

# Acromegaly

## An overview for physiotherapists

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Acromegaly is a disorder that occurs when your body makes too much growth hormone (GH). In adults, too much of this hormone causes bones, cartilage, body organs, and other tissues to increase in size. Acromegaly New Zealand National Committee Member Wayne Holtham shares a general overview of the disorder for physiotherapists.

So why an article to physiotherapists about an endocrine-based illness? The simplest answer I can give is that acromegaly can manifest itself in physical ways that a physiotherapist can identify, as for example treatment for stiff joints and muscles, and various aches and pains (collectively). The back-story to this is that treatment by a physio may well occur prior to any medical diagnosis, as treatment can be sought for the symptoms of acromegaly without there being a suspicion of a wider underlying illness.

Acromegaly literally means 'great or large extremities' and results from a pituitary gland tumour that secretes too much growth hormone (GH). However, not all those with acromegaly present as such. It is the collection of physical symptoms that a sharp-eyed professional can spot that can lead to correct diagnosis and treatment.

The most common misconceptions about acromegaly are the stereotypical extreme physical feature changes and height as a result of delayed diagnosis or non-treatment. To be fair these are at the worst-case-scenario and at the worst end of the spectrum.

In the majority of cases, by the time of diagnosis, the tumour would have been active for five to 10+ years, with gradual physical and hormonal changes over that time. Acromegaly usually develops in adults between the ages of 30-50, but symptoms can appear at any age. The illness is traditionally considered a rare disease



with a prevalence of 40-60 per million population, however more recent estimates bring it closer to 100-150 patients per million. This increase is probably due to an increased awareness of the condition, directly resulting in earlier diagnosis and higher diagnosis rates. The ratio of male to female sufferers is approximately 50/50, with about 700 New Zealanders having the illness at any one time (be it diagnosed or undiagnosed).

### Symptoms of acromegaly These may include:

- Facial changes: enlarged jaw and brow, increased spacing and misalignment of teeth, enlarged ears and nose.
- Other physical changes: enlarged hands and feet with tight finger rings and increased shoe size, thickened skin, skin tags and keloid scarring, excessive sweating, deeper voice, soft tissue swelling often described as 'puffiness'.
- Other changes: snoring, sleep apnoea, diabetes, difficult to control hypertension, headaches, painful joints, enlarged organs such as cardiomegaly, colonic polyps, weight gain and inability to control weight, peripheral vision loss, carpal tunnel syndrome, period changes in females, and general fatigue.

If left undetected and untreated it will lead to reduced quality of life, increased morbidity and mortality.

Acromegaly in childhood or adolescence will may lead to rapid height gain and is generally called Gigantism.

As you can see the symptoms are wide and varied, and many are very non-specific. Therefore, it is often very difficult to diagnose from looking at individual symptoms, but when one places two symptoms together one could suspect acromegaly, place multiple symptoms together and acromegaly is highly likely. A simple blood test specifically for IGF-1 (Insulin-like Growth Factor 1) can be done to confirm or rule out acromegaly. This can be ordered by most GP's and specialists in the country.

The physical changes of acromegaly occurs slowly over the years. With advances in modern medicine, we almost never see the severe end of the disease anymore. By the severe stage, the disease is difficult to treat, and many changes become irreversible.

### Diagnosis and Treatment

One of the main goals for us as a support organisation is for continuing earlier diagnosis than is currently experienced. Presently it may take some years before finally being diagnosed. Also, the 'she'll be right' attitude of many New Zealanders where it comes to health can also stretch out diagnosis timing.

With regard treatment, transsphenoidal surgery through the nose is the usual first line treatment, with immediate relief from many of the symptoms described above. In some cases, especially if diagnosed early and the pituitary tumour is still small, surgery results in a cure with no further treatment. However, the majority of patients will require other treatments, which include medical therapies and/or radiotherapy. Some sufferers have serious ongoing medical issues which limits their lifestyle, whilst others live somewhat normally. The larger the pituitary tumour, the less likely is successful treatment and full disease remission.

It is important to restate that not all patients with acromegaly have all the symptoms; for example, I myself did not have any foot growth, but presented with about

20 of the other symptoms described above. I could exercise 'normally' including longer-distance events, whilst others cannot walk down the street without feeling majorly fatigued.

### What can a physio do?

So, back to physiotherapists specifically. Our society's aim in producing this article is simply to increase the awareness of acromegaly as a disease that can be identified by physios. An understanding of the illness can give rise to initiate the 'courageous conversation'. By probing the patient as to any other medical issues (see above for symptoms that may be seen as being outside the scope of a physio), a picture can evolve, with a recommendation to the patient of following up with medical professionals for ongoing evaluation and testing.

At Acromegaly New Zealand we refer to our dealings with acromegaly as a 'journey' and we thank New Zealand physios for the help they give in helping diagnosed patients with that journey. In recent times, we have placed literature in hospitals and with GPs, dentists, nurses and podiatrists to boost the awareness of acromegaly and its diagnosis. Acromegaly New Zealand welcome new members be they patients, family/support person, or medical professionals with an interest in the disease.

Please feel free to visit the Acromegaly New Zealand website for more information: [acromegaly.org.nz](http://acromegaly.org.nz)

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