

## **THE PRESCRIPTION OF LOW PROTEIN FOODS FOR PATIENTS WITH PKU**

People with PKU can only eat a very restricted diet. They are unable to eat most regular foods: e.g. meat, fish, eggs, cheese, milk, nuts, ordinary bread, pasta and cereal products. There are few foods they can purchase from supermarkets that are suitable for them to eat. Although many fruits and vegetables are low phenylalanine and can be eaten without measurement, they are low in calories. Therefore, the diet requires supplementation with low protein foods that are available on ACBS prescription.

**Low protein foods are important for 3 reasons:**

- 1. They provide an essential source of calories to support growth and prevent catabolism, which may lead to metabolic instability in PKU.**
- 2. They provide bulk in the diet to prevent hunger. Without low protein foods, people with PKU will find it difficult to adhere to their very low protein diet.**
- 3. They provide variety in a very restricted diet.**

Low protein special foods that are approved for prescription by ACBS cannot usually be purchased. There are over 140 items available on prescription. To give guidance on how much should be prescribed, a table is included on page 2 indicating maximum numbers of units of low protein foods to prescribe for different patient age groups or pregnancy.

Guidelines have been calculated based on energy requirements. In general, low protein special foods are expected to provide up to 50% of estimated daily energy requirements for patients with PKU. Some patients eat a variety of low protein items, but there are others who will eat only a small number of items e.g. only requesting bread or flour on prescription. Rather than detail a recommended maximum quantity of each food item per month; a maximum number of food units per month for all low protein foods (*except milk replacements, energy supplements and protein substitutes*) depending on the age of the patient, are given. This will enable patients to have the necessary variety in their individual diets.

**The definition of one unit is given below:**

ACBS low protein prescribed foods	Definition of one unit	Suggested weight of 1 unit
Biscuits/biscuit bars	1 pack	Up to 200g
Bread/bread rolls	1 pack	Up to 600g
Breakfast cereals	1 box or pack	Up to 400g
Cakes/breakfast bars/dessert powder mixes /jelly powder/ chocolate substitute spread	1 pack	Up to 300g
Cheese sauce mix	1 pack	225g dry powder
Crackers/crispbread /mini crackers Croutons/ breadsticks/savoury snacks	1 pack	Up to 200g
Egg replacer/egg white replacer	1 tub/box	Up to 500g
Energy bars (Vitabite or Chocotino)	1 pack	1 pack
Flour mix/cake mix/waffle mix	1 packet	Up to 500g
Pasta/Rice	1 pack	Up to 500g
Pasta pots / potato pots/pasta in sauce/XPots	1 pack	Up to 300g
Pizza bases	1 box	Up to 500g
Readymade desserts	1 pack	Up to 500g
Sausage/burger mixes/fish substitutes	1 pack/box One sachet not the same as one box	Up to 360g dry powder
Soups	1 box	112g dry powder
Yoghurt substitute	1 tub	400g

**PLEASE NOTE:** The above units are intended as a guide only as package size is variable. Any pack size greater than the suggested weights should be estimated as more than 1 unit.

**Recommended maximum number of units of low protein foods for each age group:**

Age of patient with PKU	Recommended maximum number of low protein items to prescribe each month
4 months to 3 years	20 units
4 to 6 years	25 units
7 to 10 years	30 units
11 to 18 years	50 units
Adults	50 units
Pre-pregnancy/Pregnancy	50 units

**PLEASE NOTE:** Both tables do **NOT** include low protein milk replacements as part of the units allowance e.g. Calogen, Dalia milk, Duocal powder, Lattis, Loprofin drink, Prozero and SnoPro or protein substitutes e.g. PKU First Spoon, PKU Lophlex LQ, PKU Coolers, PKU Anamix Junior, PKU Explore or glucose polymer supplements. The amount prescribed will vary from patient to patient and needs to be determined on an individual basis. © NSPKU 2020