Joe's Story

Introduction

As a family we try not to focus too long and hard on Joe's PKU and although it is vitally important to stick to diet, and to make sure Joe gets his protein substitutes and things, it is not the most important thing about him and it isn't the first thing that people get to know about him.

Families today often lead very busy lives and Gary and I, with three boys, are no exception so we try hard to focus on what makes Joe the same as everybody else rather than the one thing that is different about him.

As the youngest of three boys Joe's arrival was very exciting for all of us, but especially his two older brothers (4½ and 2½) who very much wanted to be involved. As I'm sure everyone who reads this will understand, finding out that our precious, perfect baby had an inherited metabolic disease (scary words to the uninitiated) caused the bottom to, temporarily, fall out of our world and, although they were only small, his brothers felt this too - albeit to a lesser degree. However, with the enormous support around from various health workers and the NSPKU, despondency soon turned to a determination to deal with the practicalities and make life as normal as possible for all five of us.

Joe's oldest brother, Tom, wasn't quite five years old when Joe was diagnosed and he was desperate to try and understand why Joe suddenly had to have different milk and not just 'Mummy's milk'. This was how we started using the phrase 'a special tummy'. We were able to explain to Tom that Joe's tummy couldn't have some of our foods because his body didn't quite work the same as ours, and he also had to have special medicine to help keep him well. Tom, and later on Dan, found the special tummy explanation very easy to understand so we have kept on using it for Joe, who has never questioned why his tummy is special - he just knows it is. We await the day when he asks 'so how come its only me who has a special tummy, why is it special, and who's fault is it?'. I expect it to follow hard on the heels of 'where do babies come from' as he becomes more aware of his own body and of the world around him. All three of them now know that protein is the food that Joe can't have and Tom is starting to ask questions about exactly why protein and phenylalanine is so bad for Joe.

We now use the phrase 'special tummy' to explain to all of their friends why Joe can't eat the same things when they come for tea, or if he goes to their house. And to his friends at school, many of whom keep a close eye on him! Even some adults find it easier to understand if you start your explanation of PKU that way, before getting into more technical terms. We have found it that it doesn't create barriers, in fact, it is easily accepted and children take it at face value, Joe's tummy is special that is why he doesn't have the same as us.

It works for us, and Joe finds it easier to tell people that he has a 'special tummy' than to tell them about PKU (which they have never heard of) and he can't even say Phenylketonuria!

Everybody has to find their own way of making their child aware of their condition and help them deal with it - this is our way, and I hope yours is equally successful.

Lynne

Joe's Story

There is a little boy who lives not too far from your house. His name is Joe and he is 7 years old. Joe is just like any other little boy. He likes to play football, climb trees, make lots of noise, paint, and listen to stories. Which is why we wrote this one for you, because he thought you might like to hear his story.

Joe has two big brothers. Tom who is 12 and Dan who is 10. Tom, Dan and Joe all look very similar, and they all look a bit like their Dad; but inside Joe is different!

When Joe was a very new baby, only a few days old, a midwife came to see him and took a little bit of blood from his heel. All new babies have this done and people call it the heel prick test. Joe's blood went with the blood from lots of other new babies and it was tested for different things. All the other tests didn't have anything special about them but Joe's did, so Joe's Mum and Dad took him to see a doctor who told them all about Joe's insides and how he is different.

Joe has a special tummy. The proper name for the way his tummy is special is Phenylketonuria. (You say it:- feenal-key-tone-your-ear - or something like that.) To make it easier most people call it PKU. But Joe just calls it his special tummy.

Joe's tummy is special because it doesn't work like most other people's tummies. Joe's tummy doesn't let him eat protein. There is protein in lots of foods. Some food has lots and lots of protein and Joe isn't allowed to eat any of them. Some foods have a medium-sized amount of protein and Joe's Mum measures them for him. But lots of foods have only a bit of protein, or none at all, and Joe can eat as much of these as he likes. As long as Mum says so!

Perhaps Joe will tell you about all these different foods with big, middle and little proteins later. First we should explain how Joe's special tummy works and how his brothers' tummies work, then we can see why Joe's tummy is special.

When Tom and Dan eat something, anything at all, it goes down into their tummy which breaks it all down and then uses it for different things in their bodies, anything they don't use just goes out in their wee and poo. The tummy breaks things down using something called enzymes. In Joe's tummy he doesn't have the enzyme to break down protein but instead of it going out of his body in wee and poo it stays there and stores in his brain, which can be very nasty for him. So Joe just doesn't eat very much protein.

But, we all need protein to grow, I hear you cry. Yes, and so does Joe. So where does he get the protein he needs? From a special medicine called a protein substitute. Everyone with PKU has to have their special medicine for their special tummy. Some people have it as a drink, some people have it as a paste and some people have tablets, but they all have to take it. Joe's medicine doesn't really taste very nice (or look very nice either) but Joe takes it every day, three times a day. He has a little saying that goes "The first one's the worst one!" - which helps him remember that after that first mouthful it isn't so bad.

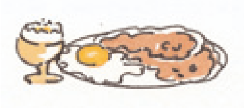
Free

fruit/jam

Restricted

chips/cereal

Not allowed



meat/egg

Here is a picture of the different foods Joe is allowed or not allowed, or just allowed a little bit of. The foods with a medium-sized amount of protein are measured by Joe's Mum and are called his 'exchanges'. Each exchange is one gram of protein and Joe is allowed four of these a day. These might be a bag of crisps, some potatoes, some peas and some broccoli. Joe isn't allowed chocolate or biscuits like Tom and Dan, at least not the same as Tom and Dan. Joe's food comes from the Chemist with a prescription and he gets lots of biscuits, crackers, pasta and a special sort of chocolate. His Mum also gets special flour so she can make him bread and cakes, and sometimes biscuits. Joe isn't allowed to eat any meat, or cheese, or fish, or .... oh the list seems endless, but it isn't as bad as it sounds really because Joe's Mum can make him lots of things like sausages, burgers, stews and things using vegetables.

Lets have a look at Joe doing some of his favourite things. Here he is having his packed lunch at school. I know what will be in those sandwiches - pickle, Joe's favourite! Look he has some crisps; they will count as an exchange, and some of his own special biscuits with a drink of squash. For his morning break Joe had a drink of his special milk and some apple, just like lots of the other children.

Here is Joe at a birthday party. It is his friend's party. As Joe can't have the party food he takes his own party food in a special box. Look at the iced biscuits and the fairy cake with Joe's special chocolate on top. Some sweeties for his party bag that don't have protein (there are lots of those) and the toys are just the same as the other children because he isn't going to eat those.

Sometimes, if they are very good, Joe's Mum and Dad take all the boys to a restaurant. If the food isn't going to be all right for Joe his Mum takes something for him to eat and he might have some chips or potatoes with it, measured by Mum. But lots of times Joe can find things on the menu that he likes and lots of restaurants are very nice about his special diet - especially if they know he is coming - and will make up a special plate using what he can eat with something Mum brings with her.

One of Joe's favourite places is going bowling. Here is Joe's Dad. He has bought Joe some chips, which will be measured for two exchanges, and a drink of Coca Cola. Tom and Dan have also got chips and Coca Cola.

In the summer Tom, Dan and Joe like to have picnics. Especially when we are on holiday in our tent. Joe will take his special sandwiches and biscuits but will share all the other things like crisps, carrot sticks, celery, apple and melon pieces, pickled onions, pickled beetroot, lettuce and cucumber, and lots of other things. After they will probably have an ice-lolly from the ice cream van.

Another summer favourite is our barbecues. Joe's Mum makes his special sausages and burgers for him and we all share the salad and vegetable sticks. Sometimes Joe likes long kebabs with mushrooms, peppers, onion and baby tomatoes. And he has ketchup with everything. For afters Tom and Dan love meringue with ice cream and strawberry sauce and sprinkles. So does Joe! Joe has special ice cream and meringue that has no protein in, but he has the same strawberry sauce and sprinkles.

Joe is just the same as any other little boy because he loves to eat sweets and cakes and biscuits. But Joe just has to be a bit more careful and he can't always have what he wants to eat because it has protein in. It is very hard for Joe not to eat some of the things that Tom and Dan and his friends eat, but he is learning what he is allowed to eat, and he knows lots of the things he can't have to eat.

To make sure that Joe is getting the right amount of protein from his food and his medicine he has to have his blood checked once a week. Mum does this at home with Joe. They make a little prick on Joe's thumb with a special pen, Joe always presses the button on the end to make the prick, and then Mum squeezes out drops of blood for testing. Joe's blood is then sent to the Laboratory at the Hospital where they test it. When it has been tested and the technician knows Joe's phenylalanine level it is sent to his Dietician. Joe and his Mum will find out the result by phone or it may be sent by post and they will know if Joe's diet is right or not.

As Joe gets older it will be harder and harder for him to see the things that his brothers and friends can eat that he can't have. But Joe's Mum, Dad, brothers and friends will always try hard to make sure his food is really nice too. And the people who make Joe's special foods are always trying really hard to make things that look and taste just like everybody else's food.

Joe doesn't find it too bad to have a special tummy because it only matters when he is eating and it doesn't matter when he is playing football, or cricket, or riding his bike, or he's working at school or when he is at church. Everything else about Joe works just fine and lots of people don't know about his PKU – because you can't see it and you only know when he tells you!

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NSPKU

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