

The Mater Misericordiae University Hospital Department of Clinical Nutrition and Dietetics

Managing your PKU Diet Post-Pregnancy

What is the target phenylalanine (phe) range post pregnancy?

Post pregnancy, we aim for a phe range of 120-600mmol/L. This range is the same whether you plan to breastfeed or bottle feed. It is normal for your Phe level to be high after you give birth. By sending regular Phe levels, the metabolic dietitians can advise you with any dietary changes needed to help get your Phe levels back within the target range.

Do I send bloodspot cards to check my phe level?

Yes, after you give birth, you will return to using bloodspot cards for measuring your Phe level. If you are unsure about how to use these, please let us know and we can arrange for nursing staff to show you.

How often should I send a bloodspot card post pregnancy?

We advise you send a dried bloodspot card sample 10-14 days post-delivery. If you choose to breastfeed, we recommend that you send a dried bloodspot card once weekly thereafter. If you choose to bottle-feed, we recommend that you send a dried bloodspot card once monthly thereafter. Please send a fasting sample (a sample taken in the morning, before you have eaten or drunk anything) on Monday. The dietitian will call you with your Phe level for 6 months after you deliver (or longer if you are breastfeeding) and advise you of any required changes to your diet. Our phone clinics run typically every Tuesday and Friday between 2-4pm, but we may call you outside of these times depending on availability of blood results. Please ensure you have set up a voicemail in case you are unable to take a call from the dietitian.

What are the most important things for me to remember with my PKU diet post pregnancy?

Coming home with a new baby can be a busy time. It is important to take time to look after yourself and make sure you recover well after the delivery. It is recommended to stay on diet post-pregnancy to ensure you are feeling your best while taking care of you and your baby. Here are some tips to help you stay on track with you PKU diet post pregnancy:

- 1. Always take your synthetic protein drinks. The dietitian will advise you if you need to change the amount you take.
- 2. Have a good supply of low protein foods.
- 3. Make sure you are keeping track of your exchanges. Keep a food diary if this helps.
- 4. Let the dietitian know if you need any scoops, exchange lists or recipe ideas to help you stick to your PKU diet.
- 5. Plan to eat regular meals throughout the day so that you are getting the energy that you need.

Should I make any changes to my PKU diet post-delivery?

Exchanges: After pregnancy, the aim is to slowly reduce your exchanges until your Phe level is back within range. You should reduce your exchanges by 10-20% post-delivery (for example, if you are on 30 exchanges by the end of your pregnancy, then reduce by 3-6 exchanges) and we can further advise you when we receive your Phe level post-delivery and when we receive further Phe levels thereafter.

Synthetic protein drinks: Continue taking your synthetic protein drinks. The dietitian will advise you of any changes needed when your Phe level post-delivery is received.

Tyrosine supplement: If you were taking a tyrosine supplement during pregnancy, this can be discontinued.

Are there any other supplements that I should take during my pregnancy?

All women of childbearing age are recommended to take a folic acid supplement to reduce the risk of neural tube defects. Even though your synthetic protein may contain folic acid, we still advise you to continue taking a folic acid supplement (400mg). If there are any other micronutrients that you are not getting enough of from your drink, your dietitian will recommend a suitable supplement for you.

Can I still breastfeed my baby if I have PKU?

Yes! It is perfectly safe to breastfeed your baby. If your baby does not have PKU, they are able to break down phenylalanine, and therefore, the phe content of the breastmilk is not a concern. However, it is recommended to follow your PKU diet and control your phe levels between 120-600mmol/L while you are breastfeeding for good health. If your baby has PKU, you will be advised on appropriate infant feeding by your baby's metabolic team.

How often will I attend clinic post pregnancy?

We aim to see patients 3 months after they have delivered. Further reviews thereafter will be scheduled depending on your needs.

What should I do if I am not managing my diet or I would like to speak with a dietitian outside of phone clinic/outpatient clinic times?

If you have a question or an issue, and would like to speak with a dietitian outside of phone clinic hours, please phone the Metabolic Unit on (01) 803 2759 and press 3 to speak with a dietitian. If we are unable to take your call, leave a message and we will get back to you as soon as possible. In the case of an emergency, please phone (01)803 2759 and press 1 to speak with the metabolic doctor on call.

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