



Thyroid cancer – radioactive iodine treatment

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You have undergone a thyroid operation and are now being treated with radioactive iodine. This treatment will ensure that thyroid tissue, which the surgeon did not manage to remove during surgery, is traced and treated.

The treatment requires you to be admitted to the iodine therapy unit at UZ Leuven. Prior to the treatment we will investigate whether there are any medical reasons in your case for it not to be administered.

The thyroid is the only organ in the human body that takes up iodine. The rest of the body barely takes up any iodine, which also applies to radioactive iodine. Radioactive iodine that is not taken up is excreted from the body via the urine.

This brochure aims to answer any questions you might have. You can also contact the physician who is treating you, the nursing unit or the radiotherapy/oncology department for further information. Relevant telephone numbers are included at the end of this brochure.

IODINE AND IODINE 131

The radioactive iodine used for this treatment is referred to as iodine 131, which emits two types of radiation. One type irradiates any thyroid tissue left behind after the operation. Tissue surrounding the thyroid and other tissue in the body will barely be affected by this type of radiation. The other type of radiation can be compared to X-rays, a type of radiation that is also absorbed by your environment. In order to minimise the level of radiation for those around you, you will be treated in a special room.

The treatment involves swallowing a capsule with water.

LOW IODINE DIET

In order for the treatment to be successful you need to adopt a low iodine diet for one week before you are admitted to UZ Leuven. This will promote the absorption of radioactive iodine. Some foods naturally contain high iodine levels. Iodised salt is also sometimes added to certain products during the manufacturing process. Information on a low iodine diet can be found further in this brochure, starting from page 21.

It is advisable not to have any iodine containing contrast media administered for a period of three months prior to the treatment. This type of medium is often used when you have to have a CT

scan involving the injection of contrast fluid. Remember to tell the physician or radiologist about this.

WITHDRAWING THYROID HORMONE BEFORE TREATMENT

Before you are admitted to hospital any remaining thyroid cells need to be stimulated, which can be achieved in two ways. Your physician will tell you which method is best for you.

- **Withdrawal:** this means that six weeks before you are admitted to hospital you have to stop taking the thyroid hormone and replace it with a rapid-acting thyroid hormone on the basis of a fixed schedule (Cynomel–T3, see page 19). You must stop taking this hormone two weeks before being admitted. You may feel weak and tired, but this is normal and will disappear once you start taking your usual thyroid hormone again following your discharge from hospital.
- **Thyrogen:** Thyrogen is a human thyroid stimulating hormone (TSH), which is manufactured using biotechnological processes and is administered via two injections in the buttock or upper thigh on two consecutive days (see page 20). This results in the stimulation of any remaining thyroid cells.

PREGNANCY

You cannot be treated if you are pregnant. In the event of doubt it is advisable to conduct a pregnancy test. Women must avoid pregnancy at least until six months after the last treatment with radioactive iodine. Men are advised not to conceive any children until six months after the last treatment. Any questions concerning pregnancy and methods to prevent it can be discussed with the physician who is treating you.

Breastfeeding must be stopped and must not be started again following treatment.

ADMISSION

ADMISSION PROCEDURE

You will be expected to be present at 9 a.m. at campus Gasthuisberg, hospitalisation 42, Yellow street, gate 4, level 3 (GE 4.3.b). You can have a light breakfast at home in the morning. We recommend a breakfast consisting of white bread and jam or honey and soy yoghurt. The nurse will provide a brief description of the treatment and run through the guidelines with you. A blood sample will then be taken, mainly to establish the level of thyroid stimulating hormone (TSH value). TSH is a hormone, which is produced by the brain and regulates the thyroid function.

Once the thyroid has been removed the TSH level in the blood will continue to rise. When the TSH level is high the absorption of iodine in the thyroid cells increases, which in turn enhances the effect of the treatment with iodine 131. You will be given iodine 131 in capsule form to ensure that it is absorbed by any remaining thyroid tissue. You will not be aware of this. It is advisable not to eat or drink anything for one hour after taking the capsule to ensure that the iodine is properly absorbed. After that, we recommend [drinking plenty, 6 to 8 glasses spread throughout the day.](#)



The iodine that is not absorbed by the thyroid tissue leaves the body through the urine. This happens largely within one to two days. [Your urine is radioactive at that time.](#)

Iodine absorbed by the remaining thyroid tissue will leave the body at a much slower rate. We can only give you a rough estimate of the duration of your stay in hospital in advance. Depending on the administered dose, the duration of stay varies from 2 to 5 days. Drinking a lot (at least 1 litre per day of, for example, water, tea, etc.) promotes the excretion of radioactive iodine via the urine.



THERAPY ROOM

You will be admitted to a single room. You must not leave your room during treatment. On the 'Octopuz screen' at your bed, you can watch television, listen to the radio, and make phone calls among other things. The room is also equipped with a fan and a laptop, and features a freeze toilet and airlock. The floor is covered with absorbent material. All bodily fluids will be radioactive (urine, saliva, perspiration, vomit, faeces, etc.), which means anything you touch can be contaminated. **You are allowed to have visitors**, but they have to stay in the area adjoining your room. You will be able to see each other through a window and talk via the telephone. Visiting times are unrestricted (until 8 p.m.). The nursing staff will limit their contact with you as much as possible and not enter the room unnecessarily. Obviously you will always be able to contact them and ask questions.

MEALS

Meals will be brought in by the nursing staff and we would ask that you keep sufficient distance when they do. Any food residue or other waste material must be deposited in the bin in your room.



WHAT TO BRING

You will have to look after yourself whilst you are hospitalised.

- Only bring what is strictly necessary.
- Clothing worn in the room will be considered contaminated material. It will be removed when you leave, stored and incinerated after six months.
- What should you bring:
 - ✓ A couple of sets of old underwear, one set of old day and nightwear and a spare set of day and nightwear. In the morning you will get dressed as usual. You can put on your old clothing before you take the capsule. Your other clothing will be kept in a wardrobe outside your room until you are ready to go home again. You will get changed again before you leave the hospital. Try to wear only one set of old clothing, because you will have to leave behind any clothing and other items you have used in the room when you leave.

- ✓ Medication you usually take, enough for five days. This does not apply to medication you had to stop taking before the treatment (your physician will have discussed this with you beforehand).
- ✓ Small amounts of products such as toothpaste, enough for five days.
- ✓ Something to keep you occupied, e.g. magazines.
- ✓ It is advisable not to wear jewellery. Spectacles are fine.



- If you wear glasses remember to clean them before you leave the room. Glasses will be tested for contamination and in principle it will be ok to take them home.
- If you wear dentures it will be ok to wear them during your admission and to take them home again when you leave.

SIDE EFFECTS

Most patients don't suffer from side effects. Some may feel bloated or have a swelling in the neck. Temporary problems may occur with taste and they can last a few weeks. You will also notice that you are more tired. Drinking sufficiently during your admission will limit the risk of side effects. You may feel slightly nauseous a few hours after taking the iodine 131.

CLEANING

You will be expected to look after yourself as much as possible during your admission. Your room and its sanitary facilities will not be cleaned and the bed will not be made during your stay, to minimise the risk of exposure to radiation for our staff. The iodine room will be cleaned when you have left.



HYGIENE MEASURES



- Urine and feces are immediately frozen to prevent odor nuisance.
- Men must always urinate sitting down to avoid splashing.
- Always wear overshoes when using the toilet. You will find them in the bathroom.
- Always use toilet paper after each toilet visit.
- Wash your hands with soap and water after each toilet visit.

SMOKING

There is a general smoking ban in the hospital, including on the nursing wards. Smoking is only allowed in the designated smoking areas outside the hospital (next to the entrance).

GOING HOME

Before you are discharged the amount of radiation still present in your body will be measured with a radiation detector. Providing the amount of radiation is below a specific norm stipulated by the authorities, you will be able to leave the iodine room. At that point in time the amount of radioactive iodine in your body will be low enough but you can still expose others to a low level of radiation. This does not constitute a direct hazard to your environment but you will still have to observe certain rules throughout the next few days. They are included in 'Routine following discharge from hospital' later in this brochure. We would ask that you make every effort to comply with these recommendations and instructions. This will keep the radiation others, i.e. your family members, are exposed to at a very acceptable level.

When you are discharged you will be given further details on the medication you have to take. You will also be given an appointment for a full body scan and endocrinology-radiotherapy check-up.

FULL BODY SCAN FOLLOWING TREATMENT

Depending on the administered dose, a total body scan is performed on the day of discharge or one week after the intake of the radioactive iodine on an outpatient basis. This involves using a gamma camera to investigate the locations in the body where the radioactive iodine from the treatment is located. This will enable us to see where in the body thyroid tissue or possibly thyroid cancer tissue is present.

This scan is carried out using the radioactive iodine which remains in your body after treatment, no further radioactive iodine is administered. The examination takes approximately one hour.

ROUTINE FOLLOWING DISCHARGE FROM HOSPITAL

When you leave the unit there will still be a small amount of (residual) radioactive iodine in your body.

As agreed during our preliminary conversations, we highly recommend that you comply with a number of instructions over the next few days. They are meant to protect those around you and people and the environment in general.

GENERAL ROUTINE

When you are told you can go home you are not completely radiation free yet. People around you could still potentially be exposed to minimal radiation. However, the radiation effect decreases considerably in line with the distance between you. That's why keeping your distance from other people is the best and most effective method to protect those around you from low radiation.

Where possible keep a distance of 1 metre (2 metres if contact takes more than one hour) from people you come into contact with at home or elsewhere.

Limit physical contact with others and in any case ensure that this contact takes no longer than half an hour per day.

These general precautionary measures must be observed for five days after your discharge from hospital. With pregnant women and children below the age of six these recommendations have to be observed longer, i.e. for seven days, because small children are more sensitive to radiation.

ROUTINE WITH YOUR PARTNER

✓ You must sleep in separate rooms or in beds at least two metres apart for two days. Do not place the beds either side of the same wall (adjoining rooms), because the wall will not absorb all the radiation.

✓ You must abstain from sexual contact for five days.

- ✓ You must not get pregnant for at least six months. Women are consequently advised to use effective contraception during this period.

- ✓ If your partner is pregnant you must strictly adhere to these recommendations (or possibly not stay under the same roof) for seven days.

ROUTINE WITH YOUR CHILDREN

- ✓ We recommend that children under the age of six, who normally stay with you, should not stay under the same roof. If this is not possible you must specifically ensure that children, and very young children in particular, can be looked after by someone else to minimise close contact. Children must sleep in a separate room.

These measures must be observed for seven days when children are around.

- ✓ Breastfeeding must be stopped before treatment in hospital and must not be resumed when you go home.

ROUTINE WITH VISITORS

- Contact with pregnant women and children below the age of six must be avoided during the first seven days.
- With all other visitors the general rules concerning distance and time constrictions for close contact must be observed. Brief close contact (e.g. shaking hands) is risk free.

ROUTINE IN PUBLIC PLACES

- ✓ Avoid busy, densely populated places where it is difficult to maintain the distance rules for a long time and where you might meet high risk individuals such as pregnant women or young children (cinema, theatre, restaurants, hairdresser, etc.) for a period of seven days. This also applies to contacts relating to your general health that are not particularly urgent (physiotherapist, dentist, routine GP visit, etc.).
- ✓ You must also not use public transport for seven days. If you have no other option, the journey should under no circumstances take longer than an hour and keep as much distance as possible between you and other passengers or your taxi driver.

PERSONAL HYGIENE

To prevent contamination of the toilet area men must always sit down when urinating. When using the toilet always use toilet paper, wipe the toilet seat and flush the toilet twice. Wash your hands with soap and water immediately after. This toilet routine must be observed for five days after your stay in hospital, both at home and elsewhere.

Personal toiletries (face cloth, towel, toothbrush, etc.) must only be used by you. Once these items have been washed they can be used by others again.

KITCHEN UTENSILS

Because your saliva is also contaminated, cutlery, cups, glasses, etc. that have been touched by you must not be used by others. Once they have been washed (as part of the normal dishwashing routine) they can be used again by others.

AT WORK

You will not be able to work for a fortnight.

FLYING

If you are planning to fly shortly after your stay in hospital, you will have to discuss this with your physician. In such cases you will be given a letter with details on your treatment.

GP NOTIFICATION

Your GP will be notified by the specialist who treated you in a letter that provides details on your treatment and, where applicable, relevant aftercare.

UNEXPECTED ADMISSION TO HOSPITAL

If you are unexpectedly admitted to hospital in the period in which these routine rules apply (= seven days), you or your family must report your recent iodine therapy when you are admitted.

MEDICATION AND ARRANGEMENTS

The physician/nurse will indicate which method applies to you.

□ WITHDRAWAL

You must meticulously observe these thyroid medication instructions. You will be notified of the exact date for each stage during your status consultation.

1. Stop taking Elthyron[®]/L-Thyroxine[®]: 6 weeks before admittance to hospital:
2. Start taking Cynomel[®]: 6 weeks before admittance to hospital:
 - Week 1: Cynomel[®] 1/2 tablet twice x a day
 - Week 2: Cynomel[®] 1/2 tablet three times x a day
 - Weeks 3 and 4: Cynomel[®] 1 tablet three times a day
3. Stop taking Cynomel[®]: 2 weeks before admittance to hospital:

Some discomforts may occur during the latter two weeks (mainly tiredness, weight gain, concentration problems, etc.)
4. Admittance to hospitalisation 42 on Thursday
5. The day you leave hospital you can start taking Elthyron[®]/L-Thyroxine[®] again: µg/d
6. Appointment for a scan at the nuclear medicine department: 1 week after admittance to hospital:
7. Check-up appointment (consultation 12, Yellow Street, gate 2, level 1): shortly after the scan:

□ THYROGEN

You can continue to take the thyroid hormone (Elthyrone[®] or L-Thyroxine[®]) as normal.

You will be given an injection (Thyrogen[®]) twice beforehand. To this end you have to report to the metabolic testing nurse (Orange street, gate 1, level 1). There are few side effects associated with this type of injection (sometimes slight nausea, headache). Providing there are no side effects you can go home after 15 minutes.

1. The first injection is planned for Tuesday
..... at 10 a.m. (no need to fast) (= day 1)
2. The second injection is planned for Wednesday
..... at 10 a.m. (no need to fast) (= day 2)
3. Taking the iodine pill (preceded by a blood test the same morning) and admittance to hospitalisation 42 at the hospital is planned for Thursday
..... (light breakfast at home) (= day 3)
4. Appointment for a scan at the nuclear medicine department: on the day of discharge or 1 week after admittance to hospital:
.....
5. Check-up appointment (consultation 12, Yellow Street, gate 2, level 1) : shortly after the scan:
.....
.....

QUESTIONS

Should you have further questions you can call the radiotherapy/oncology department from Monday to Friday (8 a.m. to 5.30 p.m.) on 016 34 76 00. You can also contact the nursing unit on 016 34 63 30.

LOW IODINE FOOD SUGGESTIONS



Avoid foods with a high iodine content for 7 days in preparation for your treatment.

- Prepared and ready-made foods often contain large amounts of salt. Because the iodine content is unclear we would recommend you don't use these types of foods.
- Many foods contain iodine, but a number of them are acceptable in small quantities. Remember to check portion sizes.
- Be vigilant with food supplements: they can be enriched with iodine and are consequently not acceptable.

- Iodine can also be found in certain cough mixtures. Check with your doctor or pharmacist.
- Isobetadine® mouthwash contains iodine and should be avoided.
- Foods containing additives such as carrageenan, agar agar, algae or alginates can contain a lot of iodine.
- Foods and medication containing red food colouring E127 (erythrosine) must be discussed with your physician.

	To be avoided	Permitted
Salt, spices	Iodine enriched salt, sea salt, diet salt, salt and spice mixtures, stock cubes, Oxo	Non iodised salt, low salt spice mixtures, green herbs, dried herbs
Bread	Bread with cooking salt (in Belgium bakery bread is made with iodised salt, ask your baker for information on other bakery products), rusks, crackers, breakfast cereals, oats.	Low salt bread, home baked bread with non iodised salt, crisp bread, honey/ginger cake.
Potatoes, pasta	Ready made potato croquettes, instant mashed potato.	Boiled, sautéed, deep fried potatoes, home made mashed potato.
Binding agents		Any rice or pasta.

	To be avoided	Permitted
Drinks	Tap water and preparations with tap water (coffee, tea, soup).	Mineral water, fruit juice (max. 2 glasses/day), soft drinks (max. 2 glasses/day), mineral water based drinks.
Milk and milk products	All milk products and preparations based on cow's, goats, sheep's milk, etc., yoghurt, cottage cheese, custard. All types of cheese.	Soy milk and soy yoghurt, soy custard and other preparations based on soy milk.
Fruit (max. 200 g/day)	Peanuts, hazelnuts, crispy nuts, trail mix, cashew nuts, walnuts. Olives	All types of fruit. Pistachio nuts, almonds, fresh coconut, chestnuts, pine nuts, sunflower seeds, cumin seeds, linseed, sesame seed. Dried fruit Tinned fruit
Vegetables (max. 200 g/day)	Seaweed, sauerkraut, mushrooms, asparagus, escarole, endives. Tinned vegetables	All other vegetables
Eggs	Egg yolks, egg preparations	Egg whites

	To be avoided	Permitted
Meat (max. 100 g/day) and meat products (max. 50 g/day)	Prepared meats such as mince, cordon bleu, veal olives, sausages, etc. Smoked meats, meat preparations containing liver (pâté, liverwurst, etc.).	Unprocessed chicken, turkey, duck, rabbit, horsemeat, pork (not every day), beef. Unsalted meat products.
Fish, seafood	All types	
Fats		Butter, margarine, low fat margarine, all types of oil.
Sweet sandwich fillers	Milk chocolate	Jam, honey, fruit syrup, chocolate paste, white chocolate, dark chocolate, peanut butter.
Other	Ice cream Biscuits (often contain too many eggs), unless specifically permitted. Aperitif snacks such as crisps, nuts, etc.	Sorbet Syrup waffles, pastries made with flaky pastry such as apple turnovers, apple squares, etc. Honey/ginger cake, meringue, macaroons.

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