



A guide to using



reachTM5

A protein substitute specifically designed to be used as part of the dietary management of Pyridoxine Dependent Epilepsy (PDE) from one year of age onwards.

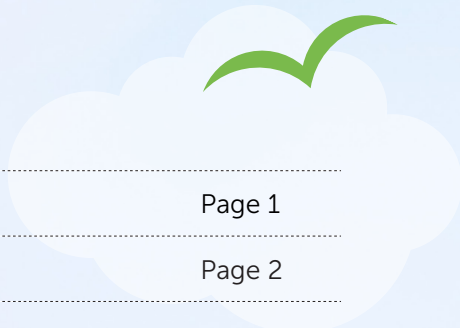


Enhancing Lives Together

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Introduction

You have been given this booklet because your child has Pyridoxine Dependent Epilepsy (PDE).

As part of the management of PDE your child is on a restricted protein diet, to help limit their intake of the amino acid lysine. Lysine is restricted in PDE to help limit the production of α -amino adipic semialdehyde (AASA) and improve outcomes. Due to the protein restriction your child may be unable to get all the nutrients they need from food alone. To help provide these nutrients they are prescribed a protein substitute named **PDE reach5**.

This booklet explains how to introduce **PDE reach5** to your child's diet.

PDE reach5 is a specially made medical food based on amino acids, the building blocks of protein. It has no added lysine but contains all the other amino acids found in protein that your child needs to grow and develop.

PDE reach5 also contains vitamins, minerals and essential fats to help ensure your child is meeting their nutritional requirements.

If you have any additional questions or are unclear about anything written in this booklet, your specialist metabolic team will be able to help.



All about PDE reach5



PDE reach5 is suitable to be used from one year of age and throughout childhood, adolescence and adulthood. This means once your child is established on **PDE reach5** they don't need to change product again.



Convenient pre-measured sachets - no measuring out required and easy to use when away from home.



Mild raspberry-vanilla flavour with no colours or artificial sweeteners - to help with acceptance.



Clinically evaluated in 11 children with PDE - **PDE reach5** was well tolerated, accepted and rated easy to use.

How to take PDE reach5 - a flexible approach

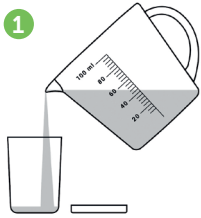
There are a few ways you can make up **PDE reach5** - whichever suits your child best.

- **As a semi-solid spoonable consistency**
This way can be useful when feeding a young child.
- **As a low volume drink**

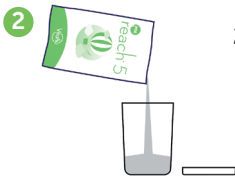
Your dietitian will advise you on how much PDE reach5 is needed every day and when to give.

Mixing instructions:

As a semi-solid spoonable consistency



1. Add 20ml of cold water into a beaker.



2. Empty the contents of the sachet into the beaker.

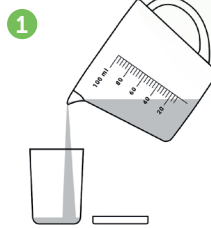


3. Secure lid and shake well for 10 - 15 seconds.

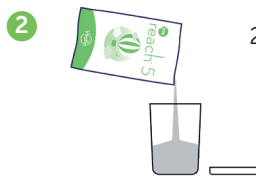


4. Leave to stand for 1-2 minutes, allowing a smooth semi-solid consistency to form. Consume immediately with a spoon.

As a low volume drink



1. Add 80ml of cold water into a beaker.



2. Empty the contents of the sachet into the beaker.



3. Secure lid and shake well for 10 - 15 seconds.



4. Drink immediately.

Water or permitted drinks should be taken after **PDE reach5**.

The product should be prepared immediately prior to feeding and any remaining product must be discarded if not used within 1 hour.

PDE reach5 can be mixed with permitted foods and drinks to aid acceptance or offer more variety.



Can PDE reach5 be flavoured?

PDE reach5 already has a raspberry-vanilla flavour so it can simply be made up with water.

Some alternative mixing ideas for different flavours are:



Just add Juice

Use juice - such as apple, cranberry or raspberry - add 80ml of the juice of choice instead of water to one sachet of **PDE reach5**.***

For a creamier taste

Add 80ml of ProZero™* to a sachet of **PDE reach5**.

You could also add a heaped teaspoon of your favourite flavour of milkshake mix powder such as Nesquik to this drink for an alternative taste.***

Don't forget to shake!



Or you can fizz it up!

Add 15ml of summer fruits cordial to a sachet of **PDE reach5** and shake well, then top up with 65ml of fizzy water.

Mix with flavoured yoghurt**

Add a sachet of **PDE reach5** to yoghurt and mix well.



* ProZero is a protein free alternative to milk - speak to your dietitian for further information and suitability for your child.

** Yoghurt will need to be counted as part of daily protein intake or else mix with a lower protein yoghurt.

*** Always check the suitability of drinks and foods for your child. If unsure speak to your dietitian.

Getting established on PDE reach5

PDE reach5 can be introduced at different ages - some children will start around one year of age, for others it may be later, your dietitian will advise.

Your child may already be taking a protein substitute and your medical team has advised a change to PDE reach5

OR

This may be the first time your child is advised to take a protein substitute.

Your dietitian will advise you on the amounts to take at each stage.

Quick introduction - if your child is already taking a protein substitute for PDE

It's rather quick and easy to swap over to **PDE reach5**.

Start by swapping out one serving of their current protein substitute and replace with the equivalent amount of **PDE reach5**.

There is no set time to make this changeover, but can be done over a few weeks (e.g.: 2-4 weeks). This will depend on acceptance.

Example

Replacing current protein substitute given 3 x day

Stage 1



Replace 1 current protein substitute with equivalent serving of **PDE reach5**

Stage 2



Replace 2 current protein substitute with 2 equivalent servings of **PDE reach5**

Stage 3



Replace all current protein substitute with equivalent amount of **PDE reach5**

Gradual introduction - if your child is not taking a protein substitute for PDE

More support and encouragement may be needed to introduce and accept **PDE reach5** and that's OK.

It is common for children to refuse new foods, not just products like **PDE reach5**.

Continue to offer **PDE reach5** - it can take 8-10 attempts before a child accepts a new taste.



Starting a new routine

Introduce **PDE reach5** at one mealtime initially. For now, offer at the same one every day.

Pick the mealtime when you and your child are more likely to be rested and relaxed.

Avoid times that feel a bit rushed, due to time pressures and commitments of everyday life.

- ✓ Offer **PDE reach5** at the beginning of the meal.
- ✓ Introduce a small amount at first – a few teaspoons or small volume of drink.
- ✓ Limit the amount of time trying **PDE reach5** to just 5 minutes.



Stepping it up

After the first few attempts, a little more encouragement may be required if your child is not taking the product.

- ✓ It is important to be positive.
- ✓ Praise your child every time they take some **PDE reach5**.
- ✓ A sticker reward chart may be useful.
- ✓ Try mixing with different flavoured drinks to help with acceptance.

Increasing the amount

When your child is regularly taking **PDE reach5** at one meal per day, start to give it at another mealtime until you build it up to meet full requirements and it becomes part of their daily routine.



Other important hints and tips when taking PDE reach5

- ✓ Always finish each daily dose of **PDE reach5**.
- ✓ It is important your child learns how important their protein substitute is and it is treated with the same importance as medicine.
- ✓ Supervise your child until the protein substitute is finished.
- ✓ Establish a routine – always give **PDE reach5** at the same time each day.
- ✓ If your child refuses **PDE reach5** – react in a firm but calm manner. Talk to your dietitian for advice on helping your child to take it.
- ✓ If your child is unwell - it is important to still offer **PDE reach5**. Contact your dietitian if your child is unwell and not managing to take it.

Top Tip: make sure **PDE reach5** is prepared the same way each time. If it is made up into a different consistency your child may refuse it.

Let others know

- ✓ Inform others involved in your child's care, as necessary. E.g., family, childminder, nursery or school staff, welfare officer or nurse.
- ✓ If necessary ask people to give the same positive, encouraging messages about **PDE reach5** if they are feeding your child.
- ✓ Keep supplies of **PDE reach5** at other locations as necessary (e.g., grandparents' houses, nursery or school).

Always contact your metabolic team if you are concerned or have any questions.

Your notes:



A series of horizontal dotted lines for writing notes, spanning the width of the page.





PDE
reach[™]5

IMPORTANT NOTICE

PDE reach5 is a Food for special medical purposes for the dietary management of PDE.
Use under medical supervision.

Not suitable for use as a sole source of nutrition.

Suitable from one year of age onwards.

PDE reach5 must only be consumed by individuals with proven PDE under supervision of the managing clinician or dietitian.

For enteral use only.

ALLERGEN INFORMATION

PDE reach5 contains fish (tuna oil). **PDE reach5** is not suitable for a vegetarian diet.



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