

My Journey Part 3 – Bulletin No 3 (8 February 2021)

It is one month since my last bulletin and in opening I would like to speak on family support which is essential with my ongoing battles. It has been 11 months since I have seen my son Darren who lives in the northern beaches in Sydney and he was finally able to make the journey to catch up with me on the weekend. What a wonderful reunion we had and it was lovely that we were able to catch up once again. I have two beautiful daughters Denise and Sue who live on the Gold Coast and they have been wonderful support for me as they worry about my every need and continually enquire what they can do for me. Thanks girls knowing you are there for me gives me so much comfort.

My eating habits have changed in recent weeks and I am having trouble in swallowing my normal meals, having to resort to soft mashed food, gravies, desserts, etc. My lovely partner Carole has been busy catering for my every need ensuring that my diet meets my current food requirements, no easy feat which can be very frustrating at times.

I last had a swallow test in December 2019 and I recently underwent another test to determine how much my swallowing ability has changed. I should receive these results shortly.

Misadventures

Following my many treatment programs my neck mobility has decreased considerably with the weakening of my neck and shoulder muscles. Following a recent visit to the GCUH physiotherapist I was given a range of exercises with a rubber strap to assist this mobility. Exercises with my left arm proved to be difficult and I pushed myself too far and consequently ended up with tendinitis in my left elbow which severely hampered movement in my left hand. This painful condition lasted for several days as they say no pain no gain. I have reduced my exercise campaign to ensure no further damage to my fragile body.

On Friday 22 January my worst health experience ever took over my body, hiccups. I continually hiccuped every 5 seconds for 6 days, calculating I had over 90,000 hiccups. This can be a common problem for neck cancer patients as the throat muscles change and the glottis does not function properly. Luckily I was able to get some relief at night by different water swallowing techniques getting 4 hours sleep a night compared to my normal 8 to 10 hours sleep. My two chemo oncologist finally recommended I try Largactil Syrup which was a cure for unstoppable hiccups. On the 7th day the hiccups disappeared, but the side effect of the drug during my treatment was frightening. Dizziness, loss of energy, muscle and balance control needing help to get up from chairs and walking around as I fell numerous times. The drug was once used for psychiatric patients, but the side effects were so dramatic that it no longer used for that purpose, but it certainly cured my hiccups. We went to the movies during the hiccups, it was too much for the patrons as they kept looking at us and we decided it is time to go home part way through the movie.

Good News Story

During 2020 I was in contact with John from Coffs Harbour who stayed on the Gold Coast for 8 weeks whilst he underwent the head and neck cancer treatment program at GCUH. I recently received an email from John who wanted to know more about the cancer trial I was on at PAH as his cancer had returned. John is on my mailing list. Within an hour he was in contact with the PAH cancer trial contact and subsequently included in my trial which I was not aware of. On 25 January during my last immunotherapy visit I got to talking to other patients and low and behold John was there, travelling up from Coffs Harbour for his first treatment. Small world. I am patient no. 6 and he is patient no. 11 of the 12 patient trial group,

The Waiting Game

During the past month I have had one infusion of immunotherapy and on the 8 February I had a PET scan to ascertain any changes to my neck tumour as a result of undergoing my current cancer trial treatment program. What will the answer be who knows? All will be revealed on Monday 22 February. People read books or go to the movies for their fix of suspense, but I can assure you as this is my 3rd suspenseful wait to find out the outcome of this and my previous two treatments nothing beats the real thing as far as suspense is concerned.

Always Look on the Bright Side of Life

Neil Raward