

## Prolactinoma – Macroadenoma by Rod



My name is Rod and after listening to an ABC radio broadcast about a woman who had a pituitary disorder, I visited the internet site they provided the address for, that of the Australian Pituitary Foundation (APF). Upon visiting the site, I noticed that the APF had a section for people to tell their stories about their own experiences, a section I found very interesting and moving given my condition. I noticed that there was only one story, from a woman, who suffered from the same condition that I had, despite it being the most common of all pituitary tumours, a prolactinoma. After reading Lindy's story and others from people with different disorders, I felt compelled to tell my story. This was especially so as I am a man and I thought it might be beneficial to help balance the ledger and to let other people know what men can expect from a prolactinoma.

### My Story

I was staying with my parents at the time and I had just packed my bags ready for a two hour drive back home to keep an appointment I had made to see my regular GP. Before I left, I sneezed and ended up with a whopping headache and did not feel as though I could make the drive back home. So I made an appointment to see a doctor at my parent's medical centre, a young female doctor. Later that day after consultation with the doctor on 10 October 2001, at the age of 45, I presented myself for a cat-scan (CT) after a ten day history of severe left sided headaches, made worse after coughing, sneezing, and bending down.

Needless to say, after getting the results from my CT scan my GP organised a number of blood tests then she rang an Endocrinologist and organised an urgent appointment for me a few days later, by which time the blood results would be available. This young female doctor had immediately made the correct diagnosis. My regular older male GP did not consider it despite numerous frequent visits. In fairness to him though, he was not presented with my ten day history prior to diagnosis.

The cat-scan revealed a macroadenoma of the pituitary gland (prolactinoma). In hindsight, I had other symptoms that appear to be of a direct consequence of my condition. Occasionally I found it impossible to hold a pen in my right hand to write, so I would use my left hand, if urgent, or wait until the condition passed, usually a few minutes. My cheeks and face were chubby, probably for only a few months prior to diagnosis. On some occasions I felt as though I was going to faint and probably did, actually, for a microsecond, resulting in me stumbling sometimes. I felt weaker than normal and found doors at work with self closers on them offering a lot more resistance than usual. I also noticed that I would cry easily if upset by something. Some people might say that I am not the quickest thinker around, but with the tumour at its peak, my thought processes were much slower than normal and perhaps flawed. Finally, my ejaculate contained a significant amount of blood, but my penis maintained its ability to become fully erect, the morning glory had not gone away.

Without trying to bore you too much with facts and figures, but to put things into perspective, prolactin levels in normal men and women should be below 380 nanograms per decilitre, in a pregnant or lactating woman the level could be anywhere between 900-1,500. My GP said she would have her alarm bells ringing in excess of 2,000 for a pregnant or lactating woman, and at diagnosis my level was 86,000!

The endocrinologist was not happy with the CT scan, so he ordered an MRI scan because he needed to know just how big the tumour was and whether it was impacting on my optic nerves. Fortunately for me, the tumour grew in every direction except towards the optic nerves, so they were left unaffected, possibly resulting in the late diagnosis. The tumour itself was about 3cm in diameter and was just starting to enter the nasal or sinus cavity. He told me that there were two viable treatments I could take; one was surgery that could have dire consequences, or medication that was non invasive but safe, although it was relatively new at that time, cabergoline (Dostinex). Naturally, I chose the medication.

Other blood results had my thyroid on upper borderline levels which the specialist said would not recover if allowed to go any higher. Also my testosterone level was only 2.6 nanomoles per litre with normal being 10-35. The specialist was adamant that my testicles would be irreversibly damaged by this very low level of testosterone, so testosterone replacement treatment would be required. I suggested to him that given that my testosterone level should increase while my prolactin level decreases, I'll wait and see what level my testosterone plateaus at before taking testosterone because that might affect the dosage that I need to be taking. About two years later my testosterone had plateaued at about 13.5 much to the endocrinologist's delight and surprise, as well as mine. As my testosterone level increased I felt a bit like I was going through puberty for a second time. Had I not made that decision to hold off on the testosterone treatment, I would probably be taking testosterone today, at some financial expense to me and the Australian Government, and living with any side effects from it. So figuratively speaking, my balls bounced!

The specialist decided to try me on Thyroxine medication given that my thyroid was on the upper limit of normal. He said it may not be necessary to take it, but it might be worth trying for a year. I have now been taking Thyroxine for several years, and instead of my thyroid level being at the top end of normal, it has settled on the bottom end of normal. He said it probably doesn't matter if I do, or do not, take Thyroxine, as I will be on one end of the limit or the other. He also said that my thyroid condition may, or may not, be due to the prolactinoma.

Since 2001, I have been seeing my specialist on an annual basis and having the blood test done every time before seeing him. I have had several MRI scans during this time with the last one being in 2007 when the pituitary was fairly normal, for me at least. Initially I was taking Dostinex twice weekly. At this dosage my prolactin level dropped from 86,000 to just 140 odd. In 2005 or 2006 my endocrinologist, decided to drop my medication back to once a week. During the next two years my prolactin level steadily started climbing again and in 2008, my prolactin level was 573. We decided it would be best to go back to taking Dostinex twice a week, otherwise my prolactin level will just continue to steadily increase and so too might the size of the tumour.

This is a fairly clinical account of my prolactinoma, but it is an accurate representation of my symptoms and treatment. One thing I can take from this is that if I had not been patient and accepted the testosterone treatment, I would be paying even more for my medication over the year, thereby leaving me with less disposable income for other things. As it is, I have been hitting the Pharmaceutical Benefit Scheme (PBS) safety net for about the last 6 or 7 years due to other medications I am taking for other unrelated conditions as well. Also natural is best anyway, if it works. I understand that testosterone injections lead to toughened skin in the injection area, and other forms of applications have their problems.

Don't be frightened to speak to your doctor if you are worried about something. Also, listen to family and friends if they are saying that something doesn't seem right, especially if they don't see you on a daily basis, as they are more likely to notice any gradual changes in you. It's a bit like seeing children you haven't seen for a while and they have noticeably grown.

Other points of note I have observed over the years and seeing various different GPs is that it does not seem to be common knowledge that Dostinex can be used for treating this condition. Another female GP I saw briefly said to me that she had no idea that Dostinex could be used for this purpose. She also asked me if I knew what Dostinex is usually prescribed for. I said normally for drying up a woman's breast milk if there is a need to stop the supply. She said yes and that one tablet alone is normally enough to do that and a second one is given to make certain a few days later. She then asked if I had been expressing milk. I said no, but if left untreated I would probably have started expressing milk and growing breasts. This said, it is worth noting that oxytocin is required to express milk, but prolactin is required to make milk. I can only conclude that my oxytocin level was normal.

I hope my account is of interest to men and women wishing to understand the symptoms and consequences of a very large prolactinoma in a man. Hopefully it will help fellow sufferers and interested people in recognising and dealing with this condition which, I have found, is easily managed just by taking one tablet twice a week.

Rod

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