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FEATURE ARTICLE: Keeping Yourself Healthy While Living With Acromegaly

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Note: This article is based on the American guidelines.
Please refer to your medical professionals for advice and guidance.

Acromegaly is a condition of excess growth hormone (GH), most often resulting from a pituitary gland tumor of GH producing cells. Patients with Acromegaly have a unique set of related medical issues, some of which are overlooked by patients or their providers. Fortunately, many of the problems discussed below are resolved or improved by proper medical and surgical treatments. However, since diagnosis is often delayed in many patients (6-8 years from onset of symptoms on average), several complications may remain for a longer duration. Being aware of the possible complications can lead to better screening, and improvement in the quality of life for patients dealing with this difficult disease.

BONE AND JOINTS:

More than 70% of patients with acromegaly have joint problems[1]. GH promotes growth of joint cartilage and enlargement of ligaments around the joints, which leads to cartilage thickening and narrowing of joint spaces. Only early on are these changes reversible, so for many patients, joint issues will be lifelong. Aches and pains in the large joints (hips, shoulders, knees) are most common as well as low back pain. Patients with Acromegaly are also at risk of osteoporosis (thin bone disease) which leads to higher rates of bone fractures.

Carpal tunnel syndrome may occur in upwards of 65% of patients with acromegaly[2]. Many patients will have had surgery for carpal tunnel syndrome prior to their acromegaly diagnosis. Soft tissue swelling occurs at the palm side of the wrist and can lead to considerable pain, numbness, tingling and weakness in the hands. After successful treatment of acromegaly, symptoms most often do improve, but changes in the health of the involved nerve (median nerve) are often permanent and may lead to a need for surgery.

What can I do?: Staying active with low impact weight bearing activities reduces the risk of fractures. Using an elliptical training machine, brisk walking and low impact aerobics are some safe and effective options. Resistance training to strengthen muscle around bones can also be helpful. Weight loss (if appropriate) can help with pain in weight-bearing joints (knees and hips). Checking and replacing vitamin D (if low) can helpful to improve the strength of weaker bones. Optimizing the amount of ingested calcium in your diet can also improve bone health. Medications aimed at preventing bone loss or increasing bone strength can also be used if bone weakness is severe (measured by a bone density exam).

DENTAL:

A common issue for patients with acromegaly is growth and protrusion of the mandible (the lower jaw) that often doesn't allow proper tooth alignment. Some patients notice changes in chewing, swallowing or even speech, partly also due to enlargement of the tongue. Jaw growth can lead to temporomandibular joint (TMJ) pain (where the lower jaw connects to the skull), jaw clicking and to wider spacing between teeth. Dental problems are commonly listed as part of a reduced quality of life for patients with acromegaly.

What can I do?: Regular dental visits are an important part of follow-up care for patients with acromegaly. Surgical procedures may be necessary but are best to be delayed until GH levels have been normalized. Similarly, in patients with oral appliances such as dentures, delay may avoid a need for additional fittings. Speech therapists may be able to help improve swallowing difficulties, and address speech issues.

DIABETES:

The high levels of GH make insulin work less effectively in the body favoring higher blood sugars and development of diabetes in patients with Acromegaly. Medications are very often required to help maintain normal blood sugars, including insulin injections, but there are no anti-diabetic medications specific for Acromegaly. As the diagnosis of acromegaly is most often delayed by years from its start, patients may have diabetes for quite a while before their treatment, and are at risk of complications such as retinal problems (bleeding in the back of the eyes), kidney injury and development of neuropathy (nerve injury).

What can I do?: Attending dietary diabetes education classes can be very helpful to make changes that will reduce weight and improve sugar control. This education is not specific to patients with Acromegaly and can often be found through their local diabetes association. Patients should be aware of the increased risk of worsening high sugars with the use of Pasireotide LAR* (Signafor®) and discuss this with their providers. Also, the anti-diabetic medications in the class SGLT2-inhibitors* have been associated with developing ketoacidosis (buildup of blood acids) in some patients with Acromegaly and should be considered when making treatment decisions[3].
**please note these drugs are not readily available in NZ*

SKIN:

Skin problems are quite common to patients with Acromegaly. Thickening and swelling of the skin frequently occurs, as well as abnormal skin growths (e.g. skin tags and nevi (moles)). There is however no increased reported incidence of skin cancer. Enlargement of sweat and sebaceous glands under the skin can cause excessive sweating and oily skin[4]. Sweating difficulties may unfortunately not resolve completely even after control of Acromegaly has been achieved. Excessive hair growth and male pattern hair loss in women can be another troublesome complication.

What can I do?: Patients experiencing hair loss may talk to their providers about topical minoxidil use. Consulting with a dermatologist may be necessary as well, especially in cases of troublesome excess sweating. Consideration of Botox injections may be helpful for severe cases.

SLEEP APNEA:

Obstructive sleep apnea (OSA) is a condition that occurs during sleep and is defined by short episodes of partial or complete blockage of the upper airway, often with reduced blood oxygen levels. Symptoms are often daytime sleepiness and snoring, and partners or family members may witness episodes of gasping for air or stoppage of normal breathing overnight. In Acromegaly, enlargement of the tongue and thickening of soft tissues in the back of the throat lead to blockage of the airway. Nearly 80% of patients with Acromegaly will have OSA. Unfortunately, even after successful treatment of their pituitary disease, many (upwards of 40%) will still have longstanding OSA that requires active treatment[5].

What can I do?: All patients with Acromegaly should be screened for sleep apnea. Some doctors can order home sleep studies for sleep apnea screening, but because of how likely it is in patients with Acromegaly, a formal sleep lab sleep study will likely be recommended. Consistency with using prescribed home appliances (CPAP or BiPAP) is crucial to effective treatment. Weight loss may also be helpful in reducing apnea episodes.

CANCER RISK:

Although in animal studies, GH promotes growth and development of cancers in patients with Acromegaly this isn't nearly as clear. There have been some conflicting reports of the likelihood of developing certain types of growths and cancers in people with Acromegaly[6]. For example, thyroid nodules (growths within the thyroid gland) are more common but the risk that they are cancerous may in fact not be higher than the general population. Small growths within the colon (large intestine) called polyps, also appear very often in patients with Acromegaly and raise some concern about risk of colon cancer. There does not appear to be an increased risk of prostate or breast cancer.

What can I do?: Make sure you have had your age-appropriate cancer screening. For women consideration of mammogram and pap smear, and for men prostate cancer screening. Given the increase in colon polyps most guidelines recommend having a colonoscopy at the time of diagnosis[6]. If polyps are present repeat testing at 5 years would be recommended and 10 years if absent. If they haven't already, ask your provider to examine for evidence of thyroid nodules and consider biopsy if present.

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