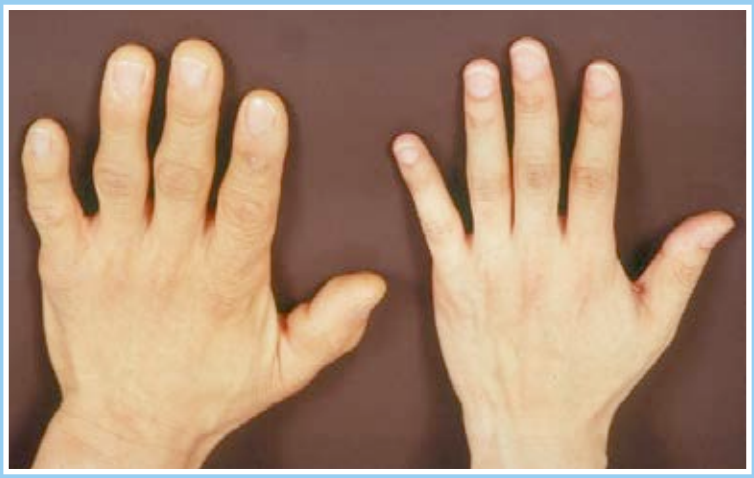
# HAND-HELD HEALTH CARE RECORD FOR PEOPLE WITH ACROMEGALY

ENSA



2nd edition 2018

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).

Editorial assistance and encouragement for the booklet was generously provided by Associate Professor Kunwarjit Sangla, Associate Professor Warrick Inder, Associate Professor Morton Burt, Dr Ryan Taylor, Tania Yarndley and Julie Hetherington from ENSA, Sue Kozij and Dr Yi Yuen Wang from the Australian Pituitary Foundation and the patients with acromegaly who trialled and reviewed this booklet.

This booklet can be downloaded from the Australian Pituitary Foundation Website *www.pituitary.asn.au*

The Hand-Held Health Care Record for People with Acromegaly is proudly sponsored by the Endocrine Nurses Society of Australasia, Ipsen Pty Ltd, Novartis Pharmaceuticals Australia Pty Ltd and Pfizer Australia Pty Ltd.



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.

1st edition 2013 and current 2nd edition 2018

# CONTENTS

# MY PERSONAL DETAILS

| |
|---|
| Name: |
| Address: |
| Telephone number: |
| Mobile phone number: |

# HOSPITAL AND HEALTHCARE PROVIDER DETAILS

| **Hospital UR Number** |
|---|

| **GP Details** |
|---|
| Name: |
| Address: |
| Telephone: |

| **Pharmacy Details** |
|---|
| Name: |
| Telephone: |

| **Hospital details** |
|---|
| Name: |
| Address: |
| Telephone: |

| Endocrinologist details |
| --- |
| Name: |
| Telephone: |

| Neurosurgeon details |
| --- |
| Name: |
| Telephone: |

| Radiation Oncologist details |
| --- |
| Name: |
| Telephone: |

| Other specialist's details |
| --- |
| Name: |
| Specialty: |
| Telephone: |
| Name: |
| Specialty: |
| Telephone: |

| Hospital nurse details |
| --- |
| Name: |
| Telephone: |

## Introduction

This booklet has been designed 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 disease 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.

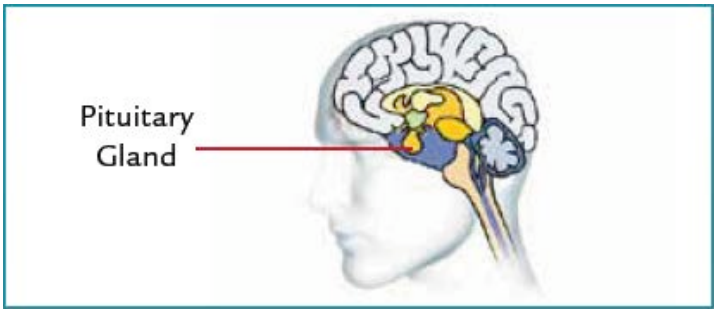
## What is the Pituitary Gland?

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 has 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 pituitary tumour or 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 1,000 people with acromegaly in Australia. 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 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

### 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 affected by the pituitary gland

- Blood tests to check the amount of growth hormone and another hormone called insulin-like growth factor-1 (IGF-1) circulating in the blood stream

- 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 the other hormones produced by the pituitary gland are working correctly
- An MRI scan of the pituitary gland
- Testing of your eyes and vision

Source: GE Health Care.
Used with permission.

## How is acromegaly treated?

The aims of treatment:

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 and control symptoms of acromegaly
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

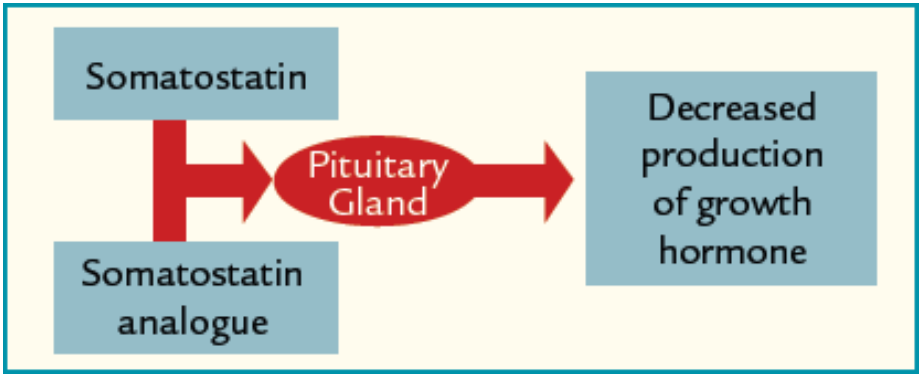
Surgery aims to remove the pituitary adenoma without affecting other normal parts of the pituitary gland. This is usually performed through the nose, referred to as trans-sphenoidal surgery.

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 however with modern endoscopic techniques has been reported as high as 80% in the hands of experienced surgeons. 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 common to wait several months however to confirm normalisation of these hormones.

Occasionally acromegaly remains active even with surgery and further treatment might be needed. This is particularly so if there is invasion into the important surrounding structures that make it unsafe to remove. Surgery is still worthwhile in these situations as reducing the tumour size and growth hormone levels make it more likely that other treatments 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 analogues 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. Medications designed to mimic the action of this naturally occurring hormone are called somatostatin analogues, and these are generally given by monthly injection. They can bring the growth hormone levels down to normal in up to two thirds of patients.

These expensive medications are subsidised in Australia through the Highly Specialised Drugs (HSD) program and Medicare Australia. Pasireotide is a new somatostatin analogue that is now available in Australia for patients that have high growth hormone levels on Sandostatin or Lanreotide. It is slightly more effective than Sandostatin or Lanreotide but can cause type 2 diabetes.

## Dopamine agonist tablets

Tablets may be used in some cases where there is an incomplete response to the injections or in cases where another hormone called prolactin is also being made by the tumour. The tablets used are called dopamine agonists, with the commonest being cabergoline and bromocriptine. These are subsidised under the Pharmaceutical Benefit Scheme (PBS) in Australia if the prolactin is also raised.

## Growth hormone antagonists

Pegvisomant (Somavert) is a medication that blocks growth hormone binding and the effects of growth hormone, significantly reducing IGF-1 levels. It is given as a daily injection under the skin and is subsidised by the PBS in Australia for eligible patients who have either not responded to or cannot tolerate somatostatin analogues. Pegvisomant (Somavert) does not reduce the size of the pituitary adenoma.

## Radiation therapy

Radiotherapy may be offered to patients whose adenomas were not cured by surgery and are not well controlled with medications. Depending on how big the adenoma is and its distance from other structures within the brain, either conventional stereotactic radiotherapy or radiosurgery may be an option. Some forms of stereotactic radiotherapy and radiosurgery such as Gamma Knife are only available in parts of Australia.

Conventional stereotactic radiotherapy is most suited to large tumours, and those not pressing on the nerves carrying information from the eyes to the brain. This therapy provides good long-term control of the high growth hormone but may take a number of years to work. Approximately 50-60% of patients have low or normal growth hormone by 10 years after therapy. This treatment however is

not without risks; around half of patients eventually develop low levels of other pituitary hormones which need treating.

For smaller tumours, more localised/targeted radiosurgery (stereotactic/Gamma Knife) may be appropriate. These treatments, typically given in a single visit, deliver a high dose of radiation to a small area, such as part of a tumour not removed by surgery. The effectiveness of radiosurgery appears similar to conventional radiotherapy but works more quickly. It also has the benefit of a lower amount of radiation to the surrounding brain.

## Pituitary hormones

If the normal pituitary gland is not functioning, it is necessary to take medication to replace the other hormones normally produced by the gland. Up to 75% of the gland can be destroyed before the other hormones 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 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 other pituitary hormones is hypopituitarism. People with this condition should have a medical alert card and bracelet or necklace to indicate what replacement hormones they are taking, especially if cortisone treatment is required.

## How do you feel?

Changes in your body can change the way that you feel about yourself. Being diagnosed with a relatively rare disease like acromegaly can sometimes have quite a big impact on your emotions. Feeling worried, anxious or depressed is probably quite normal. 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, breathing during sleep (sleep apnoea) 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), sleep study and bowel examination (colonoscopy). 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.

# 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 such as AcroQoL or SF-36. This may be done when you are diagnosed and subsequently to assess the 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 counselling 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 Australian Pituitary Foundation.

# TREATMENT RECORD (TO BE COMPLETED BY ENDOCRINOLOGIST)

Date diagnosed:

Dates of surgery:

Procedure performed:

Pathology results:

Dates of radiation:

| | Mon | Tues | Wed | Thur | Fri |
|---|---|---|---|---|---|
| Week 1 | | | | | |
| Week 2 | | | | | |
| Week 3 | | | | | |
| Week 4 | | | | | |
| Week 5 | | | | | |

# 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 |
|---|---|---|
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |

# 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 |
|---|---|---|
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |

# 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 |
|---|---|---|
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |

# REMINDERS

Always bring an updated list of your medications to all appointments.

If you are cortisol deficient or on replacement hydrocortisone ensure you have a sick day action plan. If required ensure you have solucortef acto-vial for injection and have been instructed when and how to use.

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 have made provision for scheduling of injections.

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 | Date |
|---|---|---|---|---|
| Weight | | | | |
| Height | | | | |
| Blood pressure | | | | |
| Visual field | | | | |
| MRI | | | | |
| Echo | | | | |
| ECG | | | | |
| Colonoscopy | | | | |
| Gall bladder ultrasound | | | | |
| Mammogram | | | | |
| Sleep study | | | | |
| Bone mineral density (BMD) | | | | |
| Dental Check Up | | | | |

# ROUTINE LAB RESULTS

| Ranges | | | | | | | |
|---|---|---|---|---|---|---|---|
| **Date** | IGF-1 | GH | Prolactin | Cortisol | Other | Other | Other |
| | | | | | | | |
| | | | | | | | |
| | | | | | | | |
| | | | | | | | |
| | | | | | | | |
| | | | | | | | |
| | | | | | | | |
| | | | | | | | |
| | | | | | | | |
| | | | | | | | |
| | | | | | | | |
| | | | | | | | |

# ROUTINE LAB RESULTS

| Ranges | | | | | | | |
|---|---|---|---|---|---|---|---|
| **Date** | IGF-1 | GH | Prolactin | Cortisol | Other | Other | 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 |
|---|---|---|
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |

# NOTES

# FURTHER INFORMATION

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

- Australian Pituitary Foundation http://www.pituitary.asn.au/
- The New Zealand Acromegaly Society http://www.acromegaly.org.nz/
- The Pituitary Foundation UK https://www.pituitary.org.uk/
- Canadian Pituitary Patient Network https://canadianpituitary.org
- Acromegaly Community https://www.acromegalycommunity.org
- World Alliance of Pituitary Organisations https://www.wapo.org

Australian Pituitary Foundation have a range of publications specific to acromegaly and other pituitary disorders that can be downloaded from the APF website or in hardcopy on request.


ENSA


Australian
Pituitary
Foundation


NOVARTIS


IPSEN
Innovation for patient care


Pfizer
Endocrine Care