



**The National Society for Phenylketonuria**

## **The prescription of low protein foods in PKU**

People with PKU can only eat a very limited diet. They are unable to eat many nutritious and staple foods: e.g. meat, fish, eggs, cheese, milk, nuts, ordinary bread, pasta and other cereal products. There are few normal foods they can eat in unlimited quantities and these mainly include free fruits and vegetables that have a low calorie density. Therefore, the diet requires supplementation with many low protein foods that are available on ACBS prescription.

**The prescription of low protein foods is for 3 important reasons:**

- 1. Low protein foods provide an essential source of calories to support growth and prevent catabolism, which may lead to metabolic instability in PKU.**
- 2. Low protein foods provide bulk in the diet to prevent hunger and consequently people eating higher protein unsuitable foods.**
- 3. Low protein foods provide variety in a very limited diet.**

Foods prescribable by ACBS can generally not be bought over the counter. There are over 100 items available on prescription, and it is difficult to define how much to prescribe of each item. In an attempt to give some guidance on this, a table is included on page 2 indicating maximum numbers of units of low protein foods to prescribe for different age groups of patients.

Guidelines have been calculated based on energy requirements. In general, low protein special foods are expected to provide 50% of estimated daily energy requirements in 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 prescribable foods	Definition of one unit
Pasta / Rice	1 box (500g)
Pasta or Potato pots / Pasta in sauce	300g
Flour mix / Cake mix	1 packet (500g)
Bread / bread rolls	600g - 800g
Pizza bases / pizza base mixes	2 pizza bases (300g)
Crackers / crispbread / mini crackers / croutons/ crostini/ savoury snacks	200g
Sausage / burger mixes	4 / 2 sachets (125g dry powder)
Cheese sauce mix	1 pack (225g dry powder)
Soups	4 sachets (112g dry powder)
Breakfast cereals / Hot breakfasts	375g / 6 sachets
Egg replacer / egg white replacer	1 tub
Biscuits	1 packet (150g)
Cakes / breakfast bars / dessert mixes / jelly powder / chocolate spread	240g
Energy bars (Vitabite)	175g

**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 -3 years	15 units
4-6 years	25 units
7-10 years	30 units
11-18 years	50 units
Adults	50 units
Pre-pregnancy/Pregnancy	50 units

**PLEASE NOTE: Both tables do NOT include low protein milk replacements: Calogen, Duocal powder, Loprofin drink, Prozero and SnoPro or protein substitutes e.g. PKU First Spoon, PKU Lophlex LQ, PKU Coolers, PKU Anamix Junior, PKU Gel or glucose polymer supplements.**

The amount prescribed will vary from patient to patient and needs to be determined on an individual basis.