

Chapter 12 - Emergency Preparedness



How to Prepare Yourself for an Emergency

When you have PKU or any other special dietary needs, being ready to handle difficult situations requires special planning, in addition to the typical things everyone needs to consider in the event of an emergency or natural disaster. Here are some key things to think about and discuss with your family today⁸⁶.

Hospitalization⁸⁷

If you need to be admitted to a hospital, you will need to bring your formula (and anything you mix into your formula) with you. If you are admitted for an extended period of time, you will also need to bring some low protein foods or have someone bring them for you.

Medical professionals you meet in a hospital or acute care setting who do not regularly work with PKU may not know how to manage your diet. They will need to be educated on your diet and the items that are appropriate for you.

Be sure to notify your metabolic team if you are in the hospital so they can aid in obtaining the correct care you need. They will be able to alter your dietary prescription, if needed, in response to your condition and direct the hospital staff as necessary.

And remember, some over the counter medicines may contain aspartame or gelatins, which contain PHE. Be sure to check the labeling on all over-the-counter and non-prescription medications such as vitamins, aspirin and cough syrups.

Emergencies

People with PKU require specialized care and medical foods, both of which may be unavailable or in limited supply in the event of an emergency.

You may not be able to follow your PKU diet perfectly during an emergency but it is important to adhere to it as closely as possible and continue to take your formula! Almost by definition, an emergency is something that brings added confusion and stress. Not following your diet can affect your ability to deal with and manage the situation at hand effectively⁸⁸.

Some emergencies may mean you can't obtain what you need for your PKU diet in the normal way. You may be able to stay in your home during the emergency, but you may not have electrical power. Other emergencies require evacuation from your home to a location that may be far from your PKU team or pharmacy.

It is important to prepare for both of these possibilities BEFORE THEY HAPPEN.

⁸⁶Maltzman, S. : *My PKU Toolkit A Transition Guide to Adult PKU Management*. New Jersey: Applied Nutrition Corp. 2007:48.

⁸⁷Maltzman, S. : *My PKU Toolkit A Transition Guide to Adult PKU Management*. New Jersey: Applied Nutrition Corp. 2007:49.

⁸⁸Southeast NBS & Genetics Collaborative Region 3 Genetics Collaborative Emergency Management *Strategic Plan: An Approach to Emergency Preparedness for the Medical Genetics Community*. May 2008:3.

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In the Event of Evacuation⁸⁹

It is important to create an evacuation plan to use in case of an emergency evacuation. This plan should include details on when and how to evacuate, where to evacuate, and the preparation of an evacuation kit. If you have to evacuate, you may have to be away from your home longer than a few days. Even if you are able to stay in your home during an emergency situation, you may not be able to obtain what you need for your PKU diet in the normal way.

It is safer to plan for at least a 2 week emergency or evacuation period.

When evacuating, it is also helpful to have access to your medical records so that you can establish PKU care in a new location. Ask your PKU team how to access your medical records in the event of an emergency and keep a copy of your formula prescription, most recent lab and test results in your wallet or evacuation kit⁹⁰.

Your PKU team may also have to evacuate during an emergency. Be sure to ask someone on the team how you can reach team members in the event of an emergency that requires them to be away from their offices.

Creating an Emergency Plan Ahead of Time

In preparing for an emergency you should create an emergency response plan for you and your family⁹¹. It is important to do the following things before an emergency situation occurs.

- Decide where you will go if you need to evacuate during an emergency.
- Remember that friends or relatives who live in the same neighborhood will also be evacuating and choose a place a safe distance from your town.
- Remember you may need to be gone for more than a few days. Either choose a place where you know you and your family can stay for an extended time, or have a second place in mind if the evacuation time is extended.
- If you have pets you will be taking with you, choose a place where they will be accepted.
- Tell your PKU team the place where you think you will be evacuating to and a phone number (cell phone if possible) where you can be reached.
- Keep a copy of your formula prescription, recent lab and test results.
- Ask your PKU team where there are genetics programs or other health care providers close to the location where you plan to evacuate.
- Create an extra supply of medicine, low protein food, and medical formula to last at least two weeks. Your PKU team may need to help you with prescriptions for an emergency supply.
- Put together an Emergency Kit. You may want to include additional things, but this kit should include:
 - o Medication and medical formula (at least a two week supply)
 - o Low protein foods (at least a two week supply)

⁸⁹Southeast NBS & Genetics Collaborative Region 3 Genetics Collaborative Emergency Management Strategic Plan: *An Approach to Emergency Preparedness for the Medical Genetics Community*. May 2008:14-15.

⁹⁰Southeast NBS & Genetics Collaborative Region 3 Genetics Collaborative Emergency Management Strategic Plan: *An Approach to Emergency Preparedness for the Medical Genetics Community*. May 2008:18.

⁹¹Southeast NBS & Genetics Collaborative Region 3 Genetics Collaborative Emergency Management Strategic Plan: *An Approach to Emergency Preparedness for the Medical Genetics Community*. May 2008:31.

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- o Contact information for the companies that supply your medication, medical formula, and low protein foods
- o A list of PKU resources in the community you would evacuate to
- o Contact list for family members
- o Emergency contact numbers for your PKU team
- o Water and snacks appropriate for car travel
- o Manual can opener
- o Blankets and pillows
- o Maps and flashlight
- o Cell phone
- o Extra batteries
- o Chargers for all electronic devices
- You may want to consider buying a small hot plate or similar appliance that can be used to prepare food in a hotel room.

During some emergencies you may not have to leave your home – but you may lose electricity or even water supply. It is important to plan how you will follow your PKU diet for this kind of emergency as well. In addition to the things listed above, it is helpful to have:

- Bottled water – enough for several days (estimate one gallon a day for each family member).
- Some low protein foods that don't require cooking or refrigeration.
- A camp stove (that uses propane gas) that can be used to prepare food without electricity, and a manual can opener.

Following Your Emergency Plan

If an emergency occurs you should be ready to immediately follow the emergency or evacuation plan you have put together.

- If you have warning that there will be an emergency (for example, a hurricane is predicted for your area), begin preparing to follow your emergency plan as soon as possible.
- After an emergency situation occurs, make contact with your PKU team as soon as possible.
- Your PKU team may not have access to your diet information, so be prepared to tell them:
 - o Your daily Phe restriction
 - o What medical formula you use and how much each day
 - o If you take PKU medication – what you use and how much each day
 - o How long your supply for each of these things will last
- You may need to contact the companies who supply your medication, medical formula, or low protein foods and tell them your new contact information if you do not have enough supply to last until you can return home or to your usual way of obtaining these things.
- You may need to contact the PKU team and/or other health care providers in your new location to continue your PKU care.