast milk, or once your child is taking less than 500mls of infant formula per day.



Alternative feeding methods

Cup Feeding

If your baby cannot suck sufficiently using either breast or bottle, it is possible to introduce a cup. Use a small flexible plastic cup. Those supplied with medicines are sometimes sufficient, although the edge must be smooth.

There is a special 'flexi-cup' on the market. Place the cup on your baby's bottom lip, very slowly tip the liquid into her mouth, then, if necessary, stimulate swallowing (as above).

Sometimes using a thickener may help, but please consult your speech and language therapist about this.

Spoon Feeding

A spoon is traditionally introduced when solids are started. If your baby has a very weak suck, it may be possible to increase the quantity of milk taken by spoon-feeding the last of the bottle, or combining the cup and spoon together so that the change in stimulus to your baby's mouth will enable more to be introduced.

Special Cups

Some feeding systems, e.g. Avent, have soft spouts which enable milk to be tipped into the baby's mouth rather than sucked. These cups are often available from larger chemists.



IMPORTANT!

Parents should obtain advice from their health visitor, pediatric dietitian or other health professional as to which method would best suit their baby - individual needs vary.

Weaning

Many babies with PWS in the first year may struggle to gain weight. Weaning, the process of introducing solid food to a baby, is an important milestone and help improve nutritional status.



Weaning for all children should be fun and enjoyable for everyone involved. The introduction of a wide variety of taste, textures and colours is fundamental to the process.

The Department of Health recommends weaning at 6 months, but if your child is showing signs they are ready earlier, it can be started any time after 17 weeks. Indeed, some babies with PWS may be advised to start earlier than six months, as they often find it easier to take semi-solids from a spoon, rather than sucking.

For individual advice, discuss the time when to start weaning with your health visitor, paediatrician, or dietitian.

Use commercially available foods, or make your own by cooking vegetables, fruits, and/or rice (without salt or sugar) and then liquidising, using your cooking water or breast milk, formula or water as the liquid. You can make several batches at a time and store them in the freezer.

Gradually increase the lumpiness of the food as your baby gets older by mashing food rather than liquidising it. You can increase the variety of the food as time goes on, using pureed lean meats, fish, chicken, lentils, yoghurt etc. Around six to seven months old, you can add bread and cereals.

You can use formula or follow-on milk from six months onwards in foods, and this may be recommended if your baby's growth and weight are poor, to increase the nutrient density in her foods. You can use cows' milk as a component of meals from six months, but it should not be used as a drink until after your baby is one year old.



You can start to use semi-skimmed milk from age two onwards and skimmed milk from five onwards. This may be earlier if advised to do so by a doctor or dietitian who may then also discuss the need for a vitamin supplement.

Once your baby is taking solid food they will follow the expected weaning process, but may be slower than other children as the low muscle tone can make it hard to co-ordinate chewing.

Feeding and weaning your child



About 1 year old

By the time your baby reaches a year old, they should be eating much the same food as the rest of the family. This does not, of course, include things like crisps, biscuits and sweets!

Don't worry if she hasn't reached this stage yet though - many children with PWS do have problems adjusting to new foods or coping with lumpier food, and may take longer than usual to be completely weaned.

If lumpy food is a particular problem, try introducing it more gradually by starting with very small lumps and increasing the lumpiness very slowly as they become used to it.



Establishing healthy eating

Once your child is eating a good range of textures and flavours, it's time to think about how you will manage your child's diet in future. Many different dietary approaches for children with PWS exist and have been studied, but it is unclear if any one of these is more successful than another.

It is a good idea to discuss the different strategies with your team and choose a method which best suits you and your family.

Regardless of which you choose, it is likely sticking to a structured consistent approach contributes significantly to positive success and weight control. You may have to change some aspects as your child gets older but a consistent approach as far as possible to some fundamental aspects of eating will be of benefit to both your child and your family.

Educate family members

In respect to diet, it is important that those around you and your child understand the reasons for food restrictions and the healthy eating regime you are establishing. It may be particularly difficult for others to understand if your child shows no obvious outward signs of having PWS. To avoid difficult situations, encourage non-food based treats.

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Thank you ...

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