

Prolactinoma – My story 10 years on – Daryl



My name is Daryl Lawrence and I am 45 years of age, married to Ann and have four wonderful children.

It was April 1998, at the age of 34 that I decided to visit my family GP after beginning to feel run down and had a consistent, but intermittent, pain above my right eye. I had rarely visited the Doctor except taking my children for the normal routine visits. After being sent to have a CAT scan to see if a sinus was blocked, I received the news from my GP that the sinus was OK, but I had a macro pituitary tumour that needed urgent attention. My life was about to change forever!

I immediately had blood tests and an MRI to confirm the findings, my life was in overdrive but I somehow felt on top of things. I wanted to share the situation with friends and family and always had a sense of being positive. I think with a young family and loving wife it was easy to be strong and positive for myself but more importantly for them.

The blood tests confirmed that I in fact had a prolactin secreting tumour, and my blood count showed a reading of 40000 mIU/L. This stunned my GP, as in his words, this reading is huge. My other hormones were extremely low and there were concerns for my general wellbeing. The MRI scan confirmed the tumour and it was classified macro and measured 2.5cm X 2.8cm.

I was sent to St. Vincents Private Hospital and was under the care of a Neurosurgeon and Endocrinologist. The tumour was unfortunately wrapped around the carotid artery and was also touching the optic nerve. My sight was still OK and after lengthy discussion it was decided that due to the size of the tumour and the quantity of prolactin secretion, that I should be treated by drug therapy first. I started on Bromocriptine and after 2 months of limited success, I was switched to Cabergoline. My prolactin had decreased to 6000 but there was no change in the size of the tumour. Headaches persisted and there were also the difficult side effects of the Cabergoline, these included nausea, dizziness, lethargy and low blood pressure.

Six months after the initial diagnosis I was sent back to St. Vincents for neurosurgery, I was glad in a way because I was prepared for anything that would remove the tumour and I could get back to life as normal. Ha! What foolish thoughts.

The surgeon explained the Transphenoidal procedure and the dangers and concerns involved with the surgery. The surgery went for 5 hours and I waited for the news after my recovery in intensive care. This was the most difficult time I have faced as the Neurosurgeon informed us that they could only remove approx. half of the tumour due to its position, wrapped around the Carotid Artery. I was still left with a residual tumour measuring 1.5cm X 1.5cm. No one said that this MIGHT happen!

After a short period of being cranky and annoyed I got on with it and was ready to face the next challenge. The surgery had removed a large portion of the Pituitary gland and I was now faced with hormone replacement and a return to the drug therapy. My prolactin count was still around 4000 mIU/L and so I started on Cabergoline again. After a session at the Garvan Institute I discovered that I needed testosterone, thyroid and adrenal gland replacements, and had to face the continual drama of getting the levels to an acceptable standard. Another new world was evolving.

Our lives continued on and we went through many slight changes in hormone replacements, and gradually increased my Cabergoline intake up to 3 mg per week. I couldn't handle any higher dose and managed to work and push on. I would live my life outside of HOME as though nothing was wrong, but it was at home that I became moody, irritable, and just not nice. The impact on your family is enormous and they have to manage so much and put up with so much. It took a couple of years to finally realize how I was treating the ones I really love, and to re-evaluate my management of my condition.

It was 2004 and with my prolactin readings still around the 4000 and my general health declining, I was recommended to an Oncologist for possible Radiotherapy. It was decided that this was now an option with advancements in new technology, they could minimise the risk due to the location next to the carotid artery. 32 sessions of radiotherapy were conducted and after some interesting hair loss to various parts of my head, I was feeling ready to take on the world. This goal came crashing down when I foolishly tried to push immediately back into a high stress job. I began to suffer from dizzy spells, nausea and a general lethargy. I realised that I needed to show my illness and body more respect and therefore quit my job to take 9 months to recuperate. It was the first time I had actually slowed down and gave my body a chance to recover.

I returned to a less stressful job in 2005 and continued with the Cabergoline therapy. The prolactin levels were slightly improving and have continued to decline ever so slowly up to this day. Currently the readings hover around the 750 mark which is a long way from 40000 mIU/L. My endocrinologist continues to monitor my prolactin and hormone levels and I HOPE that I can soon reduce my Cabergoline intake.

My GP [who was absolutely fantastic] moved and I have had to endure 2 others since then. This is one of the most difficult situations to deal with, trying to find someone who can relate to this condition and who WANTS to know. I have luckily found another understanding and interested GP. What a difference this makes!

The biggest issues continue to be the balancing of replacement hormones and coping with the effects of Cabergoline. Days, weeks and months can come and go without a worry. But then you can be hit by a wave of unwellness. It can be so difficult to try and explain how you feel, or what is wrong to those who care. You just have to keep persevering and include those close to you.

It has been a long journey but it has definitely made me a better person. It is so easy to take life for granted but now every day is as positive as possible. By focusing on positive thoughts, surrounding myself with positive people, I have it found it makes it so much easier to live a happy and 'healthy' life.

I am glad to share my experiences and would be willing to discuss any aspects of my journey. Thanks again to the Doctors and Medical staff that are continually helping all those affected by pituitary gland conditions.

Keep Smiling - Daryl

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