



## **Phenylketonuria - a long term condition**

*Phenylketonuria: Clair's story*

### **Clair**

I'm Clair. I live in Ashford. I'm 18. I'm at college and I've got a condition called PKU. It's a condition in which my body cannot break down protein so there's barely, barely anything I can actually eat without giving myself brain damage. I was diagnosed at 17 days old. Because they were slightly late in the results I'd been having normal breast milk, as normal babies do and I, because of this, I got some brain damage which means that I can't concentrate for long periods of time, and I can't do basic maths in my head, and some other grammatical errors in my head.

So I'll show you some of the food that I have to eat. I told you the bread was quite pale. This is the bread, and I can't eat it just raw, I have to microwave it so it's warm. I also have some chocolate chip cookies which, as you can see, are very chocolaty. I don't know why everything is pale, they just made it like that. These are nice but if you leave them overnight open they do tend to go stale, and completely crumble and fall apart. I have this cupboard that's got all my PKU food in it. I have these drinks that aren't fully orange juice, so that I can drink them any time I want, because if you eat quite a lot of fruit then it is actually quite a lot of protein. I have also a separate bag for crisps but, as I said, I've stopped eating crisps because they were just so unhealthy.

And this is our fridge that's usually full of vegetables and fruit which I eat a lot of as snacks. I also have an enormous pile of drinks that live in my room. When I was at school some people thought I was being attention-seeking. Because it's so rare, some people just thought no, you're making it up, you just want attention and it just, it was quite hard to deal with sometimes.

When I moved to secondary school my Mum had to go to every single teacher and explain Clair's a very hard worker, but she has concentration problems, and you need to explain everything word to word, so that understands what she needs to do. Even though my Mum did talk to all the teachers some just didn't understand. They'd often hand me out chocolates and things like that, and I'd be like I can't eat them.

If you're in town usually people can just go wherever they want, they can go to McDonald's, or Pizza Hut or Pizza Express for lunch but, because of my diet, I don't have much choice. I have to actually think about what I'm going to eat, and all I can have is McDonald's chips 'cos I know I'm allowed them so it's quite depressing really when you look at a menu and the only thing you can have is a side order or chips.

So the big problem is as well is going on holiday, as most people would just go into a hotel and just eat at the restaurant, and things like that, but obviously because of my diet it is quite hard. The best holiday I've ever been on was at the end of my school year we went to Italy and they actually made my own pasta, you know, and it was done in a proper Italian way. They lifted up the tray and went here you go, and it was very nice because they did all the, you decided what you want for dinner in the morning, so then I decided what I wanted, they would make it, and I didn't have to think about it, I just, I felt like someone normal for once 'cos I didn't have to think oh, what am I going to have for dinner, so it's really, it was a really nice holiday.

I work in this charity shop and I've worked here for work experience for a, I'm working here for a year, and it's been really good, teaching me how to work with customers, how to handle money, and just how to get on in a work environment. The only problem is, is my concentration problem where when I'm working the till day in, day out, you know, putting in

the same amount of numbers, some customers might be a bit impatient, you know when it is busy and when it is rushed, why is she taking so long, because my concentration is so low.

I think the major effect my diet has at the moment is the tiredness. I constantly always feel so tired and lethargic. If I don't have my drinks for the day I can really feel it. I either do want to move out, I will probably have to either live with a boyfriend, or a friend, because I don't think I will be able to live by myself and carry on my diet, like cook my own food, and have my drinks daily. I don't think I'll be able to do that.

#### **Clair's friend**

When I first met Clair and she told me about her condition like it was all new to me 'cos I didn't know anything about it or heard about it. She explained everything about it and said she needed like emotional support and minding to have her drinks, and just generally being looked after, so I just support her saying like, it's not that bad, and look after her, and she sort of says to her friends.....

#### **Clair**

Another thing is pregnancy. It's one, will I have a PKU baby, how will I cope with that? Another thing is just the pregnancy itself, is I have to have loads of protein to, you know to build it up, and then I have to have none, and then I have to constantly before we go to the hospital and have blood tests, and how am I going to cope with that? I go to the doctor's every six months. They said to me that I could go off diet if I wanted 'cos my brain is now fully developed but I have chosen not to 'cos, even though it would be nice to have meat and pizza, if I do get pregnant I have to go back on the diet, and from eating everything I can to eating nothing, that would be so hard.

My PKU is always there but I never make, I've never made a huge deal out of it. I've never gone, oh, look at me, I'm PKU, I never kind of label myself as it, because it doesn't define who I am. I think I'm Clair who's doing business, and is very excitable and very optimistic but I don't, I never go hello, I'm Clair, I'm PKU. I don't think it affects me enough to say this is a huge problem to everyone I meet.