Off To the Doctor

In 1999 my wife and I built a new home. During the construction, I began to develop severe carpal tunnel syndrome, even more so than I usually suffered from. It became so severe that I was only getting approximately 2.5 hours sleep per night and I was beginning to show signs of complete exhaustion.

I decided that it was time to visit my GP, which I was never very fond of doing.

So off I went to my GP. He indicated that, yes, I indeed had carpal tunnel syndrome and the only way to remedy it was to have a carpal tunnel release. That was something I had envisioned and was in favour of.

Off to another doctor for a nerve conduction study that confirmed what we already knew. My GP then sent me to a neurosurgeon, who is one of the two types of doctors that do carpal tunnel releases [the other being a plastic surgeon] Upon meeting with the neurosurgeon, he immediately suspected that I had something called acromegaly and he ordered an MRI and blood work. We went down to the MRI clinic at the hospital and the neurosurgeon asked me to come back to his office when I was finished. When I got back upstairs, he accessed my MRI on his computer screen and there it was – a tumour on my pituitary gland that measured 65mm by 50mm. This thing was so large that it had surrounded both carotid arteries and was putting pressure on the optic nerve.

The next appointment was to see the endocrinologist who immediately put me on a variety of medications in order to control the growth hormone levels which were extremely high.

I was also scheduled to see the neurosurgeon again to have the carpal tunnel release done. This was very successful and relieved the pain immediately.

One of the medications that I was put on was “Sandostatin” which hopefully would lower the IGF-1 levels and the tumour would start to shrink, so that I could have the transphenoidal surgery to remove all or at least most of the tumour. The drugs did not perform as expected and in fact did nothing at all. The only thing these drugs accomplished, was to wipe out my bank account over an 18 month period to the point where we were about to lose our newly constructed home.

Enough was enough, and I approached the neurosurgeon to have the operation. The operation was successful and approximately 80% of the tumour was removed. As a result of a post-op MRI three months later, it was discovered that the tumour had re-grown and was approaching the dimensions it was prior to the operation and was still producing excessive amounts of growth hormone. At this time, the surgeon told my wife and me that he would have to re-operate and would have to perform a craniotomy.

On August 13, 2001 I had this surgery and then had radiation every day at 8 am, except weekends up until November, 2001. The operation was a success and due to the surgery and the radiation, the tumour shrank very rapidly. However, I did have to continue with the octreotide (Sandostatin® LAR®) and because of its very high cost; the drug company initiated a program to help with the uninsured portion of the cost. Still, after many months of this drug, my IGF-1 levels did not come down. Then a new drug was approved in Canada. The new drug is called pegvisomant (Somavert®) and has controlled my IGF-1 levels to the point where they are in the normal levels category. My endocrinologist must be pleased due to the fact that I only have to see him once a year now to review my blood work.

When I look at the symptoms that I had, I can recognize that I had quite a few such as enlarged hands [which caused my carpal tunnel syndrome], enlarging of my feet, night sweats and thick brow.

A little sidebar to tell you about: When a patient would have their blood work done, sometimes 4-6 weeks prior to an endocrinology appointment; then appeared for the appointment, the results would not be available. That would be the most frustrating experience because it was not only wasting my time, but the also the clinic's time. The blood tests were being sent to Toronto to be done. A letter writing campaign began to convince the Health authority to secure the proper equipment and train the staff. After only two letters, this change was made.

On another occasion, while attending the endocrinology clinic, I couldn't help but overhearing a young lady explaining to another lady in the waiting room the reason for her visit that day. When leaving the clinic this same young lady was on the same elevator as me. I indicated to her that I had overheard her conversation earlier and offered her my business card and told her that if she needed someone to speak to, that she could call me at any time. Other patients must have felt the same as I did and through the efforts of patients and the clinic nurses a support group was established that meets twice a year. Guest speakers are arranged, such as neurosurgeons, dieticians, endocrinologists, and general discussions among the group. These meetings usually last from 2-3 hours and are a great way to exchange information relating to acromegaly and the well being of all patients and their families.

Clinical Pearls

Drug therapy may include the following medications:

- octreortide (Sandostatin® LAR®) and lanreotide (Somatuline® Autogel ®) both are somatostatin anologues. These are synthetic versions of a naturally occuring hormone called somatostatin. It works directly on the tumour to block the release of growth hormone.

- Another is pegvisomant (Somavert®), which blocks the receptor for GH and this drug may treat the symptoms of acromegaly, but does not have an effect on the tumour itself.

- These drugs are given by injection. The route and frequency vary with each individual drug. Occasionally, cabergoline (dopamine agonist) can be used if the tumour is producing prolactin as well as growth hormone. This drug is given orally.