The New Zealand
Acromegaly Society

Radiotherapy for Pituitary Tumours

Supporting & Educating those affected by Acromegaly and their families

INFORMATION BOOKLET SERIES

Introduction

The New Zealand Acromegaly Society is a charitable organisation supporting patients with Acromegaly, and their families.

Website: www.acromegaly.org.nz
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The aim of this leaflet is to provide general information about the condition Acromegaly. You may not find that all of the information applies to you in particular but we hope it helps you to understand your condition better and offers you a basis for discussion with your GP, Endocrinologist and Neurosurgeon.

www.pituitary.org.uk

A very special thank you to The UK Pituitary Foundation for allowing us to reproduce their Information Booklets and adapting it to the New Zealand's health system.

Medical Advisors

The New Zealand Acromegaly Society gratefully acknowledges the contributions from medical professionals to the development of this series of Information Booklets (listed in alphabetical order):

- Dr Richard Carroll – Endocrinologist, Wellington
- Sandra de Vries – Radiation Therapist, Dunedin
- Professor Ian Holdaway – Endocrinologist, Auckland
- Dr Penny Hunt – Endocrinologist, Christchurch
- Dr Lyndell Kelly – Radiation Oncologist, Dunedin
- Mr Martin MacFarlane – Neurosurgeon, Christchurch
- Dr John North – Radiation Oncologist, Dunedin

Also a Special thank you to Sandra de Vries (Stereotactic Specialist, Radiation Therapist) from Dunedin Hospital for providing us with thorough information and photos of the treatment.

RADIOTHERAPY

Radiotherapy is sometimes used as part of the overall treatment for pituitary tumours (also called pituitary adenomas)

The aim of radiotherapy treatment for patients with pituitary tumours is to control the growth of the tumour (or any remaining tumour after surgery) and prevent it enlarging. In some cases, radiotherapy also results in shrinkage of the tumour, this can take many months or years to happen.

Although radiotherapy treatment is most often used for patients with cancer, patients with pituitary tumours do not have cancer; their tumours are benign.

Pituitary tumours grow very slowly and tend to respond to radiotherapy slowly as well. Because of this, if radiotherapy treatment is required, it does not need to be given urgently within days or weeks of surgery and can safely be given months after the operation.

WHAT EXACTLY IS RADIOTHERAPY?

Radiotherapy uses X-rays to treat disease and it works by damaging the DNA in the nucleus of any cells that it passes through.

Radiotherapy uses high energy X-rays to destroy the tumour cells in the area being treated. These abnormal tumour cells are much more readily damaged by radiation and are therefore destroyed at a greater rate than normal cells which are able to repair themselves. The aim is to maximise the damage to tumour cells but at the same time minimising the damage to normal cells.

Radiotherapy is delivered using high-energy X-ray machines, called linear accelerators (Linacs). They focus an X-ray beam onto the pituitary tumour and surrounding area, from several different angles, one at a time.

Radiotherapy does not make you radioactive. It is perfectly safe for you to be around other people, including children, throughout your weeks of treatment.

External radiotherapy is usually given as an outpatient. It is planned and given by the Radiation Therapists, under the care of a Radiation Oncologist (a cancer specialist with training in radiotherapy treatment).

WHY DO I NEED TO HAVE IT?

It is not always possible to remove the whole of the pituitary tumour during surgery without running the risk of damaging surrounding structures, such as the optic nerves (the nerves that come from the eye and enable us to see) or major blood vessels. This is particularly true of larger tumours. Although pituitary tumours are

almost invariably benign, they do have a tendency to grow and if even a few cells remain after surgery, they can be the seed for a recurrence of the tumour in the same area.

Following surgery, patients undergo further scanning (MRI or CT) and blood tests. Their cases are then reviewed and discussed by the multidisciplinary team (including an endocrinologist, neurosurgeon and radiation oncologist) looking after them. A consensus decision on each case is then made by the team and recommended to the patient.

In general, radiotherapy is considered for patients:

- Who have evidence of persisting tumour outside the pituitary fossa (the space where the pituitary gland sits) following surgery
- Whose tumour is secreting a hormone that continues to be raised in blood tests following surgery despite treatment with drugs
- Whose pituitary tumour re-grows (this would be some time after surgery, perhaps following a second operation)

Some patients, whose postoperative scan shows minimal persistent tissues within the pituitary fossa only, are not given radiotherapy after surgery. They are followed up with annual scans, blood tests and visual field checks.

How Effective is Radiotherapy?

When we look back on patients treated 20 years ago, radiotherapy is very effective.

- Re-growth of the tumour is prevented in nine out of ten patients (for similar types of patients who were not given radiotherapy following surgery, the tumour re-grew in over half of all cases)
- Half the patients whose eyesight has been affected by the tumour notice an improvement following surgery and radiotherapy
- For those patients who are receiving radiotherapy in order to reduce hormone secretion, it is effective in nine out of ten patients, starting about two years after radiotherapy and continuously improving for ten to fifteen years

Types of Radiotherapy

There are 3 main types of radiotherapy used in the treatment of pituitary tumours, the type that is used will depend on the individual tumour's characteristics.

1. Conventional Radiotherapy
2. Stereotactic Radiotherapy
3. Stereotactic Radiosurgery

Pros & Cons of each type of radiotherapy is discussed in more detail below.

Conventional Radiotherapy

Conventional radiotherapy uses Linear accelerator (Linac) machines to deliver 2-dimensional beams to the patient from several directions. Most commonly three static beams are used, front or back, and both sides.

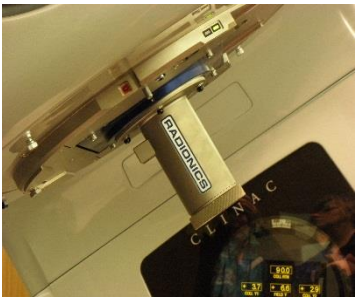
This can be carried out in the major tertiary hospitals acround New Zealand, and is well established and generally reliable. This type of radiotherapy is fractionated, meaning treatment is spread over several weeks (usually 5-6 weeks).

Most centres use thermoplastic masks as a fixation device, to ensure your head remains immobile during the treatment. Thermoplastic mask is a special sheet of plastic with holes in it. It goes soft when submerged in water of about 73°C and can be pulled down over your face and fixed to the baseboard that you are lying on. Scans for planning the radiotherapy can be carried out on the same day using this system.

The major limitation of conventional radiotherapy is that some high dose treatments maybe limited by the radiation toxicity capacity of healthy tissues that lay close to the tumour. For example, if the pituitary tumour lies close to the optic nerve, a dose of radiation high enough to treat the pituitary tumour would mean the sensitive optic nerve may suffer from radiation damage, causing problems to the patient's eye sight. In cases like this, another form of radiotherapy is required, known as stereotactic radiotherapy.

Stereotactic Radiotherapy (SRT)

Stereotactic radiotherapy is the most commonly used form of radiation treatment for pituitary tumours, and it is now possible to deliver stereotactic radiotherapy using special attachments to standard linear accelerators used for conventional radiotherapy. This is the set up at the national stereotactic radiotherapy and stereotactic radiosurgery service at Dunedin Hospital.

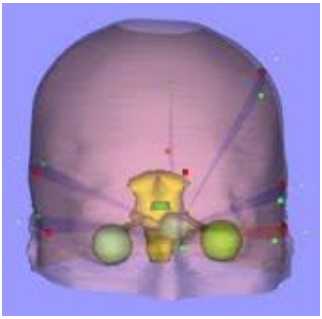


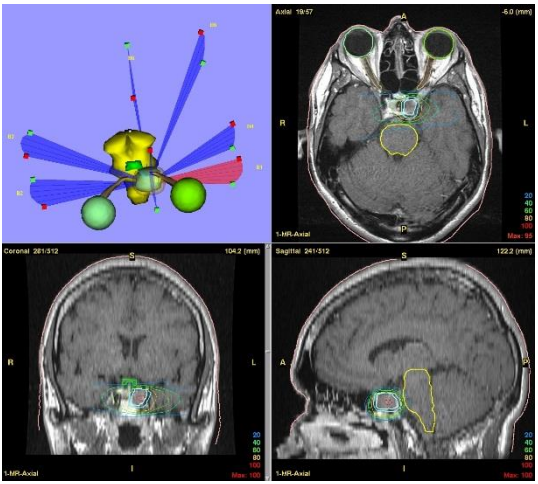
Cone attachment onto Linac machine at Dunedin Hospital

The major difference with stereotactic radiotherapy is that the radiation dose is delivered in the form of a single highly focused beam that is applied in multiple sweeps around the pituitary tumour. The radiation beams meet at the point within the pituitary tumour where treatment is needed. Therefore surrounding normal brain tissue gets minimum radiation exposure, and the pituitary tumour gets the accumulated dose of radiation from the different beams. Hence this is the preferred method for treating pituitary tumours that sits close to the optic nerves or optic chiasm.

Stereotactic radiotherapy is delivered in small daily doses over a 5 to 6 weeks course. By delivering the radiotherapy using repeated small dose treatments, the chance of permanent damage to your own normal body cells is reduced. In addition, by giving many small treatments, the total dose that can safely be delivered to the tumour is higher, thus increasing the chances of success.

The 3D planning of the treatment is done by the radiation therapist, and planning is identical for single or multiple fraction treatment.





What Should I Expect?

The Radiation Oncologist will see you and the radiotherapy treatment and side effects will be explained (see below). You will be asked to sign a consent form in order to receive the treatment. Your treatment will be carefully planned by a Radiation Therapist, who will also operate the machine that give you your treatment. A Medical Physicist is also involved in your treatment.

For stereotactic radiotherapy, the radiation is delivered over a period of five to six weeks (usually Monday to Friday only, with a rest at the weekend).

Because radiotherapy has to be given very precisely to treat exactly the right area of your body, it is essential your head and neck are kept as still as possible during treatment. Before your treatment begins, you will attend the clinic to have the fixation device & frame fitted, and an MRI & CT scan done. This is so that the treatment can be planned and the accuracy of the planned treatment confirmed. Treatment may not start for a few weeks after the planning session, in order for the treatment plan to be made.

A linear accelerator, a machine that generates high voltage X-ray beams, is used to deliver the treatment. You will lie on a treatment couch for approximately 15 minutes each day, positioning you takes the most time and the actual treatment times are very small, approximately 1 to 2 minutes.

The stereotactic radiotherapy unit in Dunedin - patient lies on the treatment couch, while the machine (linear accelerator) moves around in arcs delivering targeted beams to the pituitary tumour

How is the Fixation Device or Mask Used?

There are a number of ways of ensuring that your head remains immobile during treatment, to enable very exact and accurate treatment. For stereotactic radiotherapy in Dunedin, an individual impression is made of the upper teeth and back of head. These are attached to a frame, which fits on to the head and is pulled tight using Velcro straps over the top of the head. The Velcro straps help to hold the frame firmly in its final position.

Setting the mouth bite putty

The back pad forms an impression of the shape of the back of your head

You will be wearing the frame during your CT scan and each treatment, but not during the MRI scan. During treatment the frame is attached to the treatment couch, enabling precise reproduction of your position on the treatment couch for each treatment. This enables the dose of radiation to be concentrated in the exact area, reducing the risk of damaging the tissues the radiation passes through on its way to the pituitary gland.

The GTC frame is secured onto the treatment couch, ensuring exact positioning for each treatment

STEROTACTIC RADIOSURGERY

Stereotactic radiosurgery uses the same machine and radiation beam as stereotactic radiotherapy, but it involves a single treatment only. Single treatment radiosurgery can be delivered with an even higher degree of accuracy because the head ring is fixed securely to the patient's head by four adjustable head posts and fixation screws. This frame is known as the BRW (Brown-Roberts-Wells) frame.

The disadvantage is that because it is a single treatment, the potential for damaging normal tissues is much higher and so it is only used for selected cases where the tumour is some distance away from the brain and optic nerves, minimising the dose to these important structures. Therefore only selected patients with pituitary tumours are offered treatment using stereotactic radiosurgery.

An advantage of single dose radiosurgery is the tumour response is faster, therefore the effect of treatment is quicker.

Stereotactic radiosurgery may be delivered in two different ways - Stereotactic radiosurgery using a linear accelerator, or Gamma Knife treatment. The effect of these two different ways of delivering stereotactic radiosurgery is identical. The Gamma Knife is not available in New Zealand. The national stereotactic radiosurgery unit is based at Dunedin Hospital.

Will I Have any Side Effects?

Side effects are similar for all three types of radiotherapy described above. Radiotherapy is painless and you will not feel anything. You will leave the treatment room having sensed nothing of the X-ray beam therapy. However, some patients find that they have an altered sense of taste and smell but these should return to normal within about two months. During the course of the treatment, patients do feel increasingly tired and may need to sleep longer at night or in the afternoon. This usually wears off after a month or two. You should try and have plenty of rest and adequate sleep, however it is recommended for you to stay active and to follow your normal routine as much as possible, which will help with the fatigue.

Some patients feel queasy during the radiotherapy and occasionally patients are sick. Eating small meals frequently usually helps this. Your oncologist will give you medication to reduce nausea if necessary.

Skin irritation can occur after around three weeks of treatment, especially for patients having conventional radiotherapy, where the beam passes through the skin at 3-4 areas only. The skin at these areas where the beam passes into and out of the head in the temples, the high forehead and the nape of the neck will become pink, perhaps sore and itchy. Hair at these places will start to fall out. In most cases, this will re-grow within three to six months. Your oncologist will give you medication to reduce soreness if necessary. Often patients having stereotactic radiotherapy have none or minimal skin irritation.

Are There any Permanent Side Effects?

There are some side effects; however the majority are easily helped. It is important for you to weigh up the chances of the treatment helping you against the risk and seriousness of possible side effects.

- There is an increased chance of requiring pituitary hormone replacement therapy in the years following radiotherapy. About half of patients who are not already taking hormone replacement tablets when the radiotherapy starts will eventually need to take them. This need can take five to 20 or more years to appear. Patients are usually given male or female hormones using a gel, injections, tablets, and steroid and thyroid hormones via tablets.
- Patients with pituitary tumours have a slightly higher risk than the general population of having a stroke. This may be partly to do with radiotherapy and partly to do with the pituitary tumour.
- There are some very rare side effects. In less than one in 100 patients, the eyesight may become worse following radiotherapy. A very small number will go on to develop a further brain tumour, this is slightly higher than would be expected for people who have not had radiotherapy.

After Care

Your after care will continue to be monitored on a regular basis and this will be shared between your Endocrinologist and GP. Because pituitary conditions are relatively rare, you might find that you will be the only patient with a pituitary condition that your GP is treating.

Frequently Asked Questions

- **Will I be able to attend my local hospital for treatment?**

Linear accelerators, the machines needed to deliver a course of radiotherapy, are usually situated in large tertiary centres. These machines are sophisticated and expensive and require specially trained staff. So you will probably have to travel to your nearest specialist cancer (oncology) centre.

Since 1994, a national stereotactic radiotherapy & stereotactic radiosurgery service has been delivered from the Dunedin-based facility. The national district health boards (DHB) arrangement is that the Health Department contracts Dunedin to do the country's stereotactic radiotherapy & stereotactic radiosurgery. Usually your Endocrinologist will make a referral to Dunedin, where your case will be discussed with the team. If your referral is accepted, transport and accommodation for yourself and an accompanying person is arranged and paid for by the referring DHB.

A second stereotactic radiotherapy/radiosurgery unit was opened in 2012, at the country's first private radiotherapy centre at Auckland Radiation Oncology ARO. At the time of print of this booklet this is not yet funded by the public health system.

- **What do I expect if I am accepted at Dunedin for Stereotactic Radiotherapy or Stereotactic Radiosurgery?**

You will attend a Planning appointment first, where you will meet the radiation therapist coordinating the service, and then the radiation oncologist prescribing the treatment.

You will return to Dunedin after a few weeks for the actual treatment, where you will also meet the rest of the team including the linac technician (radiation therapist), and the physicist who together will ensure the accurate delivery of your course of treatment.

- **Will I be able to drive myself to and from the hospital?**

This will depend a little on how tired you become. If at all possible, try and have someone with you who can share the driving or take over if you are very tired. If you have to travel to and from the hospital on public transport, talk to the hospital staff as they might be able to time your treatment each day to fit in with bus and train timetables.

- **Will I be able to work? To look after my children?**

Radiotherapy affects different people in different ways. Many patients are able to continue working throughout their course of treatment while others do find they get very tired, especially towards the end of the course. If you do experience tiredness, listen to your body and allow yourself extra time to rest. Try and maintain a healthy diet and drink plenty of fluids.

- **I'm claustrophobic - will I be able to cope?**

Tell the oncologist and radiotherapy staff of your concerns. It is quite normal to feel anxious about having your treatment but as you get to know the staff (who will probably be the same every day) and the procedure, it should become easier. Do try and relax and don't be afraid to express your fears to the staff as they are there to help you. Don't be afraid to ask questions if there is anything you do not understand. This is especially important when you start your treatment.

- **How long is it before the treatment is fully effective?**

The effects of radiotherapy are gradual and cumulative over a period of several years.

RADIOTHERAPY – ONE PATIENT'S STORY (FROM UK)

I had been warned of the possibility that I might need radiotherapy (RT) after my surgery, as my tumour was very large, but, even so, was somewhat dismayed when the need was confirmed. After a short wait I headed off to the local cancer centre to see what was in store. More unknowns!

The specialist was really interested in pituitary tumours and took great care in explaining what was going to happen, in particular all the preparation that would be needed. I was concerned about my eyesight but was reassured that the beams would not affect that area. Soon I was having my mask made. The technician was brilliant. He explained exactly what was happening, and at the times when I needed to lie still and close my eyes kept talking to me. He put pink gunge over my face, allowing space for my eyes, nose & mouth and I had to lie very still while this set, making a mould of my face. I found it quite pleasant: as the gunge warmed up, I tried to imagine I was having a very expensive beauty treatment; but I'm sure many others would find it claustrophobic. When the transparent plastic mask was made (did I really look like that?) I had several more visits for fittings. At these my post-surgery MRI scans were used to identify exactly where the beams needed to hit the mask which became marked with an assortment of lines and crosses until it was ready.

My five and a half weeks of treatment went very quickly. It took much longer to get everything set up than it did to receive the treatment. I hated the sound of the screws fixing me down - the metal screeching against the plastic!
The radiographers were careful to explain everything and I had a chance to talk to the consultant at various times. I became quite sore above my ears and at the top of my forehead and some hair fell out - about the size of a 2p piece - where I was sore. It grew back quite quickly. I did get tired, perhaps the RT or perhaps the daily journey.

For several years after I still needed to take medication to keep my growth hormone levels under control, but now I don't need it.

We would like to say a special thank you to The Pituitary Foundation UK, for allowing us to reproduce their Information Booklet. The New Zealand Acromegaly Society takes sole responsibility for producing this publication in New Zealand.