

KEEP THE FLAG FLYING ONE MANS JOURNEY

Abalinx 21 August 2016 Peter Adamis

Preamble. Keep the flag flying is an apt title as it is a constant reminder that in life, the wind does not always blow in the direction we want and as such we must expect that like life itself, the flag will fly the other direction as the wind blows.

This is a long article and I ask forgiveness for those who have the patience to reach the end. I began writing it on the 2 August and finished it on the 12 month anniversary of the diagnoses. This article is not for everyone and may I suggest that the reader extract what they feel is good for their soul. If I have repeated myself in any way, I apologise and put it down to writer's privilege and forgetfulness.

This hopefully will be my last article on this subject and although I did state I was going to write a patients survey, I feel that the staff at the hospital are all professionals and I doubt that my input would be of any value or enhance existing protocols. I wish all those who are currently going through this journey, the strength, courage, stamina and remember never ever give up.

Tribute. Before I begin, let me pay tribute to my wife Yovanna who stood by my side throughout this ordeal. If it was not for her and her bedside manner, the experience alone would have either killed me or hardened me even further by closing off from the world and its reality. The other people in my life I must pay tribute to, is my family, my friends who visited, my social media mates and many many others described below. The hospital staff who I must say were outstanding even though we had our odd disagreements from time to time. But when I reflect back on that time, the relationship between the hospital staff and myself was a quasi-sort of a marriage.

I have waited over twelve months to write this article. Today is also the anniversary (twelve months) of being diagnosed with a deadly cancer. To many it is meaningless, to the few who have lived through it will understand and for me it's a milestone that is an expression of hope and some relief from the anxiety that haunts us who have survived to date. I do not write this from an egotistical point of view, but merely an expression of relief and t describe inner thoughts, feelings and what it is like going through a heavy dose of chemotherapy, stem cells and finally enduring a difficult recovery period.

I am hoping that what I demonstrate and describe alleviates fears, anxieties and in some cases coming to terms with the illness we call cancer. Having said all of the above, I ask of the reader to bear with me as I attempt to describe a journey not knowing how it ends.

I have already written about the diagnosis, the treatment, the staff, the doctors, therapists, support services and the wonderful individuals that popped in and out of the journey whilst a guest of the cancer wards. Yes there are many ill people, some with and some without hope in their eyes. I first saw that look on an Uncle of mine who passed always with cancer some years ago. It was a hollow look that saw through the lens and into the mind of the person taking the photograph. It was my Uncle Spiro who had that look and in the cancer wards I witnessed the same look every day. Mind you, I still find it difficult to sleep at nights as the looks still haunt me.

Back in late November 2015 when I had completed my fourth chemotherapy regime. I injured my left hand by a small branch that broke off a tree that I was pruning with my bare hands and no gloves. Silly me as I had no one else to blame but myself as I had already been warned many a time by the oncologist to keep away from the garden at all costs as I was still in the 'Neutropenic' stage. Well what can I say? It was only a small branch and it did not look that hard to pull off. How was I to know that the branch would swing back and the broken edges of the branch strike me on the left hand? Well that injury put a spanner I the works did it not. Gosh I was a stupid bastard.

The left hand within 24 hours had swollen and there was a redness with pus oozing out 48 hours later. What was I to say to the Oncologist? I could bullshit to him and lie right out saying that I fell over, tripped, was pushed, anything but the truth after being advised warned on more than one occasion. Keep out of the garden while you are in the neutropenic stage. The oncologist was and still is a good bloke of whom I have the utmost respect and faith in but my larrikin know it all attitude thought I could do a little bit of gardening without anyone being the wiser. What and how could it hurt? I was about to find out.

At the same time as I had injured my left hand my gums began to become sore and I found out by visiting the local dentist that my teeth and gums had become infected whilst I was in the neutropenic stage. My wife and pondered upon this matter and brought both matters to the attention of the Oncologist who immediately prescribed anti-biotics and postponed the heavy dose of chemotherapy and stem cell treatment. For another month and advised me to remove the infected teeth. I was not a happy chappie I can tell you that. On reflection not knowing what to expect is probably the most soul destroying of all.

Priscilla Gates the nurse responsible for the stem cell support services and systems was always on hand to provide advice, support and answer a myriad of queries that were needed to be reckoned with to alleviate the anxieties building up inside of me. I may not have exhibited the signs of anxiety but I can tell you now that Priscilla was so skilled that she could sense the anxieties and the many questions I need answered. Suffice to say, I looked towards her to fill in the gaps in my knowledge and I must say her bedside manner was superb.

Emails, chats and telephone conversations filled in the gaps in my knowledge cancer treatment and where to seek additional advice and support. After being disappointed to find that the heavy dose of chemotherapy and stem cell treatment had been postponed, it was pleasing to have it confirmed that the heart was still strong after having suffered three heart attacks previously. Had the heart not been strong despite the stents, I would not have endured the heavy dose of chemotherapy and the stem cell treatment.

Suffice to say, all was going well and according to schedule when I foolishly injured myself allowing infection to enter the bloodstream as well as having problems with my teeth. The other good news that I had was to find out inadvertently that I was in remission. I was pleased, surprised and a bit upset that no one had told me that I was in remission. I had to find it by talking to one of the many oncologists in support of my illness.

In December I was subjected to injections that encouraged new stem cells to flood the body so that they could be harvested, stored and then returned back to the body after the heavy dose of chemotherapy. The pain was unbearable and it reminded me of the car accident I had the year before where I had injured my spine. I would slide off the bed and writhe on the floor in order to reach the doorway leading to the bathroom. Other times I would use a belt around my waist and with the aid of a walking stick struggle towards the bathroom. Going to the bathroom at least four times during the evening was the worst, which meant that I did not sleep well and would be drugged with panadol and oxynorm a pain killer.

In the morning before my wife Yovanna went to work she would inject me with a measured dose to encourage the stem cells to be formed from the bone marrow and then the pain would follow soon after. The taking of pain killers alleviated some of the pain but not all. The bedroom had been converted into an isolation ward similar to that at the Olivia Newton John Cancer and wellbeing centre. We had set it up to ensure that everything that was needed was close at hand including the lap top to communicate with the outside world. It was a lonely existence but when faced with no other choice, one must strive to make the most of it and not complain or bitch about the moment.

Life went on as usual outside the confines of the home and I was lucky to have windows wide enough to obtain a good view on our suburb of Watsonia and watch people and vehicle traffic go past the home. The old Australian flag flying proudly whenever a breeze decided to visit out location and then slow down to a flutter once the breeze had gone through the leaves of the trees surrounding the flag. I could see the birds flying past, the cooing of the doves and pigeons that have made our backyard their home and the occasional call of the blackbirds that haunted the balcony and the plane tree in the front.

Whilst in the evening the local possums would jump from tree limb to limb trying to find holes and/or places to make a home in the roof or amongst the dense leaves of the trees that surround the home. One could say that despite being alone, I was not neglected when surrounded by the life outside the window of my room. I must admit that the resident possum who has made our rafters home could well do with relocating and give us a good night's sleep.

At times, I may be pleasantly surprised from a mate from the past or a childhood friend who would patiently wait for me to reach and lay on a bed in the back room, while he watched without becoming involved in my movements. I wanted to do everything myself and not have to rely on any one lest I fall into the trap of feeling helpless. It was important to have a sense of independence and control over my own wellbeing even though the pain was a constant reminder that not all was well.

I would play mind tricks with my body by saying that pain was good and that it was a sign telling me that the body was in fact alerting me to the body immune system giving it the best shot it had at healing. It is amazing what the mind can do despite the pain one feels. Occasionally my mind would go over and over what Priscilla Gates the nurse and Simon He the Oncologist who had advised to expect and what the procedure would be, what other matters may arise and above all keeping me well grounded by answering all of my anxieties.

I would think of Carol Smith who advised me to seek professional psychological help, once I was in the recovery phase. Of my deep friendship with Julian Grabeck, one of the Registrars, the other doctors such as Paul Turners, Daniella, Ashka, Chyn, Hannah, Karthik (transferred Northern hospital) and many other doctors and consultants, the many nurses, with a special tribute to Fler, who in my opinion was the epitome of what a nurse is all about. I thought about the personal Service assistants, the cleaners, and of the myriad of other hospital family that made it possible to survive in a world very alien to what I had been used to.

Then we have Dr George Proimos my cardiologist who provided advice on the strength of the heart to be able to withstand the heavy dose of chemotherapy, Dr GLaith Gliana, the local GP who first diagnosed me and rushed me to hospital, Department of Veteran Affairs, The RSL and the advocates, to my Russian mate Oleg who gave me his story and what he was doing to stay alive, (now deceased), to my cobber mate in Sydney and colleague at University, Dr Azhar Khan, My ex-military mates who rang, sent messages and kept my spirits up, Political friends, relatives across the globe and not to forget by siblings and long suffering parents my Mum and Dad.

However I have digressed far too much and need to return back to the hospital and being subjected to the heavy dose, followed by the stem cells being returned back into the body. I remember being spoken to by a number of consultants of what to expect, the risks involved, the signing of documents, being reassured, what steps were being taken to make my stay in hospital as comfortable as possible, the introduction of forced feeding through the tubes attached to the body, hygiene and the need to take medication and to provide as much feedback on my conditions all information would lead to a speedy recovery. At all times I was encouraged to ask questions, keep my spirits up and to have a positive outlook. I was prepared as much as I could and knew that the next week would not be pleasant but that it was essential for longevity that I had to take this journey and take it on the chin whatever came my way.

I don't think that I was the best of patients at the best of times, asking a myriad of questions, unable to sleep, not being able to eat the hospital food and mind you I was not alone in this. Remaining awake at nights certainly was not conducive to long term relationships between patient and staff and I admit that on one occasion I lost my cool with one of the nurses who for her own reasons decided not to follow protocol and give me another dose of fluids to keep me quiet rather than stopping the procedure and following protocols. Although I was correct, the matter could have been better handled by both sides. On reflection, I don't have regrets as it was my life on the line and wanted to follow exactly the consultant's advice and not that of a staff member who was on shift only.

On a number of occasions I did not make it to the toilet bowel and as a result of my failure to make it on time I left a trail of wet, smelly and streaky lines of excrement from the bed to the toilet bowel. Diarrhoea was a major problem for me and it was a sense of dignity that on completing my bowel action, I got on my hands and knees and slowly cleaned up the mess of excrement with soapy water, alcohol for cleaning of hands and used paper towels to wipe it dry.

While I am cleaning the floor, the toilet bowel, I am keeping above my head then tubes that were hanging and attached to the overhead coat hanger holding the bags of heavy dose chemotherapy and the liquid food. Once my cleaning was completed, I jumped under the showered and remained there for one hour cleaning and hoping all the excrement was washed away. Only then did I contact the nursing staff and advise them of what happened. I did not expect such a backlash but I guess I deserved it. They told me off for cleaning the mess up stating that they were used to such mishaps and were prepared for such issues arising in the cancer ward.

Although I explained that it was a matter of dignity on my part, they insisted that they should be called straight away in future. When it did happen again, I still did not call the nursing staff as I wanted my dignity intact. I just cleaned up my own mess and then asked for the room and soiled bed linen to be cleaned after the fact. My main fear within the confines of the hospital was infection and the possibility of picking up bugs, bacteria and other illnesses not associated with my cancer treatment.

To overcome this, I used other toilets that were available if I happened to be in a shared ward with other cancer patients, cleaned thoroughly door handles, toilet seats, the medial coat hanger, posts, sinks, trays, drawers, and any other hospital equipment that I may come into contact with. It may appear that I was paranoid and the reader could be right but I wanted to give my body the best possible chances of survival and recovery. It was not always easy to do this but perseverance, commitment and dedication to one's survival is probably the best way of approaching this dilemma that I was faced with. I have no regrets whatsoever, none at all.

The last heavy dose to be administered was covered in a black hood and the chemical whatever it was slowly was fed into my body. If I felt uneasy, it was too late for regrets or to protest as it had already been explained to me what was to occur. Doctors and consultants regularly came in to see me and how I was progressing. I was disappointed by later got used to the mew staff coming into look after me and soon a rapport was created which made me feel at ease.

I still asked a myriad of questions, still did not give up on my cleanliness and always looked forward to seeing my wife Yovanna who patiently came by from work to see me. Many a time she would go home, cook a meal and come back to the hospital where we would eat together. Occasionally we would be caught sleeping side by side as we did not get the opportunity to demonstrate or show affection towards each other due to my circumstances. There were times when I was not happy with the protocols and questioned whenever I felt that there was a change. There would be an endless battle of wits between the nursing staff and myself which must have sorely tested the patience of the hospital staff.

When the time came to receive my stem cells back into my body, I made small videos of the occasion, mainly to keep my spirits up and to convince me that all will be well. I still have the videos but don't have the courage to revisit them at this point in time. The transfer of stem cells was a success and I was kept in for monitoring and observation. I kept a close watch on my blood counts and each day I felt I was becoming worse and ill but I had been advised that I would suffer from a number of side effects of which nausea and loss of appetite, being the main problem as well as I mentioned above diarrhoea.

I will admit that I was not a happy chappie but something told me that everything was going to be alight if I just kept on going no matter what was thrown at me. On reflection this period was my worst experience in hospital and I don't wish it on anyone. The pain was only bearable with the pain killers and if I wanted it, I could have morphine based medication. Having a positive outlook is not to be underestimated and enjoying each day was a blessing in disguise. My wife Yovanna came in every day and the time spent together was worth the waiting during the day. A few visitors also broke the monotony and were a welcome intrusion.

Once the 14 days post stem cells period was over and the consultants could see an improvement in my demeanour, I was moved into a joint ward which I shared with one other and I was not impressed at all. I went back to my old routine of cleanliness regime when sharing and kept using the shared toilet to the bare minimum. I did not trust others to clean up after themselves no to have the same fears as I did or believe that the shared ward was as clean as I would have preferred. I knew and felt I was getting better but the blood counts indicated otherwise and my stay was prolonged. Near the last week of my stay I was allowed to go home still with the tube inside of me and returning the next day for blood testing and seeing the consultants.

On my last day, with my lovely wife Yovanna being with me, the tube was finally removed. Its removal was done so professionally that I did not even feel that it was being removed. At that time my mate Clinton Breeze an ex-military chap and friend of the family dropped by and his presence distracted me from the tube being removed. Suffice to say, I felt dizzy and unsteady on my feet but exhilarated at the prospect of going home for good and only returning to see the consultant.

I already knew that I had six months of recovery ahead of me and that I had to give my immune system time to recover which meant being coped up at home and keeping away from crowds, people, not working in the garden and to keep away from people who had an illness or even the common cold. The next three months proved to be the most painful of all the six months recovery stage.

As in the previous months the bedroom upstairs had been converted into an isolation room with everything available except the dreaded drip and tubes protruding either from my arm or chest. The tube out of my chest made showering in the hospital easier and some sense of freedom when compared to the one inserted into my arm. At home with the tubes attached is like a freedom I never experienced. I could stay in the shower as long as I liked and enjoy the warm water rain over my body.

Each day was a new day and with each day I looked forward to something new. My wife took time off to look after me until I could begin to become more independent. When she did return back to work, life was not the same and I had to fill in the day with something that would keep me occupied. The first three months at home was a welcome, sensitive and one of stress for me. I was in constant pain 24 hours of the day and it was only the strong pain killers that helped me during the difficulties at night. At the same time I was having sons/father relationships which almost drove me insane and not knowing or understanding some of the bizarre behaviour.

No matter what advice counselling or chats we had, it mostly ended up with me being angrier than before. It was not long before I became physical and lost my cool, sense of control and my emotions hit the roof. Here I was recovering and I had to put up with behaviour which I found not to be normal for any. In the end, the relationship deteriorated to the extent where there was a separation which left me an emotional wreck still trying to come to terms with my surroundings.

To keep busy, I went back to writing articles about the forth coming elections and assisting a young man who I was mentoring to stay on the straight and narrow. In April after three months had passed I found the strength to venture out in public. It was to attend a political convention to elect new office bearers. It was a great day and it was my way of reengaging with the community slowly. I was not allowed near crowds, no to mix with any groups, to avoid those with colds, infections, bugs and any other contamination as my immune system had not yet kicked in. Still from a psychological point of view it was just what I needed.

I saw many old friends and opponents of course, but they were few and far between. Although it boosted me mentally, I was still down from the stress and worry about my own environment. Nothing helped other than to keep quiet and keep to myself as much as possible with my silence and isolation affecting anyone. But unfortunately I lost my cool on many an occasion and would lash out.

I attended the cancer survivor's course, which I may add is broth brilliant and awe inspiring for me. I learnt more from the sessions that I attended than all the other therapeutic advice I had received. The survivors course made me realise that I was not alone and that we as a group could still laugh, make jokes and keep on living. I cannot speak more highly of this programme and hope that it is extended to carers as well who deserve much praise for their unselfishness.

Within the month of May, I was confronted with me new challenges which I did not want. Apart from my son's issues, there was the matter of political campaigning as a result of an election being called by the Prime Minister. I had already written a number of articles that the Prime Ministers strategy was not going to work, but then again, who am I to advise the Prime Minister how to run the country.

Suffice to say, my predictions proved to be correct almost to the letter and now the government is struggling to survive with a one seat majority, a hostile Senate and back benchers not happy with what had happened during the election. I have been a political activist since 1990 and even blind Freddy could see what was happening in Australia.

All that I got in return was abuse which affected me very badly as I expected those who I supported to come to assist me. In hind sight, I think and still believe that they are all gutless with no spine at all. I came out of retirement to assists and stupid bastards who did not know what was going on behind the scenes took it upon themselves to attack me on a personal level. This was truly un-Australian and poor form in kicking a bloke when he is down. At this stage I had also been given additional injections to boost my blood count as they had dropped remarkably low, requiring an intervention on the part of the oncologist. This did not go down well with me and I became paranoid about my health.

By the middle of July I felt strong enough to get away to Echuca and Moama for a few days. We both felt great and had a wonderful time despite the inclement and unreasonable weather patterns we experienced. I felt great on our return and looked forward to another milestone the following week which was the administration of the childhood vaccinations. These childhood vaccinations need to be injected as they had all been removed during the heavy dose of chemotherapy. Well guess what? It was not to be. I had come down with horrible flu like symptoms that kept in bed and at home for a few weeks.

At the same time I became more aware of my own mortality and the same old negative thoughts began to infiltrate into my brain and I questioned why I was still alive. I found out later that I was struggling with my own survival but could not express myself other than to appear down, dishevelled and speaking in a manner that was not conducive to living. It was not until early August that I was strong enough to be administered with the child hood vaccinations.

Although I had slight cough it was not enough to deter me from the injections. It was also a boost to my psyche as I knew it was a major milestone for me. This little boost in my psyche was just what the doctor ordered. It not only changed my perspective on life but also my outlook on my own morality and survivability.

I also reached out to mates via social media and especially my military mates recognised that something was wrong in the comments that I was leaving. Slowly I began to realise that there was not much I could do to change things other than to make sure that my own surroundings were secure and that it was important to be selfish just this once and think about myself. I have never in my life thought about being selfish, but this time I knew I had to do something out of character and rewire my thought patterns if I was to come out of this in one piece.

I began to look outside and walk around the garden, feeling the rain and wind against my face and saying what a wonderful world it is in being able to feel the elements. From that moment on I realised that all will be ok, if I just keep having those positive thoughts and not dwelling on the negative forces that wanted to weaken me unintentionally. I thought of different ways of approaching matters, not to overdo it and to take life not as serious as I once did. After all, I could cross the road and be hit by a vehicle and where would all that worrying got me. Nowhere that's for sure. I realise that it may sound silly about rewiring the brain, but that is exactly what I felt needed to be done in order to get out of the rut that I was in.

Now at the time of writing Sunday 21 August 2016, being the anniversary of being diagnosed with cancer, I must say that I am looking forward to each day with a new lease of life, ready to take on any challenge that comes my way. Obviously I can pick and choose and will only take on what is in my best interests. I began to take a more serious look at the garden and what could I do to make it even better. My responsibilities as President of the Victorian Lakonians continued to have a positive effect on my wellbeing and I must say that I have a very talented team on the Committee of Management. We also celebrated my name day upon which my parents, bless their souls, favourite auntie, cousin, brothers and sister with wives and husband as well as one of my sons, his partner and my granddaughter attending.

These and other positive occurrences helped me to stabilise and provide me with a balanced outlook on what to expect from life. I know that it will not always be that way, but I was now looking forward to new goals and horizons and no matter how far they may appear to the average person, I was not going to be deterred from achieving my new goals and objectives. I have returned to writing articles and resuming my pet projects about writing about my military mates, relatives and growing up in Australia. Life is for living no matter the challenges we face and/or how much time there is left, as the alternative is not a desirable outcome when you are in the land of shadows.

My advice to those who are about to take the same journey is to keep life simple, do what is achievable, never give up or lose hope, listen to your specialists and if your heart of hearts tells you that you are not happy. Seek a second opinion. There are many methodologies and management systems in place to make life bearable. Just don't let the cancer eat within. Just fight the bastard.

In conclusion, If, I was to be asked to name three things that helped me through this terrible ordeal, I would answer simply by saying, firstly, my faith in God, secondly, my wife, family and friends (all as one) and thirdly having a positive outlook. I cannot explain why the last one is so important other than to say that dwelling on the negative does nothing to heal the body. I thank God, My wife, Doctors, hospital staff, specialists, children, parents, family, friends and relatives throughout the world who had a hand in my healing. I cannot thank you all enough. Thank you.

As always, my apologies for the poor grammar, punctuation and savagery of the Aussie English language. All that I can say is that it is great to be alive and one does not give up in the face of adversity. Remember that life is still worth living despite the many challenges of life we face each day and my Aussie flag can still be seen from my window flying proudly in the wind.



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