

# NSPKU - DLA factsheet

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**The NSPKU supports families claiming Disability Living Allowance and the following points should be taken into consideration.**

1. PKU is an inherited metabolic disorder for which there is no cure. The treatment is a low phenylalanine diet which must be followed throughout life.
2. If the diet is not followed then the PKU sufferer will become brain damaged. If the diet is managed well and closely monitored then the outcome is very good, with PKUs becoming valuable members of society and able to reach their full potential.
3. The diet is difficult and very complicated. It requires careful attention to the weighing of small amounts of the normal food allowed and the administration of amino acid and mineral mixtures which are unpleasant both in taste and smell. It can frequently take a long time to coax children to take these mixtures.
4. Some younger children with PKU may sometimes need to be constantly supervised to ensure that they do not eat forbidden foods. When the child is old enough to be away from home at playschool, school, and friends, those taking care of him/her need to be taught how to manage the diet. The parent of a PKU child has to constantly teach and remind others about the disorder.
5. Blood samples that can be difficult to obtain, have to be taken regularly. The recommendations are weekly up to the age of 4 years; fortnightly for 4 to 10 years, and monthly for those over 10 years old. PKUs have to visit the hospital regularly for follow-up.
6. As basic foods such as bread, biscuits, flour and pasta have to be low-protein and on prescription the parent of the PKU has to make frequent visits to the doctor and pharmacy. Often products are not available and a return visit is required.
7. A great deal of time is required for cooking as there are very few quick meals available to PKUs. Parents have to bake and prepare foods in advance and freeze food in order to manage the diet well and provide variety. The low-protein products are much more difficult to cook with than ordinary foods and skill is required to produce appetising meals with them. Parents have to practise their cooking with these products.
8. A trip out for the day, weekend or longer requires careful planning. Parents have to make sure they have all the necessary amino acids, minerals and low protein foods for journeys, hotel visits and friends' houses. It can be difficult finding a suitable eating place.
9. Shopping is time consuming as all labels have to be read to make sure there is no aspartame in the product. Aspartame is being used in thousands of foods and drinks and constant vigilance is required.
10. Some children with PKU can be overactive and therefore require supervision in addition to those already mentioned.