



# Radiotherapy to the head and neck

A guide for patients and their carers

We care, we discover, we teach



## Contents

Contact information . . . . .	1
Patient journey for head & neck radiotherapy . . . . .	2
What is radiotherapy? . . . . .	3
Chemotherapy . . . . .	4
Agreeing to treatment . . . . .	5
Research at The Christie . . . . .	6
Preparation for treatment . . . . .	7
Mould room preparation. . . . .	8
What happens when you have your treatment? . . . . .	10
Some questions about radiotherapy . . . . .	13
Side effects of treatment. . . . .	15
Possible late effects. . . . .	21
Nutrition. . . . .	23
Painkillers . . . . .	24
After the treatment. . . . .	26
Appointments. . . . .	27
Further information. . . . .	28

This booklet is to tell you about radiotherapy to the head and neck area. If you would like to know about radiotherapy to the brain, please ask the doctor looking after you. The Christie is a specialised radiotherapy centre and patients come for treatments that are not available in general hospitals. If you are having radiotherapy as an inpatient, please bring this booklet with you.

Please share this booklet with your family and friends. It is important that they feel well-informed and understand what is happening. Families and carers can have a role in helping you. If you would like more detailed information about your own treatment, please ask the staff. There are also DVDs on radiotherapy which you can take home to watch. Please ask your doctor, nurse or radiographer.

## Contact information

### Consultants

**Dr Lee** 0161 446 8581      **Prof Slevin** 0161 446 3361

**Dr Sykes** 0161 446 3354      **Dr Yap** 0161 446 3331

### Nurse clinician

**Kathleen Mais** 0161 446 3428  
0161 446 3000 (bleep 12589)

Please contact Kathleen for queries about chemotherapy including appointments

### Nurse specialist

**Debbie Elliott** 0161 446 8041  
0161 446 3000 (bleep 12610)

You can contact Kathleen or Debbie before, during or after you have completed your treatment if you have queries or concerns

### Research nurses

**Kim Denton** 0161 446 3000 (bleep 12043)

**Gemma Findlay** 0161 446 3000 (bleep 12063)

For advice about feeding tubes contact Lynne Wilbraham, specialist nutrition support nurse, on 0161 446 3729 or 0161 446 3000 (bleep 12321)

### For queries about radiotherapy appointments

**Radiotherapy department** 0161 446 3485

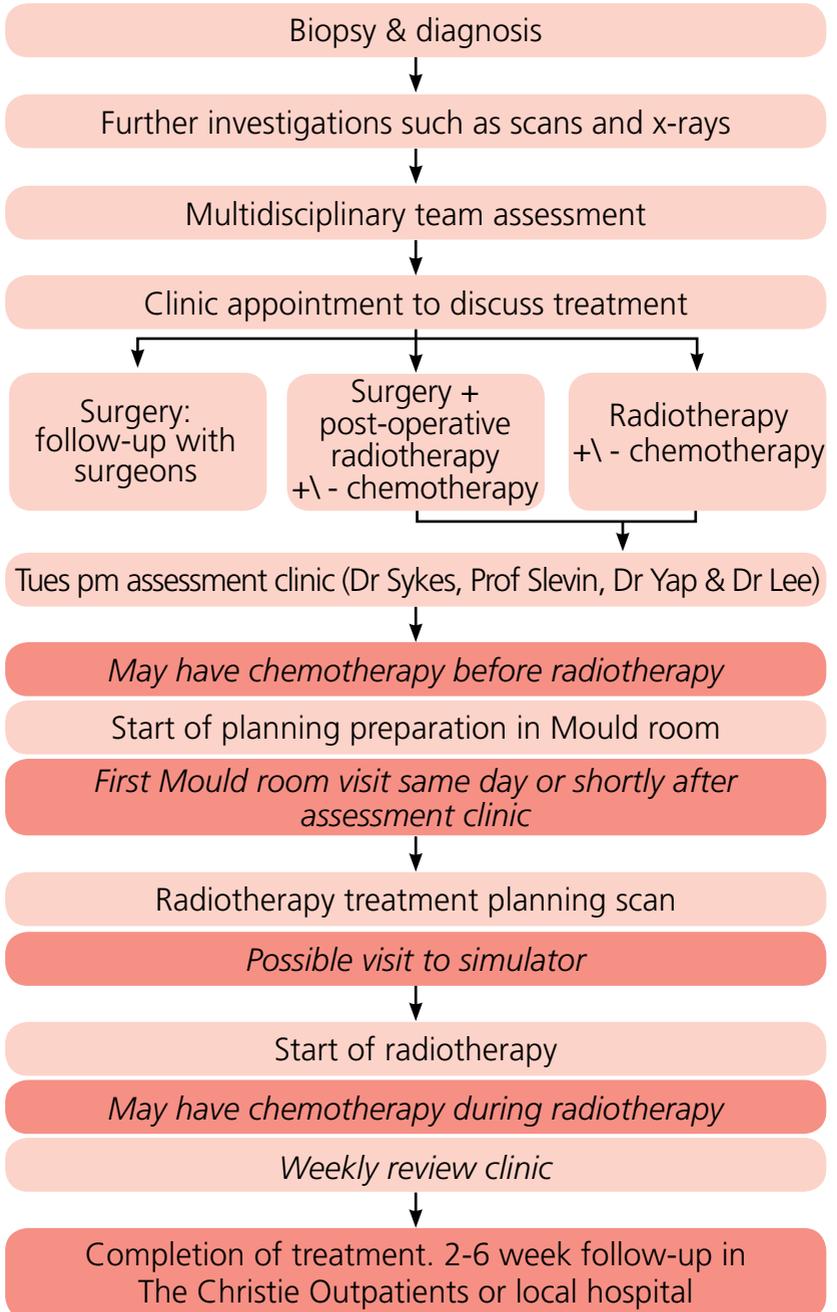
**Mould room** 0161 446 3525

For queries out of hours ring The Christie switchboard and ask to speak to the nurse practitioner: 0161 446 3000

### For urgent queries out-of-hours

**The Christie Hotline** 0161 446 3658

# Patient journey for head & neck radiotherapy



## What is radiotherapy?

Radiotherapy is the use of exact, carefully measured doses of radiation to treat disease.

Most patients having radiotherapy are treated using a high energy beam of x-rays delivered by a machine called a linear accelerator, to the precise area affected by your illness. The rays are used only to treat the tumour and a small surrounding area.



A treatment machine

While not all machines look alike, they all work in a similar way. These machines are just more powerful versions of the x-ray machines that are used to take pictures of broken bones. Radiotherapy is often given in several small doses over a specified period of days or weeks.

Therapy radiographers operate the radiotherapy machines. They are specially trained healthcare professionals who are involved in radiotherapy planning, treatment and care.

## What is the Multidisciplinary Team?

The Multidisciplinary Team (MDT) consists of healthcare professionals including:

- clinical oncologist (a doctor specialising in treating cancer with radiotherapy and chemotherapy)
- head and neck surgeon
- maxillofacial surgeon
- pathologist (a doctor who specialises in looking at cells under the microscope)

- radiologist (a doctor who specialises in interpreting scans and x-rays)
- specialist nurses, nurse clinician, research nurses
- speech and language therapist, dietitian
- restorative dentist.

## Chemotherapy

Chemotherapy is the use of drugs to treat cancer. Most chemotherapy is delivered directly into the bloodstream via a 'drip', but sometimes it is given in tablet form.

Your doctor may recommend some chemotherapy as well as radiotherapy. You may have this before and/or during radiotherapy. If your doctor feels you might benefit from this treatment, he or she will discuss this with you. Before each chemotherapy dose (cycle) you will have a blood test. Patients who have chemotherapy attend an outpatient clinic to see the nurse clinician. You will then be admitted to the ward, for between 1 and 5 days, to have your chemotherapy.

Chemotherapy can lower your resistance to infection. It is very important that you call The Christie Hotline (0161 446 3658) if you feel unwell at home, you have diarrhoea or your temperature becomes high (above 37.5°C) or very low (below 36°C). It is also important to keep up a good fluid intake (between 4 and 6 pints of non-alcoholic fluids per day). This helps to protect your kidneys from damage by the chemotherapy. If you find you are struggling to eat and drink, please ask to see one of the team treating you.

If you have any queries or concerns about your chemotherapy, please phone or ask to see the nurse clinician on 0161 446 3428 or ask to see your consultant or one of his team.

Your consultant may recommend that you have a course of a drug called cetuximab during your radiotherapy. This is one of a group of drugs called monoclonal antibodies. Cetuximab is given weekly during radiotherapy as an infusion (drip) into your vein.

If you are having chemotherapy or cetuximab during your radiotherapy, please let your radiographers know. You will need to have a morning appointment on your chemotherapy days so you can attend the chemotherapy clinic. If you attend by hospital transport please make sure it is booked to bring you in the morning on chemotherapy days.

For more information on chemotherapy see the Christie booklet 'Chemotherapy'.

## Agreeing to treatment

### Consent to treatment

For radiotherapy and chemotherapy treatment we will ask you to sign a consent form to say that you agree to have the treatment. It is important that you understand the possible risks and intended benefits of any treatment for cancer.

The doctor or nurse will give you some written information (this booklet) to back up their description of the treatment. They should tell you of the intended benefit of any treatment you are offered. Consent may be withdrawn at any time before or during treatment. Should you decide to withdraw your consent then a member of your treating team will discuss the possible consequences with you.

**Radiation can be harmful to the unborn child. It is important to let the radiographers know if you have missed a period or suspect that you might be pregnant before you are exposed to any radiation.**

### **What are the benefits of treatment?**

The intended benefit of the treatment may be to cure the cancer or it may be aimed at relieving symptoms such as pain or difficulty with swallowing.

### **Are there any alternatives to this treatment?**

Head and neck cancer can be treated with surgery, radiotherapy and chemotherapy, or a combination of two or more of these. Your doctors and nurses have discussed your case in the MDT meeting and feel that radiotherapy is the best treatment for you. Your consultant will discuss other treatment options with you.

### **What if I decide not to have any treatment?**

If you have no treatment for your cancer, it will continue to grow. It is likely to cause increasing symptoms such as pain and difficulty swallowing. In this case, the aim of your care will be to control and relieve your symptoms.

During your treatment preparation you will have the opportunity to ask questions.

### **Research at The Christie**

The Christie is the largest cancer treatment centre of its kind in Europe and an international leader in research and development. Partnerships with the Manchester Cancer Research Centre and the Manchester Academic Health Science Centre allow our research programme to have a strong focus on clinically based research. You may be approached to participate in one of the clinical trials being run at The Christie. Participation is completely voluntary. You will meet one of the head and neck Research Nurses or a Research Radiographer who, along with your consultant, will be able to explain the purpose of the trial and answer any questions you may have. You will be provided with written information about the trial and given as much time as you need to make a decision. Should you

feel you do not wish to participate, your treatment will not be affected in any way. The head and neck Research Nurses are Kim Denton and Gemma Findlay.

## Community Macmillan nurses

These nurses work in the community and have experience of caring for people with a cancer diagnosis. They are experts in the treatment of cancer and the control of symptoms such as pain and sickness. They can also provide support for you and your family during and after your treatment. If you would like to be referred to the Macmillan nurses near your home, please let us know.

## Preparation for treatment

The specialist doctor who will look after you is a clinical oncologist. He or she will ask you some questions, examine you and explain your treatment.

A specialist team including consultants, specialist registrars, ward doctors, radiographers and nurses will care for you.

One consultant will be responsible for your treatment.

Once your treatment has been decided, we will give you an appointment for your treatment preparation.

## Tuesday afternoon clinic

The first part of the treatment preparation is a visit to the assessment clinic on Tuesday afternoon. Here you will normally see your consultant - Dr Sykes, Professor Slevin, Dr Lee or Dr Yap - and their team. To check your general health, we will ask you to have a blood test and possibly a chest x-ray. The doctor will ask about your general health and any medication

## Smoking

If you continue to smoke, **this will reduce the chance of the treatment being successful.** It will also make the reaction worse and will significantly **increase the risk of serious late side effects.** It also **increases the risk of further cancers.** We strongly advise you not to smoke. The Christie Complementary Therapies team provides therapies to support smoking cessation, please ring 0161 918 7175. You can also contact Smokefree NHS 0800 022 4 332.

you are taking. Please bring a list of your medication to this appointment. The doctors will examine you and discuss the recommended treatment with you. If you have any questions to ask the doctor or nurse you may want to write them down beforehand.

You may be asked to have a dental assessment as well. As soon as you know you are going to have a course of radiotherapy, you should make an appointment to see your dentist. Ask for a check-up and tell him or her you are going to have radiotherapy to your head and neck. (See page 21).

You will also meet and be given contact details for the head and neck specialist nursing team. You can contact the nursing team for advice during or after your treatment. See page 1 for contact details.

Most patients who need treatment to the head and neck have a special plastic shell or mask made which assists in the accurate delivery of the radiotherapy. This is made in a department called the Mould room. You will probably be asked to go to the Mould room on another day, shortly after the Tuesday clinic.

## Mould room preparation

Most people will have to wear a plastic shell (also known as a mask or mould) while having their treatment. This helps you to keep still during treatment and ensures that the treatment is given to the same area each day. The shell is an important part of the planning process and it may take some time to complete. The shell is not a shield or barrier to the effects of the radiation.

## Making the shell

There are different types of shells and the preparation is slightly different in each case. Preparation can take some time and you may need to make two or three visits to the

hospital. You will have this preparation as an outpatient even if you have your treatment as an inpatient.

Many patients, especially if they are claustrophobic, worry about having a shell made. Be reassured, most people cope very well and help from our complementary therapy (or 'CALM') team is available if you need it to help you relax.

Most people will have a thermoplastic shell which is made directly on the patient. Where possible, this will be made on the same day as your treatment planning scan. To make this type of shell, warm plastic material is moulded directly on your skin and allowed to set. This material may be slightly warm but it will not feel too hot.

Some patients will need a clear plastic shell and this will require a separate visit, when a plaster of paris bandage impression will be taken. This is used to make the clear plastic shell which is then fitted a couple of days later when you come for your simulator and scan appointment.

Many people will have a CT scan taken whilst wearing the shell as part of the treatment planning process. When this has been completed you may need to come for a final appointment on the treatment simulator before your treatment can start.

If you do not need a CT treatment planning scan, the doctor will be able to mark the treatment on the shell at your simulator visit. You will not need to make any further visits before your treatment can begin.



Simulator visits can take some time as there are many x-rays, checks and measurements needed and you may need to wear the shell for a considerable time. Once treatment begins, you will not need to wear the shell for so long.

It is important to get the shell just right so that the x-rays are targeted correctly for each treatment session. No matter which method is used to make the shell, a lot of careful work goes into making it and preparing the treatment. It usually takes 10 to 14 days or longer for all the treatment planning and computer checks to be completed. The radiotherapy department will contact you to confirm your treatment start date during this preparation period.

## What happens when you have your treatment?

On the day of your first treatment, you will come to the



Being positioned by radiographer before treatment begins

Radiotherapy department. If you are an inpatient, you may be brought to the department by a therapy care assistant. You may have already visited this department as part of the preparation for treatment and met some of the therapy radiographers. The Christie is a training hospital so you may meet students in the Radiotherapy department who may be involved in the delivery of your treatment.

Radiographers operate the radiotherapy machines to give you the precise treatment prescribed by the doctor. They will explain to you what is going to happen and take you into the treatment room. The radiographer will help you onto the treatment bed, put your shell on you and will adjust both the bed and the machine to the exact positions

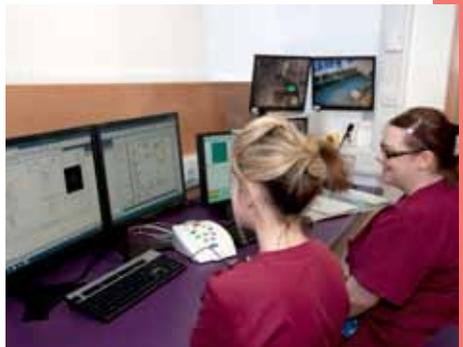
that are needed. You will be asked to remove any clothing that covers the area being treated. You will also be asked to keep as still as possible.

The radiotherapy machines are quite big and if you have never seen them before, you might feel anxious. There is no need to worry - the treatment is absolutely painless. It is just like having an x-ray picture taken, but it takes longer. Once the treatment has been set up, the radiographers will leave the room and will switch on the machine from outside. The treatment normally lasts ten to fifteen minutes. On some visits the radiographers may take scan pictures. This ensures your treatment is delivered accurately and consistently.

During your treatment you will be alone in the room, but the radiographers will be watching you carefully on a closed circuit television system. If for any reason you need them, just raise your hand and they will interrupt the treatment and come in to you immediately.

Some people are worried that they will be completely enclosed by the machine - this will not happen. The machine can move around you, but nothing will touch you. All machines make a buzzing noise when they are operating. This is how you will know when the treatment is happening.

When you leave the room, you will have an appointment made for the next treatment day. If you are having chemotherapy please ask for a morning appointment on the day of your chemotherapy. On these days please book in at the Outpatient desk and have a blood test before you have your



The radiographer at the controls

radiotherapy. Please discuss appointment times with the radiotherapy support workers on the treatment unit. They help patients plan their appointments for treatment and can usually find a solution to any small problem that can arise. This routine will go on each day until your course of treatment is finished. The prescribed radiation dose and the number of days over which it is given varies between patients. There is usually no radiotherapy treatment on Saturdays and Sundays. This is taken into account when your treatment is planned. Sometimes treatment is given on bank holidays.

It is very important that you do not miss treatment days as it may make your treatment less effective. If you feel you are unable to attend for any reason, please telephone The Christie and ask to speak to one of the doctors or nurse clinicians. See front of booklet for contact details.

Sometimes the arrangement of the treatment areas changes during the course of radiotherapy. Don't be worried by this - it has all been worked out in detail before your treatment started. You will usually be treated on the same machine throughout your course of radiotherapy, although the machines occasionally need to be serviced.

Everyone is asked to attend their consultant's treatment review clinic (reaction clinic) once a week. Here, you will see one of the doctors or the nurse clinician. The purpose of this clinic is to check that you are progressing as expected through treatment. We will weigh you and ask you about your dietary intake, your pain control and any other symptoms you may have. The doctor or nurse will also examine the area you are having treated. You will have the opportunity to ask questions.

## Some questions about radiotherapy...

### Will radiotherapy hurt?

No. You will not feel anything during your actual radiotherapy treatment. However, as the treatment progresses the treated area will become sore and inflamed.

### How does it actually work?

Our bodies are made up of cells and all cells have the capacity to divide. If radiation hits a cell that is dividing, it will be damaged. Unlike normal cells, cancer cells are much less able to repair the damage so more of them will be destroyed.

### Is it safe?

Radiation used in medical treatment is given in controlled, carefully measured doses. The aim is to treat the cancer without harming the patient.

### Will I be radioactive?

No. Patients treated by x-rays do not become radioactive. The radiation does not stay in your body after treatment, so you cannot do anyone else any harm. It is perfectly safe for you to mix with other people and to have visitors if you are on the wards.

### I already have problems with my health. Will radiotherapy treatment make them worse?

No, but some health problems such as diabetes need to be monitored more closely during radiotherapy. Ask your consultant or his team if you are worried about any health problems.

### If I have to stay in hospital, can I go home for the weekend?

Yes, if your doctor thinks that you are well enough. You must make your own transport arrangements to go home

and come back to hospital. The time of weekend leave varies, so please check with the nurse in charge of the ward and the therapy radiographers treating you about the time you need to return.

### **Can I be treated as an outpatient?**

Yes, if your doctor thinks you are well enough. You may find it difficult to go out to work, run the home and cope with treatment as well. After daily travel and treatment, you will almost certainly feel tired and need to rest. Space in the waiting area is limited, so if possible please only bring one person with you.

### **As an inpatient, when will I have my treatment?**

The radiographers will give you a leaflet at your first appointment at the Radiotherapy department, explaining how many treatments you will have and the date of your last treatment. The treating team will call for you when they have a free slot. On most wards you will be able to wear your own clothes and go out once you have had your treatment for the day. Check with the nurse in charge before you leave the ward.

If you are going on weekend leave, please let the staff know and they will do their best to treat you as early as possible.

### **What happens if I need ambulance transport to and from the hospital?**

Many patients are able to bring themselves or can ask a friend or relative to help them out. If you think you may need ambulance transport, please discuss this with a radiotherapy support worker or radiographer on your first visit to the radiotherapy department. Ambulance transport can be arranged subject to eligibility criteria based on medical need. There also needs to be a medical need for you to bring an escort on hospital transport.

There can be delays for some time either side of your appointment because of the high demand for transport. Please take this into account when you are deciding whether to use ambulance transport or not. Hospital transport is provided by North West Ambulance Service and Arriva, however you can contact the transport liaison office at The Christie directly on 0161 446 8114 or 8143 for advice.

### Can I have a 'flu vaccination during treatment?

It is safe to have a 'flu vaccination once your course of radiotherapy has finished.

### Side effects of treatment

The acute side effects are temporary and affect all patients. Remember, only the area being treated will be affected. Side effects start about halfway through the radiotherapy course and will be at their worst at or just after the end of your treatment. They will last for a few weeks after the treatment has finished, so you will need to follow the advice given below until they settle down.

#### Alcohol

While the occasional glass of wine or beer won't hurt, don't drink to excess.

#### Smoking

If you continue to smoke this will reduce the chance of the treatment being successful. It will also make the reaction worse and will significantly increase the risk of serious late side effects.

### Swelling of the glands

You may find that after the first one or two doses of radiotherapy you get swelling of the glands in your neck or the side of your face. This is simply a temporary reaction of the salivary glands to the radiotherapy and will quickly

settle. Very rarely the swelling means the mask is too tight. In this case your doctor or nurse clinician can give you some medication to help.

### Mouth and throat

Your mouth and/or throat may become very sore and inflamed if they are being treated. A white coating may appear which is normal and protective. We will give you painkillers to help you cope with the soreness, but you may find it becomes painful to swallow. It is very important that you try not to lose any weight during this treatment. See page 23 for advice on nutrition.

Try to avoid eating hard or spicy foods which can damage or irritate the inside of your mouth. It is essential that you keep your mouth clean and moist using salt and sodium bicarbonate mouthwashes - see the section on mouthcare. Your mouth may become dry, especially if you are having your salivary glands treated. Try sipping water frequently to moisten your mouth. Artificial saliva sprays are available; ask your doctor or nurse at The Christie about these. Please note, if you have your own teeth (not dentures) you should not use Glandosane spray.

### Thick Phlegm

You might start to produce a lot of thick, sticky saliva. This is a normal reaction but can be quite troublesome. It normally settles down in the weeks after treatment. The saliva and anything you cough up should be white or clear; if it is green or brown let us know - you may need some antibiotics. There are some measures you can take to help with the thick phlegm: make sure you drink plenty of non-alcoholic fluids (3 - 4 pints per day); do your mouthwashes using saltwater and sodium bicarbonate every 1 - 2 hours; take your painkillers as prescribed.

## Taste

You may lose your sense of taste or find that everything tastes the same. Some people describe the taste like 'cardboard'. It can take some months for the sense to return. In some cases, the sense of taste does not return.

## Skin reaction

The skin in the treated area can become red and itchy or sore and might even peel. You can minimise this skin reaction by following this advice.

Start moisturising the skin of your neck and face from day one of your radiotherapy using cream recommended by your nurse, radiographer or nurse at The Christie. Do not use any other creams or lotions without asking for advice.

- Wash the area gently using water and a mild, unperfumed soap such as baby soap. Pat the skin dry with a soft towel. If the skin is very sore or peeling, don't wash it at all.
- Avoid using any make-up or perfume.
- Men should use an electric razor rather than wet shave, even if the skin is not sore or red.
- Protect the area from extremes of heat or cold and from direct sunlight, during treatment and for at least 6 weeks afterwards. Be careful using a hair dryer. Use a total sunblock cream if you do go out in the sun, but do not use a sun block on the treated area during your treatment.
- Wear loose, cotton clothing around the neck.

Even if your skin does not feel sore, you should still follow this skin care advice. If necessary we can give you some soothing cream for your skin.

Sometimes the skin can peel and may become moist and red with some weeping or discharge. This discharge can

cause the skin to become dry, cracked and painful. Most people find it more comfortable to wear a dressing around the neck. This can occur in the days after treatment has finished. The district nurses attached to your own doctor's (GP's) surgery may be asked to visit you to continue applying dressings to your neck. The skin reaction can look quite alarming, but is a normal reaction and, after a few days, usually heals up quickly. If the discharge becomes discoloured, you may need a course of antibiotics. If you are at all concerned about your skin, please contact the head and neck nursing team on 0161 446 3428 or 0161 446 8041.

### Tiredness

You may find you are more tired than usual, especially towards the end of your treatment, so do try to rest as much as possible. Sometimes the tiredness or fatigue can be profound. It is important to rest and do only those activities you feel you can cope with. This fatigue can last for a long time - even up to a year - after treatment.

### Voicebox

If your voicebox (larynx) is being treated, it may become sore. If this happens, try to rest your voice as much as possible. Your voice may become very hoarse or whispery and may even go altogether. In the weeks after radiotherapy, it should gradually return. If not, you can be referred to a speech therapist to help you regain your voice.

### Noisy or difficult breathing

Occasionally when the voicebox is being treated, the tissues in the voicebox can swell, making breathing in a bit noisy and more difficult. If this happens, it is very important to let the doctors know. Ask the radiographers to contact one of your consultant's team **before** your treatment for that day. At weekends and evenings, you can ring The Christie Hotline on 0161 446 3658.

## Cough

Some people get a troublesome cough for a while after treatment. This should go as your throat settles down after treatment. You can use cough mixtures from the chemist but drinking lots of non-alcoholic fluids is often the best way to settle the cough. Try not to clear your throat too vigorously.

## Swelling

After the radiotherapy is finished some patients develop swelling under the chin. This is like a double chin or jowl. It is usually soft but sometimes firm. It is a common side effect, resulting from a collection of fluid in the tissues under your chin. It will gradually go although this can take several months. Rarely, the swelling can be permanent.

## Hair loss

Any hair, including facial hair, that is in the treatment area and where the x-rays leave the body, will fall out. In some cases it will not re-grow.

## Sickness (nausea)

Some people feel sickly during the treatment. This can be for one of several reasons. If you are experiencing nausea please ask to speak to one of the doctors or nurses, either on the ward or when you come for your daily treatment.

## Constipation

Many people become constipated during this treatment because of the painkillers or change of diet. Constipation can be an unpleasant and serious problem so please let the doctor or nurse at The Christie know as soon as you notice a problem with your bowel movements. Even if you are not eating and drinking much, you should still be opening your bowels.

## Mouthcare

Your mouthcare is very important particularly if your mouth is in the treatment area. It is essential that you keep your mouth scrupulously clean from the start of your treatment. This will help prevent infection when your mouth or throat become sore.

- The radiographers will give you an information sheet about mouthcare when you start your radiotherapy. You should use mouthwashes made of salt solution and sodium bicarbonate solution. At the start you should use the two mouthwashes four times a day. Once your mouth starts to get sore, increase the frequency to 2 hourly. You can use Difflam **as well as** the salt and sodium bicarbonate. You should not use any other mouthwashes (especially Corsodyl) without checking with your radiotherapy doctor, radiographer or nurse.
- You should continue to clean your teeth, with a soft toothbrush, after meals and before bedtime.
- If you wear dentures, you may like to leave them out except at mealtimes. Dentures should be kept scrupulously clean.

### If you have had an operation for your cancer...

You may have had an operation (other than a biopsy) before having radiotherapy. If so, you may have some specific problems. We will discuss these with you, but if you are concerned, please talk to your nurse or doctor. Patients who have had their voicebox removed (laryngectomy) may find The Christie leaflet 'Information for laryngectomy patients having radiotherapy' helpful. If you have had a tracheostomy, please ask to see the nurse clinician or nurse specialist for advice about tracheostomy care during radiotherapy.

## Possible late effects

There are some possible late side effects which your doctor 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 by radiotherapy. Some late effects can be treated with medication. Rarely, a surgical operation may be needed if the problem is serious.

### Tiredness

This can last for up to a year after the completion of radiotherapy.

### Dryness of the mouth

This occurs whenever salivary glands are in the treatment area. Loss of saliva can result in dental decay.

### Dental problems

When the mouth is dry, the teeth are no longer protected by saliva and are more prone to disease. It is important that you have a dental assessment before your radiotherapy, preferably from your own dentist, and that you visit the dentist regularly after the radiotherapy is completed. If necessary, we can arrange for you to see the dentist at The Christie. However, the dental service at The Christie is limited so it is important that you are registered with a local dentist for pre-treatment assessment and long-term follow-up. If you need any teeth removing, please speak to your clinical oncologist.

### Skin colour changes

Rarely, 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 the skin.

## Swallowing problems

Sometimes the radiotherapy can cause a tightening of the tissues in the throat. This can make swallowing more difficult. If this is a problem, the speech and language therapist may be able to help in some cases. Your doctor or nurse will refer you if appropriate. The tissues of the neck can also become tighter and feel firmer to the touch. This is especially common after surgery to the neck.

## Weight loss

If you have lost weight during your treatment, you may find that it is difficult to get back to your normal weight after treatment, even though you may be eating quite well. This is common and, as long as your weight is steady, is not usually a problem. If you continue to lose weight after your treatment, please mention it to the doctor at your follow-up clinic appointment.

## Ulcers

Sometimes the tongue and the lining (mucosa) of the mouth or throat can take a long time to heal. This can mean that you have ulcers, which can be painful, for some time.

## Damage to the bone or cartilage

In rare cases, there can be damage to the jawbone or to the cartilage of the voicebox (depending on the area treated). Occasionally you may need surgery to correct this. This is more common in patients who continue to smoke during and after their radiotherapy. Having teeth extracted from jawbone that has been treated with radiotherapy will increase the risk of bone damage. Please remember to discuss this with your clinical oncologist.

## Hormones

Occasionally patients having treatment to the neck or to the back of the nose will experience lower than normal levels of some hormones. If your doctor thinks you are showing any signs of this, the levels can be checked with

a blood test. If necessary, we can give you replacement hormones.

These possible late effects may seem very alarming, but please remember that only a minority of patients have any serious late effects. Where they do occur they can often be corrected by limited treatment or surgery. You will also have regular follow-up appointments to monitor your progress. Please discuss any worries with your doctor or nurse.

## Nutrition

It is very important for you to eat healthily and drink plenty of fluids during your treatment. We recommend about 3 to 4 pints of non-alcoholic fluids a day. This will help your tissues to heal and help you to fight off infection. If you are having chemotherapy, the fluid helps to prevent damage to your kidneys.

People often find that for a few weeks they have to go on to a soft or liquidised diet and may need high calorie liquid supplements. These are available on prescription. Please ask any of the staff looking after you for advice if you are worried about your diet. There are several Christie booklets about how to cope with eating difficulties and about nutritional drinks. Ask staff in outpatients for these booklets. We can arrange for you to be referred to a dietitian if necessary.

Your weight will be monitored throughout your treatment. It is very important that you don't lose weight as this can prevent healing of the irradiated tissues and delay your recovery. If you are not eating and drinking enough, you may need to come into hospital to be fed by a tube. Occasionally patients need to be fed by tube because food and fluids are going down the wrong way (into the air passage). This condition will normally resolve in the weeks after treatment.

Once the tube is in place and you have got used to the feeds, we can teach you to care for the tube and feed yourself at home. When you are able to eat and drink enough in the normal way the tube can be removed. If possible, it is important that you continue to swallow small sips of water. This helps to return to normal after treatment.

Sometimes a tube called a gastrostomy is inserted directly into your stomach before any of the treatment starts. This is because we know that you are very likely to stop eating properly. Your swallow should recover after treatment but there is a possibility (for one in 10 people) that your swallow does not recover and the gastrostomy will be permanent.

## Painkillers

Almost everyone will experience soreness or pain from the treatment. It usually starts about halfway through the course of radiotherapy. Some people will already be on painkillers because of pain from their tumour.

We will prescribe painkillers for you to help the pain or soreness and to make you feel more comfortable and help you to swallow food and fluids. These range from paracetamol mixture to strong painkillers such as morphine. Please let us know if the painkillers are not working.

You will need to take painkillers as long as your mouth, throat or skin are sore. As the effects of the radiotherapy lessen in the weeks after treatment, most people can start to reduce their painkillers accordingly. You may need to discuss this with your GP.

## Some of the painkillers we use include

**Paracetamol mixture:** This is available from The Christie pharmacy and is a thick white mixture containing paracetamol that coats the mouth and throat. The dose is 10 mls (equivalent to two paracetamol tablets) four times a day. It is dangerous to take more than this in a day, so if you feel the paracetamol is not working or is wearing off after a short time, please ask to see the doctor or nurse and we can give you some stronger painkillers.

There is a wide range of “medium-strength” painkillers available including codeine and tramadol. They can usually be taken alongside the paracetamol mixture. Your doctor or nurse clinician will discuss these painkillers with you. We recommend that you do not take anti-inflammatory medicines such as diclofenac or ibuprofen. If you are having chemotherapy you should not take anti-inflammatory drugs.

**Morphine** is a very effective painkiller and many patients need to go onto a morphine type drug (either liquid, capsules or a patch worn on the skin) towards the end of their treatment. As long as it is used to treat pain or soreness, there is no risk of addiction. The side effects are usually not a problem, although you will need to take a laxative to prevent constipation if you are on morphine or any drugs containing codeine.

## How long should I continue to take painkillers?

The painkillers are not part of your treatment. You will need to take them as long as your mouth and throat are sore. You should gradually be able to reduce the amount or strength of painkillers over the weeks after your treatment has finished. It is important that you do not suddenly stop taking long-acting morphine such as a patch or twice daily capsules as it can make you feel poorly.

If you have any queries about your painkillers after your treatment course, see your GP or contact your consultant's team (see page 1).

## Prescriptions

From 1 April 2009 NHS patients treated for cancer became entitled to free prescriptions. Prescriptions from The Christie pharmacy are free for NHS patients. You will need an exemption certificate to get free prescriptions from a community pharmacy. Exemption certificates are available from the pharmacy and benefits advisers at The Christie and your GP.

## After the treatment

Your side effects may last for some weeks after the treatment finishes, so it is important to continue with your prescribed treatments, mouthcare and skin care. You should also continue to take plenty of non-alcoholic fluids either by mouth or through the feeding tube. It is also important that you contact the hospital if you have any concerns about new problems or side effects getting worse (see page 1).

You may find The Christie booklet 'Follow-up information after radiotherapy for head and neck cancer' helpful.

**Please remember that you can contact us at any time after your treatment if you have any questions or concerns.** You may be asked to attend the early follow-up clinic a week or two after radiotherapy.

Your first follow-up outpatient appointment will usually be about six weeks after your last treatment and will normally be in the outpatient department at The Christie or your local hospital. This might seem a long time, but the radiotherapy reaction takes a few weeks to settle down and the doctors cannot see how effective the treatment has

been until then. Sometimes, especially if you have taken part in a clinical trial, your consultant will ask you to return to The Christie, after two to four weeks, for at least one follow-up appointment.

Some patients ask about 'warning' signs they should look for once the treatment has been completed. There can be different signs depending on where the original problem was. For this reason, you should ask the doctor or nurse to discuss this with you. Of course, if you are worried about anything you feel may be related to the cancer or the treatment, please contact us and, if necessary, we can arrange an earlier outpatient appointment for you.

Tooth decay is more common after radiotherapy to the mouth, so you must see your dentist at least every six months and tell him or her that you have had radiotherapy. He or she will advise you about dental hygiene and will avoid extracting teeth if at all possible. If your dentures become a poor fit after treatment, ask the doctor at the hospital before getting them replaced as your gums take some time to settle.

If you have any other queries or worries, please feel free to ask any of the people looking after you or to ring the contact numbers at the front of this book either during or after your treatment.

## Appointments

Once you are having treatment, if you have a problem with your appointment time, please contact the Radiotherapy department at The Christie on 0161 446 3485 as soon as possible. It is helpful if you can quote your hospital number - it will be on your appointment card or letter.

If your follow-up appointment is inconvenient, please contact the Health Records department on 0161 446 3346 or 3347. Or you could write to The Health Records

Officer, The Christie NHS Foundation Trust, Withington, Manchester, M20 4BX.

If you do write, please make sure that your letter arrives well in advance of your appointment, as this will make it easier to arrange another appointment for you.

If you change your address, please let the Health Records Department staff know your new address - and the address of your new GP.

### Chemotherapy appointments

If you have a problem regarding your chemotherapy appointment, please contact the nurse clinician on 0161 446 3428. You can leave a message and the nurse clinician will return your call. You can also contact her via switchboard on 0161 446 3000 and ask for bleep 12589.

## Further information

### Macmillan Cancer Support

This is a national cancer information charity which runs a cancer information service. The cancer support service freephone number is 0808 808 00 00 (9am to 8pm, Monday to Friday). If you are hard of hearing, use the textphone 0808 808 0121. If you are a non-English speaker, interpreters are available. You can ask to speak to specially trained cancer nurses who can give you information on all aspects of cancer and its treatment.

They also publish booklets which are free to patients, their families and carers. You can get a copy by ringing the freephone number above or by going on their website: [www.macmillan.org.uk](http://www.macmillan.org.uk)

### Booklets include:

- Booklets on specific cancers, for example, larynx, head and neck.

- Understanding cancer treatments - such as 'Understanding radiotherapy' and 'Understanding chemotherapy'.
- Booklets on living with cancer - some of these are listed below:
  - Talking about your cancer
  - Lost for words: how to talk to someone with cancer
  - Cancer and Complementary therapies

The cancer information centres have the full range of booklets available free to patients and their relatives or carers and they offer information and support. There are information centres at The Christie at Withington, Salford and Oldham.

## Christie information

The Christie produces a range of patient information booklets, DVDs. Some of these are listed below:

- **Where to get help: services for people with cancer:** Discusses sources of help when you have cancer, where to go for financial help and lists cancer support groups.
- **Eating: help yourself:** This booklet gives advice on coping with eating problems when you don't feel well, and when you are receiving treatment.
- **Advice about soft and liquidised foods:** For people who can only manage a soft or liquidised diet because of swallowing difficulties. Offers practical suggestions, recipes and nutritional information.
- **Nutritional drinks:** Describes all the special nutritional products available to help people when eating is difficult.
- **Information for laryngectomy** patients having radiotherapy.
- **DVD on 'Radiotherapy to the head and neck':** You can borrow a DVD to watch at home. Ask on the ward or the staff in the outpatient or radiotherapy departments.

- **Radiotherapy and chemotherapy** booklets are available in Urdu, Punjabi, traditional and simplified Chinese. Please ask the staff for a copy or at the Cancer Information Centre. Large print versions are available. Please contact Patient Information on 0161 446 3576.

These booklets are free to patients coming to The Christie. If you would like a copy, please ask the ward staff. If you are an outpatient please ask your nurse, doctor or radiographer.

## Stopping smoking

If you would like to give up smoking contact:

- Smokefree NHS: 0800 022 4 332
- Manchester Smoking Cessation Unit on: 0161 205 5998
- Christie smoking cessation service on 0161 918 7175

## Benefits and finance

You may have had to stop work and had a reduction in your income. You may be able to get benefits or other financial help.

No new claims for Disability Living Allowance can be made after April 2013 but you may be entitled to Personal Independence Payments.

People over 65 may be able to claim Attendance Allowance.

Find out more today:

- freephone 0800 882200 (Department of Work and Pensions Disability Benefits Helpline)
- contact The Christie at Withington general and benefits adviser on 0161 446 8539. The Christie at Oldham has a benefits advice session on Thursday afternoons phone 0161 918 7745.

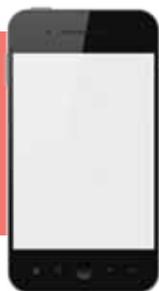
- contact your local social services department
- Macmillan Cancer Support has an advice line on 0808 808 00 00 or [www.macmillan.org.uk](http://www.macmillan.org.uk)

## Student training

The Christie is a training centre for postgraduate and undergraduate trainees so you may meet male and female students in all areas of the hospital. We train doctors, nurses, radiographers and other therapists in the treatment and care of cancer patients. Placements at The Christie are an important part of student training, so by allowing them to assist in your care, you will be making a valuable contribution to student education. Students are always supervised by fully qualified staff. However, you have the right to decide if students can take part in your care. If you prefer them not to, please tell the doctor, nurse, radiographer or other therapist in charge as soon as possible. You have a right to do this and your treatment will not be affected in any way. We also try to respect the concerns of patients in relation to the gender of their doctor and other health professionals.

## Car parking

There is a special car parking scheme to make coming for daily radiotherapy and car parking easier. The staff in the radiotherapy department will tell you about this after your radiotherapy planning session.



### **Please note:**

**Mobile phones can interfere with the treatment equipment. Please look out for signs letting you know if it is safe to use your mobile phone. If you do have one with you, you may need to turn it off.**

# The Christie Clinic

A private patient partnership between HCA International and The Christie NHS Foundation Trust

## Do you have Private Medical Insurance?

Patients with Private Medical Insurance or those who choose to pay for their care can access a full range of treatment at The Christie Clinic. This includes initial consultation, diagnostics, surgical, chemotherapy and radiotherapy treatments in one place.

The Christie Clinic is the Private Patient facility within The Christie NHS Foundation Trust. We work with The Christie NHS Foundation Trust as a joint partnership with HCA International. The partnership means that a share of the profit from The Christie Clinic is invested back into the NHS for the development of care and future service enhancement.

We value our patients as individuals so care is tailored to provide the best possible clinical outcomes; we work with a number of expert consultants who lead this tailored care plan. This consultant will be in charge of your care for the duration of your treatment.

If you wish to use your private medical insurance or pay for your treatment yourself there are three simple steps:

- 1) Check your insurance cover:** In some instances your insurance company may suggest that you have your care and/or some aspects of your treatment on the NHS. It is your choice. You have paid your premiums. If being treated in the NHS you choose to exercise your private medical insurance or wish to pay privately you may of course do this, but your consultant would guide you as to the best clinical option. Arranging a referral back into

the NHS for your treatments such as radiotherapy may cause some delays in beginning your treatment.

**2) Make an appointment:** There are no waiting lists. An appointment can be easily scheduled to suit you.

**3) For more information or advice:**

- Speak to your consultant about continuing your treatment as a private patient
- Call us on 0161 918 7296 if you have any queries about accessing our services or if you need a quotation if paying for treatment or if you have private medical insurance and wish to clarify any points.
- Email us: [info.christieclinic@hcahealthcare.co.uk](mailto:info.christieclinic@hcahealthcare.co.uk)

We care for patients at all stages of illness so it's not too late to consider private treatment.

Find out more about us and our services at [www.thechristieclinic.co.uk](http://www.thechristieclinic.co.uk)

**Christie Website**  
**[www.christie.nhs.uk](http://www.christie.nhs.uk)**

**Many of The Christie booklets and a list of UK help groups are available on The Christie website. The address is above. You can also access other patient information sites in the UK such as Macmillan Cancer Support and Cancerhelp UK via The Christie website. The address is above.**

We try to ensure that all our information given to patients is accurate, balanced and based on the most up-to-date scientific evidence. If you would like to have details about the sources used please contact **[Patient.Information@christie.nhs.uk](mailto:Patient.Information@christie.nhs.uk)**



## Visit the Cancer Information Centre:

The Christie at Withington Tel: 0161 446 8100

The Christie at Oldham Tel: 0161 918 7745

The Christie at Salford Tel: 0161 918 7804

Open Monday to Friday, 10am to 4pm.

Opening times can vary, please ring to check before making a special journey.



The Christie NHS Foundation Trust,  
Wilmslow Road, Manchester,  
M20 4BX, United Kingdom



T. 0161 446 3000

F. 0161 446 3977

Email: [enquiries@christie.nhs.uk](mailto:enquiries@christie.nhs.uk)

Web: [www.christie.nhs.uk](http://www.christie.nhs.uk)

The Christie Patient Information Service  
April 2013 - Review April 2016