

ORAL HEALTH CARE FOR HEAD AND NECK CANCER PATIENTS

Your guide to looking after
your mouth during your
cancer treatment.



INTRODUCTION

Starting your treatment journey can be daunting, but everyone is with you every step of the way.

Your journey and treatment is tailored to you. Some patients benefit from one type of treatment, others from a combination of multiple treatments. They include surgery, chemotherapy, radiotherapy, immunotherapy. You will be advised what is best for you.

Given the cancer is in the head and neck, the treatment/its side effects are likely to affect your mouth. This information booklet is designed to help you manage your oral health; especially given the side effects you may experience.

If you are struggling with anything, you must seek advice from your doctors/ oncology team looking after you.

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WHAT TO DO BEFORE STARTING YOUR TREATMENT

Your mouth may go through many changes during your journey. To help optimise your mouth before treatment, you should be directed to the dedicated member of the team to assess and discuss your mouth.

Often this is a team led by a Consultant Restorative or Special Care Dentist. They may also liaise with your own dentist:

1. **Dental Check Up:** It is important that your mouth is as healthy as possible. If there is any issue that needs to be seen to, this should be carried out before the cancer treatment starts.
2. The dentist can prescribe a **high fluoride toothpaste**. Use this to help protect your teeth. Further down your treatment journey, keep in contact with your own dentist and attend as recommended. They may provide other fluoride-based treatment if required.
3. Brush **twice a day** and clean in between your teeth. Ask the dentist to show you how this is done if you're unsure. Keep in contact with your dentist as they may change your routine if required.

This will need to be done in a timely manner so there is no delay to your cancer treatment starting

WHAT TO DO BEFORE STARTING YOUR TREATMENT

Your dentist may need to discuss all of your teeth with you and **they may recommend some to be removed**, especially if they could be a potential infection risk or problem during your treatment.

The aim is for your mouth to be as fit as possible for the upcoming treatment.

This is also particularly important if you are having radiotherapy. Unfortunately, radiotherapy also affects the strength of the surrounding jaw bone and may cause complications in the future.

If there are any teeth that have the potential to cause problems, these will be considered for removal.

Sometimes, these assessments and treatments are done in the hospital by both a specialist restorative dentistry and oral surgery team.

Whoever you see will be able to discuss this in detail with you and you can ask the team if you have any questions.

If you are struggling with your dental care, make sure to ask your dentist for advice. There is more on mouth care later

WHAT TO EXPECT WHILST IN HOSPITAL AFTER SURGERY

If you have surgery, the extent of surgery varies and that is something you can discuss with your surgical team. You will understandably feel discomfort, sore and swollen afterwards.

The team will help manage this as you recover.

BASIC MOUTH CARE

Mouth care is something that happens gradually after surgery. It starts off simply:

- Moisten the mouth as instructed
- Mouthwash
- Suction

NEXT STEPS

Ask your surgical when it is suitable for you to start brushing your teeth with a fluoride toothpaste. Try and maintain the mouth care habits as you did before, with your hospital team's advice. You may be provided with the home care tools when you are discharged

The hospital team are more than happy to give you advice, just ask

WHAT TO EXPECT WITH CHEMOTHERAPY AND RADIOTHERAPY

If you have chemotherapy and/or radiotherapy, there are other side effects you may experience. These can be difficult to manage but the oncology/surgical team can talk you through this.

During this treatment, you can stay in touch with your local dental team but any non urgent treatment should be stopped during active cancer treatment.

If you require urgent dental care, liaise with your hospital team

CHEMOTHERAPY

Chemotherapy is a medicine, usually given through a vein, used to treat/manage the cancer. The side effects depend on many things like which combination of medicines are given. You can find your specific medicine on the Cancer Net UK website and search for the side effects linked to your particular medicine.

Chemotherapy affects the lining of the mouth and can cause inflammation/irritation. This can lead to side effects (see next page).

You may have one, both or neither of these treatment options, so speak to your oncologist about your specific treatment plan

WHAT TO EXPECT WITH CHEMOTHERAPY AND RADIOTHERAPY

RADIOTHERAPY

Radiotherapy uses a beam of energy to target the cancer. Some nearby normal cells can be damaged too, which causes side effects.

These are usually short-term as the cells recover, however can sometimes be long term.

COMMON SIDE EFFECTS

- Sore mouth (oral mucositis)
- Dry mouth
- Nausea and Sickness
- Thick Saliva/mucus
- Jaw stiffness
- Jaw bone changes
- Changes in the mouth

We will also discuss good mouth care habits to easily and comfortably keep your mouth as healthy as possible

SORE MOUTH (ORAL MUCOSITIS)

You may feel as though your mouth is sore and dry. You may feel a burning sensation when you eat and notice a thicker saliva. You may also notice your mouth is red or has ulcerations.

Please inform your medical team if you notice this, especially if it is affecting your eating and drinking. It can be uncomfortable, however, these are some ways to manage your mouth:

Do

- Eat soft, colder foods
- Keep food moist with yogurt, sauce, gravy
- Drink with a straw
- Suck ice/ice lollies/sugar free sweets
- Warm salt-water rinses: 1 tsp salt: 1-pint warm water
- Use an oral barrier gel; ask the doctors which brand
- Brush your teeth gently 2-3 times a day with a soft toothbrush and flavour free/mild flavoured toothpaste.
- Mouthwash/Spray: Benzydamine (Difflam) has a numbing effect. NB: Chlorhexidine (Corsodyl) is an antiseptic mouthwash and can be quite irritating. It may make symptoms worse. Ask for alternatives.
- Keep lips well moisturized
- Ensure there is nothing sharp in your mouth eg a filling. This needs to be addressed

Check with your team if you are unsure which products to be using.

Other treatments may be available to you.

Please ask.

SORE MOUTH (ORAL MUCOSITIS)

Don't

- Drink alcohol/Smoke tobacco/ Use alcohol containing mouthwash
- Wear your dentures, especially if ill fitting
- Floss if your platelet count is low- check with your doctor. You could try a gentle irrigation instead. Please ask your doctor.
- Use whitening toothpastes. Avoid toothpastes with Sodium Laurel Sulphate
- Eat spicy, hot, acidic food as they can be uncomfortable
- Have boiled sweets/Sharp food that can cut your mouth as this can cause blistering/ulcers/more soreness

SORE MOUTH AND RADIOTHERAPY

If you are having radiotherapy, you may notice a sore mouth starting halfway through your treatment and it can be worse towards the end.

It can last for up to 10 days after treatment finishes, but most people notice an improvement in this up to 8 weeks post treatment.

*Corsodyl mouthwash can make symptoms worse
if you are having radiotherapy.
Use warm salt water rinses in this case*

DRY MOUTH

This can be a common side effect of treatment and can be uncomfortable to manage. If you are struggling to eat or drink well, please inform your medical team.

Here are some management tips:

Frequent sips of water.
Avoid fizzy drinks/sparkling water/juice/squash.

Benzydamine (Diffiam) spray/mouthwash

Artificial saliva substitutes: See on next page for some suggestions

Humidifiers in your room

Nebulisers to reduce thick saliva. Ask your team if this may be suitable for you

Keep lips moist with lip balm such as Vaseline

Ask your GP if your regular medications can cause dry mouth

Oral barrier gel: ask your medical team for an advised brand

Avoid snacking on sugary foods – see below

Your saliva acts as a buffer for your teeth. Without this, you are at a higher risk of tooth decay. It is important to avoid frequent snacks and sugary foods outside of meal times.

DRY MOUTH

Below is a table of examples of saliva substitutes you could try.

They may be available on prescription, and others are available over-the-counter.

Product name (manufacturer)	Available Form	Precautions	Contains fluoride?
AS Saliva Orthana	Lozenges or Oral Spray	-	Lozenges: No Oral Spray: Yes
BioXtra	Gel	-	No
Biotene Oralbalance	Gel	Avoid using with toothpastes containing detergents /foaming agents	No
Glandosane	Spray	Acidic – avoid if you have your own natural teeth	No
Oralieve	Gel or Spray	-	No
Saliva Stimulating Tablets	Tablets	Acidic – avoid if you have your own natural teeth	No
Saliveze (contains no animal products)	Spray	-	No
Salivix (contains no animal products)	Pastille	Acidic – avoid if you have your own natural teeth	No
Xerotin (contains no animal products)	Spray	-	No

Ask your medical team which artificial saliva product they recommend if you are unsure.

DRY MOUTH

Do

- Eat soft, colder foods
- Keep food moist with yogurt, sauce, gravy
- Frequent sips of water
- Suck ice/ice lollies/sugar free sweets/chew sugar free chewing gum
- Warm salt water rinses - 1 tsp salt, 1 pint of warm water

Don't

- Drink alcohol/Smoke tobacco
- Use alcohol containing mouthwash
- Wear your dentures, especially if ill-fitting
- Eat spicy, hot, or acidic foods as they can be uncomfortable
- Eat sticky foods
- Eat sugary foods outside of meal times
- Sip on anything other than plain water
- Drink caffeine
- Have boiled sweets/Sharp food that can cut your mouth as this can cause blistering/ulcers/ soreness

Please refer to the previous page regarding artificial saliva substitutes

NAUSEA AND SICKNESS

Chemotherapy can often cause nausea, sickness and poor appetite. The priority is to help manage this for you to continue nourishing your body as best you can during your treatment journey.

There are general tips online on how to best take care of yourself e.g. the Cancer Net UK website. For the mouth, there are few things to be aware of:

Whilst it is good to avoid fizzy drinks to reduce the risk of tooth decay, if this is the only thing helping you stay well, this takes priority.

Wait 1 hour after the vomiting episode to brush your teeth. Vomit is acidic and can slowly wear your teeth down. Teeth take around 1 hour to recover after an acid attack.

To remove the bad taste of vomit, you can use a mouth wash, use a tongue scraper and chew a sugar free chewing gum.

Ask your dentist for a high fluoride toothpaste to help protect your teeth.

Maintain good mouth care habits as explained earlier.

Ask your medical team about anti-sickness medication if needed.

THICK SALIVA/ MUCUS

Changes in the mouth

Radiotherapy can change the thickness of your saliva (spit).

It can become thicker or more stringy/sticky, like mucus. This may build up in the mouth or throat as it does not flow around the mouth as well.

Help

To help clear this, you can try a sodium bicarbonate mouthwash: ½ teaspoon salt and 2 tablespoons of sodium bicarbonate dissolved in 4 cups of water.

Next

Follow with a plain water rinse to make sure the mouthwash has been cleared from your mouth and not swallowed

JAW STIFFNESS – ‘TRISMUS’

Radiotherapy or surgery to the head and neck area can cause jaw stiffness, which can develop a few weeks or sometimes months after treatment.

The amount of stiffness varies from person to person. Your jaw may ache, and you may notice you cannot open as wide as you did before.

Tell your medical team if you have jaw stiffness or pain, even if it is mild. It often goes unnoticed and without treatment, jaw stiffness can get worse. It is best to start treatment as soon as possible. You will usually be referred to a speech and language therapist or physiotherapist for management

This can be difficult to treat so perseverance is important. These exercises may help:

Place wooden spatulas or tongue depressors between your upper and lower front teeth for a certain amount of time each day. Increasing the number of spatulas you put into your mouth over time will gradually stretch the jaw muscles. Your medical team should supply these

Open and close your mouth as far as possible without causing pain; repeat 20 times.

Passive motion device: this is a device you could research into buying/ask your team more about

Contact your team if you are getting pain or having trouble eating and drinking.

JAW BONE CHANGES: OSTEORADIONECCROSIS AND OSTEOMYELITIS

Radiotherapy reduces the blood supply/nutrition to the jaw bone in and around the target area. This can cause the bone to die. This is called- osteoradionecrosis.

This can happen unexpectedly or from trauma, infection or dental extraction after radiotherapy.

If this occurs, you may notice a loose piece of bone, pain, swelling, a heaviness in the jaw, numbness. Tell your medical team about this ASAP.

Treating this is challenging. Management depends on the extent of the damaged jaw bone.

If this area of dead bone develops an infection (Osteomyelitis), you may notice a swelling, fever, bad taste, or you may feel unwell. If this happens, you should contact your team immediately or go to A&E

Please do not hesitate to contact your team if you are worried about this

JAW BONE CHANGES: OSTEORADIONECCROSIS AND OSTEOMYELITIS

To minimise the risk of this happening:

Do

- Visit the dentist before you start treatment: see beginning of booklet
- Visit the dentist regularly
- Look after your mouth with a good oral hygiene regime
- Have a balanced diet
- See a specialist dentist/surgeon if you need a tooth removed during/after radiotherapy so they can plan treatment to reduce risk of osteoradionecrosis

Don't

- Smoke
- Wear your dentures if ill fitting
- Have boiled sweets/Sharp food that can cut your mouth as this can cause blistering/ulcers/ soreness
- Have sugary foods as they increase your risk of cavities and therefore possible infection

Once you have had radiotherapy, this is a long term risk. It is important to avoid the need for a dental extraction in the radiotherapy zone.

CHANGES IN THE MOUTH

Chemotherapy & Radiotherapy affect your immune system and its ability to fight infections.

You can become more susceptible to infections, such as oral thrush (candidiasis) or cold sores (herpes simplex).

INSPECT YOUR MOUTH DAILY!

Inform your medical team if you notice:

- White spots
- White coated tongue
- Blisters/ Ulcers
- Bleeding
- Red areas

CHANGE OF TASTE

- This may take time to come back. You can try warm salt water rinses to try and help this. If you are struggling, inform your medical team

BURNING MOUTH

- This can be difficult to manage. Avoid hot/spicy foods and keep a food diary to help identify what makes it worse

If you develop tooth pain or infection, contact the cancer team urgently

MOUTH CARE REGIME

Looking after your mouth is very important before, during and after your treatment.

With these treatments, your risk of developing cavities in the teeth is higher. Below is a good regime to follow:

- Use a **soft toothbrush to start** with. Once comfortable, use your normal toothbrush. Check with your dentist/medical team if unsure.
- Brush at least **twice a day**: once at night and at least one other time.
- Use **high fluoride** toothpaste. This may need to be on a repeat prescription
- Clean all surfaces of your **teeth and tongue** gently for 2-3 minutes. Take care to **massage along the gums** as well
- Clean **in between your teeth** once a day as advised
- **Spit don't rinse** to allow the fluoride to stay around your teeth longer. Fluoride helps strengthen the teeth
- Use a high fluoride, alcohol free mouthwash. Use **after food/different time to brushing**. If this is too sore, use warm saltwater rinses instead.
- If you wear dentures, clean these separately as per dentist's instructions.

Regular visits to the dentist are important

MOUTH CARE - EXTRA TIPS

If your mouth is too sore, try a softer toothbrush/ask for an alternative from your team.

Your dentist can provide fluoride-based treatment if needed.

Try avoiding sugary foods as much as possible to help reduce risk of cavities.

Floss as advised by your dentist/oncology team. Do not floss if your platelet count is too low. You could try a gentle irrigation instead-check with your oncology team.

Bad breath is usually helped by improving mouth care. If you find that the bad breath is not improving with cleaning, inform your medical/dental team as there may be an infection

Avoid toothpastes that contain SLS (Sodium Lauryl Sulphate) and whitening/abrasive toothpastes, especially if you have a sore mouth.

If you wear the special type of denture (an obturator) follow the hygiene advice you are given.

Please ask if you are unsure

LONG TERM CARE

Unfortunately, the risk of developing dental problems is usually long term after cancer treatment. This is particularly after surgery or radiotherapy due to the after-effects of these treatments.

If you smoke, chew betel nut/paan or drink alcohol in excess, try your best to stop this habit. You can speak to your oncology/dental team or the GP- they can direct you to services that can help you stop the habit if you feel you would like this. **Stopping these habits is also very important to prevent the cancer from coming back**

LONG TERM CARE

Long term, care is shared with your hospital team and your local dental team.

You should visit the dentist regularly: they will decide how often they need to see you.

Dentists and the dental team will help with:

- Oral cancer screening to check for anything suspicious that may reoccur
- Monitor for osteoradionecrosis – this is a long term risk
- Continue helping you with your oral hygiene and diet management, especially if you require further fluoride-based treatment.
- Management of late oral side effects of the treatment to the best of their ability. If you are struggling with this, you may require onward referral to other specialists so please let your team know.

If you need any complex dental work or tooth extractions, you will likely need to be referred to the hospital.

You are at a higher risk of developing dental decay, which can lead to infection and further problems. Good oral hygiene and diet is very important.

USEFUL RESOURCES

- Remember, your healthcare team are here to help.
- Useful contact numbers: Ask your team for the best numbers to call should you have any concerns. You can write them down below:

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Useful websites/ resources:

- Mouth Cancer Foundation
 - Cancer Net UK
 - Macmillan
 - National Institute of Dental and Craniofacial Research Patient Leaflets
 - Oral Cancer Foundation
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- The Mouth Cancer Foundation has weekly online support groups, networks and helplines. There is help for you and your carers. Please visit the website for more information

This booklet is a general guide. This does not replace any specific guidance given by your team. Please ask your team, especially if you are struggling.

NOTES

Use this space as you wish to note any questions you may have/write down any advice given to you

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References:

- Cancer Net UK
- Macmillan
- National Institute of Dental and Craniofacial Research
- National Cancer Institute
- Predicting and Managing Oral and Dental Complications of Surgical and Non-Surgical Treatment for Head and Neck Cancer Clinical guidelines
- Mouth cancer foundation
- Oral cancer foundation
- British National Formulary
- Oral Cancer Care Local Guide Toolkit, Greater Manchester
- The Oral Management of Oncology Patients Requiring Radiotherapy, Chemotherapy and / or Bone Marrow Transplantation Clinical Guidelines RCS



www.mouthcancerfoundation.org