A practical guide to tests and treatments

# UNDERSTANDING RADIO-THERAPY



# Contents

About this booklet	2
1 What is radiotherapy?	5
2 External radiotherapy	29
3 Internal radiotherapy	43
4 Side effects of radiotherapy	51
5 After treatment	65
6 Living with cancer	71
7 Further information	77

# About this booklet

This booklet gives information about radiotherapy, which is used to treat some types of cancer. You may find it helpful to read it alongside our information about your type of cancer.

The booklet is divided into different sections.

- Section 1 gives general information about radiotherapy.
- Sections 2 and 3 give information about external radiotherapy and internal radiotherapy. Your specialist can tell you which type of radiotherapy you're having. You'll only need to read the section that's relevant for you.
- **Section 4** gives information about the most common side effects of radiotherapy.
- **Section 5** gives information about what happens after treatment.
- **Section 6** gives information about living with cancer, including information about work and financial help.
- Section 7 lists some useful addresses and websites.

In this booklet, we've included a comment from someone who has had radiotherapy, which you might find helpful. This is from our Online Community **macmillan.org.uk/community**  We can't advise you about the best treatment for you. This information can only come from your doctor, who knows your full medical history.

If you have any further questions about your treatment, ask your doctor, nurse, radiographer or key worker (see page 12).

We have included some questions that you might want to ask your radiotherapy team on pages 78–80.

If you'd like to discuss this information, call the Macmillan Support Line free on **0808 808 00 00**, Monday–Friday, 9am–8pm. If you're hard of hearing, you can use textphone 0808 808 0121, or Text Relay. For non-English speakers, interpreters are available. Alternatively, visit **macmillan.org.uk** 

If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.





# What is radiotherapy?

Why radiotherapy is given	6
Ways of giving radiotherapy	7
Radiotherapy departments	8
Radiotherapy staff	8
Other members of the MDT	12
Before your treatment	14
Other things to think about	17
Planning your treatment	20
Radiotherapy moulds and masks	23

Radiotherapy is the use of high-energy rays, usually x-rays and similar rays (such as electrons) to treat disease. It works by destroying cancer cells in the area that's treated.

Although normal cells can also be damaged by radiotherapy, they can usually repair themselves, but cancer cells can't.

Radiotherapy is always carefully planned so that it avoids as much healthy tissue as possible. However, there will always be some healthy tissue that's affected by the treatment and this will cause side effects.

# Why radiotherapy is given

Many people with cancer will have radiotherapy as part of their cancer treatment. Radiotherapy may be given for different reasons.

#### **Curative treatment**

This is given with the aim of destroying a tumour and curing the cancer. Curative treatment is also known as radical treatment.

Curative treatment may be given on its own, or it may be given before or after surgery or chemotherapy. Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells.

If radiotherapy and chemotherapy are given at the same time, this treatment is known as chemoradiation.

#### **Palliative treatment**

This is given when it's not possible to cure a cancer. Radiotherapy may be given to relieve symptoms such as pain. Lower doses of radiotherapy are given for palliative treatment than for curative treatment, and they're usually given over a shorter period of time. Sometimes just a single dose is given.

Radiotherapy treatments are planned on an individual basis. This means that even if someone you've met has the same type of cancer as you, their radiotherapy treatment may be different.

# Ways of giving radiotherapy

There are two ways of giving radiotherapy: **external beam radiotherapy** (also known as external radiotherapy) and **internal radiotherapy**.

External radiotherapy is given from outside the body usually using high-energy x-rays (see section 2 on pages 29–41).

Internal radiotherapy is given from a radioactive material placed within the body (see section 3 on pages 43–49). This may be:

- a solid radioactive material that is put close to, or inside, the tumour. This is known as **brachytherapy** (see pages 44–47).
- a liquid source of radioactive material called a radioisotope. This is given as an injection into a vein or taken as a liquid or capsule by mouth. This is known as **radioisotope therapy** or **radionuclide therapy** (see pages 48–49).

Whether you have external or internal radiotherapy will depend on the type of cancer you have and where it is in the body. Some cancers are treated with both external and internal radiotherapy.

# **Radiotherapy departments**

Your radiotherapy treatment will be given in a radiotherapy department. Not all hospitals have radiotherapy departments. This is because radiotherapy machines are very complex and the treatment needs to be planned and given by specially trained staff.

Most radiotherapy departments are in the larger regional and teaching hospitals. You may have your initial cancer treatment, such as surgery, at your local hospital and then be referred to your nearest specialist cancer hospital for radiotherapy.

You can usually have external radiotherapy as an outpatient, but if you're unwell or having chemotherapy at the same time, you may need to stay in hospital. In this case, you will go to the radiotherapy department each day from the ward.

If you're having internal radiotherapy, you may have to stay in hospital for a few days.

# **Radiotherapy staff**

In most hospitals, a team of specialists will meet to discuss and agree on the plan of treatment they feel is best for your situation. This team is known as a **multidisciplinary team** (**MDT**). On the next few pages, we've listed the staff who are involved in planning and giving your radiotherapy.

# **Clinical oncologist (cancer specialist)**

A clinical oncologist, sometimes called a cancer specialist, is a doctor who is trained in the use of radiotherapy and chemotherapy. They're responsible for prescribing and supervising your course of treatment.

You may see your clinical oncologist before, during and after your course of radiotherapy so that the effect of the treatment can be monitored. If you have any problems between these appointments, the radiographers or nurses can arrange an extra appointment for you.

If you're having chemotherapy as well as radiotherapy, your treatment may also be supervised by a **medical oncologist**. Medical oncologists are doctors who specialise in chemotherapy treatment.

# Therapy radiographers

Therapy radiographers are trained in giving radiotherapy and have an important role in your treatment:

- They work closely with your clinical oncologist and a physicist (see page 10) to plan your treatment.
- They operate the radiotherapy machines that give you your treatment.
- They help to position you for your treatment sessions.
- They provide information, practical care and support throughout your treatment.

Where possible, you'll see the same therapy radiographers throughout your course of treatment. You can discuss any concerns or anxieties about your treatment with them. If you prefer, you can ask to be treated by a radiographer of the same sex as you. The radiographers will try to do this where possible.

**Specialist radiographers** Some hospitals have specialist radiographers who are experts in treating specific types of cancer. If you have a specialist radiographer, they will be involved in all the stages of your radiotherapy treatment, from planning it, to giving it and providing support.

**Information and support radiographers** Some hospitals have information and support radiographers. They are experts in providing you and your family with practical and emotional support.

### **Radiotherapy assistants**

Some radiotherapy departments have radiotherapy assistants. They help the radiographers give you your treatment and provide information and support.

### **Radiologist**

A radiologist is a specialist in interpreting scans. They review your scans with your clinical oncologist. This helps your clinical oncologist plan your treatment.

### **Physicist**

A physicist is a radiation expert who works closely with your clinical oncologist to plan your treatment. They work out the amount of radiation you need and the best way of giving it, so that it targets the cancer and any effects on normal tissue are minimised.



The physicist is also responsible for carrying out regular checks on the radiotherapy equipment. You may not meet the physicist, as they usually work behind the scenes.

#### Mould room staff

These may be technicians or specially trained radiographers. They make moulds and masks, which are sometimes needed to help a person stay still during their treatment (see pages 23–24).

Moulds and masks are usually made in a mould room.

#### Nurses

Some radiotherapy clinics have nurses who give information about the treatment and side effects. They may also give advice on skin care and medicines to manage side effects.

Many cancer centres have specialist cancer nurses, sometimes called clinical nurse specialists (CNSs), who have expert knowledge about your type of cancer. They can also be a good source of support and information during your treatment.

### Your key worker

Usually one of the radiographers or nurses who look after you will be named as your **key worker**. This is the person to contact if you need more information or support. If you're not sure who your key worker is, ask someone at your next appointment.

# Other members of the MDT

### Dietitian

A dietitian can give you advice if you have problems eating and drinking because of your radiotherapy treatment – for example, if you have difficulty swallowing or have a dry mouth. If you're having problems eating, you can ask one of the radiotherapy staff to refer you to a dietitian.

### Speech and language therapists

If the radiotherapy is being given to your mouth and/or neck area, it may temporarily affect your speech. A speech and language therapist will be involved in your recovery and can give you advice and support if your speech or swallowing is affected.

#### Social worker

Social workers can give advice about non-medical problems such as practical support and financial help. You can ask to see a social worker if you think this would be helpful.

#### Symptom control team (palliative care team)

Symptom control teams often support people who are having treatment to control the cancer rather than to cure it. They can help with symptoms due to the cancer or side effects of the treatment.

#### Counsellors

Counsellors are available in some hospitals. They give emotional support. If you feel that speaking to a counsellor would be helpful, ask the staff looking after you to arrange an appointment.

#### **Physiotherapist**

Some people may see a physiotherapist during their treatment. They can show you exercises to help prevent muscle and joint stiffness.

# **Before your treatment**

#### **Giving your consent**

You'll normally have an appointment at the clinic to see your clinical oncologist or specialist radiographer. They will discuss your radiotherapy treatment with you and explain its aims.

They will also ask you to sign a form saying that you give permission (consent) for the hospital staff to give you radiotherapy. No treatment can be given without your consent, and before you're asked to sign the form you should be given full information about:

- the treatment whether it's external or internal radiotherapy (see page 7)
- the aim of the treatment whether it's curative or palliative (see pages 6–7)
- the number of treatment sessions you're likely to need
- the advantages and disadvantages of the treatment
- immediate side effects, which may happen during and for a short time after treatment, and late side effects, which may occur months or years later
- any risks of the treatment
- any other treatments that you could have instead of radiotherapy.

It's a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment. You can find a list of questions that you may want to ask your radiotherapy team on pages 78–80.

People sometimes feel that hospital staff are too busy to answer their questions, but it's important for you to know how the treatment is likely to affect you. The staff should be willing to make time for your questions.

If you don't understand what you've been told, let the staff know straight away so they can explain again. Some radiotherapy treatments are complex, so it's not unusual to need repeated explanations.

You can always ask for more time if you feel that you can't make a decision when your treatment is first explained to you.

You are also free to choose not to have the treatment. The staff can explain what may happen if you don't have it. It's essential to tell a doctor, a radiographer or the nurse in charge, so they can record your decision in your medical notes. You don't have to give a reason for not wanting treatment, but it can help to let the staff know your concerns so they can give you the best advice.

If you decide to stop your treatment after it has started, you will need to discuss this with your doctors. They will explain what may happen to you and will talk to you about other possible treatment options.

### Pregnancy

If you're a woman of childbearing age, it's important that you don't become pregnant during your treatment. This is because radiotherapy given during pregnancy could harm a developing baby. Your doctors will be able to give you more information about this.

Before you give your consent for radiotherapy, you will need to confirm:

- that you aren't pregnant
- that you understand you should avoid becoming pregnant during treatment (this means you'll need to use a reliable form of birth control).

If you think that you may be pregnant at any time during your treatment, tell the doctors and radiographers immediately and you'll be offered a pregnancy test.

If you're a man having radiotherapy treatment, your doctors may advise you not to father a child during treatment or for a few months after it's finished. You can ask your doctors for information about this.

# Heart pacemakers, implantable cardiac devices (ICDs) and cochlea implants

If you have a pacemaker, ICD or cochlea implant (a special implant in your ear), you must tell your oncologist or radiographer either before or during your first planning appointment. These devices can be affected by radiotherapy, so your treatment has to be planned to allow for them.

# Other things to think about

Here are some other things to think about before you start your radiotherapy.

### Help at home

Tiredness is a common side effect of radiotherapy so you may need help with day-to-day chores. Although it can be hard to ask for help, family and friends are usually keen to do whatever they can. If you live alone or are caring for someone else, you can ask to see a hospital social worker about getting help.

#### Getting to your appointments and travel costs

You may want to drive yourself to hospital for your treatment, but remember you may feel more tired as your treatment progresses. If you feel tired, it's best to ask a relative or friend if they can drive you.

If you're worried about getting to the hospital, let the staff in the radiotherapy department know. They may be able to arrange transport for you. Some local support groups and charities also provide transport.

If you have difficulty meeting the cost of travelling to the hospital every day, you may be able to get help with travel expenses. Some hospitals will offer reduced parking charges or reimburse the cost of parking if you're having daily radiotherapy treatment.



# Smoking

Research has shown that stopping smoking during and after radiotherapy may make it more effective. It can also reduce the side effects of treatment. So if you do smoke, you should try cutting down or stopping.

Many hospitals provide help or advice on how to quit smoking. Your clinical oncologist, specialist radiographer, or specialist nurse will let you know if your hospital provides this service. If they don't, your GP, a pharmacist or an organisation such as Smokefree (see page 89) will be able to help.

# We have a leaflet called Giving up smoking, which we can send you.

### Work and further education

If you're working or in further education, it's a good idea to talk to your employer or tutors, so they can make arrangements to support you and organise your time off during treatment.

# **Planning your treatment**

Before you start your treatment it needs to be planned. Planning makes sure that the radiotherapy is aimed precisely at the cancer so that it causes the least possible damage to the surrounding healthy tissue. All radiotherapy treatments are planned on an individual basis by your clinical oncologist, a physicist and sometimes by a senior or specialist radiographer.

Some people may need to have a mould or mask made before treatment planning. We have more information about this on pages 23–24).

#### **First planning visit**

Your first planning visit will take 30–60 minutes. The staff in the radiotherapy department will explain what to expect and they will also tell you beforehand if you need to prepare in any special way. It's important for you to feel that you're involved in your treatment, so feel free to ask as many questions as you need to.

You'll usually have a CT (computerised tomography) scan taken of the area to be treated. This helps your oncologist and physicist plan the precise area for your radiotherapy. Before your scan, you may be asked to remove some of your clothes (from the area of your body that will be treated with radiotherapy) and to wear a gown.

The CT scan takes lots of images from different angles to build up a three-dimensional picture. You may have an injection of dye into a vein when you have the CT scan. This allows particular areas of the body to be seen more clearly. You may also be asked to have a full or empty bladder for the scan. Instead of a CT scan, some people have an MRI (magnetic resonance imaging) scan or occasionally a PET (positron emission tomography) scan to help with planning their treatment. An MRI scan uses powerful magnetic fields to give a very detailed picture of the area that needs treating. A PET scan uses low dose radioactive glucose (a type of sugar) to measure the activity of cells in different parts of the body. Your hospital team will tell you more about these scans.

During your scan, you'll need to lie still on a hard couch (sometimes called a table). If you feel uncomfortable when the radiographers position you on the couch, let them know so that they can make you more comfortable. This is important because, once you're comfortable, the details of your position will be recorded. You'll need to lie in the same position on a similar couch for your treatment.

The information from the scan is fed into a planning computer, which will be used by your radiotherapy team to work out the precise dose and area of your treatment.

Before your planning appointment, you may be asked to follow some instructions that will help the radiographers get a clearer picture. For example, you may be asked to follow a special diet or to drink plenty of water.

Depending on the type of cancer you have, extra procedures might be needed as part of your planning treatment. If this is the case, you will be given information about them.



# **Radiotherapy moulds and masks**

To help you stay still and in position during the radiotherapy, you may need to have a mould or mask made before planning starts. This is used to help keep you still so that the treatment is accurate and as effective as possible.

Moulds are used to keep a leg or arm, or other body part, still during treatment. Masks keep your head and neck area still during treatment and are often used for treatments to the brain or head and neck area. Sometimes the terms 'mask' and 'mould' are used interchangeably. Occasionally they are also called shells. They're made of a plastic mesh (see below) or clear perspex (see next page).



A warm plastic mesh is put on to your face so that the plastic gently moulds to fit your face



A finished perspex mask

Moulds and masks are commonly used for children having radiotherapy.

Your mould or mask should fit snugly. If you have a mask that fits over your face, it may feel claustrophobic. But remember, you won't have it on for very long. Your radiographers will tell you how long your treatment will take.

We can send you more information about radiotherapy masks if you're having treatment to your brain or head and neck area.

'My tip is to close your eyes when the mask is fitted and remember to take slow deep breaths. Ask the radiographers to play some music during your treatment as it does relax you.'

Joycee

# Skin markings

Once the treatment area has been decided, markings are made on your skin to pinpoint the exact place where the radiation will be directed.

Usually, permanent markings are made (tattoos). They're the size of a pinpoint and will only be done with your permission. It's a little uncomfortable while the tattoo is being made, but it makes sure that treatment is directed accurately. If you're concerned about having permanent tattoos, let your radiographers know. They can discuss alternative options with you. You may not have tattoos if you're only having a single or short session of radiotherapy for symptom control.

If you have a mould or mask, any marks that need to be made will be made on the mould or mask rather than your skin.

# Skin care

During your radiotherapy, you'll need to take extra care of the skin in the area that's being treated. This is because the treatment may cause a skin reaction (see pages 55–56).

Before your treatment starts, the staff in the radiotherapy department will give you advice on how to look after your skin. This will depend on the type of treatment you're having and the area of your body being treated.

Usually you'll be asked to avoid using any deodorants, soaps, perfumes and lotions on the area being treated other than those advised by the radiographers. This is because some products may make any soreness worse. If you shave in the area that's being treated, you may be asked not to shave during your treatment or to use an electric razor instead.

If you swim, you'll need to ask your specialist team if you should avoid swimming until after your treatment has finished. They will also tell you when you can go swimming again after your treatment.







# External radiotherapy

Having external radiotherapy	31
Different types of external radiotherapy	35
More specialised types of external radiotherapy	38

# This section gives information about external radiotherapy, which is the most common way of giving radiotherapy.

External radiotherapy is normally given as a series of short, daily outpatient treatments in the radiotherapy department using equipment similar to a large x-ray machine. Several different types of radiotherapy machines are used to give radiotherapy but they all work in a similar way. One commonly used machine is called a linear accelerator (LINAC).

How many treatments you have will depend on the aim of the treatment.

**Curative radiotherapy** usually involves having a course of treatments given once a day, often with a rest at the weekends. The treatment may last between 2–7 weeks. Each treatment is called a fraction. Giving the treatment in fractions makes sure that less damage is done to normal cells than to cancer cells. The damage to normal cells is mainly temporary, but this is what causes the side effects of radiotherapy (see section 4 on pages 51–63).

Some people may have more than one treatment each day or treatment every day for two weeks, including the weekends. Sometimes treatment may only be given on three days each week – for example, Mondays, Wednesdays and Fridays. **Palliative radiotherapy** (for symptom control) may be used in a number of different situations. For example, radiotherapy may be given:

- to one or more bones to help control pain caused by cancer spreading to the bones
- to the lungs to reduce coughing caused by cancer in the lungs
- to help control bleeding caused by lung, bladder or skin tumours.

Palliative radiotherapy may involve only one or two sessions of treatment, but it can involve up to 10 sessions. When treatment is given in one or two sessions, it may cause slightly more short-term side effects, such as flu-like symptoms (see page 57).

# Having external radiotherapy

Usually, each radiotherapy appointment takes about 10–30 minutes. The treatment itself only lasts a few minutes and most of the appointment is spent getting you in position and doing checks.

Before your first treatment, the radiographers will explain to you what you'll see and hear. It's normal to feel anxious about having your treatment, but as you get to know the staff and understand what's going on, it should become easier. The sight of large radiotherapy machines can be frightening, especially for children (see pages 40–41). Don't be afraid to talk to the staff about any fears or worries you have – they are there to help you, and the more you understand your treatment, the more relaxed you'll be. Before your treatment, you may be asked to take off some of your clothes (from the area of your body that needs treating) and to put on a gown. This is so that the radiographers can easily access the marks on your skin that show the treatment area.

When the radiographers are ready for you, they'll position you carefully on the treatment couch and adjust its height and position. This is often called 'setting up' and may take a little while. Your radiographers will tell you how long it will take. The radiographers will use the marks (tattoos) on your skin (and your mask, if you have one) to help position you. They will get you in the same position you were in for your planning scan. It's important that you're comfortable as you have to lie as still as possible during the treatment. Let the radiographers know if you aren't comfortable.

The room may be in semi-darkness while the radiographers are setting up.

Once you're in the correct position, the radiographers will leave the room and you'll be given your treatment. Your radiographers will tell you how long your treatment will take before you start. There will be a camera or a window so they can see you. Many treatment rooms also have an intercom so the radiographers can talk to you while you have your treatment.

During each treatment they will watch you from the next room. If you have any problems, you can speak to them through the intercom and they will come in to help you. If there isn't an intercom in the room, the radiographers will let you know how you can attract their attention if you have a problem. They will also take care to protect your privacy so that nobody else can see you.



Someone being positioned for radiotherapy

Some treatment rooms have CD or MP3 players so you can listen to music to help you relax during your treatment. If you'd like to listen to your own music, ask your radiographers if this is possible.

The treatment itself is painless. You may hear a slight buzzing noise from the radiotherapy machine while your treatment is being given. Most curative (radical) radiotherapy involves having treatment from several different directions. This means that during your treatment the radiotherapy machine will automatically stop and move into the new position before your treatment continues. This may happen several times and you'll need to stay lying still. Occasionally, the radiographers will come into the treatment room to change the position of the machine.

During your treatment, the radiotherapy machine may take images (x-rays or CT scans) of the treatment area as part of the normal treatment process. These are taken to make sure the treatment is given accurately. They may be taken on the first day and again on other days. The radiographers will explain more about this to you.

The radiotherapy machine doesn't normally touch you, although for some types of skin cancer it may press against your skin.

Once your treatment session has finished, the radiographers will come back into the room and will help you off the treatment couch. You will then be able to get ready to go home or back to the ward.

External radiotherapy doesn't make you radioactive. It's perfectly safe for you to be with other people, including children, throughout your treatment. It's also safe to have sex.

# Different types of external radiotherapy

The type of radiotherapy you have will depend on the type of cancer you have, and which part of the body needs treating.

#### **Conformal radiotherapy**

This uses a device inside the radiotherapy machine to shape the radiotherapy beams to fit the treatment area.

Conformal radiotherapy is used to treat a number of different cancers, including cancers of the head and neck, prostate, gullet (oesophagus), some types of lung cancer, breast cancer and brain tumours.

#### Intensity modulated radiotherapy (IMRT)

IMRT shapes the radiotherapy beams and allows different doses of radiotherapy to be given to different parts of the treatment area. This means lower doses of radiotherapy can be given to healthy tissue, particularly healthy tissue that's more easily damaged by radiotherapy. As a result, immediate and long-term side effects are reduced.

Because IMRT can reduce damage to healthy tissue and side effects, it's often used to treat tumours that are close to important organs or structures. For example, when IMRT is used to treat pelvic tumours, it can reduce the risk of long-term bowel problems. When it's used for head and neck tumours, it can reduce damage to the salivary glands and the risk of permanent mouth dryness. It may also allow higher doses of radiotherapy to be given to the tumour.

Many, but not all, treatment centres in the UK provide IMRT for people that need it. It's generally accepted that IMRT should be used for 3 in every 10 (30%) people who are having curative


treatment. It's mainly used to treat breast, head and neck, prostate, bladder and lung cancers.

You can find out more about IMRT and whether it's a suitable treatment for you from your clinical oncologist. They can arrange for you to have IMRT at another treatment centre if it's not possible for you to have it at your local centre.

#### We can send you more information about IMRT.

#### Image guided radiotherapy (IGRT)

Before, and sometimes during, a course of radiotherapy, images are taken to make sure the treatment accurately targets the treatment area. With IGRT, images are taken just before each treatment. This may involve taking x-ray images or moving the machine around you to get an image similar to a CT scan. The images can be compared to those taken during the planning scan. They are used to make adjustments to the treatment area, making it very precise.

IGRT is helpful because some tumours can shrink in size and change shape during the treatment. Others can change position between treatment sessions. For example, the position of a tumour in the prostate gland or cervix can be altered by a full bladder or bowel on the day of your treatment. With IGRT, adjustments can be made before each treatment to allow for these changes to the tumour shape or position.

Every person should have IGRT as part of their treatment. How it's carried out varies in different radiotherapy centres. You may want to ask your team for more information about how IGRT is being used to check your treatment is accurate.

# More specialised types of external radiotherapy

#### 4D radiotherapy (4-Dimensional radiotherapy)

This treatment uses a radiotherapy machine that is able to take pictures or images during your treatment. The pictures are taken over a period of time so that they capture any movement of the tumour. The information from the pictures is used to adjust the radiotherapy treatment area during your treatment. This means that as the tumour moves, it's possible to make sure it's fully treated. 4D radiotherapy is particularly helpful for tumours that are in an area of the body that moves during the time you're having treatment. For example, tumours in the lung which move as you breathe.

4D radiotherapy isn't widely available in the UK. Some treatment centres are using it in clinical trials to find out which people will benefit most from it.

#### Stereotactic radiotherapy

This treatment is very precise because it uses many small beams of radiation to target the tumour. It's able to deliver high doses of radiotherapy to very small areas of the body, which reduces side effects.

Only a small number of people have tumours that are suitable for treatment with stereotactic radiotherapy. It's used to treat a variety of brain tumours and small tumours in the body, such as in the lung and liver.

A number of different machines can give this type of treatment. They include LINACs and specially designed machines such as CyberKnife<sup>™</sup>. Gamma Knife<sup>™</sup> is another machine that's used to give stereotactic radiotherapy to the brain. This treatment is only available in a few large radiotherapy centres. If the treatment is suitable for you, your team will discuss it with you. We can also send you more information about stereotactic radiotherapy.

#### Total body irradiation (TBI)

This type of radiotherapy is used much less often than other types of radiotherapy, but may be given to people who are having a stem cell transplant as part of their treatment. TBI involves giving a large single dose, or 6–8 smaller doses, of radiation to the whole body to destroy the cells of the bone marrow.

This type of radiotherapy is described in detail in our booklets Understanding allogeneic (donor) stem cell transplants and Understanding high-dose treatment with stem cell support.

#### **Proton therapy**

Proton therapy is used to treat cancers affecting the back of the eye, the base of the skull or the spine. It's given using a machine that uses proton radiation to kill the cancer cells rather than x-rays. The proton beam is aimed directly at the cancer and causes very little damage to surrounding healthy tissues.

Proton therapy is currently only available to treat tumours of the eye in one UK NHS trust, the Clatterbridge Cancer Centre in Liverpool.

There are plans to have two new proton treatment centres, one in London and one in Manchester in 2017. Until the treatment is available in these centres, the Department of Health can arrange for people who need this type of radiation to have it in the USA or Europe, paid for by the NHS.

#### Intra-operative radiotherapy

This uses a special machine to give a single dose of radiation in the operating theatre at the time a cancer is removed. Research is being carried out to see if this could be an alternative for women with early breast cancer who would normally have a course of radiotherapy after surgery.

#### External radiotherapy for children

Radiotherapy can be a frightening experience for both children and their parents, but once everyone understands what is involved, this fear can be reduced. Radiotherapy staff are used to treating children and can offer help and support. A play therapist will often be available as well to provide support.

Young children, especially those under three, may have their treatment under a mild general anaesthetic. You'll probably have a morning appointment, as your child can't eat or drink for at least four hours before their anaesthetic. The anaesthetic is usually given in the radiotherapy department by an anaesthetist. You can stay with your child until they're asleep.

Although you won't be able to stay in the radiotherapy room during your child's treatment, you may be able to watch them through the window or a camera. The nurses will look after your child until they wake up, usually after 20–60 minutes. You will then both be able to go home unless your child is an inpatient, in which case a nurse will take them back to the ward. Older children may take a while to get used to the size and sound of the machines, but this should get easier once they get to know the staff and the surroundings. If you're finding it difficult to cope with your child's illness, you may find it helpful to contact a children's cancer group. Sharing your experiences with other parents can help you cope with your own problems and fears. Call our Macmillan Support Line on **0808 808 00 00** for details of these groups.

You may find our booklet A parent's guide to children's cancer useful. We also have more information about radiotherapy treatment for children.







# Internal radiotherapy

Brachytherapy	44
Radioisotope therapy	48

This section of the booklet gives information about internal radiotherapy. Not everyone needs internal radiotherapy, so you'll only need to read this section if it's relevant for you.

There are two types of internal radiotherapy:

- **Brachytherapy** This is when a solid radioactive source is placed into or close to the tumour.
- **Radioisotope therapy** This is when a liquid source of radiation is used inside the body. It's also called radionuclide therapy.

Your healthcare team will be able to provide you with more detailed information about these types of radiotherapy.

# **Brachytherapy**

Brachytherapy gives a high dose of radiotherapy directly to the tumour but only a low dose to normal tissues. It's mainly used to treat cancers in the prostate gland, cervix and womb but it may also be used to treat some other cancers, such as head and neck cancers. Brachytherapy may be given in addition to external radiotherapy.

#### **Prostate cancer**

There are two ways of giving brachytherapy for prostate cancer. Small radioactive seeds can be inserted into the tumour and left to release their radioactivity slowly. This is sometimes known as low-dose rate treatment. The seeds are not removed and the radiation gradually fades away over about six months. All the radioactivity is absorbed by the prostate, so it's safe for you to

3

be around other people. As a precaution, you'll be advised to avoid long periods of close contact with children and pregnant women. Your specialist will give you more information about the precautions you should take.

Alternatively, the seeds can be placed inside special catheters that have been inserted into the prostate gland while you're asleep in an operating theatre. The seeds are put into the catheters for a set period of time and are then taken out. This is known as high-dose rate treatment. After the treatment, the catheters are removed and no radioactive material is left in the prostate gland.

#### Cervical and womb cancer

Brachytherapy for cervical or womb cancer is given through specially designed hollow tubes called applicators, which are inserted into the womb or vagina. During treatment, a machine is used to place the radioactive material inside the applicators. After the treatment, the radioactive material is withdrawn back into the machine and the applicators are removed.

The brachytherapy may be given as either high-dose or low-dose rate treatment. With both treatments, the same dose of radiotherapy is given but over different times.

High dose-rate treatment is given over a short period of time (for example, 10–20 minutes), either as one short burst or several short bursts over a few days. Low-dose rate treatment is given over a longer period of time, usually over 12–24 hours.

You'll be cared for in a single room while you're having brachytherapy. Special precautions will need to be taken to prevent other people being exposed to radioactivity while the machine is giving you your treatment. Your hospital team will give you more detailed information about these precautions.

Women who have high-dose rate treatment for cervical cancer may have **image guided brachytherapy (IGBT)**. IGBT makes the radiotherapy treatment very accurate. It uses CT or MRI imaging to pinpoint exactly where the cancer is before each treatment. This makes it possible to shape the radiation dose to match the shape of the tumour and to avoid organs such as the bowel and bladder. Sometimes additional applicators may be used to boost the dose of radiotherapy to a particular area.

IGBT that uses MRI images is particularly accurate but it isn't widely available in the UK. The Royal College of Radiologists and the Department of Health recommend that women with cancer of the cervix should be offered MRI-based IGBT from 2015.

Your oncologist can tell you whether IGBT is a suitable treatment for you. They can arrange for you to have IGBT at another treatment centre if it's not possible for you to have it at your local one.

#### Brachytherapy using caesium or iridium wires

This can be used to treat a number of different cancers including cancers of the mouth, lip, cervix and breast. Very thin radioactive needles, wires or tubes are inserted while you're under a general anaesthetic in an operating room.

If you need to have this type of treatment, your healthcare team will discuss this with you and give you detailed information about it. We have more information about brachytherapy for prostate cancer, cervical cancer, womb cancer and head and neck cancers in our booklets about these types of cancer. You can order any of our booklets for free from be.macmillan.org.uk

#### Selective internal radiotherapy treatment (SIRT)

SIRT is a specialised type of brachytherapy that uses radioactive beads called SIR-Spheres<sup>®</sup> (Sirtex Medical Ltd) to treat cancers that have spread to the liver (secondary cancer in the liver).

SIRT is a way of delivering high-dose internal radiotherapy. It's only suitable for some types of secondary liver cancer, for example, those that have spread to the liver from the bowel (colon or rectum).

It uses tiny coated beads called microspheres, which contain a radioactive substance called Yttrium-90. Cancer cells need a blood supply to receive oxygen and nutrients. SIRT beads lodge in the blood vessels that supply tumours. They destroy the blood vessels and stop the flow of blood to tumours so that they die. This is called radioembolisation.

#### We can send you more information about SIRT.

# **Radioisotope therapy**

This therapy uses radioactive substances known as radioisotopes or radionuclides.

Radioisotopes are given by mouth as a drink or capsules, or injected into a vein (intravenous injection). Cancer cells absorb the radioisotope more than the normal cells do and receive a higher dose of radioactivity. This causes the cancer cells to die.

Before you have any treatment with a radioisotope, you will be given detailed information about it.

#### Iodine-131

This is the most common type of radioisotope treatment. It's used to treat specific types of thyroid cancer and is usually given as capsules or a drink but can also be given as an injection into a vein in the arm. It's also used to treat some rarer types of cancer, such as lymphoma and neuroblastoma. Some of these treatments involve a stay in hospital.

Radioactive iodine treatment makes you slightly radioactive for about 4–5 days. During this time, the radioactivity will gradually leave your body in your urine, bowel motions (stools), blood (if you have a period), saliva and sweat. You'll need to follow safety measures after treatment and for a short time after going home.

Your hospital team will give you more detailed information about treatment with radioactive iodine and the safety measures that are needed.

# There's more information in our booklet Understanding cancer of the thyroid.

#### Strontium-89 and samarium-153

These radioisotopes can be used to treat certain types of secondary bone cancer (cancer that has spread to the bones from somewhere else in the body). They help to reduce bone pain and improve quality of life. You can usually go home after having this treatment.

Strontium and samarium are both given as a single injection through a small tube (cannula) inserted into a vein.

After the injection of radioisotope, your urine, bowel motions and blood will be very slightly radioactive for a short time depending on the radioisotope used and the dose given.

You may have to take precautions to reduce any risk to others when you go home. The hospital staff will give you information about this.

#### Radium-223

This is a new radioisotope treatment for secondary cancer in the bones. It's still being researched to see how effective it is. It's mainly been used to treat cancer that has spread to the bones from the prostate, but trials are also looking at its effect on breast cancer that has spread to the bones.

We have information about strontium-89, samarium-153 and radium-223 in our booklet Understanding secondary cancer in the bone. We also have a booklet about cancer research trials.





# Side effects of radiotherapy

General side effects of radiotherapy	53
Effects on sexuality	58
Effects on fertility	60
Feelings about sexuality and infertility	62
Long-term side effects of radiotherapy	62
Second cancers	63

Radiotherapy affects people in different ways, so it's difficult to predict exactly how you'll react to your treatment. The side effects you have will depend on the type of treatment and the area of body being treated.

Before you consent to the treatment, the hospital staff will explain any side effects you may get. They can also give tips on how to deal with them and how they can be treated.

In this section, we discuss the general side effects of radiotherapy that you may experience, whichever part of the body you're having radiotherapy to.

You may also find it helpful to read our booklet about your type of cancer before you start your treatment. It will include information about the possible side effects of radiotherapy. Being aware of these in advance can help you cope with any side effects that may develop.

External radiotherapy tends to cause more general side effects than internal therapy. It's important to remember that most people will have only a few of the side effects mentioned here, and for many people, they will be mild. The use of modern treatments means that severe side effects are very rare.

Most side effects of radiotherapy will continue for about 10–15 days after treatment has finished and then gradually begin to get better. However, symptoms of tiredness may continue for longer.

# General side effects of radiotherapy

#### **Tiredness**

Not everyone feels tired during radiotherapy treatment but many people do. For example, some people are able to continue working, but others need to take time off work.

Tiredness (fatigue) can continue for weeks to months after your treatment has finished. It can often be made worse by having to travel to hospital each day, or by other treatments such as surgery or chemotherapy.

**Managing tiredness** Get plenty of rest but balance this with some gentle exercise, such as short walks. This will give you more energy and help to keep your muscles working. Save some energy for doing the things you enjoy and ask others for help doing chores if these are tiring you out.

#### We can send you a booklet about coping with fatigue.

#### **Feeling sick**

Some people find that their treatment makes them feel sick (nausea), and sometimes they may actually be sick (vomit). This is more likely to happen if the treatment area is near the stomach.

Your clinical oncologist (or sometimes a nurse or radiographer) can prescribe very effective anti-sickness (anti-emetic) drugs if this happens, and they may prescribe them anyway as a precaution. Tell your clinical oncologist or specialist radiographer if you have any nausea or vomiting, and remember that it usually stops once treatment is over. **Managing sickness** You may find it helpful to let someone else cook or prepare food for you, especially if the smell of cooking makes you feel sick. Sipping a fizzy drink slowly through a straw, or trying crystalised ginger, ginger tea or ginger biscuits, can help with feelings of sickness. If you're given anti-sickness tablets, take them regularly, as this is the best way to keep the sickness controlled. Some anti-sickness medicines work best if you take them before your radiotherapy treatment. Ask your doctor, radiographer or nurse to tell you the best time to take your anti-sickness medicines.

# We can send you more information about coping with nausea and vomiting.

#### Problems with eating and drinking

During your treatment, it's important to have a healthy diet and to drink plenty of fluids.

At times, you may not feel like eating or you might find that your eating habits change. These may cause you to lose weight. It's important to try to maintain your weight throughout treatment, as the radiotherapy will have been planned on your body's shape. Tell the radiotherapy staff if you're having any problems with eating, as they can arrange for you to talk to the hospital dietitian.

Some people who have radiotherapy to their head and neck area develop swallowing difficulties. If this happens to you, it can be difficult to eat and drink for a time until your swallowing improves. If your oncologist thinks that you may develop swallowing problems, they may suggest a small operation to put a feeding tube into your stomach. We have more information about this in our booklet Understanding head and neck cancers. **Managing eating and drinking problems** Try having small nutritious snacks throughout the day rather than large meals. If food seems tasteless, use seasoning or strong-flavoured sauces. If your mouth is dry, try sucking an ice cube. If you're losing weight, add extra energy and protein to your diet with everyday foods or by using food supplements. Our booklet The building-up diet has more information.

#### **Skin reactions**

Some people develop a skin reaction while having external radiotherapy. If this happens, it may begin after about 10 days.

How your skin reacts will vary depending on the amount of radiotherapy you have. Some people may find that the skin in the treatment area becomes red and sore or itchy. It may become darker with a blue or black tinge. Sometimes the skin will get very sore and it may break and leak fluid, although this doesn't happen very often. If your skin gets very sore, your treatment may have to be delayed for a short time to allow the area to recover, although this is rare.

The extent of the reaction depends on the area being treated and your skin type. Some people have no skin problems at all. If you have a skin reaction, it will usually settle down 2–4 weeks after the treatment has finished, but the area may stay slightly darker than the surrounding skin. **Managing skin reactions** During your treatment, you should avoid using any deodorants, soaps, perfumes and lotions on your skin other than those advised by the radiographers. If you develop a skin reaction, such as soreness or a change in skin colour, let the radiotherapy staff know as soon as possible. They will advise you on the best way to manage it.

After treatment you'll need to protect the skin in the treated area from strong sunshine for at least a year. Once any skin reaction has settled down, you should use a suncream with a high sun protection factor (SPF) of at least 30. You should also wear close-weave clothing and use a wide-brimmed hat if your head and neck area has been treated. It's important to remember that you can burn through clothing if you're out in hot sun for a long time.

You can usually go swimming once any skin reaction has settled down. This is usually within a month of finishing treatment. Remember to use a waterproof suncream if you're swimming outdoors.

Clothes can sometimes irritate the skin or cause discomfort in the area being treated. Wearing loose-fitting clothes, preferably made of natural fibres rather than man-made materials, can help. You should also avoid wearing tight collars and ties if you're having radiotherapy to your neck. Bra and handbag straps can cause irritation if they rub against treated skin. If your breast area is being treated, you may be more comfortable not wearing a bra or wearing a vest instead.

### Flu-like symptoms

If you have palliative radiotherapy given in one or two treatment sessions (see page 31), you may experience flulike symptoms. These include headaches, aching joints or muscles, and lack of energy (lethargy). If you also develop a temperature, it's important to let your radiotherapy team know.

Flu-like symptoms usually settle quickly. Drinking plenty of fluids and getting some rest can help.

#### **Hair loss**

Radiotherapy will only cause hair loss in the treatment area. Hair loss can also happen where the radiation beam leaves the body (for example, on the back of the neck), as well as where it enters the body. Ask your clinical oncologist or radiographer to show you exactly where your hair will fall out.

Hair usually begins to fall out after 2–3 weeks. Hair should grow back after treatment finishes. This may take several months, although it depends on the dose of radiotherapy you have.

Occasionally, hair loss is permanent. Your radiographer can tell you if any hair loss is likely to be permanent.

**Managing hair loss** If you lose the hair on your head, you may want to wear a wig or cover up in other ways. We can send you a booklet about hair loss, which gives helpful tips on what you can do to cover up and how to cope with the emotional effects.

#### Changes in your blood

Radioisotope therapy (such as strontium or samarium) and sometimes external radiotherapy may temporarily reduce the number of normal red and white blood cells produced by the bone marrow. When the number of white blood cells is low, you're more prone to infection. If necessary, you'll be given antibiotics to treat any infection. If the number of red blood cells is low (anaemia), you may get tired easily and may need a blood transfusion.

Your hospital team will arrange for you to have regular blood tests if the treatment you're having is likely to cause your blood count to fall.

It's very important to let your doctors know if you feel very unwell, if your temperature goes above 38°C (100.4°F), or if you start feeling cold and shaky.

# **Effects on sexuality**

Radiotherapy can sometimes cause physical changes that may affect your sex life. If you're having problems, it may help to talk these over with your partner and your medical team.

Although it can be embarrassing to talk to health professionals about intimate things like sex, remember they're used to dealing with these issues and can suggest things that will help.

Both men and women may temporarily lose interest in sex. This is common and may happen because of worries about the future, or even because the treatment is making you too tired to think about sex. Men may become temporarily unable to get an erection (erectile dysfunction – ED). Losing interest in sex can be distressing, but it will usually come back as the effects of treatment wear off.

You can get advice and support from the College of Sexual and Relationship Therapists (see page 90). You may also wish to call us and speak in confidence to one of our cancer support specialists on freephone 0808 808 00 00.

Having external or internal radiotherapy to the pelvic area can also cause specific side effects that may affect your sex life.

**Effects on women** Radiotherapy to the pelvis usually affects the ovaries. Radiotherapy to the ovaries will bring on the menopause, which can cause dryness in the vagina. Treatment to the vaginal area can make the vagina narrower and also cause dryness.

**Effects on men** Radiotherapy to the pelvis to treat bladder, rectal or prostate cancer may cause erectile dysfunction. This may develop months or even years after the radiotherapy has finished.

If you're likely to develop any of these problems, your oncologist or specialist nurse will discuss them with you before you consent to the treatment.

There are a number of practical ways to manage menopausal symptoms, vaginal problems and impotence. It's important to let your healthcare team know about any concerns you have so they can help you. You can also talk to the radiotherapy staff. You can find more detailed information about the effects of cancer and its treatment in our booklet *Sexuality and cancer*. We also have information about the specific effects of pelvic radiotherapy on women and men.

# **Effects on fertility**

**Effects on women** Most radiotherapy treatment has no effect on your ability to have children unless the ovaries are in the treatment area.

Many healthy babies have been born to women who've had radiotherapy. The risk of having a baby with health problems is not increased if you've had treatment in the past. Cancer specialists often recommend that women wait for about two years after having radiotherapy before trying to get pregnant. This is to give the body a chance to get over the effects of the cancer and its treatment.

If radiotherapy treatment is given for cancer of the cervix, womb, ovary, bladder, rectum or anus and the treatment area includes the ovaries, temporary or permanent infertility is likely. This can be very difficult to come to terms with (see page 62).

**Effects on men** In men, sperm production can be reduced if the testicles are in the area being treated, and this can lead to temporary or permanent infertility. Fortunately, it's usually possible to avoid giving radiotherapy to the testicles when treating cancers that are common in younger men.

Radiotherapy for prostate, bladder, rectal or anal cancer is likely to cause permanently low sperm counts, which can reduce your fertility.

### Information about fertility

Before you consent to have radiotherapy, your clinical oncologist should discuss the risk of infertility with you. Understandably, this can be a difficult time, particularly if you were planning to have children and have been told the treatment may make you infertile. If you have a partner, they will be encouraged to join this meeting, giving both of you a chance to discuss any concerns you have.

#### Contraception

Even if your treatment is likely to make you infertile, you will still be advised to use a reliable form of birth control. If pregnancy occurs during or shortly after radiotherapy, there is a possibility that the unborn baby could be harmed.

#### Sperm banking and egg storage

Sometimes it may be possible for men to store sperm before they have radiotherapy. The sperm are frozen and can be stored for several years until you and your partner are ready to have children. This is called sperm banking.

Before treatment starts, women may be able to store fertilised eggs (embryos) using sperm from a partner. It can take 4–6 weeks to collect the eggs so this won't be possible if treatment needs to start straight away.

It's now sometimes possible to store a woman's unfertilised eggs. This is still experimental but techniques are improving. This service is available privately and on the NHS in some fertility units.

We can send you information about fertility and cancer treatment. We also have a booklet called *Relationships*, sex and fertility for young people affected by cancer.

# Feelings about sexuality and infertility

It's not easy to come to terms with the prospect of infertility, or with the other side effects of treatment. It will take a while for you to come to terms with your feelings and be able to talk about them. When you're ready, it may help to talk openly to your partner, a relative or friend. This will make it easier for them to help and support you.

Some people prefer to talk to someone they don't know. Support groups offer you the chance to talk to other people who have been through a similar experience. Our cancer support specialists can tell you about groups in your area.

Another possibility is to talk things over with a counsellor. Your hospital may offer a counselling service or our cancer support specialists can tell you how to contact a counsellor. Call us free on **0808 808 00 00**.

# Long-term side effects of radiotherapy

All cancer treatments can result in long-term side effects. Modern ways of giving radiotherapy aim to limit the risk of permanent side effects. This has meant that the number of people who develop long-term problems is reducing. However, when radiotherapy is also given with chemotherapy, the long-term effects of radiotherapy may be increased.

Before you consent to the radiotherapy, your clinical oncologist will discuss the likelihood of you developing long-term side effects. It's important that you have the opportunity to talk these through with your oncologist, even though they might not happen to you. You can find more information about the possible long-term effects of treatment in our booklets about your type of cancer. We also have specific information in the following booklets:

- Managing the late effects of bowel cancer treatment
- Managing the late effects of breast cancer treatment
- Managing the late effects of pelvic radiotherapy in men
- Managing the late effects of pelvic radiotherapy in women.

# Second cancers

Radiotherapy can cause cancer, and a small number of people will develop a second cancer because of the treatment they've had. However, the chance of a second cancer developing is so small that the risks of having radiotherapy are far outweighed by the benefits.

If you're concerned about your risk of developing a second cancer, talk to your cancer specialist.





# After treatment

66
67
68
69

When your treatment has finished, you may have regular check-ups that will eventually become less frequent. You'll also need some time to recover, and you might want to make some positive changes to your lifestyle when you're feeling well enough.

# Follow-up

After your radiotherapy has finished, your oncologist will let you know how you will be followed up, if this is needed. It will depend on your type of cancer, the type of radiotherapy you've had and how you got on with your treatment.

Some people are given regular follow-up appointments or are referred back to the specialist who recommended the radiotherapy. Follow-up appointments usually happen about 4–6 weeks after the treatment has finished. They may be at the radiotherapy department or at your original hospital.

Other people are followed up by telephone with a nurse or radiographer. They will be able to assess how you're doing by asking you questions. If they're concerned that you're not progressing as you should be, they will arrange for you to have an appointment at the clinic.

Follow-ups are a good opportunity to discuss any problems or worries you have. It may help to make a list of questions beforehand so you don't forget anything important. If you feel anxious, it can help to have a friend or relative with you. Not everyone will need follow-up appointments after radiotherapy treatment. If you don't need a follow-up, you'll be given advice about problems you should look out for and the details of someone to contact, if necessary.

If you have any problems or notice any new symptoms at any time, or between appointments, contact your clinical oncologist or the person you've been told to contact. Don't wait until your next scheduled appointment – just ask for an earlier one.

#### You may find it helpful to read our leaflet What to do after cancer treatment ends: 10 top tips. It tells you what to expect and where you can get further support.

### **Beginning to recover**

Coming to the end of your radiotherapy treatment can be a time of mixed emotions. You'll probably feel relieved, but there can also be feelings of anxiety and uncertainty. It can take time to rebuild confidence and to come to terms with what you've been through. It may also take time to recover from treatment. You may feel tired for a while and you may have emotional changes to deal with, so it's important to give yourself time to adjust.

Support is available from the organisations listed on pages 87–90. You can also ask your healthcare team for the details of local support groups that may be able to help you.

# Lifestyle changes

When treatment is over, you may want to think about making changes to your lifestyle and find out more about healthy living. Perhaps you already followed a healthy lifestyle before your treatment, but you now want to be more focused on making the most of your health. There are things you can do to help your body recover. These can also help improve your sense of well-being and lower your risk of getting other illnesses and other cancers.

#### **Eating well**

It's important to have a nutritious and well-balanced diet with plenty of fresh fruit and vegetables, even if your appetite and interest in food have been reduced.

#### Giving up smoking

If you're a smoker, it's important to try to give up. Smoking can delay your recovery and puts you at greater risk of developing a second cancer.

Giving up smoking can be difficult but there is lots of support available (see page 89).

#### **Physical activity**

This can be an important part of your recovery after treatment. It can help you to feel better in yourself and help to build up your energy levels. It also reduces the risk of heart disease, stroke and diabetes. Talk to your cancer specialist or GP before you start exercising. Start slowly and increase your activity over time.

# You can read more about exercise and its benefits in our booklet about physical activity and cancer.

### **Complementary therapies**

Complementary therapies may help you feel better and reduce any stress and anxiety. Relaxation, counselling and psychological support are available at many hospitals. Some hospitals also offer visualisation, massage, reflexology, aromatherapy and hypnotherapy. Therapies are sometimes available through cancer support groups or your GP. Many complementary therapists also have private practices.

#### Our booklet Cancer and complementary therapies tells you about different therapies and gives advice on choosing a therapist.

Not all complementary therapies are suitable for people who have just finished radiotherapy, so it's important to check with your healthcare team first if you're thinking of having one.





# Living with cancer

Your feelings	72
Work	73
Financial help and benefits	75
Many different areas of your life can be affected by cancer and its treatment. You might find you go through many different emotions. You might also find you need to take a break from work, and need support with your finances.

# Your feelings

You may find that coping with cancer and radiotherapy can sometimes make you feel anxious, afraid or depressed.

Sometimes these feelings can be triggered by things like having to change your daily routine to fit in with your radiotherapy treatment. Or, it may be something more obvious like a particular side effect or the risk of infertility. It's natural to have these feelings during your treatment.

Everyone needs some support during difficult times and having cancer is one of the most stressful situations you're likely to face. It's often helpful to talk over your feelings with your family or close friends.

You can also talk to your doctor, specialist nurse, radiographer or a social worker about how you're feeling. It's important to let them know if you're struggling or think you may be depressed. They can arrange more support or refer you to a counsellor or doctor who specialises in the emotional problems of people with cancer. They may also be able to prescribe an antidepressant or anti-anxiety drug for you.

Our booklet How are you feeling? includes more information about the emotions you may experience and ways of coping with them.

# Work

Some people are able to continue working during radiotherapy treatment. Others need to take time off during treatment and for a while afterwards. This may be because they feel very tired or have side effects to cope with.

It can be hard to judge the best time to go back to work, and this will depend mainly on the type of work you do and how much your income is affected. It's important to do what's right for you. Getting back into your normal routine can be very helpful, and you may want to go back to work as soon as possible. It can be helpful to talk to your employer about the situation – it may be possible for you to work part-time or job share.

On the other hand, it can take a long time to recover fully from cancer treatment, and it may be many months before you feel ready to return to work. It's important not to take on too much, too soon. Your consultant, GP or specialist nurse can help you decide when, and if, you should go back to work.

Our booklets Work and cancer, Working while caring for someone with cancer and Self-employment and cancer have more information that may be helpful. There's also lots more information at macmillan.org.uk/work



# **Financial help and benefits**

If you're struggling to cope with the financial effects of cancer, you may be entitled to benefits or other financial help.

Our booklet Help with the cost of cancer contains detailed information about financial help and support. You can also find out more about what you may be entitled to by speaking to one of our welfare rights advisers on **0808 808 00 00**.

Our video at macmillan.org.uk/gettingfinancialhelp may also be useful.





# **Further information**

Questions you might want to ask	78
How we can help you	83
Other useful organisations	87
Further resources	93

# Questions you might want to ask about your treatment

It's important to make sure you understand your treatment and the effects it will have on you. The health professionals looking after you will be happy to answer your questions. You might want to ask some of these questions and jot down any others on the notes page.

What type of radiotherapy treatment will I be given?

What are the aims of the treatment?

How can I be sure I will have the most effective type of radiotherapy that also reduces the risk of damage to healthy tissue and side effects?

What type of image-guided radiotherapy (IGRT) will be used to make sure my treatment is accurate?

How long will my course of treatment take and how often will I need to have the treatment?

What are the likely side effects of the treatment (both immediate and long-term)?

Are there any risks associated with the treatment?

Are there any other treatments I could have instead of radiotherapy?

How will the treatment affect my life, such as my daily activities, my work life, my sex life and my fertility?

Will I have follow-up appointments? If yes, how often and who will they be with?

Who should I contact if I need more information or have any concerns about my treatment?

# Other notes



# How we can help you

Cancer is the toughest fight most of us will ever face. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

# Get in touch

Macmillan Cancer Support 89 Albert Embankment, London SE1 7UQ **Questions about cancer?** Call free on **0808 808 00 00** (Mon–Fri, 9am–8pm) **www.macmillan.org.uk Hard of hearing?** Use textphone 0808 808 0121 or Text Relay. **Non-English speaker?** Interpreters are available.

# Clear, reliable information about cancer

We can help you by phone, email, via our website and publications or in person. And our information is free to everyone affected by cancer.

### **Macmillan Support Line**

Our free, confidential phone line is open Monday–Friday, 9am–8pm. Our cancer support specialists provide clinical, financial, emotional and practical information and support to anyone affected by cancer. Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/ talktous** 

# Information centres

Our information and support centres are based in hospitals, libraries and mobile centres, and offer you the opportunity to speak with someone face-to-face. Find your nearest one at **macmillan.org.uk/ informationcentres** 

# **Publications**

We provide expert, up-to-date information about different types of cancer, tests and treatments, and about living with and after cancer. We can send you free information in a variety of formats, including booklets, leaflets, fact sheets, and audiobooks. We can also provide our information in Braille and large print.

You can find all of our information, along with several videos, online at **macmillan.** org.uk/cancerinformation

# **Review our information**

Help us make our resources even better for people affected by cancer. Being one of our reviewers gives you the chance to comment on a variety of information including booklets, fact sheets, leaflets, videos, illustrations and website text.

If you'd like to hear more about becoming a reviewer, email **reviewing@ macmillan.org.uk**  **Need out-of-hours support?** You can find a lot of

information on our website, macmillan.org.uk For medical attention out of hours, please contact your GP for their out-of-hours service.

# Someone to talk to

When you or someone you know has cancer, it can be difficult to talk about how you're feeling. You can call our cancer support specialists to talk about how you feel and what's worrying you.

We can also help you find support in your local area, so you can speak face-to-face with people who understand what you're going through.

# **Professional help**

Our Macmillan nurses, doctors and other health and social care professionals offer expert treatment and care. They help individuals and families deal with cancer from diagnosis onwards, until they no longer need this help.

You can ask your GP, hospital consultant, district nurse or hospital ward sister if there are any Macmillan professionals available in your area, or call us.

# Support for each other

No one knows more about the impact cancer has on a person's life than those who have been affected by it themselves. That's why we help to bring people with cancer and carers together in their communities and online.

#### Support groups

You can find out about support groups in your area by calling us or by visiting **macmillan**. org.uk/selfhelpandsupport

### Online community

You can also share your experiences, ask questions, get and give support to others in our online community at **macmillan**. org.uk/community

# Financial and work-related support

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. Some people may have to stop working.

If you've been affected in this way, we can help. Call the Macmillan Support Line and one of our cancer support specialists will tell you about the benefits and other financial help you may be entitled to.

We can also give you information about your rights at work as an employee, and help you find further support.

# **Macmillan Grants**

Money worries are the last thing you need when you have cancer. A Macmillan Grant is a one-off payment for people with cancer, to cover a variety of practical needs including heating bills, extra clothing, or a much-needed break. Find out more about the financial and work-related support we can offer at macmillan.org.uk/ financialsupport

# Learning about cancer

You may find it useful to learn more about cancer and how to manage the impact it can have on your life.

You can do this online on our Learn Zone – **macmillan.org. uk/learnzone** – which offers a variety of e-learning courses and workshops. There's also a section dedicated to supporting people with cancer – ideal for people who want to learn more about what their relative or friend is going through.

# Other useful organisations

# General cancer support organisations

# **Cancer Black Care**

79 Acton Lane, London NW10 8UT Tel 020 8961 4151 Email info@cancerblackcare.org.uk www.cancerblackcare. org.uk

Offers information and support for people with cancer from ethnic communities, their friends, carers and families.

# Cancer Focus Northern Ireland

40–44 Eglantine Avenue, Belfast BT9 6DX **Tel** 0800 783 3339 (Mon–Fri, 9am–1pm) **Email** 

hello@cancerfocusni.org www.cancerfocusni.org

Offers a variety of services to people affected by cancer, including a free helpline, counselling and links to local support groups.

# **Cancer Support Scotland**

Calman Cancer Support Centre, 75 Shelley Road, Glasgow G12 0ZE **Tel** 0800 652 4531 **Email** info@ cancersupportscotland.org **www. cancersupportscotland.org** 

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

# **The Daisy Network**

PO Box 183, Rossendale BB4 6WZ **Email** 

daisy@daisynetwork.org.uk www.daisynetwork.org.uk A charity that supports women who have experienced premature menopause. Can put you in touch with other women who have experienced a premature menopause. Also offers tele-counselling and fact sheets with further information.

### **Irish Cancer Society**

43–45 Northumberland Road, Dublin 4, Ireland **Tel** 1800 200 700 (Mon–Thu, 9am–7pm, Fri, 9am–5pm) **Email** helpline@irishcancer.ie **www.cancer.ie** 

National cancer charity offering information, support and care to people affected by cancer. Has a helpline staffed by specialist cancer nurses. You can also chat to a nurse online and use the site's message board.

#### **Maggie's Centres**

1<sup>st</sup> Floor, One Waterloo Street, Glasgow G2 6AY **Tel** 0300 123 1801 **Email** enquiries@ maggiescentres.org **www.maggiescentres.org** Provides information about

cancer, benefits advice, and emotional or psychological support.

### Marie Curie Cancer Care

89 Albert Embankment, London SE1 7TP **Tel** 0800 716 146 (Mon–Fri, 9am–5.30pm) **Email** supporter.services@ mariecurie.org.uk **www.mariecurie.org.uk** Marie Curie nurses provide free end-of-life care to people in their own homes, or in Marie Curie hospices, 24 hours a day, 365 days a year.

### **Society of Radiographers**

207 Providence Square, Mill Street, London SE1 2EW **Tel** 020 7740 7200

#### www.sor.org

This organisation is for professionals but it also provides information about radiotherapy for the public. You can access some of the national guidance documents relating to radiotherapy from the website.

### Tenovus

Head Office, Gleider House, Ty Glas Road, Cardiff CF14 5BD **Tel** 0808 808 1010 (Mon–Sun, 8am–8pm) **www.tenovus.org.uk** Aims to help everyone get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, an 'Ask the nurse' service on the website and benefits advice.

# Support with stopping smoking

**Smokefree** England helpline 0800 022 4 332 **Scotland helpline** 0800 84 84 84 **Wales helpline** 0800 169 0 169 **Northern Ireland helpline** 0800 85 85 85 **Isle of Man helpline** 01624 642 404 (Mon–Fri, 9am–8pm, Sat–Sun, 11am–4pm)

# www.smokefree.nhs.uk

Offers free information, advice and support via the helpline and website to people who want to give up smoking.

# Counselling and emotional support

# British Association for Counselling and Psychotherapy (BACP)

BACP House, 15 St John's Business Park, Lutterworth LE17 4HB **Tel** 01455 883 300 **Email** bacp@bacp.co.uk **www.bacp.co.uk** Promotes awareness of counselling and signposts people to appropriate services.

You can search for a qualified counsellor at itsgoodtotalk. org.uk

# The College of Sexual and Relationship Therapists (COSRT)

PO Box 13686, London SW20 9ZH Tel 020 8543 2707 Email info@cosrt.org.uk www.cosrt.org.uk

A national specialist charity for sex and relationship therapy. Has a list of qualified practitioners and clinics providing sex or relationship therapy in the UK.

# Support for carers

Carers UK Tel (England, Scotland, Wales) 0808 808 7777 Tel (Northern Ireland) 028 9043 9843

(Wed–Thu, 10am–12pm and 2–4pm)

# Email

advice@carersuk.org www.carersuk.org

Offers information and support to carers across the UK. Can put people in contact with support groups for carers in their area.

# Support for young people

CLIC Sargent Horatio House, 77–85 Fulham Palace Road, London W6 8JA Tel 0300 330 0803 www.clicsargent.org.uk

Provides clinical, practical, financial and emotional support to children with cancer.

# **Teenage Cancer Trust**

3<sup>rd</sup> Floor, 93 Newman Street, London W1T 3EZ **Tel** 020 7612 0370 **www.teenagecancer trust.org** 

A charity devoted to improving the lives of teenagers and young adults with cancer. Runs a support network for young people with cancer, their friends and families.

# Financial or legal advice and information

Benefit Enquiry Line (England, Wales, Scotland) Tel 0800 882 200 (Mon–Fri, 8am–6pm) Textphone 0800 243 355 Email BEL-CUSTOMER-SERVICES@dwp.gsi.gov.uk www.gov.uk/ benefit-enquiry-line Provides advice and

information for disabled people and carers on the range of benefits available.

NI Direct (Northern Ireland) Tel 0800 220 674 (Mon–Wed and Fri, 9am–5pm, Thu, 10am–5pm) Textphone 0800 243 787 www.nidirect.gov.uk/ money-tax-and-benefits

# **Citizens Advice**

Provides advice on a variety of issues including financial, legal, housing and employment issues. Find details for your local office in the phone book or on one of the following websites:

England and Wales www.citizensadvice. org.uk Scotland www.cas.org.uk

Northern Ireland www.citizensadvice.co.uk

You can also find advice online in a range of languages at **adviceguide.org.uk** 

GOV.UK www.gov.uk Has comprehensive information about

social security benefits and public services.

Personal Finance Society – 'Find an Adviser' service www.findanadviser.org Use the website to find qualified financial advisers in your area.

You can search for more organisations on our website macmillan.org.uk or call our support line on 0808 808 00 00.



# Further resources

# Related Macmillan information

You may want to order some of the resources mentioned in this booklet. These include:

- A parent's guide to children's cancer
- Cancer and complementary therapies
- Cancer treatment and fertility (we have information for men and women)
- Coping with fatigue
- Coping with hair loss
- Giving up smoking
- Help with the cost of cancer
- How are you feeling?
- Managing the late effects of bowel cancer treatment

- Managing the late effects of breast cancer treatment
- Managing the late effects of pelvic radiotherapy in men
- Managing the late effects of pelvic radiotherapy in women
- Pelvic radiotherapy in men managing side effects during treatment
- Pelvic radiotherapy in women

   managing side effects
   during treatment
- Physical activity and cancer treatment
- Relationships, sex and fertility for young people affected by cancer
- Sexuality and cancer
- The building-up diet
- Understanding allogeneic (donor) stem cell transplants
- Understanding cancer research trials (clinical trials)

- Understanding cervical cancer
- Understanding early (localised) prostate cancer
- Understanding head and neck cancers
- Understanding high-dose treatment with stem cell support
- Understanding secondary cancer in the bone
- Understanding thyroid cancer
- Understanding womb (endometrial) cancer
- What to do when treatment ends: 10 top tips
- Work and cancer
- Working while caring for someone with cancer

To order a free resource, visit **be.macmillan.org.uk** or call **0808 808 00 00**. All of our information is also available online at macmillan.org.uk/ cancerinformation

# **Macmillan videos**

There are many videos on the Macmillan website featuring real-life stories and information from health and social care professionals.

We have a video about radiotherapy. It features a clinical oncologist talking about external radiotherapy, how it's given and the side effects. You can watch it at macmillan.org.uk/ radiotherapy

# Macmillan audiobooks

Our high-quality audiobooks, based on our variety of booklets, include information about cancer types, different treatments and about living with cancer.

To order your free CD, visit **be.macmillan.org.uk** or call **0808 808 00 00**.

# **Useful websites**

A lot of information about cancer is available on the internet. Some websites are excellent, others have misleading or out-of-date information.

The sites listed here are considered by doctors to contain accurate information and are regularly updated.

# www.macmillan.org.uk (Macmillan Cancer Support)

Find out more about living with the practical, emotional and financial effects of cancer. Our website contains expert, accurate up-to-date information on cancer and its treatments including:

- all the information from our 150+ booklets and 360+ fact sheets
- videos featuring real-life stories from people affected by cancer and information from medical professionals

- how Macmillan can help, the services we offer and where to get support
- how to contact our cancer support specialists, including an email form for sending your questions
- local support groups search, links to other cancer organisations and a directory of information materials
- a huge online community of people affected by cancer sharing their experiences, advice and support.

# www.cancer.gov (National Cancer Institute – National Institute of Health – USA)

Gives comprehensive information on cancer and treatments.

### www.cancer.org (American Cancer Society)

Nationwide community-based health organisation dedicated to eliminating cancer.

# www.cancerhelp.org.uk (Cancer Research UK)

Contains patient information on all types of cancer and has a clinical trials database.

# www.healthtalkonline.org www.youthhealthtalk.org (site for young people)

Both websites contain information about some cancers and have video and audio clips of people talking about their experiences of cancer and its treatments.

### www.macmillan.org.uk/ cancervoices (Macmillan Cancer Voices)

A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

# www.nhs.uk (NHS Choices)

The country's biggest health website. Gives all the information you need to make decisions about your health.

# www.nhsdirect.nhs.uk (NHS Direct Online)

NHS health information site for England – covers all aspects of health, illness and treatments.

# www.nhs24.com (NHS 24 in Scotland)

www.nhsdirect.wales. nhs.uk (NHS Direct Wales)

# www.n-i.nhs.uk (Health and Social Care in Northern Ireland)

The official gateway to health and social care services in Northern Ireland.

# www.patient.co.uk (Patient UK)

Provides information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics.

# www.riprap.org.uk (Riprap)

Developed especially for teenagers who have a parent with cancer.

# Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photographs are of models.

# Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our medical editor, Dr Tim Iveson, Macmillan Consultant Medical Oncologist.

With special thanks to Dr Michael Williams, Consultant Clinical Oncologist and Mrs Sarah James, Professional Officer, The Society and College of Radiographers for their help and guidance with the revision of this edition.

Additional thanks to: Ms Laura Allington, Superintendent Radiographer; Ms Kerry Chapman; Senior Radiographer and Patient Information Project Manager; Ms Heather Dias, Macmillan Radiotherapy Specialist; Dr David Gilligan, Consultant Clinical Oncologist; Dr Glynne Jones, Consultant Clinical Oncologist; Ms Lisa Mann, Macmillan Radiotherapy Specialist; Dr Catherine McBain, Consultant Clinical Oncologist; Mr Stuart McCaighy, Clinical and Technical Development Superintendent Radiotherapy Cancer Centre; Ms Peggotty Moore, Macmillan Information and Review Lead Radiotherapy and Oncology Outpatients; and the people affected by cancer who reviewed this edition.

# Sources

NHS National Cancer Action Team. National Radiotherapy Implementation Group Report: Image Guided Radiotherapy (IGRT): Guidance for implementation and use. August 2012. Department of Health. Radiotherapy Services in England 2012. www.dh.gov.uk/health/2012/11/radiotherapy-2012 (accessed November 2012). Ahmad S, et al. Advances in radiotherapy. BMJ. 2012. 345: e7765. Society of Radiographers. An overview of radiotherapy. www.sor.org/about-radiography/patient-information/overview-radiotherapy (accessed November 2012). Improving Supportive and Palliative care for Adults with Cancer. March 2004. National Institute for Health and Care Excellence.

# Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we're there to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.



### Share your cancer experience

Support people living with cancer by telling your story, online, in the media or face to face.

# Campaign for change

We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

### Help someone in your community

A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

### **Raise money**

Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

### **Give money**

Big or small, every penny helps. To make a one-off donation see over.

# Call us to find out more 0300 1000 200 macmillan.org.uk/getinvolved

# Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

(Please delete as appropriate) I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

OR debit my: Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number



# Don't let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

I am a UK taxpayer and I would like Macmillan Cancer Support to treat all donations I have made for the four years prior to this year, and all donations I make in the future, as Gift Aid donations, until I notify you otherwise.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each tax year, that is at least equal to the tax that Charities & CASCs I donate to will reclaim on my gifts. I understand that other taxes such as VAT and Council Tax do not qualify and that Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box.

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.



# If you'd rather donate online go to macmillan.org.uk/donate

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way, call Macmillan on 0808 808 00 00 (Mon–Fri, 9am–8pm) or visit macmillan.org.uk

Hard of hearing? Use textphone 0808 808 0121, or Text Relay. Non-English speaker? Interpreters available.

© Macmillan Cancer Support, May 2013. 10<sup>th</sup> edition MAC11640 Next planned review 2015. Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604).



Printed using sustainable material. Please recycle.

WE ARE MACMILLAN. CANCER SUPPORT