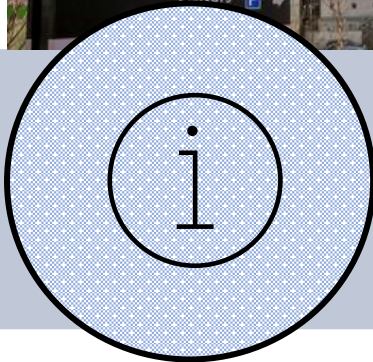


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*Patient Information Service
Bristol Haematology and Oncology Centre*

Radioactive Iodine Treatment (Radioiodine)



Patient Information

This leaflet aims to help you and your family understand more about your radioactive iodine treatment.

Each person's treatment will vary, so the information given in this leaflet is a general guide. You will be looked after by a team including a Clinical Oncologist, Clinical Nurse Specialist, and Molecular Radiotherapy Radiographers (referred to in this leaflet as 'radiographers'). This team will guide you through your treatment and explain everything in more detail. If you hear any words or phrases that you do not understand, please ask a member of the team to explain what they mean. It does not matter how many times you ask. If you have any additional needs (physical, spiritual, cultural, emotional, medical etc), please inform a member of the team so that we can accommodate them. We are here to support you.

If English is not your first language

If English is not your first language, please inform the molecular radiotherapy department so that an interpreter can be arranged for your clinic appointments. Due to data protection, family members cannot be used to translate sensitive or medical information.

 **0117 3422694**  **molecularradiotherapyunit@uhbw.nhs.uk**

Introduction to Radioactive Iodine

You have received this leaflet because you have been referred for radioactive iodine treatment for thyroid cancer.

Radioactive Iodine Treatment may also be referred to as:

- Radioiodine Treatment
- Radioactive Iodine Ablation

Radioiodine treatment reduces the risk of thyroid cancer returning and improves survival for some patients. Radioiodine can also treat cancer that has returned and may still achieve a cure. The long-term survival following treatment for papillary and follicular thyroid cancer is usually excellent.

The thyroid gland is situated next to the nerves of the voice box, and so some thyroid tissue is deliberately left behind at surgery (thyroidectomy) to avoid damaging these nerves. The aim of radioiodine treatment is to destroy this remaining thyroid tissue.

Radioiodine treatment involves swallowing radioactive iodine, usually in the form of a small capsule. The thyroid gland naturally takes up iodine from food that we eat. Similarly, the radioactive iodine that you swallow will be absorbed by the thyroid, but the radioactivity destroys the thyroid tissue. The treatment is painless.

Is Radioactive Iodine Safe?

Radioiodine has been used to treat thyroid cancer for over fifty years and is extremely safe. There has been extensive research into radioiodine treatment which shows there is very little increased risk of developing other cancers. The radiation protection precautions that are described later in this leaflet are in place to protect other people who still have a thyroid gland - particularly pregnant women and young children. It is important to avoid exposing other people to unnecessary radioactivity.

What We Need to Know

If any of the following apply to you, please inform the molecular radiotherapy team straight away:

- You take **amiodarone**
- You have had a CT scan in the two months prior to your treatment date and were given **contrast media** (either through an injection or a drink)
- You are **pregnant** or you may be pregnant
- You are currently or have recently been breastfeeding

Pregnancy, Breastfeeding & Fertility

It is very important that you do not have radioiodine treatment if you are pregnant, or if you think that you might be pregnant.

It is also important that you do not become pregnant OR cause a pregnancy for six months after radioiodine treatment.

These restrictions are in place because the radiation would be harmful to an unborn baby. Your consultant and the radiographers will have discussed this with you, but please contact them immediately if anything changes after these discussions (pregnancy status, contraception method etc).

If you are biologically female and aged between 10 and 55 years, you will be asked to sign a form before your treatment to confirm that you are **not** pregnant.

Regardless of contraceptive precautions taken, you will also be asked to take a pregnancy test immediately prior to treatment.

If you are breastfeeding, you must stop **eight weeks** before you have radioiodine treatment, and you must not start again afterwards.

Additional information regarding contraception requirements will be provided alongside this information, if relevant.

In the long term, it is unlikely that fertility will be affected. The risk of infertility becomes more significant if repeated treatments are required.

In these circumstances, fertility preservation may be available and your consultant will discuss this with you.

Advice and support in matters of pregnancy and fertility

We understand these can be sensitive matters for some patients. If you have questions or would like further support, please contact your treatment team.

Preparation for Radioactive Iodine Treatment

- Medication

Continue to take your Thyroxine medication unless you are instructed otherwise. Avoid multivitamins that contain iodine for four weeks prior to treatment.

- Thyrogen Injections

You will need to attend BHOC for Thyrogen injections on the two days before your treatment. Recombinant human thyroid-stimulating hormone (TSH Thyrogen) is given as an intramuscular injection, usually into the buttock. It raises the levels of TSH in your body so that treatment is as effective as possible, and it removes the need to stop your medication.

- Low Iodine Diet

Evidence shows that an iodine rich diet may impact the effectiveness of radioiodine treatment. Therefore, **you will need to follow a low iodine diet for one week prior to treatment**. A leaflet will be sent to you along with your booking information.

The Day of Treatment

On the morning of treatment, eat breakfast and then **do not eat anything for 2 hours before your appointment**. You can drink water as normal throughout the day.

Report to reception on Level 4 of BHOC (D401) for your appointment time. A radiographer will meet you there and take you to the treatment room. The radiographer will go through all the treatment information, confirm your consent, and answer any questions that you may have.

You will be given some radiation protection precautions; these are in place to contain the radioactivity safely, so please follow the guidelines carefully.

All patients who have the potential to become pregnant will be asked to take a pregnancy test before the capsule is given.

The radiographer will bring the radioiodine capsule to the treatment room and instruct you how to take it. This is a very straight forward process; the capsule is very small and is easily swallowed with water.

After the radioiodine capsule has been taken, some patients will go straight home while others will stay in the hospital. This is dependent on the dose you are receiving, and on your home circumstances.

All patients are advised asked to drink plenty of fluids in the few days following treatment so that the radiation is flushed through your system efficiently.

Your urine will be very radioactive, so great care must be taken when using the toilet:

- **Sit down to use the toilet (men and women)**
- **Wipe up any drips/splashes using tissue and put the tissue in the toilet**
- **Close the lid before flushing the toilet**
- **Flush the toilet twice**
- **Wash your hands thoroughly**

Your sweat will also be radioactive, so you are advised to shower daily.

If you have been told that you will need to stay in hospital, please read the next section entitled 'Your Stay in Hospital' carefully. If you are going home straight away, please skip to 'Going Home from Hospital' on page 13.

Your Stay in Hospital

Radioactive iodine treatment sometimes requires hospital admission for a period of 1-3 days. This is because your body will be excreting radioactivity (via bodily fluids, primarily urine) and this needs to be safely contained in a controlled environment.

You will have your own room on the hospital ward, and this is where you will receive your treatment.

Once you have taken the capsule:

- **Do not eat or drink (except water) for one hour**
- **Do not empty your bladder for one hour**

One of the radiographers will return one hour after you have taken the capsule and will ask you to lie on the bed so that they can measure your radioactivity levels using a monitor on the ceiling. After this measurement has been taken, you may empty your bladder, and you may eat and drink as normal. You do not need to continue the low iodine diet.

The radiographers will attend approximately every two hours for the rest of the day to take subsequent measurements. You will be asked to empty your bladder *before* each of these measurements and then you will need to lie on the bed for approximately 5 minutes. Because the measurement is taken using a monitor on the ceiling above the bed, it is important that you do not change the height of the bed during your stay.

During the evening and night-time, nurses on the ward will check on you frequently.

If you need anything during your stay, please press the call bell and a nurse will attend.

Meals will be provided. You will have your own set of cutlery to use during your stay; please keep this and wash it between meals.

No one will enter your room at any time, but the radiographers and nurses can talk to you across the threshold, from a safe distance. Visitors are not permitted.

What do you need to bring with you?

Each room has a fridge, tea and coffee facilities, and a television. There is an ensuite, and towels are provided. The following is a list of things to bring with you:

- Medication (T3 or T4, and any other medication that you take regularly)
- Slippers
- A clean set of clothes
- Toothbrush and toothpaste
- Shower gel/soap and shampoo
- Drinks and snacks (*optional*)
- Books, magazines, tablet, phone (*optional*)

When will you be discharged?

You will be discharged once your radioactivity levels are low enough (usually 1-3 days after treatment, but occasionally longer). At this point, additional radiation protection precautions will be given that you must follow until you return for your scan on the following Monday or Tuesday.

Before leaving, you will be asked to change into clean clothes. A dissolvable laundry bag will be provided in which you can put the clothes that you have worn. This bag can go straight into the washing machine when you get home.

Going Home from Hospital

You will be sent home with radiation protection precautions to follow until you return for your scan. The radiographers will go over these in detail with you in person.

A minimum requirement will be that you keep at least 1 metre away from everybody else until you return for your scan.

If you are being collected from hospital, there must only be one person in the vehicle with you, and you must be able to sit in the back of the car, on the opposite side to the driver.

You will be given a yellow wristband to wear, indicating that you have received a radioactive treatment. This should not be removed for any reason until you return for your scan. In addition, you will receive a yellow radiation alert card that you should keep on your person for six months following treatment.

If you require any medical attention during this time, you must present the card to the attending medical team.

Possible Side Effects

Most patients do not experience any side effects. However, the following side effects can occur during, or immediately after, treatment:

- Dry mouth
- Taste changes
- The feeling of tightness or swelling in the throat
- Flushing
- Nausea

In the long term, side effects are uncommon. However, they are more likely after repeated treatments:

- Persistent dry mouth
- Persistent taste disturbance
- Inflammation of salivary glands
- Lachrymal gland dysfunction (dry or watery eyes)
- Early onset of menopause
- Increased risk of miscarriage for up to one year following treatment
- Infertility may occur with repeated treatments
- Radiation fibrosis of the lung may occur in patients who have diffuse pulmonary deposits, and who have repeated treatments.

What Happens Next?

You will return to BHOC several days after your treatment for a scan. At this appointment, radiographers will measure your remaining radioactivity levels. Based on this measurement, the radiation precautions you have been given may be terminated or amended. You will then have a whole-body SPECT scan to assess uptake of the iodine. This takes approximately 1 hour.

Approximately 4 weeks after your treatment, you will have a follow-up clinic appointment with your consultant (either in person or on the telephone) to discuss your scan results and assess how you tolerated treatment.

The radioiodine treatment takes up to 9 months to have full effect. During this time, you may have blood test appointments to ensure you remain on the correct dose of Levothyroxine. At the 9-month mark, you will have a Dynamic Risk Assessment, looking at your response to treatment. This involves:

- An ultrasound scan
- A Thyroglobulin blood test

Based on the results, your TSH target will be assessed and possibly amended.

Afterwards, you will have follow-up appointments either once or twice a year.

Will I Need Further Treatment?

Some patients only need one treatment, while others may need repeat treatments. If needed, repeat treatments are usually given six months apart.


Clinical Trials

Your consultant may talk to you about clinical trials that are open which you may be suitable for. Your decision to participate or not will be respected, and it will not affect the quality of your treatment and care.

Useful Contacts

Melanie Speakman

Macmillan Thyroid Cancer Clinical Nurse Specialist

 01173427495 | 07500835461


 melanie.speakman@uhbw.nhs.uk

The Butterfly Thyroid Cancer Trust

 01207 545469

 www.butterfly.org.uk

Macmillan Cancer Support

 0808 808 0000

 www.macmillan.org.uk

Summary of Treatment Schedules

Inpatient Schedule:

- Start low iodine diet the Wednesday before your treatment.
- Monday: Thyrogen Injection 1
- Tuesday: Thyrogen Injection 2
- Wednesday: Admission and treatment
- Thursday or Friday: Discharge with radiation precautions (longer inpatient stays are occasionally necessary due to individual circumstances).
- Monday or Tuesday: Remeasurement of radiation levels and whole-body SPECT scan.
- 4 weeks post-treatment: Follow-up clinic appointment
- 9 months post-treatment: Dynamic Risk Assessment

Outpatient Schedule:

- Start low iodine diet the Wednesday before your treatment
- Monday: Thyrogen Injection 1
- Tuesday: Thyrogen Injection 2
- Wednesday: Admission, treatment, and discharge with radiation precautions
- Friday: Remeasurement of radiation levels & whole-body SPECT scan.
- 4 weeks post-treatment: Follow-up clinic appointment
- 9 months post-treatment: Dynamic Risk Assessment

As well as providing clinical care, our Trust has an important role in research. This allows us to discover new and improved ways of treating patients. While under our care, you may be invited to take part in research. To find out more, please visit www.uhbw.nhs.uk

Help prevent the spread of infection in hospital. Make sure your hands are clean by washing and drying them thoroughly and by using the hand gel provided. If you have been unwell in the last 48 hours, please consider whether your visit is essential.

Smoking is the primary cause of preventable illness and premature death. For support in stopping smoking, contact **NHS Smokefree** on **0300 123 1044**

Drinkline is the national alcohol helpline. If you are worried about your own or someone else's alcohol consumption, you can use this free service in complete confidence. Call **Drinkline** on **0300 123 1110**

For access to all patient information leaflets, please visit <http://foi.avon.nhs.uk/>

Bristol Switchboard: 0117 923 0000

Weston Switchboard: 01934 636 363

www.uhbw.nhs.uk

For an interpreter or signer please call the telephone number on your appointment letter.

For this leaflet in large print or PDF format, please email

patientleaflets@uhbw.nhs.uk