



Acromegaly – My experience – Pat

Symptoms

I suffered from the vast majority of symptoms associated with acromegaly; enlarged hands and feet, skin tags, tingling in the hands, weight gain and the onset of impaired vision amongst others. The worst symptoms were joint pain and acute sinusitis, which led me to see my GP in the mid 1980's. I saw the same GP for seven years but acromegaly was never considered as the underlying cause – my endocrinologist said that this is a common occurrence. Acromegaly is caused by excess Growth Hormone production by the Pituitary Gland.

The disorder has also caused my jaw to become more prominent and my lips to swell. During the last few years at work, my colleagues commented that I never smiled. At the time I couldn't understand why, but after I was diagnosed it was clear why this was the case – I have lost my smile. I also lost my ability to sing, which over time is slowly returning, albeit with a lower tone.

Diagnosis

I was diagnosed with Acromegaly by chance. My late husband was referred to an endocrinologist due to low blood sugar attacks and during that visit the endocrinologist happened to notice my large hands. He asked me whether I had increased my ring, hat and shoe size over the last few years, which I had, so he recommended I go to my GP and ask for a referral to an endocrinologist. I was diagnosed in 1998 and the endocrinologist estimated that the pituitary gland tumour, which was causing the acromegaly, had been growing maybe 12 – 15 years. The tumour was also pressing on the optic nerve, which could have caused blindness if the tumour was not removed, so my endocrinologist recommended immediate surgery.

Before I was diagnosed I had never heard of acromegaly. The diagnosis was a shock but also a relief as it explained the problems I had been having. The endocrinologist told me that "the disorder can take 10 years off your life".

Treatment

Surgery improved my vision and a number of other symptoms – particularly the tingling in the hands. Unfortunately due to the delay in diagnosis my arthritis and sinus problems have not improved. Following surgery, I was prescribed medication to help bring down my GH levels further. I receive monthly injections of Somatuline Autogel which is administered by a nurse at my GP's surgery.

Impact

The biggest impact that acromegaly has had on me is the effect on my weight. I used to be small framed and I am now large framed. The disorder makes it extremely difficult to lose and maintain weight loss as it affects metabolism, and this can be very depressing. The pain from arthritis is the other main effect that acromegaly has had on me. A year after being diagnosed with acromegaly I started treatment for hypertension – a condition that often comes about if acromegaly is not diagnosed and managed early. I have also recently been diagnosed as diabetic. I do not have to take medication but I have to do self blood sugar tests four times a week.

None of my family noticed that I was changing, except for my sister-in-law who noticed when we met again after a few years apart. However we only spoke about this after my diagnosis. It is now very clear when I look back at photos that my facial features have changed dramatically.

Philosophy

My philosophy is that it could be worse – you can always find people worse off than yourself.