

The New Zealand Acromegaly Society

Newsletter No 7. December 2012



Professional Article

The Stress of Living with Acromegaly

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The connection between stress and ill health is well established. Research indicates that stress can trigger or exacerbate medical problems and even delay recovery. People living with Acromegaly will relate with the stress caused by their illness, as it imposes additional demands and pressures to ordinary daily activities. Quite often these challenges are unnoticed or misunderstood by others. This article will outline some of the stressors commonly encountered by people with Acromegaly and help you identify some of the ways in which you can improve your quality of life, despite the illness

Acromegaly as a Chronic Illness

Acromegaly is a chronic illness. That means it is a long term and ongoing condition. Though individual cases vary, there may also be a possibility the condition/symptoms will worsen over time, affecting not only your physical body, but also your self-image, quality of life, and emotional well-being.

Though the diagnosis of a condition such as Acromegaly can be difficult to accept, many express a sense of relief, having lived a long time with symptoms, for finally having an explanation for the way they have been feeling. At this stage, usually friends and family are empathetic and supportive. Overtime however they may become less patient or accommodating with your ongoing needs and complaints. They may find it difficult to understand your experiences and needs, fail to recognise the type of support you need, or simply become overwhelmed by the situation. At this stage, many people feel guilty in needing extra help and care or fear they will become dependent upon them.

Communicate!

Relationships can suffer when people shy away from discussing problems that seem to have no easy or obvious solution - and that leads to feelings of distance, sadness, and resentment. Finding ways to talk openly about challenges (for both sides) is the first step toward effective problem-solving and the feelings of closeness that come from working together towards a solution.

The Symptoms of Acromegaly

Acromegaly has a particular set of signs and symptoms that make you feel unwell and make it difficult to function. Those may include pain, fatigue, muscle weakness, sleep difficulties, tension, impotence, and hypertension. Some symptoms affect your physical appearance, while others, less noticeable, can be just as limiting.

One of the greatest challenges is to adjust to your new physical limitations. A normal reaction is to increase the pace and "harden up" in an attempt to maintain productivity and personal standards. Not being able to perform tasks as well as you think you were able can have a significant impact on your self-belief and confidence, and that may lead to frustration, disappointment and sadness.

A productive and more helpful way to deal with physical and emotional setbacks is to set small, more *realistic* goals. By being self-compassionate and aware of your body limits you will find you can still accomplish many of your tasks.

One of the effects of chronic illness is sometime the attitude and negative perspective we adopt. At times like this it is difficult to notice or be aware of more positive aspects of life. By focusing on accomplishments, even small ones, and more positive factors, you may be more able to cope with your physical illness. A positive

attitude has been linked with faster remission and improved quality of life.

Healthy coping implies the capacity to tolerate and express concerns and emotions, not just the ability to put your anxieties aside. Being able to discuss the anxieties, uncertainties and fears, losses and sadness that usually accompany your illness is helpful, despite the pressure commonly exerted by family and friends for you to always “stay positive.”

Coping with Treatment

People with Acromegaly are typically responsible for treating themselves with medications. You are expected to follow sometimes complicated instructions - must take the right dose of medication, at the right time, with or without food, without improperly combining medications, have it available when it is time to take it, get refills, etc. It can feel overwhelming to accomplish these tasks and at the same time do ordinary demands such as work, family, chores, doctor’s appointments, etc.

Side effects from medications or treatments are common. Sometimes you have to stop taking needed medications because the side effects are so uncomfortable. You may start taking additional medication to treat the side effects of the original medication. It can feel hopeless and overwhelming.

Remember, you are more than your illness. That part of you that functions well also needs to be looked after. Focus on the basics like getting plenty of sleep, exercise and eating healthy. Learn to identify the signals that you are wearing your health thin. For some people, these might be lowered ability to concentrate, muscle tension, irritability and loss of sense of humour. It may also be useful to set reminders (e.g. an alarm on your phone or clock) and have a particular routine (e.g. at breakfast) for medication taking.

To live and cope well with Acromegaly requires emotional support from people who understand how it feels. Human beings can adjust to the worst traumas if they have someone in their lives who is consistently supportive and encouraging. The most damage is done when we feel alone and isolated.

