The National Society for Phenylketonuria (UK) Ltd

by
Jennifer Inskip

For Thomas, whose self discipline and cheerful disposition is an encouragement to us all.

For him, we are grateful.

A book such as this, though it has a small circulation, has as great a value as the most complicated text book.

Phenylketonuria, is not just difficult to say, it is also difficult to explain.

I hope this book, written by a mother, with her three year old P.K.U. son in mind, helps other mums in the same situation.

If Tom is anything to go by, then this book must be successful.

Chris Jarvis
Chief Dietitian
Nottingham City Hospital.

Thomas looks like any other little boy his age.
But in one way he is special.
Thomas has Phenylketonuria.
This is a difficult word to say so everyone calls it P.K.U.

When Thomas was very young he noticed that his food was different from his Mum’s, Dad’s and Sister’s.

“Mummy why can’t I eat some of your food?” he asked one day.

“The inside of your body works differently from ours,” said Thomas’ Mum. “If we use your building bricks I can explain what I mean.”

She built a brick wall with Thomas’ alphabet bricks.

“Look,” she said, “Let’s pretend this brick wall is part of your body. It needs all these proteins to make it grow properly.”

“When you eat too much protein, especially phenylalanine your brick wall will look like this, because your body cannot get rid of what it does not need.”

“Look the brick wall is not making a pattern.”

“If the building blocks of your body become jumbled like this, your brain will not grow properly.”

"WHAT IS PHENYLALANINE?" asked Thomas.

"It is part of protein food," answered his Mum. "There are proteins in a lot of the foods we eat. For example, meat, fish, eggs, cheese, bread and many more. These help to build our bodies, just like your wall. You cannot have these protein foods, but instead you have a special body building powder with no phenylalanine in it. I get this from the doctor. You can have it with a little water, taken off a spoon, or mixed with a lot of water as a drink."

"WHAT CAN I HAVE TO EAT THEN?"
asked Thomas.

"Well let us look at these traffic lights to help me explain," answered Thomas' Mum.

"The RED light means stop, so you cannot have any of these foods.

The AMBER light means be careful, so you can have these foods but they must be weighed and measured to make sure you have the correct amounts. This is because you have to have some protein so that your body can grow properly.

The GREEN light means go so you can eat normal amounts of these foods. You can also have bread, cakes and biscuits that I make with your special flour, and I get some special vitamin syrup and tablets from the doctor, which you have each day."

A SAMPLE OF THE FOODS THAT THOMAS CAN AND CANNOT EAT

STOP	**CHEESE, EGGS, FISH, MEAT, BREAD, ORDINARY CAKES, AND BISCUITS.**	**Foods Not Allowed**
BE CAREFUL	**MILK, POTATOES, CRISPS, BREAKFAST CEREALS, PEAS AND SPROUTS.**	**Foods that are weighed and measured so that you get just the right amount.**
GO	**SUGARS, FRUIT, SOME VEGETABLES, BOILED SWEETS, JAMS, ASPARTAME FREE SQUASHES, FRUIT ICE-LOLLIES.**	**Foods Allowed Anytime.**

STOP

Foods Not Allowed

CHEESE

FISH

EGGS

MEAT

**ORDINARY CAKES,
BISCUITS AND
BREAD.**

BE CAREFUL

These are the foods that we weigh and measure so you get just the right amount.

MILK

BAKED BEANS

POTATOES

BREAKFAST CEREALS

RICE

CRISPS

SWEETCORN, PEAS, AND SPROUTS.

GO

Foods Allowed Anytime

SUGARS

SOME VEGETABLES

JAMS AND HONEY

FRUIT ICE-LOLLIES

FRUIT

BOILED SWEETS

BUTTER AND MARGARINE

ASPARTAME-FREE SQUASHES

LOW PROTEIN FOODS

"How did you find out that the inside of my body is different from yours?" asked Thomas.

"When you were seven days old, the nurse took some drops of blood from your heel and sent it to be looked at to see how much phenylalanine was in your blood," Thomas' Mum explained.

Thomas regularly has a blood test.

His Mum sits him on the bed and Teddy sits on his knee. They get all the things ready.

1. The lancet is a needle to make a prick for the blood to come out.
2. A special card, to put the drops of blood onto.
3. A protective sleeve and an envelope, to put the card into and post in the post box.
4. A small plaster, to cover the hole and stop it from bleeding.

Mum washes and dries Thomas' finger to make sure it is clean and she checks that his hands are really warm so that the blood flows freely. Then she quickly pricks his finger with the lancet. She rubs his finger so that the blood comes out of the hole she has made. Then she presses his finger so the blood drops onto the card. Mummy then puts the small plaster on Thomas' finger to stop it from bleeding.

Thomas pretends to do the same to Teddy, while Mummy writes his name and address on the card. Sometimes Teddy cries, but then he is not as brave as Thomas.

The lancets, card and envelope that Thomas' Mum uses to do the blood test.

Thomas posts the card to the hospital where it is tested to see how much phenylalanine is in his blood.

His dietitian then telephones Thomas' Mum to tell her how much phenylalanine Thomas can eat.

Thomas' dietitian is very important to him because she must work out how much phenylalanine Thomas can have each day. Sometimes it stays the same and sometimes it has to be changed.

Thomas has to visit the hospital every few months, just to make sure that his body is growing.

Thomas and his Mum wait in the waiting room where there are lots of toys to play with and books to read.

When the nurse calls out his name, Thomas goes to be weighed and measured to see if he is heavier and taller.

Thomas goes with his Mum to see the doctor. The doctor asks him questions and lets him play with the toys in her room. Sometimes he draws a picture for her or writes him name.

After the doctor has talked to Thomas' Mum, they say goodbye, then go to make another appointment.

They also go to see Thomas' dietitian for a chat when they visit the hospital.

Thomas has his own baking set and likes helping his Mum to bake his biscuits, cakes and bread with his special flour.

He can make his biscuits in all different shapes but his favourite shape is the dog.

When the biscuits have finished cooking, Thomas tastes one of each shape; to make sure they are cooked!

Thomas now goes to Playschool. His Mum cannot see what he eats while he is there, so she must trust him to eat only what he is allowed.

Thomas is three years old. He is learning exactly what he is allowed to eat. This will help him to know which foods he can eat when he is not at home. If he is offered any other food he says no.

He enjoys himself like other small boys. He plays football, marbles and make believe games.

A NOTE TO PARENTS:

The National Society for Phenylketonuria UK Ltd. is a society run by parents, for parents and has:-

An Honorary Medical Advisory panel

A Newsletter

An Annual Conference

Informal Meetings

Literature and Videos to provide an understanding of PKU and its dietary management.

Further information and details can be obtained from:-

The National Society for Phenylketonuria
(United Kingdom) Ltd.
7, Southfield Close,
Willen,
Milton Keynes,
MK15 9LL

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