

Sick Day Guidelines for PKU



How do you feel when you're ill??

Tired	low energy	want to stay in bed
Nauseated	aches	no appetite
Blah	very hungry	hot and perspiring

Chances are your PKU clients will feel the same way when they aren't feeling well. It may be more difficult for your client to eat and drink.

GOAL

The main goal when your client is ill is **to prevent the breakdown of muscle (catabolism)**. When you are sick, and you don't eat enough calories, your body will break down muscles in order to make calories. Since muscles are made of protein, including phenylalanine (phe), its breakdown will cause blood phe levels to rise.

Since you can expect some catabolism during illness, and therefore you can expect higher blood phe levels, you will want to reduce the amount of phe your client is eating from food. For example, if your client is normally allowed 400 mg phe from food each day, you may need to reduce this to 200 or maybe even less!! Sometimes the goal for dietary phe is even 0!!



But you still have to provide the same number of calories. For this reason the medical formula (e.g. Phenyl-free) becomes the most important source of phe-free calories during illness.

Since your ill client may not feel like drinking formula during illnesses try these tips:

1. Offer the formula (e.g. phenyl-free) before other food is offered.
2. Split the formula into 6 or even 8 smaller drinks throughout the day rather than the usual 3 or 4 drinks.
3. Dilute the formula with more water than usual (this will water-down the taste too)

4. Some clients may prefer the formula concentrated (less water than usual) into smaller drinks throughout the day (just remember that this could cause diarrhea for some people)
5. Flavour the formula with Kool-Aid (sweetened) and freeze it into popsicles
6. Always try to ensure that formula is taken first thing in the morning and last thing at night to end/reduce overnight fasting. Fasting can lead to catabolism and higher blood phe levels.

In addition to the formula, offer your ill client low phe, yet calorie rich fluids throughout the day so they will get enough calories.

The following foods have calories (to prevent muscle breakdown) with little to no phe.

FORMULA	cranberry juice	lemonade
Fruit punch	Slurpees	Mr. Misty
Kool-Aid	Gatorade	soda pop (no aspartame)
Gingerale	apple juice	Sorbet (not sherbet)
fruit ices	popsicles	tea/coffee with sugar
Candy canes	life savers	suckers
hard candies	Syrups	jams/jelly
vegetable oils	apple butter	

LOW PROTEIN BREADS, PASTAS, CEREALS, RICE

NOTE: Jell-O gelatin has 70 mg of phe per cup.

BLOODWORK:

If your client is ill for more than 48 hours, or you are having difficulty getting anything your client to take any formula or fluids you may want to call the Adult Metabolic Diseases Clinic (604-875-5965) to let us know. We may be able to offer other suggestions and we may want to request bloodwork/blood dots.

RECOVERY:

As your client starts to feel better, you can slowly return the formula back to the usual pattern of 3-4 times a day and slowly re-introduce their usual foods.