

Diet for Life

My story by Con Giannas

My mother used to tell me a story when I was growing up that when I was born she looked at my fingers and noticed they were long and she remembers telling my Dad that I will grow up to be a surgeon someday. However, this all came crashing down shortly after when the Doctor told my parents I had PKU and what that potentially meant.

I was born in April 1970 and the Guthrie test was new and treatment was still a hit and miss. After several months in hospital my parents got to bring me home however mum used to have to go back everyday and then every week and this later become monthly. For somebody who has never driven this was an enormous task.

In the 70s low protein food was limited and low protein bread had to be ordered from the children's hospital. The formula at the time was a horrible powder type which my parents used to add with jam to make it palatable, it was still horrible and they used to have chase me around the house and even down the street to take it.

Thankfully my mother was incredibly strict on my diet and would never allow me to have anything that could risk high protein levels. In 1976 I turned 6 and in October of that year my Doctor added one egg a day to my diet. After showing no obvious signs of affect this became two eggs and on the 2nd August 1977 I came off my diet, I was 7 and 4 months. **I remember my mum put on a little party for me with every type of food thinkable, popcorn, cheese, milk, chips, chocolate etc. but after trying everything all I wanted was a salad.**

After coming off diet I went in for 6 monthly and then annual checks and my Doctor told me and reassured my Mum that I was cured of PKU and that I never have to worry about it again. He even said that I could be prime minister one day. However the reality is that whilst off diet I would never really live up to my true potential.

Going through my later childhood and teen years, off diet, affected not only my social life but I know the my ability to concentrate greatly changed my ability to achieve higher grades at school and to ultimately go to University.

As a adult in my twenties, one of the major symptoms I suffered from was chronic tiredness which no doctor could ever diagnose. I would go out to dinner in Northbridge (Perth's main restaurant and night club area) and would find myself doing laps around the street just to keep awake. Another trick to keep awake whilst out was to do star jumps in the toilets these sometimes worked but not always.

Working life was difficult, whilst I could do my job well I always struggled to concentrate and keep awake. I would regularly fall asleep in the afternoon whilst on hold to take a call and would come home and would be so tired I could not move or help around the house.



When I had children I would read them a bed time story and would fall a sleep after the second page, my daughter would often shout out "Mum, Dad has fallen asleep again!"

Mum didn't tell anybody what I had, as she puts it, she didn't want me to be treated different. It wasn't until I was about 18 that I found out what I had and the consequences of what could happened if my parents didn't enforce my diet.

Over the years I tried to learn a bit more about PKU and it wasn't until 2014 when I was 44 that I was having lunch and googled PKU, every site I went on said "Diet for Life". Reading the symptoms I had most of them. I remember going to my wife that night and saying that I think I should get checked.

Of course my GP really didn't know what PKU was and looked up in a medical book and found the testing that needed to be done. After having my blood test my GP reported my levels to be over 2800. I was referred to the Adult clinic at Royal Perth Hospital.

My appointment with the clinic was on the 26th May 2014 at around 10.30am. I walked out of there just before noon that day and I have never touched meat again.

After 37 years off diet, I made the decision to stay on diet for life. I can honestly say that it is the best decision I have made.

PKU does not define me and no longer limits me. Being on diet I can now truly live up to my full potential and enjoy life to the fullest.

In life, I have no regrets, however I do regret going off my diet.