

Shirley's Proton Experience

One Sunday afternoon, at the beginning of 2010, I found myself unusually short of breath when I walked up the hill near our home. It was so unexpected that I took myself to the GP, and she agreed with my self-diagnosis of asthma. However, an asthma puffer and a course of antibiotics did little to improve the situation. In fact, I seemed to be getting worse, so a CT scan was arranged in March.

The cause of my breathing difficulties was then revealed. A large mass was shown in the lower part of my trachea and the posterior mediastinum which was pressing on my oesophagus and windpipe. The thoracic consultant at Sydney's North Shore Hospital arranged a biopsy which was analysed and found to be adenoid cystic carcinoma (ACC). As a result of the inflammation from the biopsy I was physically aware of the mass for the first time, in the area when I fastened my bra but deeper in my body on the other side of my spine.

ACCs are very rare malignant salivary gland tumours which have periods of growth and period of dormancy; it could have been there for up to 10 years! They are found predominantly in the primary throat salivary glands, but mine was from a minor salivary gland which we have in other parts of the body, including at the base of the trachea. The odds of developing an ACC like mine were one in a few million, having grown both inside and outside the back wall of my trachea. The inside of the trachea is fairly wide but mine had got to the point where only 25% was open causing my breathing problems upon exertion.

I was of course shocked by the news, especially because I knew that a rare tumour would mean that treatment options were likely to be less prevalent and researched than other types of cancer. I was told that ACC's rarely metastasised (spread) to other areas of my body and fortunately this proved to be the case. Given this positive news, and the fact that I had a slow growing tumour, the consultants at the North Shore hospital took a few weeks to research treatment options for me. In the meantime I took care not to exert myself too much and I was able to attend my daughter's wedding on the 1st May.

On returning to the hospital the consultants explained that although the trachea was mainly cartilage, its back wall contained many nerves. To remove my tumour would mean knitting together the nerve fibres, an operation so complex that the expertise to perform it did not exist in Australia. Accordingly they had been consulting with a Dr Joel Cooper at the Penn University Hospital in Philadelphia who could do the operation. My other options were to have a windpipe stent put in, not often successful though as the body would attempt to cough it up, and an extensive course of radiotherapy but this might not be enough to destroy the tumour. I was completely taken aback.

The consultants at the hospital then put in an application on my behalf for Federal Government health funding under the Medical Treatment Overseas Program (MTO) and Dr. Cooper in Philadelphia was contacted for a cost estimate. A few weeks later we received the wonderful news that, as I met the criteria, I qualified for funding and that Dr Cooper could see me after the 4th July US holidays. It was a weight off my mind especially as Dr Joel Cooper is one of the best surgeons in the world, being the first to achieve a successful long term lung transplant.

We arrived in Philadelphia, and I felt quite anxious about meeting such a revered surgeon but Dr. Cooper was very friendly - I felt in safe hands. Over the next few days I had many tests including breathing, MRI and a bronchoscopy and oesophagus examination, with the intention of having surgery as soon as possible. However, the news was not good. Dr Cooper discovered that because of the location of my tumour my healthy right lung would have to be sacrificed and there was a 20-25% chance that I wouldn't survive the operation recovery period. He assembled further consultants, and they agreed that my best course of treatment would be oncology, supervised by a Dr Rengan at the Roberts Centre in Philadelphia. I met with Dr. Rengan and he suggested I have radiotherapy. However returning to Australia for radiotherapy was ruled out - the recent bronchoscopy had caused more inflammation (it was now like I was breathing through a straw) and the decompression of a plane journey would put me in danger. Also I was told by MTOP that as my treatment was to change I would need to put in another application to the Australian government.

The next day though Dr. Rengan contacted me - he had obtained approval for me to commence with conventional X-ray radiotherapy and have proton therapy for the second half of my treatment as the core of my tumour was in front of my spine and X-rays may damage this. I would be the first person to be treated in this way for an ACC tumour of the trachea. He then contacted MTOP for me and 24 hours later we received approval for the change of treatment plan.

My eight weeks of treatment began straight away. For the radiotherapy set up I had to lie on my back and put my arms above my head whilst a mould for the top part of my body was made using egg box type material. The mould would then be attached to the treatment table. I also had to have black tattoo dots on my chest and towards the sides under my arms. This was my first experience of what was to be many occasions, of having to lie completely still!

During the X-ray radiotherapy the machinery made a low volume noise at times, moved around and then stopped. Green beams of light traced across the ceiling, went off and came on again - I got to know this sequence very well in the coming weeks. I had good days and bad days; some days I felt like I could have lain still for longer than I had to and other days it was excruciating that I couldn't move at all. The best part though was when I heard the metallic clunk of the large door which meant that the technicians were coming in and it was all over for another day.

I was having CT scans now about once a week which were to check how the treatment was going and prepare for the next stage, the proton therapy. My chest and back just looked very red, not itchy or sore. Two weeks into the treatment I noticed my breathing was beginning to improve, it was fantastic.

The proton therapy section of the Roberts Centre is very futuristic looking. Apparently some patients had described the treatment room as something like the Starship Enterprise and I was inclined to agree with them. The very large room had a treatment table positioned in the centre and above it a semi circular gantry which at its highest point was about 5 metres from the ground. I lay in my mould as before on a table that could be adjusted to so many positions. I had to lie still and be moved; to the left at the shoulders area, to the right across the chest and left around the hips it seemed, not the position you would choose to lie in if given a choice! The table was then raised so that I was about 1.8 metres off the ground.

Unlike the X-ray radiotherapy which had more of a sequence to it; I could follow green beams of light across the ceiling for example, it was not the same for proton treatment. My treatment

consisted of four stages, two involved lights coming on from the semi circular gantry high up above, one directly over my head and the other, after the gantry slowly moved around, to my side. The other two treatments consisted of what looked like two square glass house bricks with a white pleated type arrangement in the centre - something like a chef's hat! This arrangement was mounted on the same semi circular gantry but came in on each side much closer to my chest. I needed to get some sort of fix on the time each of these four treatments would take as there were no beams moving across as in X-ray therapy. I asked them to play a Beatles CD, either Abbey Road or Let It Be and I worked it out that it would take approximately three tracks for each treatment. As these albums are so well known I could also sing along (in my head as nobody would want to hear me!) to these Beatles songs. This also helped the time go quicker. On one treatment occasion I came over very hot. I started to panic wondering what was happening and then I realised it was a menopausal hot flush! At the end of each session the technicians would come in and say, you can put your arms down now – but don't get down – yet!

I was sleeping a lot but at last I felt like I was on the mend. This treatment to destroy the cancer cells so that normal cells could grow in their place was certainly working - I could now walk and talk at the same time (up until then I could do one of the other) something which we all take for granted. During the last two weeks of my treatment I knew they were getting to the core of my tumour so it was crucial that I was manoeuvred into the correct position and didn't move. It was great though when the last day of my treatment arrived, it was the middle of September - I didn't want to go home until I was well and now I really wanted to go home. The flight back was so much easier for me than the flight there. We stayed in LA for a couple of days this time– I walked along the pathway of Long Beach for an hour without getting breathless, such a wonderful feeling.

A few weeks after arriving back in Sydney I went to the North Shore hospital and had some breathing tests which were all within normal limits – how good was that. I also researched proton therapy in Australia and found out there were plans to build a centre in Sydney. I contacted Proton Therapy Australia and spoke to Sue Bleasel their CEO who is so enthusiastic and is working really hard to bring a proton facility to Australia. I am looking forward to being able to help with this venture.

At the beginning of December it was my 57th birthday. It felt more significant than many previous ones – I made it. After Christmas I had a scan, went to the North Shore hospital for the results and sent the CD of the scan to the US. It said that my tumour had shrunk significantly. It was marvellous that I was able to have the proton therapy which had spared any damage to my spine.

In October 2011 I had a follow-up CT scan. I went to see my doctor for the results – everything was clear, they could not see or measure anything of the tumour at all. It was fantastic news and such a relief. I emailed Dr. Rengan in Philadelphia to tell him. He told me that the study report they had prepared on my treatment had been accepted by the Journal CHEST and was currently being proof read and when available they would send me a copy.

So here I am two years on, fitter than I have been for a long time. 2010 was certainly an extraordinary one for me. I was touched by the support that so many people gave me in Philadelphia and Australia. Often over that time people would give me a hug and then pat me on the back. I never said anything but this area of my back was just about where my tumour was - but luckily on the other side of my spine!