



**University
Hospitals Sussex**
NHS Foundation Trust

Radioactive Iodine treatment for thyroid cancer

Department of Nuclear Medicine

Patient information

Why am I having radioactive iodine treatment?

Radioactive iodine treatment may be recommended if you have had a total thyroidectomy after a diagnosis of thyroid cancer.

Your oncologist will have considered your need for this, weighing up the risks and benefits of having the treatment.

The intent of radioactive iodine treatment is to destroy any tissue left over from your thyroid surgery. A small amount of tissue is left over to preserve your parathyroid glands which manage calcium; radioactive iodine does not significantly affect this.

How will I be given the radioactive iodine treatment?

The radioactive iodine is usually given in the form of a tablet or capsule.

There are three different amounts (activities) of radioactive iodine that can be given and your consultant will tell you which you are having based on your diagnosis, and what was seen when your thyroid was looked at under the microscope. The smallest activity you will be able to have as an outpatient, and the two larger activities will necessitate a 48 hour stay in hospital.

What do I need to do before the treatment?

You will need to follow a low iodine diet one week before treatment and stop it two hours after you have been given the capsule. You will be given more information about this diet on a separate sheet, and can also find more information at this link: <https://www.btf-thyroid.org/low-iodine-diet>

You will need two Thyrogen injections on consecutive days before your treatment. There is more information about this later in the leaflet.

What happens if I have outpatient treatment?

If you have been told you are having **outpatient treatment**, this means you will come into the hospital and have the iodine capsule, but you will be able to go home.

Outpatient treatment usually happens on a Thursday, but there can be exceptions to this.

Outpatient treatment happens at the Nuclear Medicine department. They will contact you directly with the date and time. The Nuclear Medicine department is on the second floor of the Louisa Martindale Building at the Royal Sussex County Hospital.

Please bring the blood form with you that you have been sent. The test will be taken in the department before you have the capsule.

You are likely to be in the department for around an hour.

What happens if I have inpatient treatment?

If you have been told you are having inpatient treatment you will be staying at the hospital. This will depend on the activity you require, or your individual home circumstances and whether being radioactive at home is compatible with this.

This treatment normally happens on a Wednesday, you will be asked to go to the Renal ward. This is in the Sussex Kidney Centre. If you have not heard from the ward by 10am on the day of treatment you should call them to ask when to arrive (call **01273 696955** and dial **Ext. 67552**). Please bring the blood form with you that you have been sent and any medicines that you take routinely.

While in hospital you will stay in a private single room with its own toilet, small fridge, and shower. You will be required to remain in this room for the duration of your stay. Please bring entertainment for yourself, such as a phone/tablet/books or DVDs for a DVD player (there is one in the room).

The nurses will visit you and be able to contact you by phone. You will be able to call the nurses and you will have a call bell if you need anything. You must not leave the room without alerting a member of staff. In an emergency, a staff member will come to escort you out of the room.

You are welcome to bring in some food for your consumption, but please only bring as much as you will eat. This is because uneaten food will likely be contaminated with radioactive iodine and must be stored in waste bags for several months until it can be safely disposed.

Post treatment imaging

You will be asked to return for imaging on the Monday following your treatment, whether you are treated as an inpatient or an outpatient. This is so that you can have a scan to check uptake of the radioactive iodine. This scan will take place in the Nuclear Medicine Department at the Princess Royal Hospital in Haywards Heath.

You may be asked to come back for further scanning later in the week. If this happens, please do not be alarmed. This is so that we can achieve the best possible images which are not obscured by normal physiological uptake in the gut. By waiting a few days, the uptake can clear your gut and we can ensure that images are not obscured.

Restricted period

Radiation is emitted by radioactivity in our environment, such as food and rocks in the ground. You receive a natural background radiation dose from this, which can damage some of your DNA. Almost all the time your body repairs this damage successfully. Very rarely your body is unsuccessful, and after many years this damage can cause cancer.

Once you have taken the radioactive iodine capsule you will emit gamma radiation in all directions. Just as light from a lightbulb is brighter when it is closer to you, there will be more gamma rays close to you. This is why we ask you to physically distance yourself from other people for between a few days to a few weeks. This does not stop you from sitting at least 2 metres from other people or going outside.

The contact restrictions depend on how much radioactive iodine you retain and your personal situation; they may be longer if you have frequent contact with young children or pregnant people. By following the restrictions given to you after your scan, the radiation dose to other people will be less than 6 months of natural background radiation. The risk of cancer from this dose of radiation is very low.

Your body will have filtered most of the radioactive iodine out a few days after taking the capsule, and you will be emitting fewer gamma rays. Radioactive iodine also emits beta particles which deliver your treatment by hitting thyroid tissue in your body. It is important that your radioactive bodily fluids are not transferred to other people, or they will get a larger radiation dose. Simple hygiene precautions like washing your hands with soap and wiping up any spills as they happen will protect others.

What changes should I make at home during the contact restriction period?

These instructions are for the duration of the contact restriction period you are given by the Nuclear Medicine scientists: the contact restriction period differs slightly from person to person but is normally around four to seven days.

Restrictions on close contact:

- You will need to limit close contact (anything closer than 2m) from members of your household.
- You must sleep alone.
- No sexual contact.
- You don't need to limit contact with animals/pets.

To limit radioactive contamination in your home, we will ask you to do the following for 5 days after your treatment:

- Wash dishes in a dishwasher if you can.
- Re-use one set of cutlery/crockery if you can, do not use plastic.
- All patients must sit down on the toilet to urinate. This helps with urine contamination outside of the toilet. Flush the toilet twice after use.
- Wash your bed sheets 5 days after treatment.
- Wash clothes on the highest temperature setting appropriate: don't use eco mode.
- Shower once a day.
- Drink plenty of fluids, especially for the first two days after the treatment.
- Wash hands with soap and water regularly. Please note that hand sanitiser does not work to remove radioactive iodine.

Will I be given thyrogen injections?

If you live in Brighton the thyrogen injections will be given in the chemotherapy department, although this is not a form of chemotherapy.

In order to stimulate any remaining thyroid tissue so it can be treated, we have to fool the body into thinking there is no thyroxine in the blood stream. We would like for you to continue to take your thyroxine as normal through the treatment.

Giving two injections of thyrogen (a synthetic form of TSH) two days before your treatment and blood test stimulates any remaining thyroid tissue, when usually it is suppressed by giving the thyroid hormones T3 or T4.

Are there any risks or side effects of this treatment?

Radioactive iodine treatment is safe and effective and has been used since the 1940s. The increased risk of developing a cancer because of this treatment is low. Your doctor has judged that that the benefits of treatment outweigh any potential risks.

Possible early side effects

- **Radiation thyroiditis** (neck discomfort and swelling). You have a 10 to 20% chance of experiencing this.
- **Dysgeusia** (change in taste and smell). This may persist as a late side effect.
- **Xerostomia** (mouth dryness). You have a 10 to 20% chance of experiencing this, but it is rare after the first treatment.
- **Nausea** (feeling sick). This can be treated with medicine.

Possible late side effects

- **Xerostomia** (mouth dryness).
- **Dysgeusia** (change in taste).
- **Sialadenitis** (infection of salivary glands).
This is only common in people who have multiple treatments.
- Low risk of second primary malignancy.

Please note that most people do not suffer any symptoms at all.

When someone has had thyroid cancer, their brain tells the thyroid gland to make more thyroxine, as it doesn't know that the thyroid gland has been removed.

We will give you a higher dose of thyroxine to switch the TSH (Thyroid Stimulating Hormone) off, which is responsible for trying to make more. With thyroid cancer, if the TSH is not switched off, it can cause a re-growth of thyroid tissue, which we want to avoid.

This is why you will be on a slightly higher dose than a person with an underactive thyroid gland.

We will check your dose regularly and check your bloods show that your TSH is suppressed.

Pregnancy and breast/chest feeding

If you are pregnant you should not have radioactive iodine treatment. A urinary pregnancy test will be performed prior to the treatment.

If you are breast/ chest feeding this must be stopped at least eight weeks before your treatment starts so that you are no longer lactating at the time of treatment. You will not be able to re-start breast/ chest feeding your baby after treatment.

You should not have sexual intercourse in the restriction period given by the hospital.

Following radioactive iodine treatment, you must avoid conceiving a child for the following periods of time and must use at least one form of contraception:

- You must avoid becoming pregnant for a period of four months following treatment.
- You must avoid impregnating another person for a period of four months after treatment. Sperm cells live for four months and there is a risk of these sperm cells having been damaged by the radioactive iodine.

Please contact us if you conceive a child within these time periods so we can advise you further.

Information for transgender and non-binary patients

We are committed to ensuring patients are free from discrimination regardless of their gender or sexual orientation. If your gender was female at birth and you are transgender or non-binary, please inform a member of staff as we legally need to rule out the possibility of pregnancy before we can go ahead with this treatment. This information will not be recorded or shared without your consent.

What is the safest way for me to travel?

If possible, it is advised you avoid public transport after you have had your radioactive iodine treatment.

You can travel in a car with one other adult who is not pregnant. Maximise your distance from them by sitting in the rear passenger seat opposite the driver.

Please let us know if you plan to travel abroad after your treatment, we will need to discuss this and the time frame for travel.

What follow-up can I expect after this treatment?

After your treatment we will not know if the treatment has got rid of all the thyroid tissue: your body takes nine months to do this. At this point you will have a stimulated blood test and USS scan.

You will also have a Dynamic Risk Stratification assessment: this will enable us to put you in the correct risk category for follow up. You can have radioactive iodine treatment more than once.

In some situations patients don't respond to iodine: if this relates to you, we will be able to tell you this three to four weeks after you have had the iodine treatment. We can then discuss other treatment options.

We test regularly for a protein in your blood called Thyroglobulin. This is a very useful follow up tool and can tell us from a blood test if you have any thyroid tissue in your body. On some occasions people don't have this protein, and it would not show as a marker on your blood test. If this applies to you it is not a cause for concern, we can follow you up with a neck ultrasound scan or an iodine scan.

Who can I speak to for further information and advice?

If you have any questions about anything in this leaflet, please contact:

uhsussex.cancernursespecialists@nhs.net

01273 696955, Ext. 67435

Other sources of support for thyroid cancer:

Butterfly Charity

Telephone number: 01273 545649,

email: enquiries@butterfly.org.uk

Macmillan Support

Telephone number: 0808 808 0000

Author: Amy Gough-Smith and Toria Rowse

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in Brighton & Hove or Haywards Heath

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