


Katie

Hi MPNers…

My name is Katie and I now live in Maitland, Australia but previously lived in the UK for most of my life. I was diagnosed with a Myleoproliferative Neoplasm (MPN), in December, 2005. I have Essential Thromocythaemia (ET) Jak2+. This is my story:

In 1988, my husband had a heart attack in the South of France where we had a mobile home on the Mediterranean. We used to go on holiday for several weeks each year, with our three children.
My husband lived for 5 years after this event but only after he had 6 heart by-passes and a pacemaker fitted. This was an extremely stressful time for the entire family as we knew his days were numbered. He died in 1993 at the age of 53.

I began to notice subtle changes in my body which I dismissed at the time as all part of my grief. I lost a lot of weight which I presumed was quite natural after a death. I also noticed burning in my feet and could never find shoes which were comfortable.
Like so many other people when they are stressed I started drinking wine in rather large quantities.

I continued to run my husband's business together with my son, in the hopes that he would eventually take over. This never happened and although he tried to make a go of things, he was not happy and wanted to travel. He left for Australia with his girlfriend in March, 1999. They were supposed have gone for a year but in my heart, I knew he would love Australia……he never came back!
By this time my daughters were both working in London so I was left to ramble around my big, old house with just my cat and dog. The stress I felt was dreadful, until I met up with my present partner, whom my husband and I had known for several years prior to his death.

I feel that an MPN is exacerbated by stress and although my symptoms were not obvious, I was, I am sure, incubating ET. I was quite fit and went to the gym 3 times a week, skiing in the winter and did a lot of walking in the Lake District. I noticed after a lot of exercise, I often became dizzy. I put this down to not eating enough. I never felt hungry but could demolish a bottle of wine quite easily.

In 2001 I had an operation and the consultant remarked that my platelets were rather high after a blood test. They were 660 and my white blood cells were elevated to 12.3.
We put this down to a bout of Labyrinthitis I had developed during a journey to Australia to see my son, earlier in that year. After this, I had many strange eye disturbances with flashing lights in my peripheral vision but was told it was connected to Benign Paroxysmal Vertigo, caused by the Labyrinthitis.

In December 2005, I had a frozen shoulder and due to headaches after a cortisone injection, I had both an MRI scan and a routine blood test. The hospital contacted me immediately and I was rushed in to see a Consultant Haematologist as my platelets were now 1200. He performed a Bone Marrow Biopsy within two hours. I could not believe it when he informed me I had a rare blood disease called Essential Thrombocythaemia. In those days it was not classed as cancer. He told me my prognosis was 15 years and I may lose my hair due to the drug I would have to take for the rest of my life. This drug was Hydroxycarbamide (Hydrea) and I was instructed to take two per day. This was soon increased as two capsules did nothing to control my rising platelets.

It was difficult for my partner to understand that although I looked well, I was quite sick inside. However, he was supportive and helped me through some very grim moments but we were both still drinking far too much.

I ached all over and had great problems with my feet. The local GP told me I had Plantar Fasciitis which was rubbish. It was a side effect of the drug.
With the increase in Hydrea, I started to develop mouth ulcers. Huge, very sore ulcers causing great discomfort.

I took Hydrea for many years and was lucky that most of my symptoms went away and I was able to lead a fairly normal life. I travelled twice a year to Australia, as by this time my 2 daughters had also made their homes out here. They wanted me to sell up my own home and come to live here too but I had responsibilities in the UK at the time.

Eventually, my partner and I applied to the Australian Government for an immigration visa so I could be near the family. It took a long time and was costly but I was very grateful that I was finally accepted. My entire family are here. Two daughters, two sons-in-law, my son and his wife and 7 grandchildren. They are all truly Australian now.

That is not the end of my story though. I had given up drinking copious amounts of wine prior to leaving the UK on the advice of my haematology nurse. He suggested it might compromise my liver with the high dose of Hydrea I was taking. 1500 grams on 4 days and 2000 grams on the other three.

I stuck to a healthy diet but I kept having problems with elevated platelets until the dose of Hydrea was so high it poisoned my system. I developed a dreaded ulcer on my ankle. The only way to cure these is to stop the drug immediately.
Although I had a haematologist in Sydney, he did not seem to be too worried about this extremely painful ulcer. With help, I found one of the very few specialists of MPNs in Australia.

A marvellous consultant who has tried her very best to control my proliferative platelets. I am lucky in so many ways as I am fairly asymptomatic but it is what is going on inside the body that matters. I am now on Busulfan and Peg Interferon and have to inject myself once a week. The Busulfan will be dropped when the platelets have reached 300. Peg has to be introduced very slowly especially at my age. I am 79 in April.

So, on a concluding note, cheer up you MPNers. I have had this disease for many years and have survived. My hair has thinned a little and I do not always feel very energetic but I am still alive and kicking.
I have started a new journey in life and am an avid supporter of the MPN-Mates forum and totally support the new MPN-MATE Research Foundation which has been set up by Steven Shah. This is to promote research into MPNs for better treatments and management solutions. I look forward to Steve's' mammoth cycle ride around Australia in June 2020 and hope you will all support him too.

Best wishes, Katie