

My Journey Part 3 – Bulletin No 5 (16 April 2021)

Hi folks after six weeks it is time for another update. For the first four weeks things were bouncing along fine, not a care in the world, life was great, although I was noticing difficulty in swallow food and that Carole was having trouble providing food that I could easily swallow I was also coughing more often as I ate. We were both a bit worried what to do next as I was using thickened water to assist with the swallowing process to little avail. I was also feeling a lack of energy and motivation which had taken over my life.

During this time I visited an ENT specialist and tests showed that my left hand vocal cord was not vibrating caused by my exposure to radiotherapy. At the follow up visit he injected some filler in to this vocal cord to see if this could generate more vibration. After this procedure my voice improved slightly. I have a whole range of exercises from my speech pathologist to also assist with my voice production.

Past Two Weeks

On Thursday 1 April my daughter accompanied to the hospital to visit my speech pathologist for a normal visit and during the consultation she noticed that I was not looking that great and that I should go to A & E to check up. After tests and xrays I was diagnosed with aspiration pneumonia caused by particle of food entering my lung. It was suggested that I should enter hospital for treatment, but after being prescribed antibiotics I was allowed to go home, under the proviso that if my condition worsen I return to the hospital. On Saturday night (3 April) nothing had changed and the ambulance was called and I was immediately transported to the hospital.

A & E Experience

On entering hospital I was in a very serious condition my B P was 77/45 and for six hours two of the most wonderful nurses worked continuously to improve my condition. Ventilators where even spoke of, following antibiotics and many other medical procedures my condition improved. After this I was admitted to the intensive care ward for 24 hours to monitor my condition. With the return to almost normal B P and other medical markers I was transferred to a general ward where I remained for 7 days

Hospitalisation

I was introduced to puree food to assist with my intake of food without much success. Further swallow tests showed that my swallowing had once again deteriorated. I was faced with a dilemma as to what should I do continue eating puree food with risk of aspiration pneumonia returning or being fed via a tube. After speaking with family the decision was made to commence tube feeding. A nose tube was inserted and I commence being fed Resource 2 nutrient. I was released from hospital on Friday 9 April and I await a PEG (feeding tube being fitted into my stomach) on Tuesday 20 April.

Tube Feeding

I used a PEG for 4 months during my first radiation treatment in 2016. 6 x 200mls of Resource 2 with 2 litres of hydration each day. I have not had a chance to speak with my dietitian yet, however there is a likely hood that this will continue for the rest of my life, Gone are the pleasures of food and drink.

What does the Future Hold

Who knows? At least the swallowing and pneumonia problems have been resolved, however at great personal cost. With hard work hopefully my speech will improve. I have a visit to the PAH on Monday 19 April for my next session of immunotherapy, hopefully this will be the silver bullet which will make all my current issues worth the sacrifice.

Always Look on the Bright Side of Life

Neil Raward