Patient information on radiotherapy for upper head and neck cancer
Side effects of radiotherapy to the head and neck (upper throat, nose, sinuses, salivary glands, ear, and the neck)

This leaflet tells you:

- what side effects you might get
- how to look after yourself during and after treatment

Our radiotherapy team has written this information to help you know what to expect. Your team has planned your treatment just for you. They will tell you if anything in your care is different.

What are the side effects and how do I manage them?

Most side effects of radiotherapy only happen in the area being treated. Side effects affect people in different ways.
There are two types of side effects:

- Early and short-term. These can start during your course of radiotherapy. They usually get better by two to six months after finishing radiotherapy.
- Late and long-term. These are side effects that may happen many months or years after radiotherapy. Some of these side effects may not go away. Sometimes we may give you medicine to help.

How likely am I to get a side effect?

Words are used to explain how likely you are to get side effects

Word	How many people will get these side effects?
Expected	50 to 100 people out of 100 people
Common	10 to 50 people out of 100 people
Less Common	less than 10 people out of 100 people
Rare	less than 1 person out of 100 people

Your radiotherapy team will talk about these with you. They will tell you if anything is different for you. You may not get all the side effects discussed in this leaflet. Please ask your team if you have any questions.

As radiotherapy treatment to the head and neck region can cause swelling, soreness, and pain, it is important that you take care of your skin and pay attention to what you are eating and drinking.

EofE RTN Patient information radiotherapy to the upper head and neck V1.1
Author: Network Patient Information Group (NPIG)
Date agreed:
Date to be reviewed:

How do I care for my skin during and after radiotherapy?

- Wash your skin gently with soap and warm water. Pat it dry — do not rub.
- Apply Sodium Laurel Sulphate free creams (e.g. Aquamax, Epimax, E45, Aveeno, Aloe Vera Gel, CeraVe) in the morning and evening.
- Do not use thick creams or creams with a lot of paraffin or petroleum jelly.
- If skin becomes sore, please speak to a member of your radiotherapy team.
- Do not use zinc oxide creams such as Sudocrem.
- Avoid wet shaving in the treated area
- Do not use wax or hair removal creams on the treated area.
- Wear clothing that protects the treatment area from the sun. Wear loose fitting clothes made of natural material such as cotton.
- Do not use sun lamps or sun beds.
- Do not apply cold or heat packs such as a hot water bottle.
- You can swim in a chlorinated pool but stop if the skin becomes sore. Take a shower in chlorine-free water after your swim and apply moisturiser.
- Avoid hydrotherapy pools, jacuzzis, saunas and steam rooms.
- Radiotherapy causes changes to the skin which makes it more sensitive to the sun forever. Your skin will burn more easily and take longer to heal. During and after treatment, keep the treated area out of strong sunlight. Once your skin has healed, cover the area with clothing or a hat when it is sunny. If you cannot cover it, use a high-factor sun cream — at least factor 50, with a minimum UVA 5-star rating. This is important in summer and in hot countries. Your GP might prescribe sun cream if you have had radiotherapy.

Follow the skin care advice from your radiotherapy team. You can also find guidance from the Society of Radiographers here or by going to:
https://www.sor.org/news/radiotherapy/scor-updates-radiation-dermatitis-guidelines

What should I eat and drink during treatment?

- It is important that you continue to eat during your treatment.
- It is important to drink plenty of fluids, at least four to five pints (two and a half litres daily). This can include: water, milk, tea and coffee, herbal teas, milkshakes, soups, jellies, custard, and chocolate drinks made with milk.
- Avoid:
  - Drinking alcohol, particularly spirits
  - Hot (in temperature) food and drinks
  - Very cold food and drinks, but you can have ice cream that is room temperature

- Spicy food
- Coarse or rough texture and dry food, e.g., toast.
- Citrus juices or foods containing citric acid, e.g., tomato soup, tomatoes, oranges, lemons, etc.

What are the early and short-term side effects?

Expected (50 to 100 out of 100 people)

- **Tiredness**
  Advice: Rest when needed, break up activities into smaller tasks, and try light exercise (if approved by your doctor). Try to drink plenty of fluids, such as water and herbal tea.
- **Skin soreness, itching, blistering and colour changes in treatment area**

Your skin may change colour in the treated area. If you have white or light skin, it may turn pink, red, or darker. If you have brown skin, it may turn maroon or darker. If you have black skin, it may get darker, and you may also notice yellow, purple, or grey areas. The skin in the area being treated with radiotherapy can become sore, dry, and itchy. You may get some peeling of the skin. Some patients have peeling of the skin that is moist and can be very sore. If the skin behind the ear is included in the treatment area, it can become painful.

- **Red or watery eyes** – avoid rubbing your eyes; you could try saline eye drops.
- **Irritation in the lining of the nose or blocked nose** – avoid picking this area or over-blowing your nose.
- **Mouth ulcers** – you should keep your mouth as clean as possible. Speak to your team about fluoride toothpaste and mouthwash.
- **Pain in the mouth and throat which can cause problems with swallowing** – speak to your team and review your pain relief medicine regularly. Some medicines such as morphine or codeine-based painkillers can slow the bowels down and cause constipation. Please tell the radiotherapy team as soon as possible if you are finding it hard to poo. You can be given medicine to help with the constipation.
- **Loss or change of taste**
- **Patchy hair loss in treatment area –** This will not be all of your hair on your head or face. Hair can sometimes grow back. Please ask your radiotherapy Dr if your hair is likely to come back. Your treatment team can tell you where the hair will fall out.
- **Worry, feeling scared, low mood and feeling fed up.** It is common to have feelings of anxiety and low mood. If you can, speak with family, friends, or your

team and share how you are feeling. There are some other numbers of support services at the end of this leaflet.

- **Not being able to get to sleep or waking up a lot in the night,** because of worry.

Common (10 to 50 out of 100 people)

- **Changes in or loss of sense of smell**
- **Hearing loss or earache** which should get better after treatment
- **Dry mouth**
- **Mouth infections, including oral thrush**
- **Voice changes**
- **Thickened and sticky spit that might be difficult to swallow,** try to keep drinking plenty of water and the other recommended drinks.
- **Feeling sick**

If you feel sick, tell your radiotherapy team. You can also try:

  - ginger products, such as ginger biscuits or ginger tea
  - eating something plain, like plain pasta
  - trying to eat something, as not eating can make you feel more sick

- **Being sick**
- **Not wanting to eat as much as usual**
- **Weight loss**
- **Finding it hard to swallow** you might need a feeding tube put into your tummy. This may mean that you are admitted to hospital and spend some time there.

Less common (less than 10 people in 100 people)

- **Chest infection,** which may be due to food and spit going down the windpipe instead of the food pipe
- **Dehydration** because of drinking less
- **Being sick**
- **Sudden electric shock-like feeling when you bend your neck**. This may happen three to six months after treatment

There may be other rare risks, and your care team will talk about these with you if anything is different for you.

What are the late and long-term side effects?

These are side effects that may happen many months or years after radiotherapy and might not get better, medicine can sometimes make them feel better.

Expected (50 to 100 out of 100 people)

- **Skin colour change in the treatment area** – usually lighter or darker in any skin tone
- **Swelling in the chin and the treatment area – called lymphoedema**

Common (this means 10 to 50 out of 100 people)

- **Changes to how the skin looks and feels –** thicker or thinner skin
- **Small visible blood vessels in the treatment area,** which look like spidery marks.
- **Patchy hair loss in treatment area**
- **Dryness of nose which can get crusty** you might be given medicines to help
- **Dry mouth** this might cause problems with eating, and intimate relationships
- **Change in taste or loss of taste –** sometimes this can get a bit better 18 months after treatment. After your mouth is no longer sore, you can try to add strong flavours like garlic and herbs to food, to try and make your taste buds start working
- **Your thyroid gland stops working properly** you might need to take medicine for this
- **Clouding in the lens of the eye**, called a cataract, you might need a small operation to make this better

Less common (less than 10 people in 100 people)

- **Dry eye**
- **Eye damage and the eye looking different**
- **Fluid coming out of the nose**
- **Loss of smell**
- **Hearing loss or hearing changes**
- **Dental problems –** It is important that you continue to have regular dental checks after treatment. For more information see: https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/mouth-care-after-head-and-neck-cancer-treatment

- **Trouble opening your mouth** this might cause problems with eating, and intimate relationships.
- **Voice changes**

- **Swallowing problems –** you might need a feeding tube put into your tummy.
- **Increased risk of stroke**
- **Your pituitary gland stops working properly**, you might need to take medicine for this.
- **Damage to the jawbone**

Rare (this means less than 1 person in 100 people)

- **Changes to brainstem, spinal cord and nerves to the face, arm or hand** which cannot be repaired
- **Damage to a small area of the brain** which cannot be repaired
- **A different cancer in the treatment area**

There may be other rare risks and your care team will talk about these with you if anything is different for you.

We know that some of these side effects sound worrying. Your medical team has looked carefully at all the risks for you. The benefits of radiotherapy outweigh those risks. Your team will talk with you about them.

Where can I get more advice and support?

- **Your radiotherapy team**: They can give more information about your treatment. If you are having any problems related to your radiotherapy after treatment, contact your radiotherapy team.
- **How to contact your radiotherapy team**: The numbers are given to you at the beginning of your radiotherapy. If you can't find the numbers, please ask for them. Keep the numbers handy in case you need urgent advice. We will give you contact numbers in the information handed to you when you finish your radiotherapy treatment.
- **National Support Services**:

Cancer support charities such as Macmillan and Maggie's, offer information, counselling, and support groups.

- Macmillan website: **www.macmillan.org.uk**
- Macmillan Support Line: **0808 808 0000**
- Maggie's: **www.maggies.org**
- OUTpatients for LGBTQI+ patients: **www.outpatients.org.uk**
- The Mouth Cancer Foundation: **www.mouthcancerfoundation.org**
- Changing Faces: **www.changingfaces.org.uk**
- Salivary Gland Cancer UK: **www.salivaryglandcancer.uk**

- The Swallows, Head and Neck Cancer Support: www.theswallows.org.uk

What should I remember?

- Our radiotherapy teams have put this information together to give you a clear picture of what to expect.
- This is general information. Always follow the instructions from your radiotherapy team.
- Your treatment is planned only for you, and your team will let you know if anything is different for your care.
- The key points above should help you prepare and know when to ask for help.
- If you are unsure of anything in this information, please ask your radiotherapy team.

We worked with patients to write this leaflet. We welcome your feedback. To share your thoughts anonymously, scan the QR code or visit:
https://forms.office.com/e/6spj6B4HQk

For more information about radiotherapy, visit:
www.eastofenglandradiotherapynetwork.nhs.uk and click on 'Information for patients'.