



The Mater Misericordiae University Hospital
Department of Clinical Nutrition and Dietetics

Managing your PKU diet during pregnancy

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

During pregnancy, we aim for a phe range of 120-360mmol/L. This range is lower than normal because there is a doubling of the phe concentration across the placenta. For example, if your phe level is 300mmol/L, your baby's will be approx. 600mmol/L. Maintaining levels between 120-360mmol/L is safest for the baby's growth and development.

Do I still send bloodspot cards to check my phe level?

No. During pregnancy, blood tubes are used to measure 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 and when should I send blood samples when I am pregnant?

During pregnancy, we advise you send a fasting blood sample (before you have eaten or drank anything) every Monday and Thursday. It is recommended to send your sample by Swiftpost, as sometimes the normal postage service can be slow or delayed. Our phone clinics run every Tuesday and Friday between 2-4pm. We will call you between these times with your phe level and to advise you of any dietary changes needed. Don't forget to set up a voicemail in case you are unable to talk to the dietitian during these times. We can then report your Phe level over voicemail if we cannot reach you.

Will I stay on the same exchanges throughout my pregnancy?

No, as you progress through the pregnancy, the number of exchanges you will need to keep your phe levels within range will increase. This usually happens from around 16 weeks onwards. This is because the baby is using some of the phe for growth and secondly the baby's liver will start to metabolise some of the phenylalanine. Your dietitian will then advise you to increase your exchanges.

Why does my prescription list 'Calogen', 'SOS' and 'L-Tyrosine'?

When you become pregnant, you will automatically be provided with a prescription for Calogen, SOS and L-Tyrosine. Calogen and SOS are energy supplements, and L-Tyrosine is an amino acid supplement. The metabolic dietitian will monitor your bloods and will let you know if you need to start taking any of these supplements during your pregnancy.

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 (400mcg) for the duration of your pregnancy. 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.

How often will I attend clinic during my pregnancy?

We aim to see patients once every trimester during their pregnancy. However this can vary between pregnancies and the individual needs of the patient. We will also be speaking with you twice per week during maternal phone clinics and advising you as we monitor your Phe levels.

What are the most important things for me to remember with my PKU diet during 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.

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) 8032759 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)8032759 and press 1 to speak with the metabolic consultant on call.



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