Radiotherapy for cancer in the Head and Neck Region



Information for patients

Revenue from these services is spent on the treatment of poor cancer patients.





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You have been given this leaflet as you have been recommended treatment with radiotherapy for a tumour in your head and neck region. This leaflet provides details about the type of treatment planned for you, including how you can help yourself during and after treatment. This leaflet is intended as a guide, because the timing and effects of treatment may vary from one person to another. Family members and friends may also find it helpful. We hope that this leaflet answers most of your questions, but if you have any concerns please speak to a member of the team.

Before Starting Treatment

Before you start your treatment you may need to have a number of tests, to make sure your treatment goes smoothly and safely.

Dental Assessment

Radiotherapy to the mouth area can cause long term problems with your teeth and jaw bone. Radiotherapy may cause a permanently dry mouth; as it can damage your salivary glands.

Your main salivary glands are situated in front of your ears, on either side of your face. Saliva is important in preventing tooth decay. Without saliva, you will be more prone to developing dental problems. If your tumour is close to this area, or the lymph glands in your upper neck on both left and right sides need treating, you may develop this side effect.

If the area treated includes your jaw bone, over time your teeth may discolour or decay. This is because the radiotherapy can cause the blood supply to that area to be reduced.

Radiotherapy may also cause gum shrinkage, which may cause further dental problems. If a tooth is removed from an area that has been treated with radiotherapy, healing may be slower and the jaw bone in which the tooth sat may develop longterm problems.

To minimise these late effects (effects that can develop years after treatment) we may ask a specialist dentist to see you. They will examine your teeth to make sure that any dental work you need is done before you start radiotherapy. You may not require any specific dental treatment before radiotherapy, however the dentist may suggest it is safer to remove some, or rarely, all of your teeth before radiotherapy starts. If you have any teeth removed, this may cause some temporary swelling for 1-2 weeks.

Certain chemotherapy drugs or radiotherapy near your ears can affect your hearing, so your doctor may arrange for you to have a hearing test before you start treatment. If your doctors know your baseline level of hearing, they can monitor any future changes to your hearing with more accuracy.

Nutrition

Nutrition is important, as it provides your body with energy, protein and the vitamins and minerals needed for your body to function well. It helps your body to cope better during radiotherapy and may improve your rate of healing and recovery after treatment. Your requirements for calories and protein increase during and after radiotherapy, so it is important to increase your intake to keep your weight stable. If you have lost weight or are finding it difficult to eat and drink enough before you start treatment, please ask to be seen by the Dietitian.

Eating and drinking can become quite difficult during and after radiotherapy treatment, particularly if you are having both sides of your" mouth and neck treated, or if you have swallowing difficulties before starting treatment You may be advised to have a feeding tube (gastrostomy tube) inserted into your stomach, which can be used for nutrition, water and medications if you are unable to eat or drink enough.

Your Dietitian will advise you on what liquid nutrition you need. You can still eat and drink whilst the feeding tube is in place and we encourage you to keep swallowing for as long as possible, if it is safe to do so. This helps to keep your muscles involved with swallowing as strong as possible and may help you to get back to eating and drinking sooner once radiotherapy has finished. If you have been recommended to have a feeding tube placed, this will usually be inserted either before you start treatment or within the first two weeks of treatment. Feeding tubes are usually inserted in the Endoscopy department as a day case and does not require overnight hospital stay. Once you return back to full eating and drinking, the feeding tube will be removed; this is generally a straightforward procedure which can also be done as a Day Case (with no overnight stay).

Coughing When Eating or Drinking (Aspirating)

The position of the tumour before treatment or the effects of radiotherapy once treatment has begun, may cause you to cough during or just after swallowing, or may make you feel you might choke when eating or drinking. This may be because food or drink is going into your lungs, which can put you at risk of developing a chest infection. If you think you are coughing during or just after swallowing, please inform your care team. They may suggest you see a Speech and Language therapist, who will assess your swallow and advise on safe swallowing. They may suggest different swallowing techniques or thickened drinks to help you swallow safely.

Swallowing exercises

Radiotherapy can affect the range, speed, timing and coordination of the muscles in the mouth and throat that are required for swallowing. This may reduce how widely you can open your mouth and can cause coughing when

eating and drinking. You may be given some preventative exercises to help with swallowing during radiotherapy, depending on what part of your mouth and throat are being treated.

If you have had eating and drinking difficulties following surgery, these may become a problem again or get worse during and after radiotherapy. It is important that you follow any swallowing exercises given to you by your Speech and Language therapist.

If you are having problems swallowing before you start your treatment, please ask to see a Speech and Language therapist.

Treatment Plan

When you have radiotherapy will depend on your treatment pathway. Radiotherapy for head and neck cancers can sometimes be given in combination with chemotherapy. Radiotherapy may also be used on its own instead of surgery, or after surgery. When high doses of radiotherapy are given with the aim of curing a tumour then it is called radicalradiotherapy. Radiotherapy can also be given to treat symptoms that are causing you problems, usually due to tumour growth on other parts of your body. The treatment relieves this pressure by shrinking the tumour. When lower doses of radiation are given to control symptoms then this is called palliative radiotherapy. The team will discuss with you which treatment has been recommended for you.

The Radiotherapy Planning Process

Your first appointment for radiotherapy planning will take at least 90 minutes. For the planning scan and for daily treatment, you will need to we are a plastic shell or mask. This helps to position you, so that we can accurately deliver the radiotherapy. The mask will be made before you have your planning scan. You may already have had scans as part of your diagnosis, but you will still need to have a radiotherapy CT scan, as this will allow us to plan where we need to treat you.

Lines will be marked on your mask and a permanent tattoo mark (the size of a pin head) may be made on your chest. These marks will be used to make sure you are in the correct position each day for your treatment.

Before you leave from this appointment you will be given a schedule of your treatment appointments.

Side Effects During Treatment

Radiotherapy treatment itself is painless. However, there are some side effects which are associated with radiotherapy. You will notice some of them gradually developing over the course of your treatment. Side effects gradually increase in severity as you go through treatment and it is likely they may become worse

10-14 days after your last session of radiotherapy. During the treatment reviews, your care team will assess how you are coping with the treatment and will provide advice and support.

During your treatment you will see a member of the medical team, who will see you at a weekly

appointment in the radiotherapy department. If you have any issues that need medical review on any day other than your appointment, please ask one of the radiographers on the treatment machine to guide you.

Skin Reaction

The skin in the area of the treatment will become red, dry or sensitive, itchy and then often become moist and sore. You will lose the hair in the area treated. This may grow back after treatment. It is important to keep these areas clean and dry. It is likely that the skin in the area, especially around creases, will become broken and produce a discharge. It is normal for this to be coloured or bloody. It is common for the skin reaction to become worse during treatment and for about 10-14 days after your last treatment of radiotherapy.

The medical tam will assess your skin each week and advise you on the different lotions and dressings which will ease the discomfortand, help heal your skin. During radiotherapy, generally you should avoid "wet" shaving with a razor in the area which is being treated. Please ask your medical team for more advice about this.

If you have had a laryngectomy before radiotherapy you will be given advice about how to care for the skin around your stoma, which tube to use (if you need one) and which baseplate to use as treatment progresses.

Sore Mouth and Throat

The treatment will cause your mouth and throat to swell and become sore, which can make eating and swallowing more uncomfortable or difficult. This usually happens around the end of the second week.

When your mouth and throat become sore you may need to avoid very spicy or 'acidic' foods such as curry, chillies, vinegar, tomatoes and citrus fruits. Food and drinks at room temperature may be more comfortable, so you may need to allow hot food and drinks to cool before eating and drinking.

It is important to regularly take the pain relief you have been prescribed, if you are using anti-inflammatory painkillers such as ibuprofen, these need to be taken with food to prevent irritation to your stomach. We recommend that you take other painkillers half an hour before meals. Rinsing your mouth with dissolvable aspirin half an hour before meals will also help to reduce the soreness and swelling, which will help you eat more comfortably.

Your Oncologist will advise you about increasing or changing your pain relief, as needed, to keep you as comfortable as possible throughout your treatment.

Some painkillers (e.g. those that contain codeine or morphine) can cause constipation or sickness, so it is important to take regular laxatives, or antisickness drugs while you are taking this medication. Let the team know if you are not opening your bowels regularly.

Dry Mouth and Throat

You may notice that your throat also becomes dry, and your saliva becomes sticky and thick. Sipping drinks throughout the day can help to keep your mouth and throat moist and loosen thick saliva. You may want to carry a bottle of water, to sip from regularly. Salt water mouthwashes may help make your saliva easier to clear. The care team can also discuss other products for you to try. Breathing in warm steam when you are in a steamy bathroom or kitchen, or from a mug of hot water, may be helpful in loosening thick saliva. Nebulisers, which send moist air through your airway, may be beneficial if you are still having difficulties clearing thick saliva. Your oncologist can prescribe mouthwashes and protective gels that coat the lining of the mouth and can also help with the discomfort.

Foods that are soft and moist may be easier to chew and swallow when you have a dry mouth, rather than dry, hard and rough textures such as toast, cereals, biscuits or salad. You may also find potato, bread and meat the most difficult foods to chew and swallow. Adding extra gravy or sauce to your food and chewing all food well before swallowing will make eating easier. If you have a feeding tube and find that you are drinking less, you can give extra water flushes via the feeding tube; this will help to keep your body hydrated. Please discuss this with your care team or Dietitian for further advice. Oral thrush is common when your mouth is dry. You may notice a white coating in your mouth and soreness. This can be easily treated with medication. Thrush can be painful and so may affect how well you can eat and drink.

Here are some meal ideas when soreness and dryness are a problem.

Breakfasts	Light Meals
Breakfast cereal soaked in milk	Soups with soft lumps or smooth
Smooth bland cereals with extra milk	bland soups
Soft boiled eggs	Cook soups for longer for softer
Poached eggs	lumps or you can use a blender to
Fried eggs	liquidize soups to the right
Scrambled eggs with extra butter	consistency for you
and milk	Soak pieces of bread in soup

Omelettes

Full fat yoghurt with honey and soft tinned fruit in syrup or fruit puree Yoghurt based smoothie drinks ("lassi") High energy/protein milkshake

Eggs

(e.g. soft boiled / scrambled / omelets / egg mayonnaise)
Fish mousse
Mashed avocado
Baked or boiled potato with extra butter with mayonnaise / cheese / egg mayonnaise

Main Meals

("Haleem")

Cauliflower cheese

Macaroni cheese

Noodles in sauce

Well cooked pasta with sauce

style drinks

Minced meat with extra gravy
Meat balls in gravy
Fish in sauce
Tinned spaghetti / Noodles
Mashed sweet potato, carrots with
extra butter and grated cheese
Soft boiled vegetables (e. g.
cauliflower, carrots, squash) with
extra butter and / or cheese sauce
or gravy
Lentil / bean soups enriched with
cream or cheese or butter
Lentil soup with oats, wheat & oil

Desserts

Rice pudding or ground rice pudding
Creamed tapioca
Creamed semolina
Mousse/instant whip
Crème caramel
Egg custard
Chocolate desserts
Ice cream
Trifle
Jelly
Tinned fruit (peaches, pears,
mangoes) or can be pureed with
cream / evaporated milk / ice cream
Stewed fruit with cream /
evaporated milk ice cream Plain

yoghurt with honey

cream ice cream

custard or cream

Cake sponge with extra custard /

Mashed banana and custard

Bread and butter pudding with extra

6

Taste Changes

Radiotherapy can affect your taste. People experience a range of taste changes, so it can be difficult to predict how your taste will be affected and to what extent Some people lose their sense of taste altogether and often report that" everything tastes like cardboard", while others find that food can taste very salty or metallic. Here are some ideas that may help you cope with taste changes:

- Go along with food cravings and enjoy the foods you can taste
- . Try eating food cold or warm, rather than hot
- Experiment as much as possible with different foods and flavours.
- Retry foods you previously did not enjoy and try new foods
- Try eating stronger tasting foods (extra flavour)
- Use plastic cutlery if you experience a metallic taste in your mouth.
- Continue with mouth care and mouthwashes as recommended

Usually the side effects may become worse for a short while and slowly settle overa few weeks. Please do not worry, as this is quite normal.

Loss of appetite

It is common to lose your appetite during treatment. Eating smaller amounts of food more frequently or eating things that you particularly like may help. If you are eating less than normal it is important to make sure that each mouthful gives you as much nourishment as possible. To increase the calorie and protein content of what you are eating you can add the following to food or drinks:

Full fat milk

Milk powder

Cream

Butter, "ghee", margarine or oil

Mayonnaise or salad cream

Sugar or honey or syrup

Full fat yoghurt Jam

Ice cream Ground nuts

Evaporated milk Pureed beans or lentils

Cheese

If you are struggling with finishing your meals your Dietitian may recommend nutritional supplement drinks such as Complan shake™, Ensure plus™ or Fortisip™,to help improve your food and drink intake. These are high energy/protein milk shake style drink that you can use between meals. They are available to buy or on prescription.

If your speech and language therapist has advised you to thicken your drinks it is important that you follow this advice for safety reasons. Yoghurt, bananas or pureed fruit can be added to help thicken drinks, or you may have been advised to use a thickening powder.

7

Nausea (feeling sick)

If you suffer with nausea, we can give you anti-sickness tablets to take before each treatment. It is important to continue to eat and drink; try eating small meals more frequently. If you continue to feel sick, or you are vomiting (being sick) despite taking anti-sickness medication, then tell your therapeutic radiographer or medical team.

Tiredness

You may feel tired, especially toward the end of treatment. Listen to your body and, if necessary, allow yourself extra time to rest and sleep. While your energy levels are low you may want to avoid strenuous activities and do only what you feel is manageable. You may need to consider reducing or stopping your work commitments for a short period of time. Your medical team may be able to give you a note for sick leave, if needed. Tiredness can take several months to improve, and may last for up to ayear after the treatment ends. Feeling too tired to eat and drink is also very common. It may help to make meals in bulk and freeze into individual portions. Take a portion from the freezer the day before you want to eat it and place itin the fridge. Reheat until piping hot and then cool to room temperature before eating, if you suffer with soreness when eating.

Low Mood

Having periods of low mood during and after your treatment is common. If you have any concerns or worries, please speak to a member of your medical team. We can refer you to our psychologist or psychiatrist for support.

Speaking

If the treatment has included your voice box, you may find that you lose your voice. Try to use your voice gently and quietly (but avoid whispering as this can strain the voice further). It might be helpful to carry a paper and pen with you so you can write messages rather than speak, if needed. Your voice will gradually return and you may be referred to the Speech and Language therapist for advice. If you notice that your breathing becomes noisy, please tell your care team or call the emergency helpline.

If you have had a laryngectomy operation before starting radiotherapy, you can continue to use your voice valve if you have one, as long as you are able. If the skin becomes sore around the stoma you may find it difficult to use the valve. You will be given advice about managing your valve and stoma tube by the Speech and Language therapists, as you go through treatment.

Difficulty Opening Your Mouth

Radiotherapy and some operations carried out before starting radiotherapy treatment may cause tightening of the muscles that open your mouth, making

8

your jaw tighter and more difficult to open. This is called trismus. It is important that you practice the exercises that the Speech and Language therapists have given to you regularly throughout the day. It may be more comfortable to do these exercises after taking your painkillers.

Important Advice During Treatment

Smoking while you are having treatment can cause the side effects to develop earlier, possibly be worse than usual, and be harder for you to cope with. We strongly recommend that you try to give up smoking before starting radiotherapy. We know this is often difficult - please talk to your therapeutic radiographer or family doctor for help and support.

Alcohol can also make the side effects of radiotherapy worse. We recommend that you don't drink alcohol during your course of radiotherapy. If you have any questions about this please speak with your medical team.

It is very important that you come for all your treatment appointments. Any missed treatments have the potential to reduce the success of the radiotherapy. If for any reason you are unable to come for treatment, please inform us at the earliest opportunity. We may be able to make suggestions so that you can still come or will arrange for you to make up for the missing treatment.

Possible Long Term Side Effects

Long term side effects can occur many months to years after radiotherapy has finished. These are called 'late effects' and are hard to predict. Unfortunately if they do occur they can be permanent. We plan the treatment to avoid the surrounding areas around the tumour as much as possible, to reduce these side effects.

Swallowing and Taste

As you recover from the side effects of radiotherapy treatment, eating, drinking and talking should gradually become easier. Everybody is different and the length of time it takes can depend on where you had your radiotherapy treatment, the severity of radiotherapy side effects, how easily you could swallow before radiotherapy and whether you were able to continue swallowing during treatment. There may be small a chance that your swallowing may not recover completely and you might need a long term feeding tube. The Speech and Language therapists and Dietitians will aim to help you work on swallowing as much as possible after treatment.

Your taste can take several months to recover and some foods may not taste the same as you remember them. It is important to re-try foods regularly and perhaps try foods that you disliked before treatment. Swallowing may also be different after treatment and may not completely recover back to "normal". You may find that you need to eat softer foods with extra sauce or gravy, particularly if you suffer with a dry mouth and throat.

Mouth and Dental Problems

Following your treatment you may be advised to see a dental therapist. Where possible, teeth that needed to be removed before treatment may be replaced over a series of visits.

As saliva normally protects your teeth from dental decay and your mouth from infections, it is important that you take extra care to keep your mouth clean. It may continue to be sore and it may take a long time for your tongue and the lining of your mouth to heal. Your mouth may become more difficult to open over the months after treatment. You may need to be reviewed and given a long term exercise programme from Speech and Language Therapy.

A Dry Cough

A dry tickly cough can occur as the reaction to radiotherapy settles. This maybe eased by sipping drinks. Some people find a simple cough medicine helps. The irritation caused by the radiotherapy should 'settle within a 'few weeks of completing your treatment. If you develop a persistent cough, contact your family doctor. If the cough happens when you eat or drink you should ask to seek Speech and Language therapist for a swallowing assessment

Skin Color Changes

Following treatment, the area of your skin that has been treated can remain darker (generally or in patches) or you may notice tiny blood vessels - this is rare.

Tight Neck and Throat

Your neck and food pipe may continue to feel tight and may affect your swallowing. Your treatment team may refer you to the Speech and Language therapist for assessment and advice.

Dry Mouth and Throat

Radiotherapy may cause you to have a permanently dry mouth as it can damage your salivary glands. You may find that using the products you used during treatment and modifying your diet (taking regular sips of water and choosing softer foods with extra sauce or gravy) is helpful in the long term.

Speech and Voice

As the side effects of treatment reduce, your speech and voice will become clearer. If you continue to find it difficult to speak words clearly and precisely, the Speech and Language therapist can give you further advice and exercises. If the treatment area has included your larynx (voice box), your voice may remain permanently weaker or huskier.

If you have a laryngectomy and it became difficult to use your voice valve during treatment, you can now start to use this again, as your skin and stoma recover. Speech and Language therapists will guide you through the equipment to get the best voice, and will change the valve when it leaks.

Weight Loss

It may be difficult to get back to your normal weight after treatment, even though you feel that you have regained your appetite and are able to eat good amounts. This is normal, but if you lose more weight after your treatment has finished it is important to tell the care team when you have your follow-up appointments.

Lymphoedema

Lymphoedema is a buildup of lymph fluid that causes swelling in an area of the body. This may occur because the lymph drainage channels or lymph nodes are blocked or may have been removed if you had surgery. Not everyone who has a tumour or tumour treatment develops lymphoedema, but your doctor should discuss with you whether this is a possibility.

Bones and Cartilage

Radiotherapy can make the jaw bone brittle. It is important to discuss with your dentist that you have had radiotherapy treatment and if you need any future dental extractions, as there is a risk that your jaw bone may not heal well afterwards. The cartilage in your voice box can also be affected if this area has been treated. This is rare but may be more common if you smoke during treatment. Please let the doctors know of any changes in your mouth when you come for your follow-up appointments

Hormones

If your treatment has included the thyroid gland in your neck or the pituitary gland at the back of your nose, it may affect hormone production. Hormone levels can be checked with a blood test and your doctors will discuss this with you if necessary.

After Treatment

You will be asked to return to the Outpatient clinic to be seen by your oncology team. Radiotherapy takes time to work, so at this appointment your doctor will assess and discuss your progress and any continuing side effects with you and will plan future appointments.

You may be anxious to know if the treatment has been effective. However, it is important to wait until all the inflammation caused by radiotherapy has settled before we carry out any scans. This may be approximately two to three months after the treatment has finished. Your Oncologist will book the scan for you, when appropriate.

We do not recommend that you book a holiday for at least six weeks after the completion of your radiotherapy treatment, to make sure you feel well enough to enjoy it.

You may want to make some notes of the advice you have been given at your weekly reviews during treatment.

