

Radioactive Iodine Treatment

What you need to know

Why am I having radioactive iodine treatment?

Radioactive iodine treatment maybe 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 to having the treatment.

The radioactive iodine treatment will destroy any tissue left over from your thyroid surgery. A small amount of tissue is left over in order to preserve your parathyroid glands which manage calcium; radioactive iodine does not 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, but can also be given as a liquid if requested.

There are three different doses of 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 dose you will be able to have as an outpatient, and the two larger doses will necessitate a 72 hour stay in hospital.

This short film about radioactive iodine available at this link will give you more information: bit.ly/thyroid_radioiodine.

What do I need to do before the treatment?

You will need to follow a low iodine diet two weeks before treatment and stop it three days after. You will be given more information about this diet on a separate sheet.

You will need to have a COVID-19 swab before and self isolate from having the swab until treatment. This is so you can't contract the virus between your swab and the treatment date. The swab will normally be taken in the hospital a few days before your first thyrogen injection. Anyone in your household will also have to isolate for this time. We are currently looking to using the home testing service in the future.

If your COVID-19 swab is positive, we will defer your treatment to a later date.

You will need two Thyrogen injections in 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.

Both inpatient and outpatient treatment normally happens on a Friday, but there are exceptions for this.

The treatment happens at the Nuclear Medicine department. They will contact you directly with the date and time. The Nuclear Medicine department is in the main building at BSUH.

You will be given a blood form which you will need to bring with you to the hospital. 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, and will be invited back on the following Monday for a scan and to give you a personal radiation isolation time frame.

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 dose you require, or how it may affect your home circumstances having the treatment as an outpatient.

This treatment normally happens on a Friday, you will be asked to go to the Haematology/oncology ward at midday. This is in the Sussex Kidney Centre. Please bring the blood form with you that you have been sent.

You will be scanned on the Monday and be allowed home after that. You will be given your iodine isolation time frame at this point.

While in hospital you will be isolated in a single room with its own toilet, fridge and shower.

Please bring entertainment for yourself, such as a phone/ipad/books or DVDs for a DVD player (there is one in the room).

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

You maybe asked to come back for further scanning after the Monday scan: if this happens please do not be alarmed. This is normally because the visibility is poor due to the amount of iodine you have taken up.

You are welcome to bring in some food for your consumption, but please only bring as much as you will eat. This is because it is a hard and long process for us to dispose of this food if it is left in the room when you are discharged.

Isolation and distancing: what can I do?

Anyone coming into contact with you after the radioiodine treatment will be exposed to a very small amount of radiation. Typically, they will get less radiation than the amount they would normally get in about two months from the radiation that occurs naturally around us. This exposure to radiation for others represents a very low risk of developing cancer in the future.

This exposure decreases with time because the radioactivity decays, and some passes out of the body. Radioactive iodine is passed through bodily fluids, so it is about reducing this risk to pass on to others. To keep this risk as low as possible we will ask you to avoid prolonged and close contact with friends/relatives for a period after your discharge from hospital.

On the Monday after treatment you will be told the length of time you will need to stay away from other people. It may differ if you live with them or if they are children or pregnant women. It is different for each individual but ranges from four to seven days.

Limit the contact of people you live with to four hours a day and at two metres apart. You will need to stay away from children and babies if at all possible.

What changes should I make at home during the radiation isolation period?

- You don't need to limit contact with animals/pets.
- Wash dishes in a dishwasher if you can.
- Use own cutlery/crockery if you can, do not use plastic.
- Please clean toilets after use.
- Sleep alone and wash bed sheets daily.
- Wash clothes on a 60 degree wash: don't use eco mode.

What personal changes do I need to make?

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

- Live alone if you can. If this is not possible please use the guidelines on the previous page about living with people.
- Shower once a day.
- Drink plenty of fluids, especially two days after the treatment.
- Wash hands with soap and water regularly. The iodine can be transmitted onto surfaces.
- If you are male, please sit down on the toilet to urinate: this helps with contamination of urine outside of the toilet.
- Sleep alone if you can.
- No sexual contact.

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 detected, 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.

Before thyrogen was given people had to withdraw from thyroxine for 28 days, which could result in them feeling unwell. This can be an option if you would rather not have the injections. Please do speak to your oncologist or Nurse Specialist about this.

Are there any risks or side effects of this treatment?

Radioiodine treatment is safe and effective and has been used since the 1940s. However, there may be a very small increase in the risk of developing a cancer as a result of this treatment. 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.
- **Sialadenitis** (infection of salivary glands).
- **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.
- Very low risk of second primary malignancy.

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

This list of side effects is from the British Thyroid Association:

www.british-thyroid-association.org.

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.

Can I continue breastfeeding or try for a baby?

If you are lactating mother, you will need to stop breast feeding six to eight weeks before your treatment starts. You will not be able to breastfeed your baby after treatment.

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

It is advised not to attempt to conceive for at least four months if you are male and six months if you are female. Use at least one form of contraception. Sperm cells live for four months and there is a risk of the sperm cells still containing iodine.

What is the safest way for me to travel?

It is strongly advised you avoid public transport after you have had your radioactive iodine treatment.

You can travel in a car with one person, but keep a distance, for example sitting in the back passenger seat from the driver. Do not travel with pregnant women or children in the car.

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: the iodine 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 [bsuh.thyroid.support@nhs.net/](mailto:bsuh.thyroid.support@nhs.net) **01273 696955, extension 7435.**

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**

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Disclaimer

The information in this leaflet is for guidance purposes only and is in no way intended to replace professional clinical advice by a qualified practitioner.

Ref number: 1098

Publication Date: January 2021 Review Date: January 2024

