

Being Invisible... Steven's MPN Journey...



Hey there readers...

My name is Steven, and I live in Sydney, Australia. May 2016, was when I became diagnosed with a Myeloproliferative Neoplasm, an MPN, (at that time... I had no idea what that was...), and I was soon to learn that I wasn't alone in that department. Today, in 2020, as I pen this account with 20/20 hindsight, I guess that there is never a good time to learn that one suffers from an all-but incurable chronic blood cancer condition. However, the timing of mine was particularly cruel in some respects...

Naturally, I was blaming my then fiancée for all that had transpired within our failed relationship, when in truth there was much within my own behaviour that I simply could not begin to see... because, as I was to eventually learn, having an MPN is not an easy illness to come to terms with or indeed to understand the many ways it impacts on one's life and livelihood. Aspects of extreme fatigue and living in a mental fog can contribute to making poor decisions... Having an MPN is realising that it really can have a way of sneaking up over many years gradually altering one's mind and bodily ecosystems. The symptoms can evolve slowly at first, and one almost grows into them, over time... Nonetheless, some documenting of the data might have helped future sufferers become diagnosed sooner and thereby evade an earlier demise than planned, in my view... having a minor brain stroke was a real wake-up call!

Depression and general melancholy had already settled hard upon me after the failure of my engagement, which also eventually lost me my previous very well-paid career-position, and a separate private publishing enterprise. That failed relationship definitely endured much longer than was needed. However, I eventually took advice from Taylor Swift, and tried to "Shake-it-off".

Extremely depressed and disillusioned... First, I travelled abroad for a while in SE Asia, to locations where devastating natural disasters had recently intervened adversely in the lives of tens of thousands of people. Through those journeys, I experienced an epiphany of sorts, and made the decision to remake myself. Upon my return, I committed to full-time study, while also becoming my aged mother's default carer, (my partially immobile mother believes herself to be extremely independent of course...)

However, after five (5) plus years of study, and a final year where I ended my studies abruptly because everything seemed more of a struggle... Suddenly, one of my applications had become accepted for a Posting abroad working in International Aid through a DFAT volunteer program. Just getting through that approval process was a feat in itself... Nevertheless, I was so elated that my application passed all the obstacles and within 48 hours I would be winging it away to a remote island in the Philippines to commence my first assignment... At last, it seemed I was ready to end my working hiatus and reorganise my life doing something that I was truly passionate about... at that juncture everything was falling nicely into place... or so I believed...

On that fateful, final Friday afternoon, (my last in Australia for some time I assumed), I had taken my mother to her scheduled medical appointments, and decided that her medical centre would suffice to also provide the mandatory service of a 'standard medical' examination, prior to my departure. The Sunday evening that followed brought with it an unexpected late evening call from the Chief Medical Officer of the program, advising me that further tests would be required, (as there were abnormalities in my blood-work), and that for the moment my overseas assignment was placed on hold...

My first reaction to this news was that it was simply human error... a mistake in the blood reports. When that assumption proved incorrect, I believed that it must be a viral or bacterial infection of some sort that would soon clear of its own accord etc... Wrong again. However, due to not wanting any of this to be true I kept seeking out alternate escape routes, before finally concluding I was simply in denial. Then everything seemed so overwhelming and my despair and depression soon returned... I began drinking copious amounts of alcohol and no longer caring about myself or my future prospects... Everything I had studied for and planned for was now gone! All of this was like a rude awakening for a man in his late fifties trying to regain some new meaning, philosophically speaking...

The next 12 months was an escape, a flight from the harshness of my new reality... I was wallowing in my new depression and once again contemplating suicidal ideation, as my life seemed to have little or no purpose whatsoever...

Only with the benefit of a retrospective rationale, was I able to deduce that I had been living with a great many MPN symptoms, for quite sometime... Possibly as long as 20+ years (?) In any event, all that news was eventually like an emotional tidal wave that swept over me, and changed the course of my life and my planned direction.

Initially, I was diagnosed with ET, platelets over 1.7M, (normal range between 150-450k), and I discovered I had already suffered from one Transient Ischemic Attack (TIA – minor brain stroke) that basically went undiagnosed coincidentally on the same day as my BA graduation, (August 19, 2015). After, a couple of months and a Bone Marrow Biopsy (BMB) of Grade2 results, my MPN was reclassified as Post ET / Myelofibrosis (MF).

My experience of having my first Transient Ischemic Attack (TIA), was equally a fascination as it was a moment apprehensive dread... I was engaged in a simple trivial café discourse with a friend, when suddenly I began to sense a small audible sound growing in my left ear. I recall just ignoring it before it rose up into a crescendo, which felt like a mini explosion inside my head. My vision became monocular and impaired with flashing white lights in my periphery. My head was sort of buzzing and my speech had become notably slurred. Then I noticed my right arm was completely paralysed, and then the strangest of all things was my consciousness itself... Somehow, I now felt as though this was an 'out-of-body' experience, as I no longer commanded total control over my bodily assets. I felt as a spectator might, watching my friend who had no concept whatsoever that I was not my usual self... Astounding! I can recall sensing and thinking to myself, "...so this is what is like to be trapped inside one's body..." Fascinating...

I immediately announced my dilemma, (in my best slurred speech), to my friend, and after a few moments went straight to the nearest medical centre to have a series of tests run... All my tests were negative, all except for a blood test as they were not able to take any blood from me at that time... So they simply diagnosed this event as a likely pinched nerve...

There had been other symptoms too, that I supposed I had earlier ignored; fatigue of course was ever-present, things like minor internal bleeding that had showed up in urinalysis, the odd nose bleed, bleeding gums, weird headaches and white lights in my periphery vision. Another very interesting symptom that was later revealed was the yellowing and flaky growth of my nail cuticle on both hands and feet... Much later, and once started on blood thinners that problem corrected itself almost overnight, after having unsuccessfully having it treated for well over Ten (10) years... Possibly, the thing that disturbed me most however, was the knowledge that some of my mental acuity had become notably impaired. At times I struggled to recall very basic thoughts and or vocabulary... I recall vividly one experience when I found myself driving, suddenly I pulled to the kerb with tears flooding in my eyes, because I did not know where I was driving to or even why I was in the car...? Naturally, I did not share this knowledge with anyone at all at the time...

After diagnosis, initially, I like many others could not well tolerate the Hydroxyurea (HU), (an oral chemotherapy drug). I suffered from a very debilitating form of mental fugue and memory failure that was extremely disturbing for me. Mouth ulcers, burning sensations in my legs and extreme fatigue were making my life a most unbearable version of hell... the bleeding episodes in the back of my throat and into my nasal passages each morning were most disturbing, (portal vein hypertension was suspected). In that first instance, I did not

cope very well at all. In the absence of any useful rationale, I continued drinking myself into oblivion, and cared very little about myself. Believing that I had been rendered quite useless, with little left to contribute to the bigger picture...

No one knew what I was going through, because naturally I looked reasonably fit and healthy to most conventional observers. In reality, I was dwelling in an invisible dimension, where I was soon to discover that very few people knew little to nothing about my MPN illness. And it may have been that fact alone that made me even angrier that all of this had somehow happened to my existence. Not only had it ruined the chances of my reinventing myself and an my early twilight career, but it appeared that next to nobody in the medical fraternity really knew much at all about these very rare, chronic blood cancer conditions. Many even said that they were NOT a form of cancer at all, just a benign blood disorder...

Eventually, this lack of knowledge concerning my MPN spurred me on to a new study; that of my MPN condition, and anything and everything I could teach myself about it. It didn't take long at all to conclude that it was indeed treated like a 'Leukemic poor-cousin', and dismissed as something for the 'too-hard' basket by many practitioners, who in my view were more interested in writing prescriptions and forward booking my next monthly consultation...

To be fair, we dwell in a world where the global paradigm is a simple one of 'money begets money'. These rare forms of chronic blood cancers, which suffer from a couple of commonplace obstacles:

1. Because they are so rare, their incidence is very small in any population, and Australia's population is so very small by global standards, placing us collectively into an MPN minority, via an economy of scale
2. Secondly, the 'Driver Mutations' believed to cause them have only been relatively recently uncovered in the preceding 1.5 decades, meaning that the learning curve is still in its genesis and there is much to learned...
3. Hence, in the Australian context there is a very distinct knowledge gap where MPNs are concerned, and especially so within the medical fraternity... With just two (2) recognised MPN specialists in Australia...

In my quest to better inform and educate myself as to Myeloproliferative Neoplasms (MPNs), I utilised my university access to medical and scientific, peer-reviewed articles and journals to study and glean information, and I scoured the global Internet and found an MPN Patient's Forum website in the UK called "MPN Voice". In Australia at that time, (2016), only the Leukaemia Foundation of Australia (LFA) provided any type of assistance by producing some literature and holding the odd state conference. I would soon learn that GPs knew little or nothing of these conditions, and most haematologists very rarely had any patients with an MPN, which translates into that there were very few MPN Specialists doctors in Australia... There was an individual in Victoria that had started a Bulk email List but this was not really very effective assistance to MPN Patients, in my view... Both the aforementioned groups suggested that they were considering creating an Australian Patient's MPN Forum website. However, after dutifully waiting for two (2) years, nothing materialised... and the LFA stopped holding Sydney conferences and began working more closely with the Melbourne-based MPN group, largely leaving the rest of the MPN community in Australia 'out of the MPN involvement loop'.

Christmas 2017 saw me self-absorbed by my own self-pity and depression. Everywhere around me I observed how our society's denizens continued to live their largely dysfunctional and chaotic existence one day after the other, barely missing a beat of the economic drums dispersed by a variety of automated mechanisms keeping them all mindlessly programmed into some bizarre dance to the grave... Empathy for each other seemed to be at a global all time low, in my view...

Education, fitness & longevity...

My journey had only just commenced when I slowly came to realise that there were always people in a worse off state than myself... and besides, I was still able to try at least to do something about all of this...

While one might argue that Lance Armstrong might not be the greatest example to hold up as a mentor because of his cheating using drugs to win cycling events... However, in many ways, he really is! Armstrong did survive having cancer, and he did create a rather unique charity that helps kids and people with cancer in a very real and big way... His foundation is quite an inspiration that most certainly would not have come about without Lance Armstrong - <https://www.livestrong.org/>

I really love their motto:

“Unity is strength, knowledge is power and attitude is everything...”

It was Armstrong who initially inspired me to take up cycling... When I commenced I was overweight and not as fit as I once thought... However, in a rather short space, I changed my lifestyle, my diet and my fitness regime... After about a year, my results on a BMB showed a small but significant reversal at the molecular level reduced down from Grade2 to Grade1 in bone marrow scarring...

That was when I realised that perhaps others might benefit by adopting a similar approach... In April 2019, I commenced building the MATES Australian MPN Patient’s Forum website. Just being more positive about my MPN and myself was already seeing me improve my levels of fitness and health. My anti-inflammatory diet, which includes intermittent fasting and eating mainly plant-based unprocessed food staples that include wild-caught seafood (where possible); but not farmed-raised red or white meats, seems to be helping me a great deal. I am also now well over 20kgs lighter than I was when I started this new health and fitness regime...

As of January 2020, MPN-MATE.COM is now the MPN-MATE Research Foundation, an Australian Registered ‘Not-For-Profit’ Health Promotion Charity organisation to aid all people suffering from an MPN by aiming to promote research into Myeloproliferative Neoplasms (MPNs), and hopefully helping to create better treatments and MPN management solutions... Ultimately, leading towards a real MPN cure someday...

Everyone with an MPN is most welcome to join us on this journey, we are always looking for new members who also want to add their voices to the myriad of ways we might all work to improve the MPN story and experience here in Australia...

In my view, this MPN journey has really only just begun...

Best wishes ...

Steven