

Information for patients receiving radiotherapy to the adult brain and spinal cord



This leaflet is for patients receiving radiotherapy to the brain and spinal cord (whole CNS radiotherapy). It describes:

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

We treat each person as an individual and the effects of treatment may vary from one person to another. Your doctor, specialist radiographer, and clinical nurse specialist will explain specific aspects of your treatment.

What is Radiotherapy?

Radiotherapy is the use of carefully measured doses of radiation to treat cancer. It damages the cells and stops them dividing and growing. Most patients having radiotherapy are treated using a high energy beam of x-rays delivered to a precise area.

Your radiotherapy involves the treatment of your whole brain and spine. It is sometimes followed by an additional 'boost' of treatment to a smaller area in your brain or spine.

Your radiotherapy is given in small daily doses. It is usually delivered 5 days per week, Monday - Friday, for around 6 weeks.

Preparing for your radiotherapy

Before you begin your treatment we must carefully plan it. Your first visit will involve having a plastic mould (also called a shell) made of your head and shoulders. The shell is individually made to fit you and will be worn for your planning scan and your treatment each day.

The shell has three purposes:

- To ensure you are in the same position for each treatment.
- To keep your head and shoulders still during treatment.
- To minimise the number of treatment marks on your skin.

The shell is made to fit you in the **Mould Room**.

Mould Room

The process of making the shell will be explained to you in detail by the mould room team. Making the shell is completely painless. There are small holes in the material used to make the shell, and an opening for your nose and mouth.

This appointment will last about 50 minutes.



Picture 1 - Shell

If you have a beard and/or moustache we advise you to shave it off before coming to the mould room. It is important that your skin is smooth before we start to make your shell.

Radiotherapy planning - CT simulator

Following your visit to the mould room, the planning of your treatment will begin with a CT scan at the CT simulator. These scan images will be used to produce a unique plan for your own individual treatment.



Picture 2 - CT Simulator

You will lie on your back on the scanning couch wearing your shell. Your radiographers will make you as comfortable as possible. They will put some pen marks on your shell, chest and pelvis. They will then place some small markers on top of the pen marks. Once you are in the correct position, they will leave the room to start the scan.

The scan does not take long, usually only 5-10 minutes. You must stay very still but you can breathe and swallow as normal.

Once the scan is finished, your radiographers will make the pen marks on your pelvis permanent. This is done by giving you three tiny tattoos, one on the front and one on each side of your pelvis. These are used to make sure you are in the correct position for treatment each day.

Contrast injection

You may need to have an injection of contrast (dye) that will help us to see the area we want to treat more clearly. Your doctor or radiographer will put a small needle (cannula) into a vein. The needle is removed leaving a small hollow plastic tube in your vein. This will be taped in place and will stay in position during the scan. We will inject the dye through this tube. It may feel a little cold but you should not feel any discomfort. You may need this dye for the CT planning process, but you will not need it for your treatment appointments.

Radiotherapy treatment

Your radiotherapy treatment will start two to three weeks after your planning scan.

When you attend for your first treatment, your radiographers will explain what will happen and answer any questions you may have.

You will have your treatment on a machine called a linear accelerator.



Picture 3 - Linear Accelerator

For each treatment you will be lying on your back wearing your shell. Your radiographers will dim the lights in the room while they ensure you are in the correct position.

They will move the machine into position and check your personal treatment plan. They will then leave the room to begin your treatment. Although your radiographers are outside the room, they will monitor you closely on CCTV.

Your radiographers will take some x-ray images to finalise your position. You may feel the couch move slightly when they do this. Once they are happy, they will deliver your treatment. You won't see or feel anything. The whole appointment takes 50 - 60 minutes.

Once a week, you will be seen by your doctor or specialist radiographer. They will check how you are coping with the treatment and any side effects. You will also have a weekly blood test done to monitor your bone-marrow function. Your treatment radiographers will let you know when and where this will take place.

Effects of treatment

There will be some side effects which will gradually develop during the course of your radiotherapy. Each patient is an individual and the effects of the treatment can vary. Some side effects occur during radiotherapy, soon after treatment has finished, and some months to years after treatment.

We give radiotherapy in addition to surgery and/or chemotherapy. Patients who have chemotherapy as well as radiotherapy, **may** experience additional or more severe side effects to those listed below. Your doctor will discuss this with you. The main side effects are:

- **Tiredness** – You may become tired as your treatment progresses. This can continue for a few weeks after your treatment finishes.

Try to get enough rest and sleep, especially when the treatment begins to make you feel tired. It is also important that you try to continue with some of your normal daily activities. A sensible balance between rest and activity may be most beneficial. Research has shown that gentle exercise is also beneficial for people who have had a cancer diagnosis both in the short and longer term. There are programmes available that can help with this. Please let us know if you are interested in finding out more.

- **Skin changes** – The skin in the treated area may become red, dry and itchy. Some areas of your skin may also get sore and moist. The following skin care advice will help to minimise any reaction:
 - » Bathe as normal, ensuring that the water is not too hot and pat your skin dry.
 - » Do not use any creams or lotions on the treatment area unless we have advised you or given you them.
 - » Wash your hair with lukewarm water using your normal shampoo. If your skin becomes irritated we may advise you to stop using shampoo.
 - » Pat your hair dry gently with a soft towel and allow it to dry naturally.
 - » Do not use a hairdryer as this will irritate your scalp.
 - » Avoid using curling tongs or straighteners.
 - » It is important you protect the treatment area from the sun when the weather is hot by wearing a hat and a top that covers your back. This is because your skin and scalp will be much more sensitive during and after radiotherapy. You will need to be especially careful for the first year after your treatment has finished as this area will always be much more sensitive to the sun. We advise you use sunscreen with both UVA/UVB protection and minimum SPF 50.

- **Hair loss** – Hair loss usually starts two- three weeks into treatment and it is usually all gone by the end. Hair loss varies from person to person, but will include the hair on your head, eyebrows and on areas of your chest and abdomen.

Hair usually starts to grow back about 3 months after all treatment has finished. The texture may be different to before, and you may have thin or patchy areas. Sometimes the hair does not grow back, especially over the lower part of the back of the head.

Losing your hair can be distressing. If you have long hair, you may want to consider cutting it short before you begin treatment (and before you have the shell made). We can arrange for you to get a wig on prescription. The radiographers can help you to arrange this.

- **Nausea (feeling sick)** – You may experience nausea and vomiting. Your doctor will prescribe anti sickness medication for you to take before treatment each day. If you find you lose your appetite, try eating little and often.
- **Headaches** – Some people find they have more headaches at the beginning of their treatment. Let your radiographers know if your headaches are troublesome or persistent.
- **Ocular irritation** – You may experience dry, red eyes during the radiotherapy. This will recover a couple of weeks after radiotherapy has been completed.
- **Dry mouth, sore throat, hoarse voice** – You may develop a sore throat which can sometimes cause discomfort when eating or swallowing. This usually happens about 3 weeks after treatment has started. Your doctor may prescribe some medication to help ease this. This completely recovers a week or two after treatment is finished.

- **Diarrhoea** – Your bowels may become looser towards the end of your treatment. If this happens, please let your radiographers know and they will give you advice on how to manage this. You may also experience pain and/or cramping. Drinking enough fluids can help with this. You should try to drink two litres of water or squash a day.
- **Bone marrow function** – Radiotherapy can affect the function of your bone marrow. This means that you become anaemic or your body may not be able to fight infection. Your blood will be checked weekly and your doctor will let you know if your bone marrow is affected. You may require some medication or a blood transfusion.
- **Seizures or fits** – There is a slight increased risk of seizure (or fit) after your treatment, although this is usually only a problem if you have had seizures in the past. Your doctor or specialist radiographer will discuss this with you.

Possible long term side effects

Long term side effects can occur many months to years after radiotherapy has finished. It is hard to predict who will experience these side effects, and to what degree. They can be permanent.

- **Chronic fatigue** – You may feel extreme tiredness or lack of energy, often described as being exhausted. It may continue even when you feel you are getting enough rest and sleep. Your doctor can give you advice on how best to manage this.
- **Hormone changes** – You may experience changes in your hormone levels as your pituitary gland is in the treatment area. This gland controls several hormones that your body needs (thyroid, adrenal, and ovarian or testicular hormones). This can lead to problems with your thyroid, sugar metabolism, fertility, or ability to process water. Your blood levels will be monitored yearly and you may be given medication to help with the production of these hormones.

- **Fertility issues –**
 - » Menstruation may become irregular and even stop after the radiotherapy. Your doctor will discuss this with you before treatment begins.
 - » **Ovaries** – may receive very low doses of radiation resulting in reduced egg production, which may be temporary or permanent. Your doctor will discuss this with you before treatment begins.
 - » **Testicles** – may receive very small doses of radiation which can very occasionally result in reduced sperm production or infertility. It can also affect the production of the male sex hormone testosterone which is important to achieve an erection.
- **Prolonged nausea and stomach ulcers** – gastrointestinal side effects may continue after the radiotherapy has been completed.
- **Short term memory** – Some people may find that their short term memory is not as good as it was in the past. This is due to changes in the brain caused by long term effects of radiotherapy. The small vessels in the brain may be affected by the radiotherapy long after it has finished. The effect on the small blood vessels is similar to the changes that occur within the brain as it ages. Symptoms may be mild, moderate or severe, depending on the area of the brain affected and the extent of damage to normal brain cells. You may experience:
 - » Problems thinking clearly.
 - » Difficulty managing tasks you previously found easy.
 - » Poor memory.
 - » Confusion.
 - » Personality changes.

If you are experiencing such symptoms please report these to your medical team. Neuropsychology assessments can be undertaken and strategies to help manage any memory problems you may be experiencing can be suggested.

- **Secondary malignancy** – A very rare but potentially important effect is that radiation can cause tumours. Although this is a serious possible consequence of your radiotherapy, it is important to bear in mind that the chance of this happening is very small. If it does occur it is likely to be many years after treatment.

Some other potential long term side effects that you may experience are listed below. Your doctor will discuss these with you individually if appropriate.

- **Hearing loss.**
- **Changes in kidney function.**
- **Cardiac toxicity.**
- **Shortness of breath.**

Remember we believe that the benefits of radiotherapy treatment for your condition far outweigh the risks described here. Your doctor will discuss this in more detail with you.

After Treatment Ends

Any symptoms which have developed during treatment will wear off a few weeks after it ends, however the tiredness will take a little longer. You may begin to wash normally once your skin no longer looks red or feels itchy.

Your radiotherapy doctor will arrange to see you 6 weeks after treatment ends.

If you should feel unwell after your treatment is finished, please contact your GP or NHS 24 on 111. Your GP and NHS 24 are able to contact the Beatson any time, night or day, should they require information or advice regarding your care.

Where can I get help?

You will probably have lots of questions and concerns about your diagnosis and treatment. You may also feel that you need some extra support to help you through this worrying and difficult time. The professionals and organisations listed below can help you with any issues you might have and provide you with the information and support that you want.

Information and Support

All our staff are here to make sure your treatment goes as smoothly as possible and will try to help with any questions you may have. Further specialist help and information is available from:

- **Neuro-Oncology Nurse Specialist 0141 301 7602**
- **Macmillan Information Radiographer and Counsellor 0141 301 7423**
- **Information and Support Radiographer 0141 301 7427**

This leaflet deals with the physical aspects of your treatment, but your emotional wellbeing is just as important to us. Being diagnosed with cancer can be a deeply distressing time for you and those closest to you. Within the Centre we have a counselling and clinical psychology service that can help with worries and difficulties you might be having. If you think this may be helpful to you, please ask staff to put you in touch.

The Macmillan Information & Support Centre is on Level 1 at the main entrance of the Beatson. They offer emotional support, information and signposting to services within and near to the Beatson and in your own local area. Open Monday to Friday 8.15am to 4.15pm. **Tel: 0141 301 7390**

The Centre has a Radiotherapy Advice Line available for patients who have completed their treatment. It is an answer phone service. Please leave a message and your contact details and you will be called back as soon as possible. This service is available Monday – Friday only. **Tel: 0141 301 7432**

The Cancer Centre also has a Cancer Treatment Helpline for Urgent Calls. This is for patients on or within 6 weeks of treatment who have urgent or severe symptoms such as -

- Shivering or flu-like symptoms.
- Temperature greater than 37.5°C.
- Gum/nose bleeds or unusual bruising.
- Worsening or sudden breathlessness.
- Leg weakness/difficulty walking.
- Severe nausea/vomiting/diarrhoea/constipation.
- Sudden increases or uncontrolled pain.
- Other concerning symptoms associated with your cancer treatment.

Please call the following:

Beatson 8am-8pm Tel: 0141 301 7990

National 8pm-8am Tel: 0800 917 7711

Other Support

There are also voluntary organisations providing information and support. These include:

- **Macmillan Cancer Support: 0808 808 0000**
www.macmillan.org.uk
Providing practical, medical, emotional and financial advice for those affected by cancer.
- **Maggie's Gartnavel: 0141 357 2269**
- **Maggie's Lanarkshire, Monklands Hospital: 01236 771199**
- **Maggie's Forth Valley: 01324 868069**
Maggie's Centre provides a comprehensive cancer support programme for people and their families affected by cancer.
- **Cancer Support Scotland, The Calman Centre, Gartnavel Complex. Freephone 0800 652 4531.**
Provides emotional and practical support on a one-to-one basis and through community based groups.
Complementary therapies available.
www.cancersupportscotland.org
- **Brains Trust: 01983 292405**
Provides information, support and advice at the point of diagnosis and beyond. www.brainstrust.org.uk
- **The Brain Tumour Charity: 0808 800 0004**
Provide a variety of information and support and fund research to address the needs of brain tumour patients.
www.thebraintumourcharity.org
- **Scottish Adult Neuro-Oncology Network (SANON).**
Aims to link together health professionals, patients and their families/carers, voluntary sector representatives, and external companies to design and deliver the best service to patients and carers in Scotland. www.neurooncology.scot.nhs.uk

- **Macmillan Benefits Team** (within the Beatson)
Provides free and confidential financial advice for people affected by cancer and their carers. Please speak to your health care professional who can refer you.
- **Beatson Cancer Centre** – if you want to find out more about our Centre please visit www.beatson.scot.nhs.uk
- **NHS 24 111**

You may find some useful information on the websites listed above. However, it is important to note that The Beatson West of Scotland Cancer Centre cannot accept responsibility for the quality and content of any information provided by other organisations.

