



Phenylketonuria - a long term condition

Phenylketonuria: Jack's story

Jack

My name is Jack. I am 18 and I live with my parents. I have the condition Phenylketonuria, also known as PKU. I was diagnosed at seven days old by the heel prick test and from there I have been on the PKU diet ever since. My body cannot break down protein so I have to monitor and can only have a certain amount of protein each day. I do my blood tests once a month, and I am on 17 exchanges a day. An exchange is a certain amount of protein that I can have. I have a special diet which consists of bread, milk, pasta, and flour and cake mix that all come on prescription. I receive a lot of help from my parents. My Dad knows the weights of everything I can and can't have.

Jack's Dad

So what we try to do at mealtimes is make sure that what we eat is as close as possible to being the same thing so, for example, Jack's making a vegetable stir fry here so what we would normally do if we were eating together is that we would have a bit of chicken with ours so that we would have a chicken stir fry and Jack would just have a vegetable one. Okay, so for this one we're going to have rice noodles, so we get in the habit of looking at the ingredients of anything we buy and on the back of this one, Jack, it says...

Jack

2.2 per 100g.

Jack's Dad

Okay.

Jack

It's 300g, that would mean it's 6.6 exchanges in the bag.

Jack's Dad

Okay, so there's 6.6 exchanges in the whole bag, so if we were eating this for three people we would know that a third of the dish would be just over two exchanges.

Jack

PKU prescription food is fine for, probably for people who haven't tried the real versions, so like the bread and the pasta and the milk is, is fine and I, I like that. However, with the cookies and the crackers I don't like them as much, and I tend not to eat them because I've tried the real versions of cookies and crackers. When I go out with my family to restaurants such as Italian's and Indian's there, if I take my own pasta, if it's sealed in its box, most restaurants will cook it for me. Overall I haven't been affected by having the PKU diet. I haven't suffered with lapses in concentration or attention, which some people tend to do, who are perhaps on lower exchanges than I am, but I seem to be doing fine academically. I play a lot of sport such as football, golf, tennis. My energy levels don't seem to be affected by the diet. I'm always looking forward to playing sport and don't seem to get tired, just get tired like normal people do after running around for 90 minutes on the football pitch.

Jack's Friend

I've known Jack since nursery. We've been best friends ever since and whenever he comes round he'll always bring his own food with him, but it'll just be pastas or be what we're having, and so it didn't look any different to what we'd have. And yes, so Jack was always, seemed like one of us really.

Jack's Dad

In terms of family life I mean I think we've nothing to compare it to so it's all we've ever known. It's been difficult so, you know, as well as the diet he's had other things to contend with but, you know, now after many years of having to cope with it, it just becomes second nature, to be honest, and we know no different, Jack knows no different, and I think we're as normal as anybody can be, I guess.

Jack

Having PKU doesn't make me feel any different. I'm not bothered by it because I've done it through my whole, my whole life, like I said, at primary school and secondary school, and now at college, so now just people just around me just have to get used to I suppose, so.