

You should have received a copy of the ARO 'My Treatment Book' from your radiation oncologist specialist or the patient care specialist. It covers what to expect before, during and after your radiation treatment and useful information such frequently asked questions and parking facilities. If you have not received your copy please ask any ARO staff member. It is important you read this information.

This sheet aims to provide information specifically for patients receiving radiation therapy treatment for head and neck cancer at Auckland Radiation Oncology (ARO).

Topics include:

- Overview of radiation therapy
- ARO team members
- Special instructions and information related to your treatment pathway
- Potential side effects
- Websites and organisations of interest

For more information we encourage you to visit the ARO website www.aro.co.nz which includes this information and more. Our patients, their family and friends have found the website a useful way to learn more about what to expect before, during and after radiation therapy treatment.

WHAT IS RADIATION THERAPY?

Radiation therapy is a treatment in which an x-ray beam, coming out of a machine called a linear accelerator, is aimed specifically at the site of the cancer. The x-rays damage the DNA (genetic code) in the cancer cells, and this damage then results in the death of the cancer cells. Radiation therapy is planned to treat as little of the normal body as possible.

The machine moves around you for treatment and can treat from a number of different angles. The machine or equipment may come close to you but it will not touch you. You do not feel the radiation as it is being delivered.

ARO TEAM

You will meet various members of the ARO team during your visits. The radiation therapists and nurses work closely together to deliver your treatment under the direction of your radiation oncologist.

We aim to give you the best possible care during your treatment. Please approach any ARO staff member with your concerns or questions. If they are not able to assist, they will direct you to someone who can. We also encourage you to visit the ARO website.

PATIENT INFORMATION

Receiving Radiation Therapy to the Head and Neck

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Team members and their roles:

Radiation Oncologist	A specialist doctor who is qualified in cancer treatment with radiation
Radiation Therapist	Qualified technical professionals involved in the planning and delivery of your radiation treatment as well as day to day care
Student Radiation Therapist	ARO is a training facility and there may be students involved in your treatment. You have the right to ask that students not be present during your procedures.
Registered Nurse	Experienced nurses with advanced knowledge of caring for cancer patients. The nurses and radiation therapists will provide advise on how to look after yourself during treatment.
Receptionist/Scheduler	Responsible for helping you with scheduling your appointments. They will also be able to discuss your account details
Medical Physicists	A scientific officer who performs regular checks to ensure the safety of radiation equipment and treatment plans
Engineer	Responsible for the maintenance of equipment

USUAL ARO TREATMENT PATHWAY

Your radiation treatment will be given at ARO located on the Mercy Hospital campus, Epsom, Auckland. Most patients will follow the seven steps in the ARO patient treatment pathway. Please refer to My Treatment Book.

Once you have met with your radiation oncologist specialist and confirmed your decision to proceed with treatment at ARO (step 1) we will require information as part of the orientation (pre-treatment planning) stage.



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SPECIAL INSTRUCTIONS AND INFORMATION

The following information is specifically for patients receiving treatment to the head and neck region.

Step 1:

SPECIALIST APPOINTMENT

Your specialist will be required to arrange a dental appointment for you prior to you attending orientation with us. This is to check your mouth and teeth are in good condition prior to starting treatment.

Step 2:

ORIENTATION (pre-treatment planning)

At orientation you will need to have immobilisation pieces made. These immobilisation pieces typically include an accuform, which is a specially moulded pillow and a shell or mask.

The shell is a thermoplastic sheet which is heated in a water bath and moulded over the head, neck and shoulder area in order to hold you in the correct position for treatment and prevent permanent marks in the facial region. There may be other devices required depending on the area to be treated, for e.g. mouth bites, gum guards, tongue depressors and bolus.

Having this area immobilised and treated can bring about a feeling of claustrophobia. If you are very claustrophobic, discuss this with the patient care team prior to your immobilisation fitting so they can help you cope through the process.

You are likely to need a number of scans as part of the pre-treatment planning process, e.g PET and MRI and they can be over the course of a couple of days. Some of these scans will be off the ARO site and may have their own instructions. Please follow the instructions provided by each scan provider. These separate scans all give us different pieces of information in order to plan your treatment appropriately.

If you are able to get pregnant, remember to be conscientious with protection during this time as pregnancy is not recommended. If you are concerned or suspect you are pregnant when you come in for your initial appointment at ARO or at any stage during the treatment course, please talk to a member of the team.

Step 4:

DURING TREATMENT

Each day you will be positioned as you were when the immobilisation devices were made.

As you have a shell on for the duration of treatment, the best way to communicate with the radiation therapists is to use hand signals when asked yes/no questions:

- Thumbs up is you are OK
- Thumbs down you need assistance



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When the treatment is being delivered, the radiation therapists are outside the room watching you on a closed circuit camera, so if you need assistance give a wave with one of your hands.

You will have a number of appointments during your treatment course with the patient care team and your oncologist. You will be required to see our dietician each week to manage your eating and drinking as maintaining a consistent weight during the course of treatment is important for your wellness and treatment accuracy.

POTENTIAL SIDE EFFECTS

X-rays used in radiation therapy can damage the DNA (genetic code) of cells. The radiation also affects the normal tissues of the body, and this can cause side effects. However, we know that normal tissues are better able than cancer cells to heal the radiation damage, and most of the normal tissues will recover.

Due to improvements in treatment planning systems and treatment delivery, the side effects of radiation therapy have been reduced remarkably. However, some side effects still occur and can be categorised as **Acute** (short term) or **Chronic** (long term) side effects.

ACUTE SIDE EFFECTS (Short Term)

These are side effects that occur *during* the treatment course and usually take a few weeks to resolve after completion of treatment. At the beginning of the course you may notice little change, except perhaps, some fatigue. Acute side effects often occur about two weeks through the treatment course and then increasing toward the end. Please let the patient care team or the radiation therapists know of any changes. Your treatment team will help you manage any side effects.

The peak of any reactions/side effects that you may experience will occur approximately 7-14 days after the completion of your radiation treatment. This is due to the cumulative nature of the treatment.

COMMON ACUTE REACTIONS

Fatique

General tiredness may occur during and after the treatment course. Some people may still be able to work and only take time off for the daily appointment, but others may find it too tiring and prefer to stay at home. Also, you may be more emotional than usual and wish to call on family and friends to help during this time.

Advice to help combat fatigue includes:

- It is recommended that you keep up your fluid intake while on treatment (1.5-2L a day).
- We recommend you maintain a well-balanced diet
- Mild exercise e.g. walking for 30 minutes three times per week has been shown to be beneficial
 in dealing with the fatigue associated with radiation therapy. Generally you can carry on your

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usual level of activity, however, it is important that you listen to your body and do not over exert yourself if fatigue is an issue.

• Getting plenty of rest each day facilitates the normal body tissues to recover on a daily basis from the effects of the radiation therapy.

Skin reddening and irritation within the treatment area

Skin in the area of treatment may pinken or darken as you go through the treatment course. The timing of the skin changes depends on the course of treatment prescribed, but commonly slight reddening occurs by the second week of treatment. The skin becomes increasingly red towards the end of treatment, with the peak of the reaction occurring 7-14 days after the completion of treatment.

There may be patches of skin that peel toward the end of the treatment course. This is most likely to occur behind the ear (if treated) or in an area where the tumour lies close to the skin. You will be given advice and appropriate prescriptions to help manage these effects at the beginning of treatment.

The nurses should see you on one of your initial days of treatment to advise you on the use of a gel called STRATA, which is designed to cover the area being treated and help minimise the skin reaction.

Advice to help combat skin reactions includes:

- When washing in the treatment area, use warm water, avoid scrubbing, and pat dry. You may
 use any mild soap such as Dove Extra Sensitive or Simple Soap.
- Do not apply heating or cooling devices in the treatment area. This includes heating pads, hot water bottles, ice packs, hairdryers etc.
- It is recommended you avoid wet shaving/waxing hair in the treatment area during the course of treatment and until any skin reaction has completely settled. You may use an electric razor.
- Avoid hot pools while on treatment and until any skin reaction has completely healed. Discuss swimming in salt or chlorinated water with your Oncologist, as this may be determined on an individual basis.
- Be aware of the clothing you wear over the treatment area. Loose fitting, soft, cotton clothing is recommended.
- Try to keep the treatment area protected from the sun and wind. However, **do not** apply sunblock to the treatment area while you are on treatment.
- Even after you have completed your treatments the irradiated skin will always be more sensitive to the sun, and therefore ongoing care is necessary. Anytime you are out in the sun, cover previously treated skin with a hat or clothing or apply a sunblock with a SPF of 30 or higher. Before applying sunscreen make sure skin is well healed from the radiation.

PATIENT INFORMATION



Receiving Radiation Therapy to the Head and Neck

Mucositis (inflammation of the lining of the mouth or throat)

This is a common and troublesome side effect that affects the majority of patients receiving radiation near the mouth or throat.

Symptoms of tenderness and discomfort will usually start in the treated area approximately two weeks into therapy. This will progressively worsen to a peak reaction experienced between weeks 5-8 (after the start of treatment).

At its' worst, patients will have mouth ulcers and often need strong pain killers to control symptoms. White patches can occur in your mouth, caused by candida (oral thrush). Mouth washes from the start of treatment are recommended after each meal using the saline recipe provided in 'keeping your mouth clean'. Please inform your treatment team if you notice any changes.

Dietary modification is often required, supplement shakes are often added to your diet and in some cases patients will need supplemental feeding through a tube placed directly into the stomach. This is called a PEG tube (See PEG care advice). Your doctor will explain this in greater detail should you need one.

Patients having higher doses of radiation (especially given together with chemotherapy) may find that the mucositis takes six weeks to two months to settle.

It is important to try and maintain your weight during the course of radiation, however side effects of the treatment can make eating and swallowing difficult or painful. **Avoid the following** to help minimise these problems:

- Alcohol
- Smoking
- Very hot or very cold foods
- Sticky, sugary foods
- Foods with a high acid level (e.g. grapefruit, tomatoes, oranges)
- Dry foods (e.g. toast, crackers)
- Spicy foods

Alterations to the texture of your food may be required. For example, mince, chop, or blend. It may be useful to have a blender or food processor available during this time. Try moistening food by using sauces and gravies. Tinned or commercial foods may be convenient (see websites of interest).

You may also find it easier to have lots of smaller meals more often than larger ones less regularly. When eating, have high protein based food with each meal and add high calorie products to your meals and do not buy/eat reduced fat products.

High Protein Foods include:



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- Meats
- Eggs
- full fat dairy products
- beans
- protein shakes

If at any stage you are having difficulty eating or drinking, or you are suffering from a loss of appetite, please inform a member of the treatment team or patient care team.

Saliva

Most patients having treatment near the mouth will have a reduction and thickening of saliva. For some there may be partial recovery.

It is advisable to obtain a water bottle and sip fluids frequently. You can purchase artificial saliva from most pharmacies to help.

You are advised to do mouth washes regularly throughout the day to keep your mouth clean and help prevent infections that can occur due to a lack of saliva.

Keeping your mouth clean:

- Brush with a soft toothbrush after each meal and before bed.
- Use an alcohol free mouthwash from day 1 of treatment.
- Rinse your mouth regularly with saline mouthwash: ¼ tsp Baking Soda; ¼ tsp salt; 1 cup warm water. Do not swallow.
- Floss teeth gently, stop if gums bleed.

Management of Xerostomia:

The salivary glands produce saliva. Saliva is important because it moistens food (making it easier to swallow), aids digestion and protects the teeth from decay. Xerostomia is the name given to the condition when your salivary glands do not produce saliva.

The following suggestions may help with the management of a dry mouth:

- Frequent sips of water or water rinses (you might want to carry a sipper drink bottle)
- Sugarless chewing gum
- Artificial saliva substitutes (Oralube saliva substitute can be bought from the chemist)
- Regular dental checks and prompt treatment of dental decay
- Avoid hot, spicy or acidic food
- Lip-salve (eg. Chapstick, Vaseline) for dry lips

Hair loss:

This may occur but will depend on the specifics of the area being treated.



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Eyes:

Patients receiving radiation near the eye may notice an increase in tear production as well as conjunctivitis (inflammation of the eye). Your eye may also become dry and gritty feeling.

Eye drops or ointments will be prescribed to help relieve symptoms. The reaction should start to settle a few weeks after radiation.

Ears:

Radiation near the ear can result in hearing changes and ringing in the ears. This is generally a temporary issue, but discuss with your radiation oncologist if you are concerned.

CHRONIC SIDE EFFECTS (Long Term)

Most people experience only short term effects after completion of their radiation treatment, but a few may experience some long-term side effects. Chronic side effects may arise many months or even years *after* the completion of radiation therapy. These side effects relate to the 'scarring' effects of the radiation therapy on normal tissues within the area of treatment.

COMMON CHRONIC REACTIONS

Skin changes

- Skin breakdown can occur. A district nurse referral may be required if you have had skin breakdown and require dressings. Your doctor or the nurses at ARO can arrange this should the need arise.
- Skin pigmentation and texture can change.

Salvia Production

Some patients may have a permanent dry mouth, particularly if both sides of the face or neck are included in the overall treatment.

Eyes

Long-term effects of radiation near the eye may result in cataracts (treated with lens replacements) or a condition called dry eye, due to damage of the tear gland. Very rarely treatment can result in decreased vision due to damage of the retina or optic nerves. Your Oncologist will discuss this with you if you are at risk.

Ears

Radiation near the ear can result in temporary or permanent hearing damage. Once again your Oncologist will discuss this if you are at risk.



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UNCOMMON CHRONIC REACTIONS

Skin changes

The skin within the treatment field may appear darker for a while. *Telengiectasia* may develop. These are tiny blood vessels under the skin that may become swollen. These can be unsightly but do not require treatment.

Mucosa (lining of mouth and throat)

The early effects should settle. Rarely patients may develop a mucosal ulcer which requires additional interventions to help healing.

Radionecrosis

This is a rare (<5% of patients) side effect where patients develop problems with healing in the bone or soft tissues. This is often precipitated by trauma (such as dental extraction) to the irradiated area and can occur many years after treatment.

To minimise the risk of this happening many patients will have preventative dental extractions prior to treatment. This is arranged through maxillo-facial (dental) surgeons. There may also be a requirement for ongoing preventative dentistry.

Blood vessels and nerves

There is a small risk that radiation will damage the blood vessels in the neck. In some patients this may require treatment with blood thinning tablets such as aspirin in the long term. This effect is usually only noticed years after therapy. There is an extremely small risk of damage to the nerves or the spinal cord in the long term.

Second cancers

There is a theoretical risk of developing second cancers, usually many years after radiation. This is an extremely rare side effect (<1/1000).

PEG CARE: (This section only applies to patients who have a PEG)

- Wash hands with soap and water.
- Inspect surrounding skin for redness, tenderness, swelling, irritation or leakage. If the skin is red or inflamed apply an iodine solution such as Betadine.
- Cleanse skin with soap and water.
- Clean under the skin disc with a cotton bud.
- Dry thoroughly.
- Gently rotate the tube 360 degrees and check for some in and out movement. The skin disc should remain close but should not feel tight against the skin.
- Flush tube with 20-30 ml of warm water using a large syringe 60ml before and after feeds.



Administering medications:

- Using side/medication port, flush the tube with 20-30 ml of warm water.
- Give medications in liquid form where possible. If liquid is not available, tablets may be crushed and dissolved thoroughly in water.

Do not mix medications with formula and check with your Doctor or pharmacist that tablets can be crushed.

Tube Positioning:

- Daily check the graduation marks (numbering) on the tube nearest the skin disc to ensure the tube has not moved.
- If the tube appears longer or shorter please contact your health professional before feeding.

WEBSITES AND ORGANISATIONS OF INTEREST

Pure Foods: Commercial soft food, useful for when you are eating less or are finding it difficult to eat due to radiation side effects. https://thepurefoodco.co.nz/

Look Good Feel Better: mailto:info@lgfb.co.nz

Head and Neck Cancer Survivors Support Network Inc: http://headandnec.org.nz/ or headandnecknetwork@gmail.com

You can get eating well or living with a dry mouth booklets from the Cancer Society, the dietician or your patient care team.