

Breastfeeding and Maternal PKU

Can I breastfeed my baby if I have PKU?

Yes you can breastfeed! Breastfeeding is possible for women who have normal babies and who have phe levels in the safe range.

The mother should keep her phe levels in the safe range (2-6mg%) while waiting for the baby to be tested for PKU, and hopefully for life after having the baby! If the baby has received the newborn screening test and does not have PKU, breastfeeding is not a problem. If the baby does not have PKU, their liver is able to breakdown phenylalanine, so the phe content of breastmilk is not a concern.

However, if the Mom's phe levels were high before the baby was born, and the baby's brain has been affected, the baby may not be able to suckle well enough to get enough milk for growth.

What if I 'go off' my diet while breastfeeding - will this harm the baby?

Firstly, it is recommended to stay on the diet for life to ensure you are thinking clearly and are healthy - especially with a little one that you have to take care of. Some people who stop the diet in adulthood have learning and behaviour problems. Since half of all pregnancies are unplanned, it is especially important for women to keep their phe levels in a safe range (2-6mg%) even if they are not trying to get pregnant.

If the Mom has high phe levels, she may have difficulty breastfeeding. She may have trouble getting her milk to flow, or trouble responding to the baby's cues of hunger and fullness, and may have difficulty appropriately caring for the baby. The first few months with a new baby are challenging enough without adding high phe levels on top of everything else! High phe levels can make you even more moody and emotional, and may cause you to have difficulty concentrating.

What if the baby does have PKU - can I still breastfeed?

Maybe. If the baby has PKU, the breastmilk is usually withheld for the first 2-3 days after the baby is diagnosed in order to bring the blood phe levels down. The baby is fed a phe-free formula during this time.

After the phe levels are lowered, the baby is given the phe-free formula first, and after that, the Mom can breastfeed as much as she would like. Then the amount of phe free formula is adjusted up or down depending on the baby's blood phe levels (which are tested 1-2 times weekly).

Breastmilk from a Mom with PKU may be higher in phe than the 43 mg/100 ml in normal breast milk (especially if the Mom's phe levels are not in the safe range). There could be a potential problem breastfeeding if the amount of breastmilk that the baby is allowed to consume (to keep phe levels in the normal range) is too small to maintain milk production.

Some clinics discourage women with PKU from breastfeeding an infant with PKU. The reason for this is that the post-partum period is difficult for the new Mom, and keeping her blood phe levels in the safe range can be more difficult as her body is returning to normal. At this time when Mom's phe levels are the most unstable, the baby with PKU could have high phe levels as a result.

The goal is to support a plan for feeding the baby that provides the greatest opportunity for the baby to develop as normally as possible. In this situation, formula feeding may more easily and effectively meet this goal rather than struggling with adjusting phe from breastmilk.