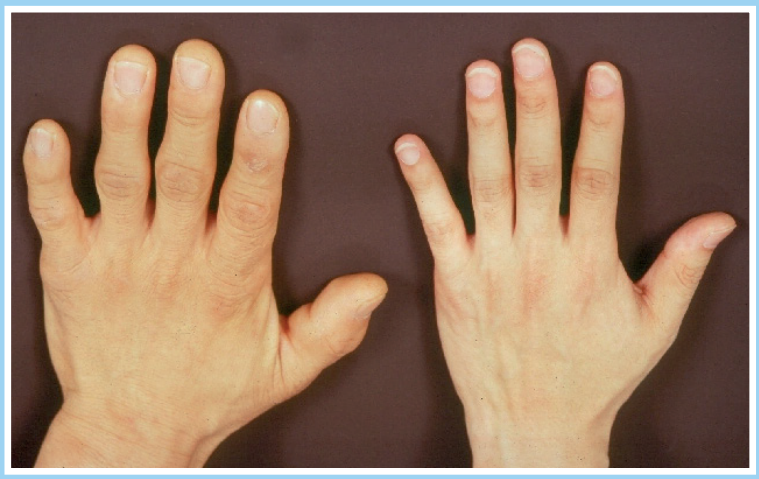
HAND-HELD HEALTH CARE RECORD FOR PEOPLE WITH ACROMEGALY

ENSA

NEW ZEALAND VERSION



The *Hand–Held Health Care Record for People with Acromegaly* has been compiled by Ann Robinson RN-NP, as an initiative of the Endocrine Nurses Society of Australasia (ENSA).

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The New Zealand version of the *Hand-Held Health Care Record for People with Acromegaly* has been reviewed, adapted to the local circumstances and endorsed by Associate Professor John Conaglen, Endocrinology Consultant at the Waikato Hospital, Professor Ian Holdaway Endocrinology Consultant at Greenlane Clinical Centre, Doctor Catherine Chan for the NZ Acromegaly Society, and Tania Yarndley, Endocrine Nurse at Waikato Hospital.

The New Zealand version of the *Hand-Held Health Care Record for People with Acromegaly* is proudly sponsored by Novartis New Zealand Limited and the Endocrine Nurses Society of Australasia.

This booklet is aimed at providing information for patients with acromegaly and their families and to assist with communication between services. Please bring this booklet to all health related appointments, use it as a reference and encourage your health professional to update your records regularly.

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MY PERSONAL DETAILS

Name:
Date of birth:
Address:
Telephone number:
Mobile phone number:

NHI number:

HEALTHCARE AND TREATMENT RECORD

(to be completed by Healthcare Provider)

Date Diagnosed:
Dates of Surgery:
Details of Surgery/Procedure Performed:
Pathology Results:
Radiation Dates and Dose:
Other comments:

SPECIAL AUTHORITY NUMBERS AND DATE OF EXPIRY

Drug Name	SA Number	Expiry Date

HOSPITAL AND HEALTHCARE PROVIDER DETAILS

GP Name:
Address:
Telephone:

Pharmacy Name:
Telephone:

Hospital Name:
Address:
Telephone:

Endocrinologist Name:
Telephone:

Neurosurgeon Name:
Telephone:

Radiation Oncologist Name:
Telephone:

Other Specialist's details:
Name:
Specialty:
Telephone:

Name:
Specialty:
Telephone:

Hospital Nurse Name:
Telephone:

Introduction

This booklet has been developed to provide you and your family with information about acromegaly. It is also for you to record dates, appointments, pathology and screening results for your own records.

This section provides some information about acromegaly. Further information can be accessed at websites listed at the back of the booklet.

After you have read this you may have further questions about the disorder and how it will affect your everyday life. Talk to your doctor and nurse about any extra information you need or any concerns you have.

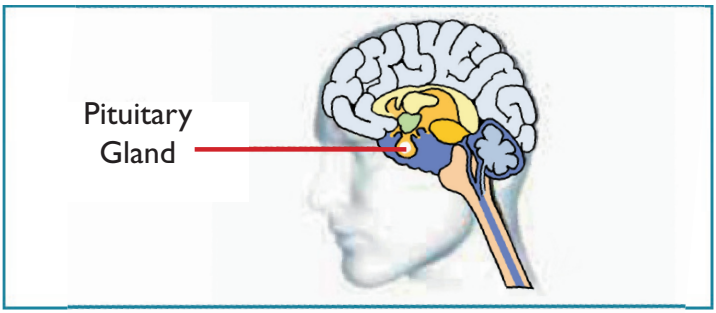
What is the Pituitary Gland?

The pituitary gland is a pea-sized gland about 1cm in size. It sits at the base of the brain around the level of the bridge of the nose and is connected to the brain by a stalk. It is in two parts, the anterior and posterior lobes. The anterior pituitary secretes hormones which are chemical messengers. These hormones are:

- Thyroid stimulating hormone (TSH)
- Adrenocorticotrophic hormone (ACTH)
- Luteinising hormone (LH)
- Follicle stimulating hormone (FSH)
- Growth hormone (GH)
- Prolactin

What is Acromegaly?

Most patients with acromegaly have a benign pituitary tumour (adenoma) that produces too much growth hormone. Growth hormone is a chemical that stimulates the normal growth of organs and bones and helps control the body's metabolism. The tumour, called a pituitary adenoma usually grows very slowly over a period of many years.



How Common is Acromegaly?

Acromegaly is a rare condition. It is thought to occur in about 40-60 people in every million, with 3-4 newly diagnosed cases per million each year. This means there would be in excess of 250-300 people with acromegaly in New Zealand. Acromegaly is found in people of all races, is equally common in men and women, and uncommonly can run in families. It is most often diagnosed in people in their 40s and 50s but can occur at any age. It can occur in women who wish to have a baby and whilst it may be more difficult to conceive, pregnancy may still be possible.

What are the Symptoms of Acromegaly?

People with acromegaly may present with progressive enlargement of hands and feet, headaches, voice changes, increased perspiration, joint pains, high blood pressure, diabetes and/or heart disease.

Possible Effects of Acromegaly

Effects of acromegaly can include the following:

GENERAL

- Headaches
- Visual changes
- Tiredness, sleepiness
- Weight gain
- Intolerance of heat
- Numbness of hands
- Weakening of muscles
- High blood pressure
- Enlarged heart

BONES AND SKIN

- Enlarged feet and hands
- Joint pains - shoulders, back, knees
- Prominent jaw, cheekbones, forehead

SKIN AND HAIR

- Excessive sweating
- Oily, thickened, leathery skin
- Wrinkles on forehead
- Increased growth of dark, coarse hair and/or acne

TONGUE, MOUTH, VOICE

- Deeper, more resonant voice
- Increased size of tongue
- Teeth spreading apart
- Heavy snoring and sleep apnoea

SEXUAL FUNCTION

- Decrease in sex drive
- Erection problems in men
- Changes in menstrual cycle in women

BOWEL

- Increased risk of bowel polyps which can become cancerous in some people

Diagnosis

The changes that happen in acromegaly may develop slowly over a period of years and it may take some time before the condition is finally diagnosed. Often people are aware of subtle changes in their bodies before the signs of acromegaly become obvious to others.

A series of tests are used to confirm the diagnosis to see exactly how your pituitary gland has changed, and to check other organs potentially affected by the pituitary gland.

- Blood tests to check the amount of growth hormone and another hormone called insulin-like growth factor-I (IGF-I) circulating in the blood stream

(This is an important measure in acromegaly as it is generated in the liver by GH and acts as a very good indicator of average GH levels over time)

- A glucose test to see if growth hormone levels go down after you have a drink containing glucose. The amount of growth hormone released from the pituitary gland usually drops when there is an increase in the amount of glucose in the blood stream
- Blood tests to check whether the other hormones produced by the pituitary gland are working correctly
- An MRI scan of the pituitary gland
- Testing of your eyes and vision

MRI Scanner

Source: GE Health Care. Used with permission.

How is acromegaly treated?

The aims of treatment are:

1. To reduce the production of growth hormone to normal levels. This should prevent further physical changes and help reverse some of the changes that have already occurred
2. To remove or reduce the size of the pituitary adenoma - or at least stop it from growing
3. To maintain the normal function of other parts of the pituitary gland

Successful treatment will reverse many of the changes in your body that have resulted from acromegaly. Three different types of treatment are used

- Surgery
- Treatment with medicines
- Radiation therapy

Often more than one type of treatment is used.

Your doctor will discuss the best type of treatment for you and help guide you through the decisions that will need to be made.

Surgery

Surgery aims to remove the pituitary adenoma without affecting other normal parts of the pituitary gland. Surgery is usually performed through the nose. You may hear it referred to as trans-sphenoidal surgery. Sometimes the surgeon may need to perform a transfrontal approach through the skull due to the size or location of the adenoma.

Many patients with small pituitary adenomas can be completely cured by surgery. The success rate is less when the adenoma is larger than 1 cm. Growth hormone levels may return to normal levels within hours of surgery and improvement in symptoms of acromegaly may be noticed before leaving hospital.

It is often not possible to remove all of the adenoma and further treatment might be needed. Surgery is still worthwhile, even if the adenoma will not be completely removed. Reducing the size and growth hormone levels makes it more likely that other treatments will work. Recurrence in a patient completely cured after surgery is relatively uncommon, occurring in less than 10% of people.

Treatment with medication

Medication is the next best treatment option if the growth hormone levels are still too high after surgery.

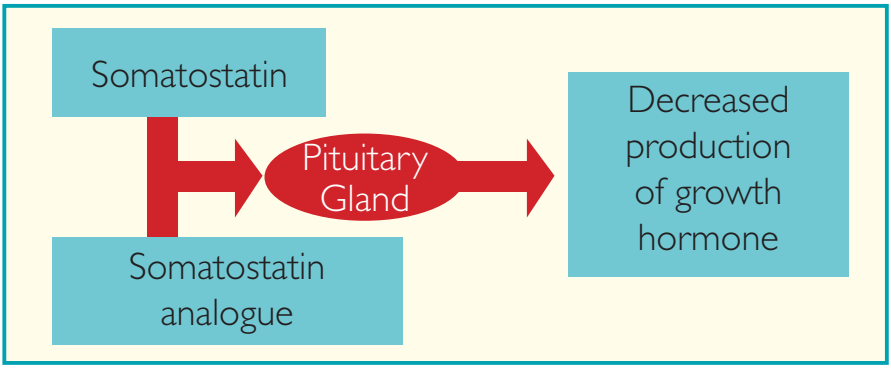
Somatostatin analogue injections

The amount of growth hormone released from the pituitary gland is normally controlled by another hormone called somatostatin. Somatostatin acts like a brake and reduces the amount of growth hormone that is released into the blood stream. As the level of somatostatin goes up, the level of growth hormone goes down. Medication designed to mimic the action of this naturally occurring hormone is called a somatostatin analogue, and these are generally given by monthly injection. This can bring the growth hormone levels down to normal in up to two thirds of patients.

These expensive medications are accessed in New Zealand by your Specialist completing a Special Authority application to PHARMAC. Sandostatin is available in New Zealand. Sandostatin and Lanreotide are available in Australia.

Tablets may be used in some cases where there is an incomplete response to the injections and in cases where another hormone called prolactin is also being secreted by the tumour. The tablets used are called dopamine agonists,

with the commonest being cabergoline and bromocriptine. Carbergoline, as for Sandostatin, is accessed, by means of a Special Authority application to PHARMAC and is fully subsidised.



Radiation therapy

Radiation is rarely used as the main treatment for acromegaly. It may be required after surgery if medication fails to control the growth hormone levels. Radiation stops tumour growth and may result in some tumour shrinkage. Stereotactic radiosurgery may be used depending on location of the tumour.

Radiation therapy is usually given five days per week for a period of four or five weeks. Stereotactic radiotherapy may take a shorter time. Radiation therapy is generally only available in larger hospitals. This type of treatment aims to prevent further growth of the pituitary adenoma but it is slow to produce any improvement in the symptoms of acromegaly.

Radiation therapy may gradually reduce the function of the normal pituitary gland. If this happens, it is necessary to take medication to replace the affected hormones.

Pituitary hormones.

If the normal pituitary gland tissue is not functioning, it will be necessary to take medication to replace the hormones normally produced by the gland. Up to 75% of the gland can be destroyed before the hormone levels become too low. The pituitary gland controls the thyroid gland, adrenal glands and the testes in men/ovaries in women. Depending on which of these hormone systems are not functioning, people may need to take 1 to 3 forms of hormone replacement therapy.

Treatment to replace other pituitary hormones is very effective, but usually must continue for the rest of your life.

The term used to describe low levels of pituitary hormones is hypopituitarism. People with this condition should have a medical alert bracelet or necklace to indicate what replacement hormones they are taking.

How do you feel?

Changes in your body can change the way that you feel about yourself. Being diagnosed with a relatively rare disorder like acromegaly can sometimes have quite a big impact on your emotions. Feeling worried, anxious or depressed is probably quite common. Learning about the condition and what it means should be a great help.

It's important to realise that with modern methods of treatment, acromegaly can be cured in some people, and effectively controlled in most people. Your doctors, nurses and other health care professionals will be keen to answer your questions. Often it will take some time to come to terms with this change in your life, and it will probably take more than one discussion with your doctor to get all the information you need. You will probably think of new questions as time goes on - so keep asking!

Other Health Screening

If the pituitary tumour affected your vision, you will need follow-up eye checks after treatment. These are not required in people whose vision was not affected. Because high growth hormone levels can affect the heart, thyroid gland and bowel, it is important that you have periodic check-ups of these organs. The exact timing will vary between people, depending on their age and how well controlled their growth hormone levels are.

The check-ups may include a heart scan (echocardiogram), bowel examination (colonoscopy) and thyroid gland ultrasound. Your doctor will also monitor your blood pressure, lipid levels (cholesterol) and blood glucose periodically. You may need additional medication if any of these are high. Women should have breast screening mammograms and men should have prostate checks at the appropriate stage in their lives, generally after age 50.

Follow up

Attendance at all scheduled follow-up appointments is essential even with a cure status. You may feel well but monitoring and management of acromegaly is long-term. It is vital to your overall health and life expectancy to be pro-active in attending all medical appointments.

QUALITY OF LIFE

The symptoms and health effects of acromegaly can impact on your life. Changes to physical appearance, bone and joint pain, sweating, numbness in fingers, snoring and sleep apnoea may impact on quality of life. It is important that you discuss any concerns with your doctor and nurse.

Some centres may routinely or periodically assess the effects of acromegaly on your quality of life (QoL) by asking you to complete a QoL survey. This may be done when you are diagnosed and subsequently to assess any changes. It may be used to assess your disease progress in addition to routine blood testing. Please discuss the use of these quality of life measures with your health team.

Remember to keep your health team advised if you are having any difficulties. Referral for psychological support and counseling can be arranged. Speaking with other people with acromegaly may offer some support and this can be arranged through consumer/peer organisations such as the NZ Acromegaly Society and the Australian Pituitary Foundation.

INJECTION RECORDS

Injection record and sites

Date	Drug Name	Administered By	Site	Next Due

INJECTION RECORDS

Injection record and sites

Date	Drug Name	Administered By	Site	Next Due

INJECTION RECORDS

Injection record and sites

Date	Drug Name	Administered By	Site	Next Due

MEDICATION RECORDS

Make a list of all the medications you are taking, how often, and what dosage. Include any over the counter medications you may have purchased from the pharmacy, supermarket or health food store.

Name of medication	Dosage/Time	Date commenced/ ceased

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REMINDERS

Always bring an updated list of your medications to all appointments. Remember to do blood tests prior to your appointment, if required.

If you are cortisol deficient or on replacement hydrocortisone ensure you have a sick day action plan. If required, ensure you have solucortef hydrocortisone injections available and that you have been instructed when and how to use this medication.

Do you need to wear a medical alert bracelet stating "I have cortisol deficiency"? Discuss this with your doctor or nurse.

Plan ahead for holidays. Ensure you have adequate medication and made provision for scheduling of injections if needed.

There are a range of baseline and follow up screening tests that may be requested from time to time following your acromegaly diagnosis depending on your individual needs.

These may include:

Test	Date	Date	Date
Baseline weight			
Height			
Blood pressure			
Ring size			
Visual field			
MRI			
Echocardiogram			
ECG			
Colonoscopy			
*Gall bladder ultrasound			
Mammogram			
*Sleep study			
Bone mineral density (BMD)			

* If needed

ROUTINE LAB RESULTS

Date		
	Range	Units
IGF-I		
GH		
Prolactin		
Cortisol		
Other		

Date		
	Range	Units
IGF-I		
GH		
Prolactin		
Cortisol		
Other		

Date		
	Range	Units
IGF-I		
GH		
Prolactin		
Cortisol		
Other		

Date		
	Range	Units
IGF-I		
GH		
Prolactin		
Cortisol		
Other		

Date		
	Range	Units
IGF-I		
GH		
Prolactin		
Cortisol		
Other		

Date		
	Range	Units
IGF-I		
GH		
Prolactin		
Cortisol		
Other		

ROUTINE LAB RESULTS

Date		
	Range	Units
IGF-I		
GH		
Prolactin		
Cortisol		
Other		

Date		
	Range	Units
IGF-I		
GH		
Prolactin		
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Date		
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Prolactin		
Cortisol		
Other		

Date		
	Range	Units
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GH		
Prolactin		
Cortisol		
Other		

Date		
	Range	Units
IGF-I		
GH		
Prolactin		
Cortisol		
Other		

HEALTH PROFESSIONAL APPOINTMENT SCHEDULE

(Record all appointments with your healthcare providers here)

Date	Health Practitioner	Details

HEALTH PROFESSIONAL APPOINTMENT SCHEDULE

(Record all appointments with your healthcare providers here)

Date	Health Practitioner	Details

HEALTH PROFESSIONAL APPOINTMENT SCHEDULE

(Record all appointments with your healthcare providers here)

Date	Health Practitioner	Details

NOTES

FURTHER INFORMATION

Further information about acromegaly and its treatment can be obtained from:

- New Zealand Acromegaly Society http://www.acromegaly.org.nz/
- Australian Pituitary Foundation (APF) http://www.pituitary.asn.au/
- The Pituitary Foundation UK http://www.pituitary.org.uk/
- US Based Acromegaly Community http://www.acromegalycommunity.com
- Canadian website http://acromegalysupport.ca/index.html

The NZ Acomegaly Society and APF have a range of publications specific to acromegaly and other pituitary disorders that can be downloaded from the website or in hardcopy on request.

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