



The Mater Misericordiae University Hospital
Department of Clinical Nutrition and Dietetics

Managing your PKU diet while planning a pregnancy

Why is it important for me to plan a pregnancy if I have PKU?

If you are planning on having a baby, it is always advised to talk to the metabolic dietitian. They can support you in bringing your phe levels within range prior to conceiving and advise you around any other necessary changes to your diet. This means that from the moment you become pregnant, you know your levels are in a safe range to keep your baby protected from the potential harm higher phe levels can cause. The dietitian will advise you how long you need to have your diet established and your levels in range before discontinuing contraception and trying to conceive.

What is the target phenylalanine (phe) range while planning for pregnancy?

When planning for a pregnancy, we aim for a phe range of 120-360mmol/L. This range is lower than normal because during pregnancy, 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, and therefore levels between 120-360mmol/L are safest for the baby's growth and development. We advise you to aim for a phe of 120-360mmol/L so that your levels are well controlled in preparation for pregnancy.

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

Yes, you will continue to use bloodspot cards to measure your phe level while you are planning a pregnancy. When you are pregnant, we will provide you with blood tubes to provide liquid samples. The metabolic nurses will show you how to obtain the liquid samples when you are pregnant.

How often should I send bloodspot cards if I am planning a pregnancy?

When planning for pregnancy, we advise you send a fasting blood sample (taken in the morning before you have eaten or drank anything) once per week. Our phone clinics run typically every Tuesday and Friday between 2-4pm. We will call you between these times with your phe level and 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.

Are there any other supplements that I should take if I am planning a 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 take a folic acid supplement (400mcg) while planning a pregnancy and throughout your pregnancy. If there are any other micronutrients that you are not getting enough of, your dietitian will recommend a suitable supplement for you.

What are the most important things for me to remember with my PKU diet if I am planning a 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 find out I am pregnant?

It is important to call and let the metabolic team know if find out you are pregnant. We can then further advise you of any steps you need to take. We also recommend sending a dried blood spot sample to measure your phe as soon as possible.

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, 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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