

Member Stories

PKU Adult

Susan

PKU Adult returning to Diet

Describe growing up with PKU / family life

Growing up with PKU at times was a challenge, especially at school. I was asked a lot about why my food was different and also with outings I had to take my own food. Back in the 60's PKU wasn't as recognised as it is now.

Were there any challenges you/family faced growing up and now any challenges as a PKU Adult

Challenges were the temptation of trying normal food which happened once or twice as a child. I find I have adapted well returning to diet which is now a lifestyle for me.

Why did you go off diet?

I received a letter from my Dietician on my 11th Birthday informing me I could go off diet.

What led to you wanting to return to diet?

After getting in touch with MDDA and doing a lot of research about the benefits of Diet for life. I wanted to feel better within myself.

Have you noticed any immediate benefits from returning to diet?

I have noticed my concentration is more focused, less anxiety and not as tired. Also it has improved my digestion and helped in losing some weight.

Do you find it easier now to educating friends and family about PKU then when you were younger?

I did find it easier educating friends and family about PKU when I was younger.

At school the challenge was mainly at lunch times when others would ask why my food was different once I explained why. They were pretty good though some would occasionally try and tempt me with the wrong food. I would have to explain why I couldn't have their food and what could happen if I ate it.

The workplace is easy as I work on my own and at night I eat before I start work. I explain PKU so it's easy for others to understand

What did you find was the most challenging things about taking the steps to return to diet?

The challenging things about returning to diet were the steps you had to take to return to diet. It was 3 to 4 weeks before I could start back properly etc appointments then I had to take samples of supplements pick which I like best. Then purchasing food took time as well. Once everything was sorted returning to diet was straight forward.

What would you like everyone to know about returning diet as a PKU Adult?

I would like everyone to know the benefits in your health and wellbeing when you return to diet.

Any tips in incorporating living with PKU into their everyday life and ensuring it is as easy as possible?

When I cook I freeze leftover food, I find it makes life easier and find you are not constantly cooking.

What was it like attending your first MDDA retreat?

I had the best time attending my first retreat, just glad to meet other adults with PKU.

Was this the first time you met other PKU adults?

The retreat was the first time I have met other adults with PKU.

Did you grow up knowing any other PKU children?

I grew up knowing mainly one other child with PKU who attended PKU clinics the same time as myself at the Royal Children's Hospital

The only time I saw others were at the PKU Christmas parties at the Royal Children's.

What is your "go to" low protein snack?

I like smoothies made with coconut milk, banana's and coconut yoghurt as a snack

Your favourite low protein food/recipe

Favourite food is pizza with chillies, mushrooms, zucchini, eggplant, pineapple.

What have you found most helpful in your journey returning to diet?

I find most helpful in the journey returning to diet is my health and wellbeing, it is a lot better also weight management.

Also meeting other adults with PKU and joining MDDA which makes you feel part of a community.

