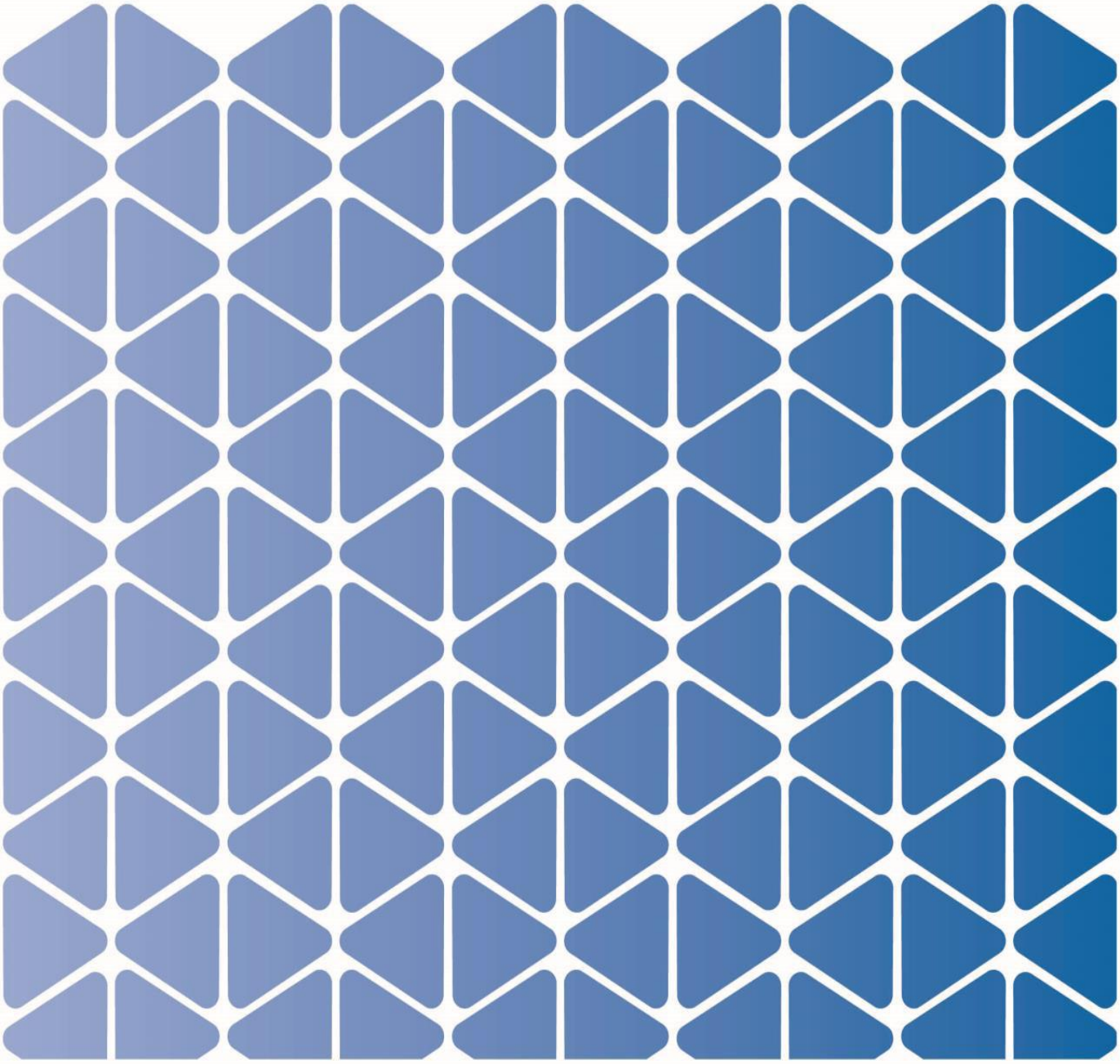
NHS
Worcestershire Acute Hospitals NHS Trust

PATIENT INFORMATION

Radiotherapy to Head and Neck: A guide for patients and carers



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1) Introduction

Radiotherapy is a treatment that involves the use of high energy radiation. It can be used alone, with or without surgery and/or in combination with chemotherapy.

Radiotherapy requires you to be very still so the treatment is accurate. To ensure treatment is in the same place every day, a personalised mask and head cushion are made.

2) What to expect on your first visit

To have the mask made you come to a department called the Mould Room at Worcester Oncology Centre.

If you have a beard or moustache, it would be helpful to shave it off prior to your first visit to the radiotherapy department. If you need a haircut, please have it before the first appointment or leave it to the end of treatment.

Whilst the mask is being made jewellery, glasses, dentures, hearing aids and wigs will have to be removed. The mask making process will probably smudge any make-up you are wearing or mess up your hair (if styled) so be prepared for this.

3) Mask production

The procedure will be explained to you in full before we begin and you will have chance to ask questions before we start. You will be asked to remove all upper clothes and change into a gown to make it easier to make your mask. You will lie down and be positioned on a couch. Once we are happy with your position a cushion will be made that fits under your neck and behind your head

The mask is made from thermoplastic mesh which is softened in a warm oven and the shaped to your features. It is connected to the headboard on the couch by some poppers. The process may feel a little strange, but it is painless. The mask is perforated therefore allowing normal breathing.

Once the mask has cooled done and gone rigid it is then removed. It is important to remember that the main function of mask is to keep you still so it will be tight fitting. The appointment usually takes up to 30 minutes in total with 10 minutes of that being mask shaping and setting. A member of staff will be present with you to help you though the whole process.

4) The planning stage

After your mask is made you will have a CT scan with the mask on. Marks are placed directly on the mask in the scanner to help us set you up in the same position each time you have treatment. The scan also provides us with a picture of your internal anatomy and to aid this you may be given an injection of a contrast dye. If you require this the radiographers will explain the process when you arrive.

After the CT scan, and with your permission, a tiny permanent dot on your chest is made with a small needle and dye placed just beneath the skin and will not wash off (a tattoo).

5) The treatment stage

Therapeutic radiographers operate the radiotherapy machines to give you the precise treatment prescribed by your Oncologist. They will explain what is going to happen and escort you into the treatment room, asking you to remove any clothing and jewellery that covers your head and neck area. You may be asked to remove dentures if necessary. The radiographers will help you onto the treatment couch, place the mask on you and adjust the couch and the machine to the exact positions that are required. You will be asked to keep as still as possible and breath normally.

The radiotherapy machines are quite big and if you haven't seen them before you might feel anxious. There is no need to worry – you won't see or feel anything during treatment. Once you have been positioned for treatment the radiographers will leave you and operate the machine from outside the room. They will be watching you carefully on a closed-circuit camera and can speak to you over an intercom. The machine will rotate to different positions during treatment. You might expect setting you up for treatment and giving it to take about 15 minutes each day.

6) General information about the side effects of treatment

The side effects are individual. Every patient is different and you may not have the same side effects as someone else. They depend on the area you are having

treated, the dose of radiotherapy and the length of treatment. They are also affected by chemotherapy if you are having this at the same time. You would have been given specific written information about chemotherapy and consented separately for this.

Acute (early) side effects may start at varying times during radiotherapy and mostly disappear in the weeks after treatment finishes

Late side effects may not occur for quite a long time after the treatment has finished

The Radiographers will explain the possible side effects in more detail and answer any questions you may have before you start treatment.

Occasionally, it may be necessary to come into hospital to help you cope with your side effects during treatment.

It is strongly recommended that you **stop smoking** completely whilst undergoing radiotherapy as it can make the side effects worse and the treatment less effective. For help to stop smoking call the National smoke free helpline on 0300 123 1044 or contact the hospital's stop smoking service 0300 123 0619 or 01562 513225

It is advised you **reduce the amount of alcohol** you drink during radiotherapy avoiding spirits completely although beer and wine can be drunk in moderation. If you are concerned that you might suffer from alcohol withdrawal during treatment, please speak to your GP or Consultant before starting radiotherapy.

Specialist counselling is also available for patients and their families having treatment for head and neck cancers. Please ask a member of your treatment team about how to be referred

7) Acute (early) side effects

Fatigue/Tiredness

This can occur from week 3 onwards. Try gentle exercise when you feel able. but have rest periods. Maintain a good nutritional intake with the advice of your dietician. This may be improving from 8-12 weeks after treatment but may take up to 12 months to recover completely. Continue a gentle daily exercise gradually increasing over a few months. Walking and swimming are suggested.

Your skin

- Your skin may become red, dry, sore and sometimes broken. The redness appears around weeks 2 and 3, broken skin from around 4 weeks onwards. Please discuss which moisturising creams to use with your treatment team. Dressings will be applied to the broken areas, and you may need to organise these through your GP after the end of treatment.

Shave only with an electric razor.
Avoid perfume, talc and aftershave in the treatment area
Avoid sun exposure in the treatment area
The skin reaction will peak around two weeks after treatment finishes and then settle over 8-12 weeks.

Your mouth and throat

- Radiotherapy to your face and neck may make the inside your mouth, tongue, lips and throat red sore and ulcerated. It may become uncomfortable to eat, speak and brush teeth. Occasionally an infection called thrush can develop

  The treatment is with mouthwashes and regular pain relief. Suitable mouthwash will be supplied to you from the department. Some commercial mouthwashes contain alcohol and should not be used as they can dry and irritate your mouth. Lip balms can be suggested by your radiographers.

  Clean your teeth with a soft toothbrush and fluoride toothpaste. Later in the treatment a baby toothpaste and toothbrush can be used. Dentures should be removed and cleaned after each meal at least twice a day. At night they should be left out and soaked in an appropriate cleanser for up to 20 minutes. Afterwards they should be kept dry.

  If you develop an irritating cough particularly when lying down, it may be helped by frequent sips of fluid (carry a bottle of water around with you). Steam inhalation can also help with this and thickened saliva.
  Mouth and throat side effects settle over 6-10 weeks after treatment

- Painful swallowing and nutrition

  Painful swallowing may occur 2-3 weeks into treatment is managed with the help of the dietitian and the Speech and Language therapist (SLT). It is important to avoid citrus and spicy foods, using soft, moist foods with plenty of sauces and gravy. Other suggestions are breakfast cereals with plenty of milk, scrambled eggs, omelettes, mashed potatoes, soups, cottage pie, milk puddings and mousses.

  Sometimes towards the end of treatment a liquidised diet may be required, and supplement drinks can be supplied by your GP or the hospital. A feeding tube into your stomach may be required (PEG) in some instances. This can cause problems with reflux and anti-reflux medication may be used.

Painful swallowing will last for at least two weeks following treatment before gradually improving.

- Taste changes

  This can be from about the two week point but can occur earlier in some patients. Although this may reduce appetite it is important to carry on trying to eat. The use of herbs, honey and sauces for flavour or experimenting with unfamiliar foods may help.
  This can improve over weeks or months after treatment but may take much longer and in some patients it is permanent.

- Salivary glands

  Your saliva may become thick and sticky making your throat feel dry. It is important to drink plenty of fluids. Saltwater mouth washes may be helpful. Mix 1 teaspoon of salt and 1 teaspoon of sodium bicarbonate in a tumbler of water, swill around mouth and spit out.
  The hospital will supply you with a nebuliser to take home with you if required. It will take 8-12 weeks following treatment to improve but some patients have sticky or thicker saliva permanently

- Hoarse voice

  This may occur 3-4 weeks into treatment and will be assessed by the SLT.
  Recovery takes 8-12 weeks although some voice changes can be permanent
  Avoid straining to speak

- Restricted mouth opening (Trismus)

  This depends on where your cancer is situated. You will be given specific mouth exercises by the SLT which can be a lifetime activity as it can be a long-term problem

Lymphoedema

Facial and neck swelling can sometimes occur towards the end of treatment but usually occurs 8-12 weeks after finishing. Sometimes you may need a course of massage treatment, and you will be referred to a specialist lymphoedema clinic. It usually gets better 6-12 months after your treatment has finished. You may need to carry on self-massage for longer than twelve months

Hair loss in the treatment area

This can be facial or side of head but will not be the whole head of hair. It can stop growing from three weeks into treatment. Use an electric shaver.

If the treatment area is below your earlobes, you can wash and dry your hair normally. If part of your scalp is included, use a gentle shampoo and dry naturally to avoid irritation. Your hair may not grow back in the area that has been treated. If it does, it will usually regrow within three months.

8) Late effects of treatment

There are some possible long term side effects that your oncologist will discuss with you. These can occur months or even years after treatment. These late effects depend on what part of the head and neck was treated. Some late effects can be treated by medication. Rarely, a surgical operation may be need if the problem is serious

- Dryness of your mouth.
  This occurs whenever the salivary glands are in the treatment area. It may be permanent

- Dental problems
  If you have any of your own teeth you may be sent of a dental assessment before treatment starts.

  When the mouth is dry the teeth are no longer protected by saliva and are more prone to disease. If you need any teeth removing your dentist should refer you to a local maxillofacial unit.

- Change in taste
  This can take some time to return to normal and occasionally it may not completely recover.

- Skin changes
  The skin in the treated area can become discoloured (usually slightly darker than your normal skin colour) or mottled. There may be patches of small blood vessels near the surface of your skin.

- Swallowing problems
  Tightening of the tissues of your throat may make swallowing more difficult. The speech therapist may be able to help in some cases. The tissues of your neck may become tighter and feel firmer to touch. This is especially common if you have had prior surgery to your neck.

- Damage to jawbone or cartilage
  In rare cases there can be damage to the jawbone or to the cartilage of the voice box (depending on the area treated). Occasionally surgery is required to treat this. This is more common in patients who continue to smoke during and after their radiotherapy.

  Having teeth extracted from a jawbone that has been treated with radiotherapy will increase the risk of bone damage.

- Weight loss
  If you have lost weight during your treatment, you may find it difficult to get back to your normal weight after treatment even though you may be eating quite well. This is common and, if your weight is steady, is not usually a problem. If you continue to lose weight after treatment, please discuss with your Oncologist.

- Ulcers
  Sometimes the tongue and the lining of the mouth or throat can take a long time to heal, temporarily causing ulcers which can be painful

- Hypothyroidism
  If your thyroid gland is in the radiation area, then over time it can become underactive.

- Second cancers are a rare consequence of having radiotherapy

9) Follow-up

After finishing treatment, the Head and Neck Team will continue to support you. Joint clinics with the head and neck team will be offered one week after finishing treatment and then weekly until symptoms are resolved.

You will also receive an appointment to see your consultant in the outpatient department between 4 and 6 weeks later. These appointments are to check your progress and may continue for several years. If you haven't received notification of this within three weeks of completing treatment, please telephone radiotherapy reception on 01905 761400

10) Contact details

Worcestershire Oncology Centre- Mon-Fri 8.45am - 4.45pm (For queries concerning appointments, parking and ambulance transport) 01905 761400

Cancer and Radiotherapy Information and advice (Mon-Fri 8.45am - 4.45pm): Macmillan Radiotherapy Specialist Radiographer: 01905 761420

Head and Neck cancer specialist support (Mon-Fri 8.45am - 4.45pm):
Head and Neck radiographer: 01905 761 400
Head and Neck CNS team: 01905 761 440
Head and Neck Dietetics team: 01905 760 136
Head and Neck SALT team: 01905 760 475

If your symptoms or condition worsens or if you are concerned about anything please call your GP, 111, or 999

11) Support groups

The Swallows, Head and Neck support group, meet 2nd Wednesday every month
www.theswallows.org.uk
Email: info@the swallows.org.uk

Lets face it (facial disfigurement)
www.lets-face-it.org.uk

National Association of Laryngectomee Clubs (NALC):
020 7730 8585 or www.laryngectomy.org.uk

Macmillan Cancer Support
Macmillan booklets about coping and living with cancer and treatment side effects are available free of charge. These can be ordered by telephoning 0800 808 000 or by visiting one of the Cancer Information and Support Centres in our hospitals.

The Macmillan Information Units can be contacted by telephone:

Worcester Royal Hospital – Main Reception and Oncology Centre

Main Reception; 01905 733837

Oncology: 01905 760674

Alexandra Hospital

01527 503030 ext. 44238

Kidderminster Hospital

01562 513273

If your symptoms or condition worsens, or if you are concerned about anything, please call your GP, 111, or 999.

Patient Experience

We know that being admitted to hospital can be a difficult and unsettling time for you and your loved ones. If you have any questions or concerns, please do speak with a member of staff on the ward or in the relevant department who will do their best to answer your questions and reassure you.

Feedback

Feedback is really important and useful to us – it can tell us where we are working well and where improvements can be made. There are lots of ways you can share your experience with us including completing our Friends and Family Test – cards are available and can be posted on all wards, departments and clinics at our hospitals. We value your comments and feedback and thank you for taking the time to share this with us.

Patient Advice and Liaison Service (PALS)

If you have any concerns or questions about your care, we advise you to talk with the nurse in charge or the department manager in the first instance as they are best placed to answer any questions or resolve concerns quickly. If the relevant member of staff is unable to help resolve your concern, you can contact the PALS Team. We offer informal help, advice or support about any aspect of hospital services & experiences.

Our PALS team will liaise with the various departments in our hospitals on your behalf, if you feel unable to do so, to resolve your problems and where appropriate refer to outside help.

If you are still unhappy you can contact the Complaints Department, who can investigate your concerns. You can make a complaint orally, electronically or in writing and we can advise and guide you through the complaints procedure.

How to contact PALS:

Telephone Patient Services: 0300 123 1732 or via email at: wah-tr.PALS@nhs.net

Opening times:

The PALS telephone lines are open Monday to Friday from 8.30am to 4.00pm. Please be aware that you may need to leave a voicemail message, but we aim to return your call within one working day.

If you are unable to understand this leaflet, please communicate with a member of staff.