

Preface

As I sat in the Doctor's office, she explained to me that the tumour in my head needed to be removed the following week. I felt very distressed about what would happen to me. The next few weeks would certainly prove to be even more stressful and confusing than it was that day in the first Doctor's office.

I prepared and travelled to Halifax to have the tumour removed. I went through the pre-op clinic testing, which took two days. It was the night before my operation that would devastate me the most. As the surgeon sat and explained to me that the tumour was inoperable because of its location, I felt this fear come over me that I would surely die from this condition.

I spent months, which seemed like years trying to understand this condition. I felt so alone and trapped in the feelings about what was happening to me and certainly the fear of what was going to happen.

Several times in clinic, I would stress to the nurse [one of our clinic angels] that we needed some sort of support in place for people with this condition. I would find myself feeling so alone and confused about the tumour and I felt I was the only one who could understand what was happening to me. My understanding and outlook would certainly change the day I met another person with acromegaly.

As the clinic nurse, my husband, and I talked and joked about some of the side effects of this condition, I did not feel alone any more. Not that I did not have my family support around me, because I did: especially from my husband Kenny, but it was more reassuring talking to someone else with this condition. Then I would be alright. I was more determined than ever to gather some people with acromegaly together in support for each other.

It was in June of 2005 that we successfully held the first ever Acromegaly Support meeting in the conference room of the Endocrinology Clinic in Halifax, NS. We had a very successful meeting. We had twelve acromegaly patients, along with two clinic nurses and an endocrinologist. The feeling in the meeting was one of relief. To finally see other people and hear their stories of being diagnosed and the way it affects their lives. It was awesome.

We met again in the fall of 2005 and agreed to meet at least twice per year. We set up a phone list for each of us to phone when we need support. On April 20, 2006, we successfully formed The Atlantic Acromegaly Support Group. To the clinic nurses – thank you for helping me reach my goal of putting a face on acromegaly. To the patients who have been at the meetings thus far and for those who will take the time to come in the future – thank you. Thank you for helping me understand this condition and teaching me ways to cope with it. I will be eternally grateful.

1. What is Normal? Is This Normal?

I can only describe the effects of acromegaly from hindsight, for I suspect few people realize that they have acromegaly until much damage is done.

My case may be different because I contracted polio in 1937. I always had a spinal misalignment problem because of this and frequently endured back pain.

But...everyone complains of a “sore back” once in awhile. Before I was diagnosed, my pain did become more intense. Gradually I couldn’t walk, and I found it very hard to work.

I truly don’t know what started the investigation the first time. For sure, a pain in my neck- I think. My family doctor sent me for some checks. He may have suspected acromegaly but, I don’t remember him mentioning it. This doctor was also a surgeon. But he got a fast growing cancer and died within a few months. I didn’t continue the tests and follow up. I got doctor two who supposedly took over doctor one’s practice. I suspect he didn’t have all the records, or didn’t read them, if he had them.

This particular one I sought help for occurred on a weekend. My doctor two wasn’t on call, so doctor three treated me. Then doctor three conferred with doctor two stating that I showed the visible signs of acromegaly.

My next visit to doctor two was because of weakness in my left hand, with a loss of flesh between thumb and first finger, and once in awhile a sharp piercing pain on the inside of my left wrist. Now doctor two grabbed a book off the shelf, read about nerve entrapment and its possible causes.

The ball started rolling on tests again.

I had the pituitary surgery and re-location of my left ulnar nerve. Some strength was restored to my left hand. Most remarkable, there was freedom from back pain. A couple of days out of hospital I was back at work, pain free, and walking. Fantastic!

It was all in my head!

The last year or so before the pituitary investigation, my sexual desire waned to near nil. Because I was nearing 50 years of age, I thought this was normal. Who knows what is normal? Not being a person who “chats with the boys” about one’s abilities, or lack of, I didn’t have a clue.

After the surgery on the tumour, and balancing of hormones and restoring where necessary, it was marvelous to regain one’s sexuality.

I do believe now, again in hindsight, at the time my testosterone injections were too large – should have been halved and frequency doubled. I had trouble with the highs. Looking

back I should have sought some changes. But I still don't know what "normal" is, and it doesn't matter.

Most of the visual indicators for acromegaly develop over 15 years or more. Those who live with us, or work with, or are in our circle, including our primary health care providers, will not notice the subtle changes. Usually a new developing problem initiates the investigations.

Fifteen years before my investigations, I saw a doctor in Ontario about a cold I had, and he pointed it [acromegaly] out. I thought he was a quack. I had no other problems at that time.

I guess I was lucky. I had about 23 years free of tumour activity. These last few years have required an additional drug to control my growth hormone within acceptable limits. I enjoyed a reasonable quality of life.

One more thing...

Low staff turnover at your clinic [pituitary] give "us" a personal connection to "you". To "us" you're a helping hand when we're in trouble through no fault of our own. We feel we're more to you than a slab of humanity on the table and a couple of charts.

Thanks.

Clinical Pearls

- Acromegaly comes from the Greek words "akros" meaning end or extremity and "megas" meaning big.
- Acromegaly develops slowly, sometimes over many years. Common presentations of acromegaly include menstrual disturbances in women of child-bearing years. Increase in ring and shoe size, and change in appearance. Carpal tunnel syndrome and diabetes are also common in people with over production of growth hormone.
- Most cases of acromegaly take up to 10 years to diagnose.
- Family, co-workers, close friends and even primary caregivers often miss the subtle beginning changes in the appearance of someone with acromegaly.