INTRODUCTION

The purpose of this booklet is to provide answers to some of the questions that go through the minds of patients who have been told by their doctor that radiotherapy is needed in order to treat their illness.

Patients who have more detailed questions can of course speak directly to the staff of the radiation oncology department. They will be happy to help.

The Department of Radiation Oncology
When choosing the appropriate radiation technique, it is important to select the correct energy or strength of radiation and to apply it to one or more treatment volumes from a variety of radiation angles.

By administering individual treatment sessions of a few minutes several times a week, it is possible to damage cancerous cells effectively while ensuring that healthy tissues have the chance to recover.

Radiation cannot be seen, smelled or felt. Irradiation causes no pain. Finally, it is good to know that patients do not become radioactive after radiotherapy, so patients can have contact with other people, even children and pregnant women, completely freely.
WHAT DOES A COURSE OF TREATMENT INVOLVE?

Consultation

Before your treatment starts you will meet the radiation oncologist, the doctor who specialises in radiation oncology. The first meeting may take place in the department of radiation oncology, in the doctor’s consulting rooms, or on the hospital ward. The radiation oncologist will discuss the treatment that is most appropriate for you (your treatment plan).

Definition of the treatment volume (simulation) can often be arranged on the same day. If not, another appointment is made. If you wish, you can then meet the social worker who works in the department of radiation oncology. He can provide additional information about the various stages of the treatment and discuss with you how to solve any practical problems you might have. If you have already been admitted to hospital, you can also ask to meet the social worker on your ward.

Simulation or definition of the treatment volume

Depending on the volume to be treated or the irradiation technique, you may have to undergo a simulation or just a CT scan. A simulator is not a radiotherapy machine, but it resembles one. It takes X-ray images in order to determine the treatment field. A simulation procedure, or field definition, is painless.

First of all, the nurse will take a picture of you. It will be printed on your radiotherapy chart. Some names are more common than others and it is possible for two patients with the same name to be having treatment over the same period. The picture avoids potential confusion. After this, the nurse will ask you to lie down on the table of the irradiation machine.

During the simulation process the treatment field is determined following a series of X-rays. The area is then marked and photographed.

In most cases, you will be irradiated from different directions.

When patients are to be treated in the chest area, abdomen or limbs, the treatment field is marked on the skin. A special ink is used which is difficult to rub off and only fades as the skin peels off. It is important that the marks remain visible for the duration of the treatment so that the nursing staff can see exactly which area is to be irradiated.
If a patient’s head or neck is to be treated, it will first be necessary to make a protective support, called a mask. You will be duly informed if this mask is needed for your treatment. When the treatment area is defined, no lines or tattoo marks will be made directly on your skin, only on the mask.

Finally, a number of contour measurements are made using the CT scanner, in order to calculate the exact dose of radiation required.

The whole process of defining the treatment volume may take between 30 and 60 minutes.

Afterwards, the nurse will give you details of your first treatment appointment (date, time and duration) and the number of the therapy machine. Your family doctor will be kept informed of your treatment.

**What is a mask?**

The first step in planning the treatment of a head or neck tumour is to make a mask. There are two reasons for this.

Firstly, it means that the treatment area can be marked out on the mask, rather than on your face or neck. Secondly, the mask ensures that you lie in the same position on the table for every session.

The mask is made in the simulator room or CT room before the treatment area is marked out.
The procedure is as follows:

You lie on your back on the treatment table, with your head and neck on a special cushion. The radiation oncologist and the nurses determine the correct position of your head and neck. The product used to make the mask is first warmed in water to make it soft and easy to mould around your head and neck. The temperature is easily tolerable and your mouth and/or nose areas are left free so that you can breathe comfortably throughout the procedure.

The mask does not stick to your skin or hair and can be removed easily at any time. Clothing might get wet during the procedure, so you will be asked to remove your clothing above the waist. It takes about ten minutes to make the mask.

If you suffer from claustrophobia, please tell the doctor or nurse in advance so that this can be taken into account.

Your mask is kept in the treatment area throughout your treatment period and will be used exclusively for you.

CT-scan

CT is the abbreviation for Computed Tomography. The technique consists of scanning part of the body with X-rays and then using a computer to construct a three-dimensional image of the scanned body part. Scanning takes about 30 minutes.

You lie on a table similar to the table subsequently used for the radiotherapy. The table moves slowly into and through a complete ring during the scanning procedure so that the body receives only a minimal dose of X-rays per second. The recorded data are evaluated by the radiation oncologist and the nurse in order to draw up a treatment plan.

For the purpose of this examination, the doctor may deem it necessary to inject a contrast medium into a vein in your arm. You will be informed in advance and told not to eat or drink anything for at least four hours before the examination.

The contrast medium makes the organ more visible on the CT scan. When the contrast medium is injected you will feel a pin-prick, just like when a blood sample is taken. The product generates a warm feeling throughout your whole body, especially in the throat and stomach. This feeling fades after a minute and should not bother you any more.

After the CT scan, which is carried out in our department, a verification may be needed. You will then need another appointment.
The duration of the treatment is calculated for each individual patient. It takes approximately one minute for each direction. The nurse will follow the treatment procedure on a TV monitor in a neighbouring room. You can be in touch with the nurse over the intercom at any time.

Once the treatment is finished, the machine switches off automatically and the nurse will come back into the room.

When the session is finished, you may get dressed and leave the department of radiation oncology.

**The Treatment**

**First session**

The first treatment session generally takes place one week after the simulation. This delay is needed to enter all the data into the treatment machine, to make the necessary calculations and to take any specific precautions.

Before treatment can start, you will be carefully placed on the table and the treatment machine will be correctly positioned. This position is the same as the position adopted in the simulation session.

On the first day of treatment, several images will be taken and the radiation dose will be checked with a dosimeter on your skin. As a result, your first session will be longer than the following ones.

Control images will most probably be repeated on the second and third days of treatment as well as later, for instance at weekly intervals or when the radiation direction is modified.

After the nurses have adjusted the focus of the treatment volume, they will leave the room and the treatment will be started. It is very important that you remain motionless during the treatment. When the session is finished, you may get dressed and leave the RT department.

Remain calm and breathe normally during the treatment. You will not feel the radiation itself, but the treatment machine will produce a penetrating, buzzing noise.
Subsequent sessions

The total number of radiation sessions, the total dose and the required interval between sessions will depend on the type of tumour, its location in the body and the conclusions drawn from any observations made during the course of treatment.

The radiation oncologist decides how the treatment is to proceed. For a given illness, the treatment can vary from patient to patient. You will undergo one or sometimes two treatments per day and the total number of sessions may vary from 1 to 37.

Normally, you will not be treated at weekends or on public holidays, unless the machine has been out of use for several days for maintenance and quality control the week before.

FOLLOW-UP

During your course of treatment

Every week you will be able to talk about your treatment with the radiation oncologist or a resident in training. He will check that the treatment is going well and you will have the opportunity to ask questions. All the doctors in the department have fixed morning and afternoon consulting hours.

Every group of doctors is identified by a colour code and every patient will be followed by an individual group of doctors. The colour coding makes it easier for the radiation oncology staff to know who is following which patient and whom they must contact if problems arise.

If necessary, the doctor may order some blood tests. The nurse in charge of your machine will inform you whether a blood test is needed, then he will take the blood samples. For these tests you do not need to fast.

After your treatment

On the last day of your treatment you will be given an appointment for your next check-up with the doctor.

You will remain under supervision so that the effects of the treatment can be monitored.

If you feel unwell or if you are worried about anything during the days or weeks following your course of treatment, you can phone for an early appointment with a specialist after talking to your family doctor.
SIDE-EFFECTS

GENERAL SIDE-EFFECTS

Reactions to radiotherapy depend on the part of the body being treated. Although there are a number of possible reactions, these generally occur during the course of treatment. Fatigue, skin reactions, increased need for sleep and reduced appetite are some examples. Your doctor will talk to you about this before the treatment starts and discuss ways in which you can cope with the reactions.

If you experience any worrying symptoms, it is best to talk to your doctor or the nursing staff about them. Information booklets about specific problems are available. The effects of the radiation can last quite a while and it can take several weeks for all the effects to disappear.

If you suffer few or no ill-effects from the treatment, you should not worry. The effectiveness of the treatment is not related in any way to the severity of the side-effects. Talk about this with your doctor; he will be able to put your mind at ease in this respect.

SPECIFIC SIDE-EFFECTS

The development of specific side-effects will depend on the area of your body that is treated.

Hair
You will experience hair loss (often temporary) only if your hair grows within the treatment area. The degree of hair loss depends on the administered radiation dose and the size of the treatment area. Hair loss can occur anywhere (head, beard, pubic hair, armpits, chest).

Head
Nausea and vomiting, sometimes dizziness and headaches.

Oral cavity, throat and neck
Production of mucus, sensitive lining of the mouth, unpleasant taste, changes in taste and smell, diminished saliva production, dry mouth, then, later in the treatment, difficulty swallowing, occasional huskiness, nausea and vomiting.

Oesophagus
Swallowing disorders, such as pain when swallowing and occasional difficulty swallowing. Occasional tickling sensation, huskiness.

Lungs
Swallowing disorders, difficulty with mucus expectoration, loss of appetite, occasional tickling sensation and shortness of breath.

Chest
Reddening of the skin, swelling of the chest, difficulty swallowing for a few days if treatment is administered to the glands behind the breastbone.

Stomach area
Nausea, urge to vomit, loss of appetite. Occasional stomach pain, intestinal cramps and diarrhoea.

Abdomen
Nausea and vomiting, intestinal cramps, diarrhoea, loss of appetite.

Lower abdominal area
Occasional nausea, abdominal pain, intestinal cramps and diarrhoea. Sensations similar to cystitis, painful urination, frequent urination. Vaginal irritation. Loss of pubic hair.

Talk to the nurse or doctor about your concerns. They can advise you about the best way of curing or coping with the problems.

SIDE-EFFECTS
**Care of the skin**

It is perfectly normal for your skin to react to the irradiation. The intensity of the reaction depends on several factors: the type of rays, the administered dose and the treatment area.

Your skin will only react in the treatment area. It may become dry or change colour and become slightly swollen. Afterwards, it will peel off. In the treated area, your skin will feel itchy and sensitive.

In some cases, the treated skin can become dark red, shiny and painful. Blisters may form and then break open, with fluid loss. This often occurs in skin folds, for instance, behind the ears, in folds in the neck, in the armpits, under the breasts, in the groin or between the buttocks.

**Duration**
The skin reaction usually occurs around the third week after the treatment and slowly intensifies. But it may be that the worst reaction occurs in the first week after the end of the treatment.

Minor skin reactions improve within one to two weeks of the treatment. More severe reactions diminish after two to four weeks. The dark red or brown discoloration of the skin fades gradually over a period of weeks or months.

**Recommendations**
These recommendations apply only to the areas of skin that have been irradiated. The rest of your skin does not need any special care.

**During the treatment**

- Protect the irradiated area from any additional irritation, injuries and bites throughout your treatment and until the skin is fully healed.
- Wash the skin of the treated area with a neutral, unscented soap (e.g. glycerine soap).
- Use lukewarm water preferably.
- Wash yourself very carefully. Use your hands rather than a washcloth. Gently pat dry the irradiated parts; do not rub.
- Dry your skin carefully and thoroughly. Keep skin folds very dry because this is where the skin is more liable to become sore.
- Place a soft cloth in skin folds. These cloths are available in each unit.
- You may take a shower. Avoid bathing because the skin markings may fade (demarcation of the treatment area). If the markings become paler, never touch them up yourself.
- Protect the skin in the treated area from excessively high or low temperatures. Never use a hot water bottle or electrically heated pillow.
- Avoid using deodorants in the irradiated area.
- Do not shave irradiated skin, for instance in the armpit area.

**Male patients:** if your face is being irradiated:
- Use an electric razor.
- Do not use any pre-shave or after-shave products because they irritate the skin.

**If you suffer from itching or burning sensations or dry skin:**
- Apply a moisturising cream twice a day.
- Cool your skin down with a moist, cold washcloth or with a cold pack that you keep in the refrigerator (not the freezer).
After your treatment

Continue to protect your skin even after the end of your treatment and even if your skin appears healed.

During the first few weeks after your treatment:

- Observe the care instructions that are given to you, apply the moisturising creams or special dressings.
- Avoid injuries, chafing and pressure.
- If possible, avoid using products that might irritate your skin, such as deodorants, pre-shave and after-shave products.
- If your skin becomes raw after the end of the treatment, phone the department immediately to make an appointment with a member of the nursing staff who treated you.

During the three months following your treatment:

- Protect all irradiated skin from direct sunlight.
- Use a sunscreen with a protection factor of at least 50 if you cannot avoid exposing your irradiated skin to the sun.
- Protect your skin from the direct effects of wind and cold.

Contact your doctor or nurse if your skin becomes:

- very red
- blistered
- moist and sticky
- very painful
DIETICIAN

Radiotherapy damages not only malignant cells, but also healthy cells. Depending on the area of treatment, you may suffer from various symptoms. For instance, a sore throat, dry mouth and difficulty swallowing if your neck is treated, and intestinal problems if your abdominal area is treated.

Radiotherapy places the body under severe stress. In order to maintain your body weight and fitness, you must absorb sufficient energy (calories), fluids and nutrients.

A good diet is obviously important for everyone. But when you are undergoing radiotherapy it is important to be very careful about what you eat and drink as soon as the treatment starts. If you are eating properly you will cope better with the treatment and you will have a lower risk of complications.

Adapting your diet can make everything easier for you by ensuring that you do not suffer unnecessary stress from the irradiation and that you receive the required nutrition to recover from your treatment.

The dietician will be happy to give you advice on this. If you wish and/or if your symptoms are severe, the dietician will follow your progress throughout the duration of your treatment.

The dietician is present in the department of radiation oncology every Wednesday and Friday. You can make an appointment by speaking to the nurse operating your machine or to the radiation oncologist.

SOCIAL WORKER

When you are ill, this can be very worrying for you and your family. The social workers in the department of radiation oncology can help you tackle the difficulties that you encounter in your personal and family life.

You can contact them with questions or worries concerning:

- personal integration, relationship with your partner, family life
- social contacts, activities, working life
- practical arrangements relating to the treatment (e.g. transport)
- money matters, social services, insurance
- help at home
- residential accommodation (e.g. for convalescence).

You can request an appointment either by contacting the social worker directly, through the radiotherapy nurse in charge of your machine, or through the radiation oncologist or the staff at the reception desk.

Social workers:
Lieve Lenders
Wilma Wilmots
Tel. 016 34 86 20
MORE INFORMATION

Many programmes and initiatives are available for providing patients with information and support.

INFORMATIVE AFTERNOONS

Twice a month the department organises an ‘informative afternoon’ for patients and their families. These afternoons are an informal way of learning all about the practical aspects of radiation treatment.

First of all, you are given a brief description, then you are shown around the department. You can see at close quarters how a simulator and a radiotherapy machine work. The whole programme lasts about two hours.

The relevant information can be obtained from the reception desk, from the nurses in charge of your machine or in the patient information area.

INFORMATION AREA, BROCHURES AND THE INTERNET

Near the reception desk you will find a special information area with brochures published by the UZ Leuven and information about your illness, prevention, healthy living, social services, self-help groups and other topics.

Several computers are also at your disposal near this area, if you want to look up further information. Or you can have something to drink and perhaps sit and chat with other patients.

The documentation is also available on the UZ Leuven web site: www.uzleuven.be/radiotherapie-oncologie

VLAAMSE LIGA TEGEN KANKER (VLK)

The Vlaamse Liga tegen Kanker (VLK) is an organisation that provides cancer patients and their families with information and support during the period of treatment and convalescence. They have built up an extensive range of services for this purpose. Together with UZ Leuven, the VLK organises information sessions about various aspects of the illness. Voluntary workers from the VLK are regularly present at specific times at the information centres in the hospital.

For more information, contact the drop-in centre:

Vlaamse Liga tegen Kanker
O.L.Vrouwstraat 44, 3000 Leuven
Tel. 016 23 00 91
leuven.vliga@tegenkanker.be
www.tegenkanker.be

STICHTING TEGEN KANKER

The Stichting tegen Kanker organisation provides various services to facilitate the lives of cancer patients and their families.

For more information, contact:

Stichting tegen Kanker
Leuvensesteenweg 479, 1030 Brussel
Tel. 02 733 68 68, www.kanker.be
MISCELLANEOUS

Appointment system

On the day of your simulation you will receive a beige parking card that gives you access to the car park and a list of all the appointments for the entire course of treatment. You must leave the parking card in a clearly visible place inside the windscreen of your car.

If you are unable to attend certain appointments, tell the nurses in charge of your machine when you come in for your first radiotherapy session. Every possible effort will be made to take your needs into account. After your first therapy session, you can go straight to your radiotherapy machine. Give your appointment sheet to the nurse before going to the waiting room. A nurse will call your name and you will receive a personal card with your barcode. As soon as you hear your name, you should first scan your card and then go to the changing room.

Transport

If you have to visit the hospital for radiotherapy every day, you can ask the social worker for help organising your transport. You have several choices.

Public transport
The campuses of UZ Leuven are easily accessible by bus. Buses run approximately every five minutes between the Gasthuisberg campus and the town centre or Leuven station. Good rail connections are also available between Leuven station and the rest of the country.

Your own transport
If you prefer to use your own car, it would be best to discuss this first with your doctor. You could also ask a relative, friend or neighbour to drive you.

Taxi
Some health insurance companies will arrange for transport by taxi at a reduced cost.

Reimbursement
Radiotherapy treatment entitles you to reimbursement of your travel expenses. Some health insurance companies provide an additional transport allowance.

On the last day of your treatment, you will receive a signed declaration for the reimbursement of your travel expenses, with a list of all your travel dates. You must forward the form to your health insurance company.

Parking
At the beginning of your treatment, you will receive a parking card so that you can park in the immediate vicinity of the radiotherapy department.

Coffee, tea and water
You can use the coffee machine in the reception area at any time. Coffee and tea are free of charge.

If you would rather drink water, two water coolers are available, one near the reception desk and one near the simulator.

Studies
One of the tasks of a university hospital is to conduct research in order to improve treatments. This research can take the form of a study or a trial. We may ask you to take part in a research project of this kind, but participation in a trial is entirely your decision.
FREQUENTLY ASKED QUESTIONS

Whom to contact if there is something you do not understand?
If you have any questions, you can speak to the reception staff, one of the nurses or your doctor. You will see the nurses every day and the doctor once a week.

Whom to contact if you have a complaint or problem?
If you have any complaints about the treatment or rate of progress, we hope you will discuss them with us so that we can try to find a solution. It is possible that you may have your own suggestions for improvement. You can talk about your problems to your doctor, the radiotherapy nursing staff, the social worker or the staff at the reception desk. You can also make an appointment with the chair of the department or a senior nurse. Feel free to write down your comments at any time and put them in the suggestion box at the reception desk.

What if any problems arise after the treatment?
If you have any problems or questions, you should first speak to your family doctor. He will always be kept fully informed of your medical situation, your treatment and any side-effects that need to be monitored. In most cases, he will also be able to give you the help you need. If necessary, he will arrange for an appointment at the hospital as soon as possible.

Are there any additional costs involved?
The full cost of the radiotherapy treatment is covered by your health insurance fund. As regards doctors’ fees, you will be required to pay the standard share of the cost of a doctor’s visit, but only for two visits, irrespective of the number of visits actually made. If you choose to go private and consult a specific doctor, an additional amount may be charged. You can speak to your doctor for additional information.

USEFUL INFORMATION

Chair of the Department:
Prof. dr. Karin Haustermans

Senior nurse:
Katleen Luyten

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