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We will try our best to meet your needs.
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Introduction
This booklet has been written for patients who are receiving radiotherapy treatment to a part of the back (spine). We give radiotherapy treatment to patients with various tumour types including: primitive neuroectodermal tumours (PNET), ependymomas, medulloblastomas, spinal gliomas, and spinal sarcomas. The booklet describes:

- What is radiotherapy.
- How your treatment is planned and delivered.
- The side effects you may experience during and after treatment, and how best to cope with them.

We understand that this is an anxious time for patients. You may feel that you have been given lots of information about what needs to be done in a short period of time. We hope this booklet answers some of your questions. If you still have any questions or concerns, please let your doctor, nurse or radiographer know. We are here for you.

What is radiotherapy?
Radiotherapy is treatment using high energy X-rays, aimed specifically at the site of the cancer. It is a quick and painless procedure.

Radiotherapy has clear benefits since it is a localised treatment which destroys any microscopic cells and reduces the risk of recurrence. However, no treatment is completely risk free. In recommending your treatment, your doctor (Clinical Oncologist) has weighed up the risks and benefits. Please do discuss these issues with your doctor or a member of the radiotherapy team if you are worried.

Radiotherapy is planned to treat as little of the normal body tissue as possible and treatments are usually extended over a period of weeks. This allows normal cells to recover from the effects of the radiation. Common treatment prescriptions vary between five to seven weeks, treating daily, excluding weekends. The exact schedule will be decided by your doctor and confirmed on your first visit to the radiotherapy department.
Planning your treatment

Planning treatment to the cervical spine (neck)
Your first visit will involve having an impression taken of your head and shoulders to ensure you are in the correct treatment position. Because radiotherapy is a very precise treatment a plastic mould (also called an immobilisation shell) is made of the area to be treated in order to ensure treatment accuracy on a daily basis.

The immobilisation shell has three purposes:

- to keep your neck immobilised during treatment
- to ensure you are in the same position everyday for treatment
- to minimise the number of treatment marks on your skin

The immobilisation shell is made from a sheet of thermoplastic material called Posicast®. The sheet is hard when dry and is placed in warm water to allow it to soften. This is placed over your head and neck and held into position until it begins to dry and harden.

Once the immobilisation shell is made your next visit will be for a radiotherapy computerised tomography (CT) planning scan.

Having a radiotherapy CT planning scan
You will be positioned on the scanner couch wearing your immobilisation shell. The radiographers will place some tape on your shell and draw marks on this tape. They will also place a reference mark on your chest using felt tip pens. The CT scan will take about five minutes, during which time you can breathe normally. Once the scan is complete the radiographers will remove the immobilisation shell. They will make the reference mark on your chest into a permanent mark. This is done by placing ink on your skin and gently scratching the surface of the skin with a fine needle.
Planning treatment to the thoracic and lumber spine (upper and lower back)
You will be positioned on the CT scanner couch lying on your back with supports under your head knees and ankles. Your arms will be positioned either by your sides or across your chest.

The radiographers will ensure your body is straight. They will then place some temporary marks on your skin using felt tip pens. They will then place sticky wire markers on these marks which will show up on the scan. The scan will take about five minutes, during which time you can breathe normally.

Once the scan is complete the radiographers will mark three or four specific points on your chest/pelvis. These are the co-ordinates for your treatment and ensure repeatable treatment accuracy on a daily basis. The points are permanent and are made by placing ink on your skin and gently scratching the surface of the skin with a fine needle.

Radiotherapy and chemotherapy
Some patients will be given drug treatment (chemotherapy) before or during their radiotherapy. The chemotherapy increases the activity of the radiotherapy against cancer cells. Your doctor will tell you which chemotherapy you will be having. Patients receiving chemotherapy in addition to radiotherapy may experience more severe or additional side effects to those listed here, depending on the drug regimen used. It is possible the use of chemotherapy may increase the likelihood of nausea with your treatment. It may also cause small ulcers in the mouth. The doctors will discuss these issues with you.

You will be given detailed fact sheets about the chemotherapy drugs and their side effects by the chemotherapy nurses. If you have any concerns or further questions please do not hesitate to ask for help.
Radiotherapy treatment

The radiotherapy treatment is daily, Monday to Friday. Your radiotherapy doctor will have already told you how many treatments you will be having. Your treatment will be on a machine called a Linear Accelerator, or Linac, for short. The radiographers will explain the treatment procedure to you and answer any questions you may have.

For each treatment session you will be lying on your back on the treatment couch. If you are having your cervical spine (neck) treated you will be wearing your mask. If you are having treatment to the thoracic spine (upper back) or lumbar spine (lower back) you will be lying on your back with supports under your head knees and ankles. Your arms will be positioned either by your sides or across your chest.

The radiographers will ensure you are in the correct treatment position by aligning the marks on your mask or the permanent marks on your chest or pelvis with laser lights. They will then move the treatment machine and couch into position using your personal treatment plan.

When final treatment checks have been made, the radiographers leave the room. To give you the best treatment you will be treated from several different angles. The linear accelerator will move around you, but will not touch you. You will not feel anything and you do not have to hold your breath. All we ask is that you keep still.

The radiographers will be watching you at all times on a closed circuit television. Please check with your radiographers if you have any questions or concerns. Each treatment session takes about 15 minutes. Most of this time is spent getting you in the right position. The treatment from each angle only takes a few minutes.
Side effects during treatment
There will be some side effects which will gradually appear during your course of radiotherapy, although these will vary from person to person. The risk and severity of any side effects occurring depends on the dose of radiotherapy given. Your radiotherapy doctor will discuss this fully with you. There are side effects that occur during treatment, some happen soon after treatment, and some can occur months or years after radiotherapy. The main side effects that occur during treatment are:

Skin changes
The skin in the area being treated may become slightly pink, and feel warm to the touch during the radiotherapy treatment. During the course of treatment we advise that you wash your skin gently using warm water and a non-perfumed soap. You can bathe in warm water but avoid the use of perfumed bubble bath or shower gels. Gently pat the skin dry with a soft towel. Do not vigorously rub the skin in the treatment area.

Aqueous cream can be applied to the treated skin. This is a simple, unperfumed moisturising cream which can be used from the start of treatment. It helps prevent the skin from becoming too dry. Smooth a little cream very gently onto the treatment area two to three times per day. The radiographers or nurses will provide you with some cream. Avoid exposing the skin in the treated area to strong sunlight, both during and after your radiotherapy treatment. Ensure that you wear a hat, cap or head scarf at all times when outside to protect your head. Radiotherapy causes changes to the skin which makes it more sensitive to the sun. Your skin will damage more easily and take longer to heal. The treated area will be especially sensitive for the first twelve months and you should avoid exposing the treated area to strong sunlight. After this time you can gradually increase the sun exposure but we recommend that you always use a high protection sun cream (Factor 25 or more) in strong sunlight.

Do not use any other creams or lotions in the areas being treated unless advised by a member of staff.
Avoid exposing the treated area to strong sunlight or extreme temperature changes during and after treatment. Ensure you wear a top (especially during the summer) to protect your skin. Radiotherapy causes changes to the skin which make it more sensitive to the sun. The skin in the treated area will be especially sensitive for the first 12 months after treatment. After this time, you can gradually increase your sun exposure but we recommend that you always use a high protection sun cream (Factor 25–40 or more) in strong sunlight. In the longer term, we advise you to seek urgent medical advice for any moles that itch or bleed, grow very fast or occur on the palms of the hands or soles of the feet.

**Sore throat**
If you are having radiotherapy to the cervical spine (neck) or thoracic spine (upper back) you may experience a mild discomfort when swallowing food. This is a normal reaction as the radiotherapy irritates the gullet. In most cases you will still be able to eat and drink normally. Some people may require oral medication to ease the discomfort. If you are having difficulty eating and drinking please speak to a member of staff.

**Feeling sick (nausea and vomiting)**
Occasionally, you may feel sick (nauseated) and vomit because of the radiotherapy treatment. This can be well controlled with anti-sickness medication which will be prescribed if you experience such symptoms. Please ask for a copy of the leaflet “Coping with nausea”.

**Diarrhoea**
You may experience diarrhoea if you are having radiotherapy to the lumbar spine (lower back). This is due to the radiation irritating the bowel. You may also experience wind pains and/or cramping sensations. You may be prescribed regular anti-diarrhoeal medication whilst you are on treatment. If the diarrhoea persists or becomes severe the doctor will prescribe stronger medication. The radiographers will also offer advice on nutrition or refer you to the dietician, who can offer advice on maintaining a nourishing and pleasant diet.
If you are experiencing diarrhoea, it is important that you try to maintain a good fluid intake. Try to drink at least one to two litres of fluid a day. This can include water, squash or hot drinks. Please ask for a copy of our leaflet on “Coping with constipation or diarrhoea”.

**Appetite**
It is important that you try to eat a well balanced diet during radiotherapy treatment, and drink plenty of fluids. Many people experience a loss of appetite which may be accompanied by a feeling of fatigue which can last some months. These are normal reactions to the treatment. However, the severity of the symptoms can cause anxiety.

The loss of appetite may be due to a number of factors including the side effects of radiation and anxiety. It can occasionally mask a thyroid or other hormone deficiency occurring as a result of the illness or the spinal radiation, for which you can ask to see the endocrinologist (hormone specialist). You will be weighed weekly by the radiographers and if there is significant weight loss you will be referred to the dietician. Please ask for the leaflet “Eating hints for patients”.

Your appetite may be suppressed for a number of weeks or months from the end of treatment. This will be monitored by the medical team.

**Hair loss**
There may be a loss of hair at the back of your neck if this is in the treatment area. The hair usually starts to grow back about three months after treatment, the new growth often being slightly different in colour and texture. However, hair might not grow back in the areas which have had a high dose of radiation. The doctors will advise you about this.

**Blood and bone marrow system**
Treatment of the spine can affect your bone marrow. Bone marrow makes blood cells and is found in the centre of bones such as the spinal bones. The white blood cells (which fight infection), red blood cells (which carry oxygen around the body) and platelets (which are important for blood clotting) might be affected. You will have regular blood tests if a long portion of your spine is being treated. You will be informed of the number of blood tests required at the start of your treatment.
Tiredness and fatigue
A course of radiotherapy may make you more tired. This occurs towards the end of treatment and in the following weeks. This is a normal reaction to the radiotherapy. Allow yourself to rest when the need arises. However, many people do not have a problem with tiredness and you should try to lead a normal life as much as possible.

Late side effects of radiotherapy
Late side effects incurred during treatment can appear to develop months or years after radiotherapy has finished. They are the hardest to predict and, unfortunately, when they do occur they are permanent. Some, however, like hormone deficiencies are very easy to treat and routine follow-up can prevent symptoms occurring. Your radiotherapy doctor will have explained to you the potential late side effects of radiotherapy as part of the consent process. These may include:

Lung function
It is possible for lung function to be affected by the radiotherapy treatment if you have received radiotherapy to the thoracic spine (upper back). This can take two forms:

• Six to twelve weeks after radiotherapy your may experience some shortness of breath and a dry cough. This may be due to radiation pneumonitis, which may be treated with a short course of steroids and usually recovers completely. In most people symptoms never occur.

• There may be some long-term effect on your breathing. This is very unusual, but if it occurs, it tends to be noticeable on moderate to severe exercise only.

Heart
If you have received radiotherapy to the thoracic spine (upper back) the heart may also be in the treatment field. Usually the radiation doses given are too low to cause a problem. Your doctor will discuss this side effect with you, if it is relevant to your treatment.
Thyroid gland
The thyroid gland (in your neck), if it is included in the treatment area, can be affected by the treatment. Your thyroid may become swollen or feel lumpy. It may also become underactive or, very rarely, it may become overactive, many years after your treatment has finished. You will be carefully monitored by your medical team after your radiotherapy treatment has finished. If a thyroid dysfunction is detected or if you experience swelling, fatigue (symptoms of an underactive thyroid) or weight loss and hyperactivity (symptoms of an overactive thyroid) all these symptoms can easily be treated.

Female fertility
For women who have radiotherapy to the lumbar spine (lower back) the ovaries and the womb may be near the treatment area. We are careful to minimise the risk to the ovaries, but sometimes we cannot avoid them receiving some radiation. This can lead to sub fertility (reduced egg production) which may be temporary or permanent. The doctors will discuss this with you. If you wish to discuss this further please feel free to ask to see a specialist before your radiotherapy treatment begins.

Male fertility
The testicles are usually away from the treated area. However, if you are having treatment to the lumbar spine (lower back) small doses or radiation can scatter there. The doctors will be able to tell you if the dose to your testicles is likely to cause sub fertility (reduced sperm production) or infertility (absent sperm production), or affect the production of the male sex hormone testosterone which is important for potency. Your doctor will talk to you about this, if it is relevant to you.

Kidneys
Radiotherapy may affect the kidneys, if they are near the treated area. We are careful to minimise the risk to the kidneys but often cannot avoid them receiving some radiation. Your kidney function will be closely monitored at follow-up.
Osteopaenia (low bone density)
Low bone density can occur for a number of reasons. These can include immobilisation, poor nutrition, low calcium, steroid therapy as well as radiotherapy to the skeleton. Weight bearing exercise, eating a healthy diet and timely hormone replacement therapy can all prevent osteopaenia occurring.

Transient radiation myelopathy
Also called L'hermitte’s Syndrome. The doses that we use to treat spinal tumours are designed to prevent long term damage to the spinal cord, but sometimes patients may notice some nerve symptoms related to treatment. The radiation can cause a temporary inflammation of the membrane surrounding the spinal cord. Within four to six weeks after the end of treatment you may experience tingling or a feeling of pins and needles in your arms and legs. This is not a sign of serious nerve damage and recovers without treatment. These symptoms can take four to six months to settle.

Second malignancy
Very rarely, people who have received treatment for one particular tumour may develop another type of tumour some years later. The radiotherapy doctors will discuss this with you if it is relevant.
Support
This booklet deals with the physical aspects of your treatment, but your emotional wellbeing and that of your family is just as important. Having treatment can be deeply distressing for some patients. Within the radiotherapy department there will be access and support from the radiotherapy nurses, your specialist nurse, the Macmillan information and support radiographer and the treatment radiographers. However, if you feel you require further medical or emotional support you can be referred to a variety of health professionals who can help with any worries or difficulties you may be having.

All the staff are here to make sure your treatment goes as smoothly as possible and to support you through this difficult period. We will try to help you with any questions or problems you may have.

After your radiotherapy has finished
Once you have finished your radiotherapy treatment you will be given a follow-up in two to four weeks time. This will be at University College London Hospital. If you have had radiotherapy only, you will have a baseline post radiotherapy MRI scan six to eight weeks after your radiotherapy has ended. If you are having combined radiotherapy and chemotherapy treatment, you will have a scan once chemotherapy is completed (in approximately seven months). The first post treatment scan will not show how effective the treatment has been, but it will be used to compare with any future scans you have.

The side effects you may have experienced will continue after radiotherapy treatment has finished. It is common to experience a worsening of the skin reactions for about 10 to 14 days after radiotherapy. Please feel free to contact the department, your specialist nurse, the nursing staff or the Macmillan information radiographer if you are worried. You could also contact your GP or call outpatients to request an earlier follow-up appointment. However, most of the side effects should resolve after you have finished treatment.

Before you finish your course of treatment please ask for a copy of the leaflet “Finishing treatment”.
Useful contact numbers

Local
Brain Tumour Team at The National Hospital for Neurology and Neurosurgery

For general enquiries contact The Brain Tumour Unit
Elaine Hill (Co-ordinator)
Telephone: 020 7391 8830
Email: braintumourunit@uclh.nhs.uk

Macmillan Information and Support Radiographer
Mark Williams
Direct telephone: 020 3447 3711
Main switchboard: 0845 155 5000
ext 73711
bleep 1458
Alternative switchboard: 020 3456 7890
ext 73711
bleep 1458
Email: mark.williams@uclh.nhs.uk

Dr Short’s Secretary:
Direct telephone: 020 3447 9287

Dr Fersht’s Secretary:
Direct telephone: 020 3447 9358

Dr Cassoni’s Secretary:
Direct telephone: 020 3447 9087

Dr Seddon’s Secretary:
Direct telephone: 020 3447 9866
National
Brain Tumour UK
Helpline: 0845 450 0386
Monday to Friday, 09:00 to 17:00
Email: enquiries@ukbts.org.uk
Website: www.braintumouruk.org.uk

Samantha Dickson Brain Tumour Trust
Telephone: 0845 130 9733
Email: enquiries@sdbtt.co.uk
Website: www.braintumourtrust.co.uk

Brain and Spine Foundation
Freephone Helpline: 0808 808 1000
Website: www.brainandspine.org.uk

Sarcoma UK
A website and newsletter offering further links and advice to patients and their families
Email: info@sarcoma-uk.org
Website: www.sarcomauk.org

Macmillan Cancer Support
Cancer Line freephone: 0808 808 0000
Monday to Friday, 09:00 to 21:00
Textphone: 0808 808 0121
Monday to Friday, 09:00 to 18:00
Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

Cancer Help UK
Freephone Helpline: 0808 800 4040
Monday to Friday, 09:00 to 17:00
Website: www.cancerhelp.org.uk
Carers UK
Freephone: 0808 808 7777
Wednesday to Thursday
10:00 to 12:00 and 14:00 to 16:00
Email: info@carersuk.org
Website: www.carersuk.org

Cancer Research UK
Website: www.cancerresearchuk.org

National Library for Health
Covers all aspects of health, illness and treatments
Website: www.library.nhs.uk

NHS Direct
Telephone: 0845 4647
Available 24 hours
Website: www.nhsdirect.nhs.uk

Patient UK
Comprehensive, free, up-to-date health information
Website: www.patient.co.uk

NHS 24
Telephone: 0845 424 2424
Website: www.nhs24.com

NHS Choices
Website: www.nhs.uk

Health Talk Online
Website: www.healthtalkonline.org
Space for notes and questions