

Onwards and Upwards

with PKU Protein
Substitutes

GETTING YOUR CHILD
FROM HERE...



...TO HERE!



Enhancing Lives Together

Your child is currently taking a second stage protein substitute.



This is the protein substitute that was introduced to their diet after the special Phe-free formula that they took when they were a baby.





IT'S NOW TIME TO
START MOVING THEM
ON TO THE NEXT,
OR THIRD STAGE OF
PROTEIN SUBSTITUTE.

THIS GUIDE OFFERS PRACTICAL HINTS
AND TIPS ON HOW TO SMOOTHLY
AND SUCCESSFULLY MOVE ON TO THE
NEXT STAGE OF PROTEIN SUBSTITUTE.

You may have some questions about this before starting the process...

At some point, your child's current protein substitute won't meet their nutritional needs anymore.

The next stage of protein substitute will be better at meeting their changing nutritional needs.

WHY DOES MY CHILD HAVE TO SWITCH PRODUCTS?

WHY NOW?



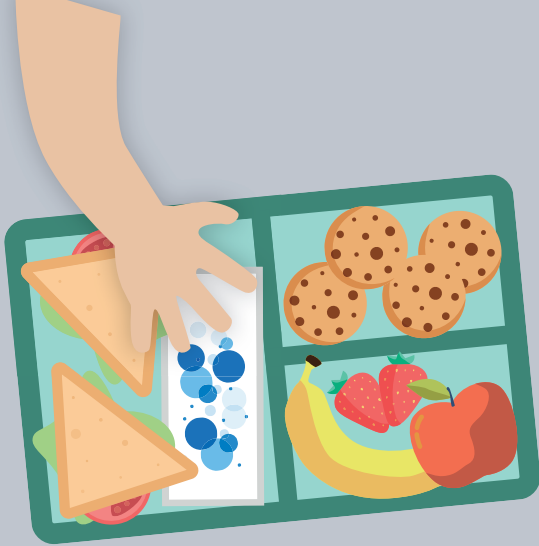
There are several advantages to switching to the next product now:

Your child might never need to change again!

Many of the next stage protein substitutes are suitable for teenagers and adults. As your child gets older, they won't need to change to a new type of product – they will just take more of their third stage protein substitute.

Changing products can be done at the same time as they start school or at pre-school.

Young children often want to appear more grown up and introducing the next stage of protein substitutes as a 'big girl' or 'big boy' drink is often helpful in encouraging your child to make the switch.



You can use it as an opportunity to encourage independence.

A new protein substitute is a new opportunity for your child to begin to manage their diet. This may enable them to stay at grandparents more easily or go on day trips with the school. Perhaps they could be given the job of putting their new protein substitute in their lunch box every day?

ARE YOU SURE
IT CAN'T WAIT?

Making the change later can be more difficult as change for older children can be harder.

Every child is different, and some children may make the change effortlessly whereas others may take more persuasion.

The keys to success are persistence and time.



What are the options?

THERE ARE SO MANY! YOUR CHILD IS SURE TO FIND ONE THEY LIKE.



Liquids



Powders



Ready flavoured products



Products you can flavour yourself

AND MANY MORE!

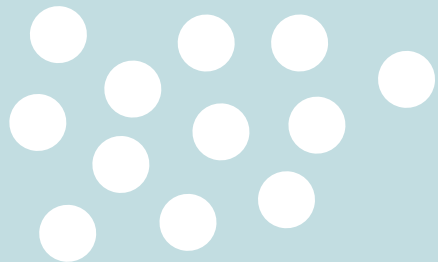
I LOVE THEM BOTH!



Up to now, your child will have been taking a product based on individual amino acids - the building blocks of protein. Protein substitutes for PKU provide all the amino acids that make up natural protein, except for Phe.

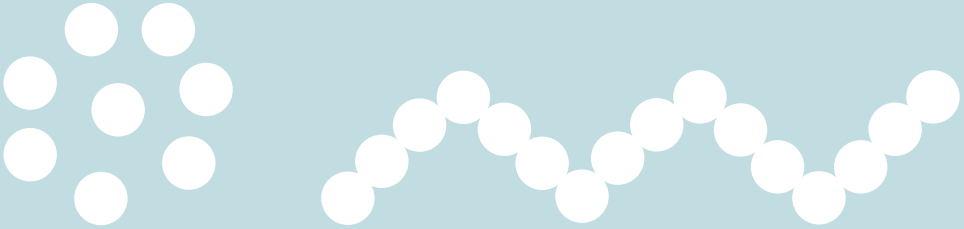
With your child changing products, they may switch to:

- Another amino acid-based product.



Amino acid-based product

- A product based on glycomacropeptide (GMP). GMP is a long chain of amino acids, produced during the cheese-making process. GMP-based protein substitutes also contain some individual amino acids.



GMP-based product

- A combination of a GMP-based protein substitute and an amino acid-based one.

GMP-based protein substitutes contain a small amount of Phe.

What will be the right product for my child?

That will be different for every child. The right product or products will be one your child is happy taking every day and that helps keep their PKU well managed.



Let's get started

1

GETTING YOUR CHILD USED TO THE IDEA OF CHANGE

Place the new product in visible locations around the home. This will help your child become familiar with the new product.



2

START A NEW ROUTINE

- Introduce the new product at just one mealtime initially and, for now, try it at that same mealtime every day.
- Pick the mealtime when your child is least likely to be tired — for some families, that will be breakfast, for others it may be lunch or the evening meal.
- Mealtimes which feel a bit rushed, due to time pressures and commitments of everyday life, are best avoided.
- Sometimes, with young children, it may suit better to start with a taster amount away from mealtime.
- Introduce a small amount at first (a few mouthfuls).
- Limit the time for trying the new product to around 5 mins.



AT THIS STAGE, DO NOT REDUCE THE AMOUNT OF YOUR CHILD'S SECOND STAGE PROTEIN SUBSTITUTE.

3

STEPPING IT UP

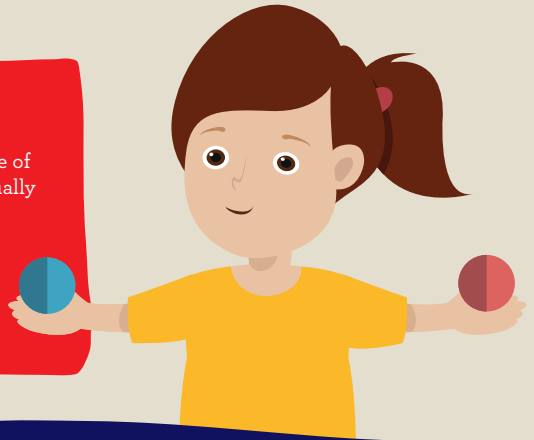
- After the first few attempts, a little pressure can be applied if your child is not receptive.
- Perhaps you can challenge them to finish an agreed volume or beat the clock. Can your child take their protein substitute in a quicker time than yesterday?
- It is important, however, to keep things positive and encouraging. Using a sticker reward chart is recommended to help keep your child interested and engaged.



4

OUT WITH THE OLD

- When your child is regularly taking some of the new product every day, start to gradually give more of the new product and less of the old product at a pace acceptable to your child.
- When the split is around 50:50, consider swapping entirely to the new product.



5

MAKE IT A DAILY ROUTINE

- When your child has successfully swapped over at one mealtime, the next step is to make the swap at other mealtimes.
- Again, this should be done at a pace acceptable to your child.
- Some children may be prepared to completely swap over all at once. Other children may need to do things more gradually.

6

SPREAD THE NEWS!

- The next stage involves informing everyone else involved in managing your child's diet.
- This would include people like extended family, particularly grandparents and siblings, childminders, nursery and school staff. Nurseries can be particularly good at helping out if your child is resisting making the change at home.
- The same positive and encouraging messages about the new product should be given by anyone involved with your child at mealtimes.
- If stocks of protein substitute are kept at locations outside the home (for example nursery, grandparents' house), now is the time to ensure that you replace the old product for the new one. Your child's dietitian will help you with this.



Frequently Asked Questions

“WILL I NEED TO MAKE OTHER CHANGES TO MY CHILD'S DIET?”

Possibly. Your child's dietitian will guide you on any adjustments required. Some examples of changes are as follows:

- The new product may contain less energy (also called calories) than your child's current product. If that's the case, your child's specialist dietitian can advise on how to bring extra calories into your child's diet.
- GMP-based protein substitutes contain a small amount of phenylalanine (Phe). Some children can switch entirely to taking a GMP-based protein substitute whereas other children are better suited to a combination approach, taking both a GMP-based protein substitute and an amino acid-based product of their liking.

“WHAT WILL HAPPEN IF MY CHILD'S METABOLIC CONTROL GETS WORSE DURING THE PRODUCT SWITCH?”

This should not happen if you follow the steps outlined above but unexpected things, such as illness, during this time could impact control.

- Your child's metabolic team may ask you to do more blood samples.
- In this way, they can keep a closer eye on your child to ensure they stay on track as they make this adjustment to their diet.

“CAN I MIX THE OLD AND THE NEW PRODUCTS TOGETHER TO HELP GET MY CHILD GRADUALLY GET USED TO THE NEW TASTE?”

Sometimes this approach is used. GMP-based products are generally not mixed with amino acid-based products because of the significant taste difference. Mixing amino acid-based products may be an option.

- It is easiest when the old and new products are both powders. You can mix a small amount of the new powder with the old powder, gradually giving more of the new and less of the old, until a complete switch can be made.
- Consider the flavours of the two products. Some flavour combinations work better than others!
- Your child's specialist metabolic dietitian can advise you if you think this approach might be best for your child.



Enhancing Lives Together
A Nestlé Health Science Company

Trademark of Société des Produits Nestlé S.A.
©2022 All rights reserved. Société des Produits Nestlé S.A.

Vitaflo International Ltd
Suite 1.11, South Harrington Building, 182 Sefton St, Brunswick Business Park, Liverpool, L3 4BQ, UK

+44(0)151 709 9020 vitaflo@vitaflo.co.uk www.vitafloweb.com