My MPN Journey so far...

Deteriorating health began for me at age 45. Before this I had always been healthy, given birth naturally to six beautiful children and only suffering the occasional cold. As a child I did have scarlet fever, measles and a bout of shingles at age 16 but these didn't seem anything out of the ordinary at that time.

At 45 I noticed my ankles were swelling at the end of the day and after some tests, discovered I had autoimmune Graves Disease, an overactive thyroid disorder otherwise known as hyperthyroidism. A consultant in the UK where I was living at the time, told me I would need to have the thyroid gland either irradiated or removed, both of which would mean spending the rest of my life taking replacement thyroxine. I didn't think much of these options so I saw a herbalist for some years and the disease seemed to be under control. I was however, also suffering from intermittent bouts of shingles.

Fast-forward to age 49 and upon returning to Australia with my youngest two children, I began working fulltime.

I saw a new doctor and discovered my thyroid test results were off the scale. I began to take Propylthiouracil (PTU) for this. The GP also noticed a comment which had appeared after the fourth blood test results since returning from the UK which said " Persistent thrombocytosis in the presence of a normal ESR is suggestive of Essential Thrombocythaemia". My platelets at this time were in the 400-500s so not particularly high but persistently so.

The GP referred me to the reviewing haematologist Dr Raven however I was his last patient and he retired soon after seeing me. He was old school and actually took my blood himself and did his own testing. He confirmed "diagnosis of myeloproliferative disorder" after twice testing for positive JAK2 mutation. He then suggested Aspirin twice weekly and Hydroxyurea to be considered if the platelet count reached 750 or higher. Dr Raven had also seen my mother who suffered from immune thrombocytopenia (ITP), another autoimmune platelet disorder.

At the same time he also found I had an IgG type Lambda Paraproteinaemia otherwise known as Monoclonal Gammopathy of Unknown/Undetermined Significance (MGUS). Ths is an abnormal protein

made by plasma cells in the bone marrow. Dr Raven seemed to think this was nothing to worry about for possibly 10-20 years at which time marrow studies may be considered if the paraprotein level reached around 10g/L. My level has since consistently stayed around 4g/L for which I am thankful as this problem can progress into Multiple Myeloma or Lymphoma. These diagnoses came in early December 2015.

So I took the aspirin intermittently for the next six months or so and didn't worry too much about anything other than my Graves Disease. I had changed my mediation for this to Carbimazole and was seeing a Consultant GP at the local hospital rather than having to travel to Perth for treatment. Around this time I began to take Valacyclovir (anti-viral mediation) for the recurrent shingles.

In 2017 I had a couple of trips abroad and on returning from the latter one found I was suffering from headaches and visual disturbances (scintillating scotoma). I was referred to an opthalmologist who thought it might be migraine until I mentioned the ET at which point he decided I better go and have an MRI scan on my head. This found I had a venous sinus thrombosis and I was referred to a new haematologist (Perth) who started me on Apixaban (blood thinner) and Hydroxyurea. After three months and another scan the clot had disappeared, yay! This event began me on my research journey into ET and my various other health problems. I discovered MPN Voice and began talking to Steve (fellow Aussie – where I am a MPN-MATE RESEARCH FOUNDATION Committee Member & MATES MPN Australian Patient's FORUM contributor). Great to have an Australian MPN site working for all of us MPNers… 8-)

At the beginning of 2018 I was suffering from exhaustion due to the extensive bleeding caused by Apixaban (three week super-heavy periods!). I underwent an edometrial ablation which resolved that problem.

In June 2018 I went to ED (via my GP) with abdominal pain. I was told after a CT scan that they had seen "something nasty" on my kidney. A biopsy showed a stage 2 clear cell carcinoma at the top of my left kidney near the adrenal gland. Both kidney and adrenal gland were removed by laproscopic surgery in August 2018. I had four weeks off work and follow-up scans have shown no return or metastatic cancer.

Following this surgery I developed a frozen shoulder and carpal tunnel syndrome. Physio helped the shoulder recover after about 15 months.

The carpal tunnel can still be a problem but resolves by wearing wrist splints at night.

At the beginning of 2019 I had a hook-wire day surgery for a breast lump which was clear of cancer and also a colonoscopy which came back clear.

By this time my Graves Disease had been under control for some time and the dose of Carbimazole gradually reduced. Around June, the doctor and I decided to discontinue the medication.

The next problem to appear was autoimmune psoriatic arthritis, diagnosed in August 2019 after suffering pain in the joints of my hands and feet. I was prescribed Methotrexate and around this time discontinued the Hydrea and the Valacyclovir.

The Methotrexate caused a sharp rise in my liver enzymes and so was discontinued. I was feeling much more energetic which I put down to a fantastic holiday to the UK to see family and stopping the Hydrea.

I then discovered that the Graves Disease had come back with a vengeance and so a high dose of Carbimazole was commenced.

Following Methotrexate not being tolerated, I began taking Arava which has caused hair loss and makes me grumpy and teary whereas I believe I am usually rather laid back and positive. The dose has been reduced by half until my next appointment. My liver enzymes are raised again but with GGT raised now along with ALT and ALP. The next step may be a biological medication which lowers the immune system...

On Australia Day 2020 I went out for a lovely pub lunch and then to the cinema. During the cinema screening I began to get a pain in the centre of my chest which went straight through to my back. This continued into the next day when I saw my GP who (surprise, surprise...) sent me to ED with a note asking them to check my gallbladder. They didn't do this, instead concentrating on whether my heart was ok (which it always has been and still is). They sent me home after six hours telling me to see my GP to get a gallbladder scan! I was still in pain the next day and following a scan, was found to have a "sludgy" gallbladder. The doc gave me some antibiotics and after four days the pain cleared. The pain is still returning every now and then and a HID scan has revealed a dysfunctional gallbladder. I also have had a bout of shingles after being clear for a couple of years.

So I have brought you up to date now. At present I see a local Consultant Physician for my thyroid, a haematologist in Perth for ET/MGUS, a kidney nurse in Perth for follow ups (every six months for five years) for the kidney cancer, a rheumatologist in Perth for the psoriatic arthritis and most recently, a general surgeon to look at the gallbladder. I am still working full-time and will do so as long as possible.

Symptom-wise I suffer from headaches, severe itching, pain in hands and feet and sometime numbness due to the carpal tunnel, the gallbadder pain described above, sore red eyes (with worsening vision) and fatigue.

I am getting back into the exercise (I know how much it improves mood, mind and body), I try to eat well and have cut out as much dairy as possible. Most of all, I try to stay positive and get on with enjoying life as much as possible.