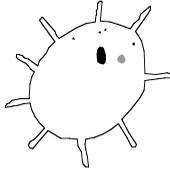


+ NSPKU +
The National Society for Phenylketonuria (United Kingdom) Limited

Travelling with PKU **Hints & Tips** (for happy holidays!)



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 is required. Getting accustomed to travelling away from home, and maintaining the diet enables a child to develop confidently.

Try not to think '*You/I can't do that because you/I have PKU*'.

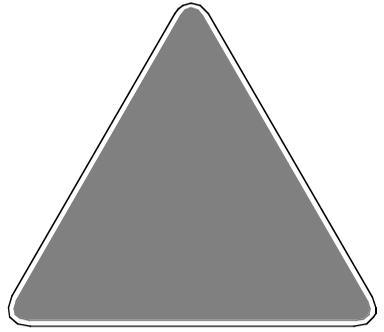
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① General advice prior to travel

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, mineral and vitamin supplement (if needed), low protein foods and milk substitutes. Make sure these items are kept separate from items you are using all the time. 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 or GP on headed notepaper which lists all your special products and the reason why you need to take them with you. This is useful for customs and may also be helpful in this country if you need emergency treatment.
3. Replace the old batteries in your scales with new ones just before you pack them.
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 to mix your protein substitute without spillages. If you use powdered low protein milk, take a measuring jug.



Remember the correct scoop if you have to measure out powdered minerals and/or vitamins.

② 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 as these are useful 'fillers' when hungry or for travel delays. They are also useful to have whilst on holiday, especially if abroad, as food labels may be difficult to read.
2. Take pre-weighed protein substitute in a labelled, strong freezer bag(s) and a bottle of water so the protein substitute can be made up easily. If the protein substitute is made up as a drink, a covered beaker to shake the mixture is useful. Remember if travelling abroad to have a letter explaining about the protein substitute, particularly if taken out of the tin.
3. Take some suitable squash 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.

③ 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 any dietary requirements with the group leader or caterer as soon as possible.
Explain that you will provide the special low protein foods but that some special cooking will be necessary. Offer to look at any menus 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 your dietitian to contact the group leader or caterer to discuss the diet and protein substitute.
5. Provide plenty of low protein products; and a little extra in case of wastage or spillage.

④ Self-catering or hotel?

Both types of accommodation are possible. The following information may be 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 available 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 rings** – to cook vegetables, pasta, freshen bread and make toast.
- **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, jelly crystals, blancmange powder, fruit tea bags etc.

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 food easier. Alternatively, in a hotel with a large range of dishes, side dishes and salads may be suitable.
2. Some hotels and guesthouses may prepare low protein pasta or pizza for you, if you discuss dietary needs in advance and provide the low protein products. Most hotels can offer a good range of salads, vegetables and fruits at mealtimes and juices and cereals at breakfast. Hotels will often provide a toaster for you to use.
3. Ask if the room has a fridge which you can use. Check it is not just for hotel snacks and drinks. If not, a cool bag will keep milk and other items cold as long as a new ice pack is used daily – usually available in a hotel. Alternatively, take two freezer blocks with you and ask if they can be kept in the deep freeze, swapping them each day.
4. If there isn't a fridge in the room ask if you can keep your necessary foods (labelled) in the hotel fridge.
5. Ask for a kettle in your room.

⑤ Going abroad

1. If you are staying in a hotel abroad, tell your travel agent about any dietary needs from the outset. They should be able to tell you what types of meals are offered at the chosen hotel. They may be able to arrange for you to have a fridge in your room or let you use space in the kitchen fridge.
2. When going through customs on the return journey it is advisable to carry only unopened tubs and sealed low protein products. Opened ones could be construed as suspicious.
3. Pack your protein substitute in several different 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 to allow for delays in travelling. Always pack sufficient of your protein substitute in your hand luggage for use on your journey and in case your luggage is delayed.
4. You may be able to negotiate extra baggage allowance because of the extra things you have to take. Ask your travel agent whom you should contact to do this. This can be especially helpful for those travelling for a long time.
5. Foil sachets of Phlexy 10 can be packed in hand luggage or suitcases. Foil sachets carried on your person will set off the alarm of the body scanner.
6. Do not pack bread which is vacuum-sealed or L.P. Snack Pots in your suitcase as it will be stored in the hold of the plane. This is subject to changes in pressure which will burst the packaging. You can pierce one or two loaf packets and put these in the case in the hold for immediate use when you arrive.
7. 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.
8. Virgin airlines have provided accurate low phenylalanine diets and have even measured the exchanges for previous travellers.
9. 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 into the appropriate language and for a list of hospitals in the country you are visiting which specialise in PKU. Also ask your 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.

10. Take other 'free' food items with you instead of bread e.g. Loprofin crackers, Aprotin crispbread and Loprofin breakfast cereal. Other useful foods are low protein pasta and low protein rice. Take a few of your favourite simple recipes. A friendly chef might make a sauce for your pasta.
11. For babies, powdered food is lighter to carry.
12. Use bottled water to make up your protein substitute.
13. Drinks abroad may not be labelled as containing aspartame. Look out for the E number E951.
14. If travelling to high humidity areas make sure your protein substitute is sealed properly. It will go lumpy if it isn't.
15. Avoid taking Duobar or other low protein 'chocolate' to a hot country, it can be very messy.
16. 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 will require diluting.
17. Low protein bread will refresh in foil on a balcony in the sun. You can also refresh it by placing it in two sealed plastic bags and boiling for a few minutes.
18. 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!
19. If you love your 'McDonalds' you should be able to buy your usual favourites in most countries! Portion sizes for chips are similar to the UK.
20. If travelling abroad for extended holidays it may be useful to obtain a local company contact number for emergency use. This is in case of problems with supply of your protein substitute or low protein special products. Please discuss this with your dietitian. A list of local contact numbers of the main UK manufacturers or subsidiaries is printed separately and accompanies this booklet.
21. If going self-catering abroad check beforehand what the local food supply is like.

⑥ 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 meals
- ✓ Plastic bags and ties/foil
- ✓ Coolbags
- ✓ Ice pack(s)
- ✓ Measuring jug
- ✓ Measuring spoon
- ✓ Dietary scales
- ✓ Diet information
- ✓ Letter from hospital
- ✓ Recipes
- ✓ Translation of useful phrases

⑦ Additional Holiday Information

The Society has produced a list of useful questions/phrases translated into various languages.

At present the following languages are available:

FRENCH / GERMAN / ITALIAN / SPANISH / DUTCH / SWEDISH/
NORWEGIAN / DANISH / POLISH / GREEK / SERBO-CROAT

PLEASE NOTE THAT FRIENDS AND MEMBERS OF THE SOCIETY HAVE KINDLY PREPARED THESE TRANSLATIONS AND WE RELY ON THEIR ACCURACY. WE CANNOT BE HELD RESPONSIBLE FOR ANY ERRORS.

If you would like a copy of any of the translations, please contact the NSPKU administrator. They are also available on the website at <http://www.nspku.org>

E.S. PKU website: <http://www.espku.org>

③ Insurance

Within the European Economic Area you are entitled to free or reduced cost emergency medical treatment if you have a form called an E111 (called E one eleven). This form 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'. The booklet contains information about the level of emergency medical cover available to UK residents in countries around the world i.e. in the European Economic Area countries, Reciprocal Agreement countries and countries with no health care agreements with the UK.

You are advised to take out comprehensive insurance for travel abroad as the E111 will not cover you fully.

Some members who have specified PKU on the policy schedule have found companies reluctant to cover them. If you experience any problems, contact the Society administrator for details of companies who have given cover in the past.

For extended visits abroad you will need to make individual arrangements in consultation with your consultant, GP and dietitian.

Produced by the National Society for Phenylketonuria
and its Medical Advisory Panel.



The National Society for Phenylketonuria (United Kingdom) Limited

The Society is a registered charity.
It offers support to PKUs and their families by producing various
publications including a quarterly newsletter, organising formal and
informal meetings and conferences.

Further information and details can be obtained by contacting:
The NSPKU Helpline on: 0845 603 9136
or writing to:
The National Society for Phenylketonuria (United Kingdom) Ltd.
7, Lingley Lane, Wardley, Gateshead, Tyne & Wear, NE10 8BR