

## **Travelling with PKU Hints and Tips for Happy Holidays**

### **Introduction**

Holidays and school trips should be enjoyable but their organisation can be stressful. This is true for anyone so if you or your child has PKU a bit of extra planning and organisation is required. Getting accustomed to travelling away from home, and maintaining the diet enables a child to develop confidently. Try not to say 'We can't do that because you are PKU'.

This leaflet has been divided into sections:

- ☞ General advice prior to travel
- ☞ Tips for any journey
- ☞ School and club trips
- ☞ Self catering or hotel?
- ☞ Going abroad
- ☞ Checklist
- ☞ Other information available
- ☞ Insurance

### **General advice prior to travel**

Forward planning is essential before any trip.

1. Build up a supply of the essential prescribable products you will need for your trip well in advance; protein substitute, minerals and vitamins (if needed) and low protein foods and milk substitutes. Make sure these items are kept separate from items currently used. It may be helpful to put these things in a box and leave it with other items you need for your holiday.
2. If you are travelling abroad obtain a letter from your hospital, on headed note paper which lists all your special products and the reason why you need to take them with you. This is useful for customs when travelling abroad and may also be helpful in this country if you need emergency treatment.
3. Buy new batteries for your dietary scales and replace the old batteries just before you pack the scales.
4. Collect suitable containers and tubs in which you can carry prepared meals e.g. empty ice cream tubs. See 4 in next section.
5. Find a container with a secure lid which will enable you mix your protein substitute without spillages .

### **Tips for the journey**

When going on a journey you will need to plan what will be eaten for any meals/snacks needed on the way. You may take a packed meal or decide to stop at a café.

1. Take plenty of low protein biscuits and free sweets so that you / your child can fill up on these if hungry or you are delayed. They are also useful to have whilst on holiday, especially if abroad as foods labels may be difficult to read.
2. Take pre-weighed amino-acid substitute in a labelled, strong freezer bag(s) and a bottle of water so that you can make up the substitute easily. If the protein substitute is made up as a drink a covered beaker to shake the mixture in is useful. Remember if travelling abroad to have a letter explaining about the protein substitute, particularly if taken out of a tin.
3. Take some suitable squash with you for flavouring. Small cartons of juice are useful too.
4. Take packed meals in suitable containers e.g. ice cream boxes, margarine tubs, cottage cheese cartons. These can be thrown away at the end of the meal.
5. If you make up your low protein milk, take a measuring jug and an appropriate scoop for any extra vitamins and minerals.

### **School and club trips**

1. Encourage your child to attend school or club trips away from home. It will build their confidence and encourage them to take responsibility.
2. You should discuss the dietary requirements you, or your child with PKU, have with the group leader or caterer as soon as possible.  
Explain that you will provide the special low protein foods that are needed but that some special cooking will be necessary. Offer to look at the menus the group members are going to follow and suggest simple alternatives that could be prepared by yourself or your child. It may be helpful to provide simple, suitable recipes.
3. Pre-measure protein substitute and any vitamins and minerals.
4. It may be helpful to ask the dietitian at your PKU clinic to contact the group leader or caterer to discuss the diet and the need for a protein substitute with meals.
5. Provide plenty of low protein products; and a little extra in case of wastage or spillage.

### **Self catering or hotel?**

Both types of accommodation are possible.

The following information maybe of help when making your decision.

#### Self catering accommodation

The obvious advantage of this type of holiday is that you are completely in control of what food is prepared. You can also eat when you wish.

The disadvantage is that the cook does not get a rest from the kitchen chores!

Successful self catering depends on adequate cooking facilities. Ask what equipment is in the kitchen before making your booking.

You will probably need:

**Fridge** – to store milk substitute, protein substitute and perishable foods and drinks.

**Oven** – to make or freshen bread, make casseroles, crumbles, pizzas.

**Hot Plates/gas/oven rings** – to cook vegetables, pasta, freshen bread and make toast if you are patient.

**Microwave** – to refresh bread, bake, cook.

**Toaster** – is very useful but seldom available.

If you decide to self cater you may wish to take a few 'stand-by' basics for favourite dishes e.g. sauces for pasta.

### Hotel accommodation

1. Ask about the type of meals that are served before you make your booking. Many hotels have a buffet system which makes choosing the right foods easier. Alternatively, a hotel with a large range of dishes, side dishes, salads may be acceptable.
2. Some hotels and guest houses may prepare your low protein pasta or pizza for you, if you discuss your dietary needs in advance and provide the low protein products. Most hotels can offer a good range of salads, vegetables and fruits at all meals and juices and cereals at breakfast.
3. Ask if the room has a fridge which you can use and which is not just for hotel snacks and drinks. If not, a cool bag will keep milk etc. cold as long as a new ice pack is used daily – usually easily available in a hotel or take two freezer blocks with you and ask if they can be kept in the deep freeze, swapping them each day. If there isn't a fridge in the room ask if you can keep your necessary foods (labelled) in the hotel fridge.
4. Some hotels do not allow food in the room. If this is the case you can hide it and make sure there is no obvious mess from food which would attract bugs, and the hotel staff might turn a blind eye or follow advice as above. *Can we advocate this?*
5. Ask for a kettle in your room.

### **Going abroad**

1. If you are staying in a hotel abroad, tell your travel agent about your dietary needs from the outset. They should be able to tell you what types of meals are offered at your chosen hotel. He/she may be able to arrange for you to have a fridge in your room or let you use space in the kitchen fridge. An ice pack can be useful used with a fold up insulated bag for keeping foods cool in your room.
2. When going through customs it is advisable to carry only unopened tubs and other products. Opened ones could be construed as suspicious. Just before setting off on the return journey throw away opened tubs and packets not needed.
3. Pack your amino acid mixture in a few items of luggage so that if some part of your luggage gets lost you have a supply to see you through a few days. Pack enough amino acid mixture to allow for delays in travelling. Always pack as much as possible of your amino acid mixture in your hand luggage for use on your journey.

4. You may be able to negotiate extra baggage allowance because of the extra things you have to take. Ask your travel agent who you should contact to do this.
5. Do not pack bread, which is vacuum sealed, in your suitcase which goes in the hold of the plane as the change in pressure will burst the packaging. You can pierce one or two loaf packets and put this in the case in the hold for immediate use when you arrive.
6. Take some food on the plane/boat for the journey as there may be very little which is suitable on board and it could be useful if the plane or boat is delayed. You can contact the airline in advance to let them know what you will require. It might be easier to tell them what you can eat rather than what you cannot eat.
7. Take translations of foods with you so that you know how to ask for what you want in another language. Ask your dietitian to contact the society for a list of useful phrases translated and for hospitals abroad which specialise in PKU. Ask dietitian to write a letter to explain about the diet and ask the travel company if they can translate it. This is useful when visiting restaurants.
8. Take other 'free' food items with you instead of bread e.g. Loprofin crackers, Aprotin crispbread and Low Protein cereal. Other useful foods are low protein pasta and rice. Take a few of your favourite simple recipes. A friendly chef might make a sauce for your pasta. Don't be shy and ask nicely! (We assume you would!)
9. For babies, powdered food is lighter to carry.
10. Use bottled water to make up your amino acid mixture.
11. Drinks abroad may not be labelled as containing aspartame. Look out for the E number E951.
12. If travelling to high humidity areas make sure your amino acid is sealed properly. It will go lumpy if it isn't.
13. Avoid taking Duobar to a hot country, it can be very messy.
14. Snopro curdles at high altitude. Take Loprofin instead or another milk substitute. Milupa LPD is useful abroad as it is a powder milk substitute and therefore less bulky but it will require diluting.
15. Low protein bread will refresh in foil on a balcony in the sun.
16. When eating out either abroad or in this country it is sometimes easier to select items from the side dishes rather than juggle about with a main course e.g. order chips, side salad, fried onion rings etc. It could be cheaper too!
17. If however you love your 'McDonalds' you will be able to buy your usual favourites!
18. If travelling abroad for extended holidays it may be useful to obtain local contact number e.g. SHS in USA for emergency use if problems with protein substitute. Please discuss with your dietitian.

### **Check list**

Have you packed these, if you need them?

Protein substitute

Minerals

Vitamins

Prescribable low protein foods

Milk substitute  
Free foods e.g. fruit, sweets  
Aspartame free squash  
Bottled water  
Containers and lid to mix protein substitute  
Tubs to carry protein free meal  
Plastic bags and ties  
Coolbag  
Ice Pack(s)  
Measuring jug  
Measuring spoon  
Dietary scales  
Diet information  
Letter from hospital  
Recipes

### **Further information which is available**

E.S. PKU web site:

<http://www.espku.org/>

This gives information on parent associations and centres which treat PKU patients in Europe.

### **NSPKU**

Has translations of useful phrases for most European countries.

Please contact your dietitian who will be able to obtain this information for you.

### **Insurance**

Within the European Community you are entitled to free or reduced cost emergency medical treatment if you have a form called an E111 (called E one eleven). This insurance does not cover anything other than health. It might not cover all the things that you would expect to receive free through the NHS such as ambulance transport, x-rays and blood tests. The E111 is available free of charge from post offices and travel agents and can be found at the back of a very useful booklet called 'Health advice for travellers'. You need to fill in the form and get it stamped at the post office. Once validated by the post office, a single E111 will cover you, your spouse and dependent children up to the age of 16 (19 if in full time education). There is no time limit on its validity, although if you submit one to claim treatment you will need to apply for a replacement. Don't forget also to pick up leaflet T6, which sets out procedures for making claims.

If possible both parents/carers travelling with a PKU child should take an E111. If you have to use one of the forms you will still have another one as a back up. Photocopies of the form are not always accepted but can be useful to give to doctors and chemists. The

E111 is still useful even if you take out holiday insurance as most medical insurance will not pay out for the first £50. If the cost of treatment is over £50 some insurers will waive the excess that would otherwise be charged on a medical claim if you submit your E111 form to them as part of the claim. (They can then recover some costs directly from the health service concerned.)

You are not covered for ongoing treatment for a pre-existing condition. For this you need form E112. Contact your doctor to find out whether you are eligible.

*Does anyone know anything about PKU and this different form?*

The E111 is accepted in all 15 EU member countries plus Iceland, Liechtenstein and Norway. Reciprocal health agreements have also been negotiated with some countries outside the EU. British passport-holders are entitled to urgent medical treatment at a reduced cost or, in some cases, free at public hospitals in most former Soviet countries, Malta, Australia and New and Zealand, and some Caribbean islands.

There are no reciprocal health agreements in several popular holiday destinations, including Turkey, Cyprus, Mexico, the US and Canada, and Switzerland.