



# TRAVELLING WITH **PKU**

Hints and tips for a happy holiday

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# Introduction

Holidays and school trips should be enjoyable for everybody. With good preparation this doesn't have to be any different for somebody with PKU.

Travelling both in the UK and overseas is a great opportunity to develop confidence with PKU. From preparing foods in new accommodation to enjoying family meals out.

This booklet contains some useful tips and advice to help make your holiday as easy to prepare for as possible.

“ I think the key to travelling with PKU is not to panic. You shouldn't plan your holidays around PKU. PKU should just fit in. No matter where you go, it's possible to do it. It just requires organisation. ”

Heather, adult with PKU, Nottingham

## Tips for the journey

Whether you are travelling by car, train or plane you will need to prepare for the journey. Here are some useful tips:

- Take low protein and exchange snacks. Remember that you may experience bad traffic or flight delays so it's worth taking extra.
- Always try to ensure you have enough meals for the journey so that you don't have to rely on purchasing food from shops and service stations whilst you travel.
- It is a good idea to have a plan for the first meal when you arrive at your destination.
- Take a protein calculator with you to help you to calculate unfamiliar foods.
- Have your protein substitutes within easy access. If you take a powder protein substitute, remember to pack a small covered beaker, spoon and bottle of water to make it up.

## Holidaying in the UK

**Home delivery provider** – They can discuss options with you for delivery to another address in the UK. Contact your dietitian to arrange a delivery six weeks in advance.

**GP** – If you plan to take the products yourself, your GP may need to prescribe additional products to cover the duration of your holiday. You may need to ask for the next months prescription earlier than planned.

**Hotel** – If you are staying in a hotel, you may want to contact them or your holiday provider in advance to find out information about meals provided.

Your hotel may be able to:

- Store low protein milk/protein substitute in a fridge
- Keep frozen prepared meals and reheat when needed
- Cook low protein foods eg. pasta, rice
- Prepare low protein recipes

### **Self-catered accommodation**

Check before hand as to what facilities are available in your accommodation for preparing, cooking and storing food.

You may want to look online to research local places to eat.

# Holidaying outside the UK

At least eight weeks before you travel, contact:

- **Your dietitian** – Ask your dietitian or GP for a letter on headed paper listing all the products you are taking and why you need them. You will need this for Customs or for any emergency treatment. Your dietitian may suggest a suitable alternative powder form of your protein supplement which is lighter for packing.
- **Home delivery provider** – Options for delivering protein substitutes to most countries are available and can be discussed with your delivery provider. Travel trunks may be organised so that you can take your protein substitutes/foods yourself.
- **GP** – Your GP may need to prescribe additional products to cover the duration of your holiday. You may need to ask for the next months prescription earlier than planned.
- **Airline** – If you are not using a delivery service, then you must contact the airline to enquire about extra baggage allowances.
- **Hotel** – Ask your holiday provider what food is available. Many hotels offer all-inclusive packages providing plenty of fruit and vegetable options for meal times.

# Advice for flying

(Taken from the current government advice April 2013)

There are restrictions on what items you can take in your hand luggage and hold luggage when boarding a plane in the UK.

## Hand luggage allowances

Check with your airline about how many and what size bags you can take on the plane with you.

## Taking liquids through security

There are restrictions on the amount of liquids you can take in your hand luggage. If possible, pack liquids in your hold baggage (luggage that you check in). If you do take liquids in your hand luggage then:

- Containers must hold no more than 100ml and must be placed in a clear plastic bag.
- For information on infant formula please see the **Babies and Infants** section of this booklet.
- Essential medicines including liquid protein substitutes over 100ml can be taken through security but you must have the following:-
  - Approval from the airline
  - Supporting documentation from a relevant medical professional

Remember to divide your protein substitute between bags just in case of any lost luggage.

## Useful phrases

There is a list of useful questions and phrases translated into various languages – including French, German, Italian, Spanish, Dutch and Swedish – available on the website [www.nspku.org/publications/travel](http://www.nspku.org/publications/travel)

You may want to print off relevant phrases as these can be shown at restaurants and hotels.

Examples include:



### FRENCH

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I have a medical condition called phenylketonuria

**J'ai une maladie qui s'appelle la phénylcétonurie**

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For medical reasons (a disorder called phenylketonuria), I am not allowed to eat any products which contain a lot of protein, for example meat, fish, eggs, cheese and soya.

**Pour des raisons médicales (soit une maladie qui s'appelle la phénylcétonurie), je ne dois pas manger de produits qui contiennent beaucoup de protéines, comme, par exemple, de la viande, du poisson, des oeufs, du fromage et du soja.**

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Please could I have some potatoes/chips/French fries with vegetables/salad?

**Est-ce que je pourrais avoir des pommes de terre/des frites avec des légumes/de la salade?**

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### ITALIAN

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I have a medical condition called phenylketonuria

**Soffro di fenilchetonuria**

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Can you bring me a plate of vegetables only?

**Posso avere solo un piatto di verdure, per favore?**

---

Can you cook a portion of this pasta/rice/pizza base for my meal tonight?

**Puo' prepararmi una porzione di questa pasta/riso/pizza speciale per la cena di stasera?**

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### SPANISH

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I have a medical condition called phenylketonuria

**Tengo una afección llamada fenilketonuria**

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Can I eat my special medical food in your restaurant?

**Puedo comer en su restaurante mi comida médica especial?**

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I cannot take food or drinks containing ASPARTAME (E951)

**No puedo comer o beber alimentos que contengan ASPARTAME (E951)**

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## Babies and infants

Make sure you take enough of your infant formula substitute with you on holiday and make sure it is sealed. If you are not breastfeeding and have introduced formula, take enough of this in sealed containers with you. Make sure you take plenty of baby foods and jars that your baby likes. You will also need to take your bottles and sterilising equipment.

If you are taking infant formula with you make sure you have suitable facilities for making up feeds, eg. a kettle or a container for sterilising bottles.

Remember to take with you an up to date baby food list. All baby jars are allowed freely if they have less than 0.5 grams of protein in 100 grams.

### **Travelling abroad with your baby**

If you're travelling with a baby you're allowed to take enough baby food, baby milk and sterilised water for the journey. The sterilised water must be kept in baby bottles. In some cases this may be over 100ml, but the adult carrying the baby food or milk may be asked to taste it.

When abroad you will need to boil water. Do not use tap water.

## Children, teenagers and adults

Anything with protein content of up to 0.3 grams protein per 100 grams can be taken freely.

Be aware of soft drinks that might contain aspartame. Labelling may be different in other countries and may not show the phenylalanine warning.

Be aware of alcoholic drinks and mixers which have a higher protein content or contain aspartame. Please refer to the NSPKU website before travelling.

### **Food labelling**

Be aware that American and other countries will give per serving information and not per 100g. Always check every label.

## School/group trips

Going away on a school trip plays an essential part in confidence building for your child and this should be no different for a child with PKU. With careful preparation and planning everything can go smoothly.

Contact your dietitian as soon as you know you will be going on a trip. Tell them the following information.

- The dates of the trip
- The name of the accommodation
- How they are going to be catered for
- A named member of staff from the school/group

The dietitian can help liaise with the caterers to ensure the PKU diet will be followed accurately whilst being away.

## Blood levels

You may need to take all your blood taking equipment on holiday:

- Lancets
- Blood forms
- Envelopes with lab address

If you are on holiday in the UK you should take your blood sample and post it in the usual way.

If you are on holiday abroad, discuss level taking with your dietitian.

You will need to provide the dietitians with a contact phone number so they can ring you with your blood results.

## Illness on holiday

Illness should be treated in the same way as with anybody else.

Take appropriate medicines with you as a precaution.  
If purchasing medicines abroad make sure you tell the pharmacist you or your child has PKU.

Speak to your GP/dietitian about any specific advice.

## Insurance

Within the European union you are entitled to reduced cost or free emergency medical treatment if you have an EHIC card. You can get these by calling **0300 3301350** or visiting **www.ehic.org.uk**



You are also advised to take out a comprehensive insurance for travel abroad. Ask your travel agent for more information on this.

## Item checklist

- **Protein substitute** – enough packed in suitcase and five days worth in hand luggage
- **Low protein foods** – LP breads, LP rice, LP pasta, LP biscuits, LP cakes
- **Low protein milk**
- **Containers and spoons to mix protein substitutes** – if using powder
- **Scales** – with newly replaced batteries
- **Diet information** – exchange calculator, diet sheets, recipes
- **Letter from hospital**
- **Useful foods** – cereals, aspartame-free squash, snacks
- **Accessories** – sandwich bags, measuring jugs, small bowl for scales, cool bag, ice packs
- **Mobile phone and charger**
- **Hospital contact numbers**
- **Blood testing equipment**
- **Suitable medicines**
- **NSPKU food list**
- **Translations** – useful questions and phrases translated into the language of your holiday destination  
[www.nspku.org/publications/travel](http://www.nspku.org/publications/travel)

**Useful contact numbers:**

GP

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Dietitian

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Home delivery company

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