



University Hospitals Bristol
NHS Foundation Trust

Patient information service
Bristol Haematology and Oncology Centre

Radioactive iodine ablation and therapy



Respecting everyone
Embracing change
Recognising success
Working together
Our hospitals.

**Above
& Beyond**
Fundraising for Bristol city centre hospitals

Contents	Page
If English is not your first language	4
Introduction to radioactive iodine	5
Female patients: pregnancy, breastfeeding and fertility	6
Male patients: pregnancy and fertility	6
CT scanning prior to treatment	7
Preparation for the radioactive iodine treatment	7
Following a low iodine diet	8
Thyrogen injections	9
Eating on the day of admission	9
The radioactive iodine treatment	9
Possible side effects during or immediately following treatment	10
Possible long term side effects	10
Staying in hospital	11
Going home from hospital and radiation protection precautions	13
Returning to work	14
Follow-up appointments	14

Contents	Page
Will I need radioactive iodine treatment again?	15
Clinical trials	15
Useful contacts	16
Treatment schedules	18

If English is not your first language

If English is not your first language, please contact the molecular radiotherapy unit to discuss whether there is a need to have an interpreter present. If you do not do this and staff consider that an interpreter is necessary, it could delay your treatment.

Telephone: 0117 342 2694

You have been referred to receive treatment with radioactive iodine.

You will be receiving:

1.1GBq

3.7GBq

Other

GBq = Gigabecquerel. This is a unit of measurement for radioactive isotopes.

Introduction to radioactive iodine

You may be reading this leaflet because you have been referred for radioactive iodine as part of your treatment for thyroid cancer.

Radioactive iodine 'ablation' is a treatment with radioactive iodine. It has been used for over 50 years. It comes in the form of a capsule (similar size to antibiotics), which is taken with water.

As the thyroid gland naturally takes up the iodine from the food we eat, once digested, the radioactive iodine is absorbed by the thyroid and destroys any remnants of thyroid tissue that may be left after surgery.

In order to receive radioactive iodine treatment, you will need to be admitted into hospital, where you will stay until the radioactivity in your body is at a level low enough for you to be discharged home.

Upon discharge, you will be given radiation protection precautions to follow to protect your family, friends and the public from receiving radiation they do not need.

Female patients: pregnancy, breastfeeding and fertility

It is very important that you do not have radioactive iodine treatment if you are pregnant or think there is a chance you may be. Your doctor will have discussed this with you, and the radiographers will also ask you about it before treatment is given.

We only treat women within 10 days of the start of their last menstrual period, or if there is absolutely no possibility of pregnancy. Please discuss this with the radiographers prior to your treatment visit.

If you are aged between 10 and 55 years you will be asked to sign a form to confirm that you are **not** pregnant.

If you are unsure, please let your treatment team know **BEFORE** you have any treatment.

It is important **not** to become pregnant for at least six months after radioactive iodine treatment.

In the long term, your fertility is unlikely to be affected, but there may be a small risk that it may be affected if repeated doses of radioactive iodine are needed. It may bring on an earlier menopause in women approaching this age.

If you are breastfeeding, you should stop eight weeks before you have the radioactive iodine treatment, and you **MUST NOT** start again afterwards.

Male patients: pregnancy and fertility

Male patients are advised **not** to cause a pregnancy for six months after radioactive iodine treatment, and until they are sure they will not need any more radioactive iodine treatment.

In the long term, your fertility should not be affected, but there may be a small risk that it may be affected if repeated

radioactive iodine therapy is needed.

If repeated doses are necessary, please discuss this with your consultant, as sperm storage may be available.

CT scanning prior to treatment

Please inform your consultant or radiographer if you have had any scans that have required you to have any drinks or injections (contrast media) within the two months prior to the date of treatment.

Preparation for the radioactive iodine treatment

If you are taking **amiodarone**, you **MUST** discuss this with your consultant.

Following surgery to remove your thyroid gland, you will have been asked to take daily thyroid medication. In preparation for treatment, most patients will be asked to have Thyrogen injections on the two days before treatment. Occasionally, patients will be asked to stop their thyroid medication instead – usually when the thyroid gland has only been partially removed.

You should avoid multivitamins containing iodine for four to six weeks prior to treatment.

Please note: if you are taking any other medication, you should carry on doing so and bring a supply with you to take while you are in hospital.

All patients must follow a low iodine diet

Some studies have shown that reducing iodine intake may improve the effectiveness of treatment. Therefore, for two weeks before coming into hospital, and for 48 hours after receiving the radioiodine, we recommend you follow a low iodine diet. You will be given low iodine diet information to help guide you.

Avoid food from restaurants, fast-food chains and takeaways, and imported processed foods. In the USA and in many European countries, iodine is added to table salt and used in baking.

Some cough mixtures and health foods (such as seaweed, kelp, cod liver oil, vitamins and mineral supplements) contain iodine. If the label lists iodine, do not take the supplements while on this diet.

Patients staying on the ward for treatment will be offered a low iodine option at mealtimes. If what you are offered doesn't appeal to you, there is an alternative range of low iodine options to choose from – please just ask.

Please do not feel anxious about this diet. It is not necessary to limit yourself other than what has been listed. Radioactive iodine was used successfully in the UK for many years before this diet was introduced.

Thyrogen injections

In most cases, thyrogen injections will be prescribed. Having thyrogen injections immediately before a treatment dose of radioactive iodine means you do not have to stop taking your thyroid medication, and you will continue to take it throughout the treatment.

The thyrogen medication is given by intramuscular injection (usually into the buttock). Most patients do not report any side effects following these injections, but occasionally some mild sickness (nausea) or slight diarrhoea may be experienced.

In **ALL** cases, you will be asked to follow a low-iodine diet for two weeks prior to coming into hospital.

Eating on the day of admission

BEFORE taking the radioactive iodine capsule, you **MUST NOT** eat or drink anything apart from water for two hours.

AFTER treatment has been given, you should not eat or drink anything apart from water for one hour.

The radioactive iodine treatment

On admission to hospital, you will be seen by the nurse who will be looking after you. You may be seen by a doctor, who will pre-assess you for treatment, but in some cases this may have been done at your clinic appointment.

Radiographers will come up to your room with the radioactive iodine capsule, and will make sure that you have everything you need for the duration of your stay. They will give you some general housekeeping information and confirm your consent to treatment and, if necessary, your pregnancy status. The capsule

will then be given to you to swallow with water, after which you **MUST** stay in your room until you are discharged.

Radiographers will measure the radioactivity levels each day. This is done using monitors mounted on the ceiling.

Possible side effects from radioactive iodine treatment

During or immediately following treatment

Most patients do not have side effects from radioactive iodine treatment.

Some patients may experience a feeling of tightness or swelling in the throat, or feel flushed. This usually lasts for no more than 24 hours and can be managed with anti-inflammatory medication.

Nausea may very occasionally be experienced. This can be managed effectively with anti-sickness medication.

Sometimes, having radioactive iodine can result in a temporary taste disturbance. This can last for a few weeks. Drinking plenty of fluids after the treatment helps to reduce this problem.

Possible long-term side effects

Most people do not have any long-term side effects from radioiodine treatment, but these are more likely with multiple treatments.

Some people may experience:

- a persistent dry mouth and taste disturbance
- inflammation of the salivary glands and lachrymal gland dysfunction (dry eyes)

- early onset of the menopause
- increased risk of miscarriage up to one year following treatment
- infertility may occur with repeated doses of radioactive iodine
- radiation fibrosis of the lung may occur in patients who have diffuse pulmonary deposits, and who have repeated doses of radioactive iodine
- very small risk developing secondary cancers or leukaemia.

Staying in hospital

You will stay in isolation in a single room with your own bathroom, which has a shower, washbasin and toilet.

Visitors are not allowed during your stay. This is to prevent them from receiving exposure to radiation unnecessarily.

There is a waist-high lead screen just outside the doorway to your room to remind people not to enter, and to offer some protection to ward staff when they speak to you from the doorway.

Radiographers and nurses will check on you frequently. However, they will not enter your room once you have received your radioiodine, so nursing care will be limited during your stay.

The catering staff will bring your meals and drinks to you. They will place them on a tray, which is on a trolley at the doorway to your room. When they do this, you should try to stay on the opposite side of the room and not get close to them. You should avoid leaning over the lead screen to take the tray from them.

Any uneaten food or fruit skins or cores should be left on your plate and placed on the trolley immediately outside your door.

You will be asked to wash your cutlery in your room; washing up liquid will be provided.

There will be a fridge in your room if you wish to bring in any low iodine drinks or snacks. We ask that you take home any uneaten food or drink when you leave, and don't put any food into the bin in the room.

You will also have access to a water boiler, so you can make your own teas and coffees. Tea bags, coffee and soya milk will be provided. Please feel free to bring in any herbal tea bags etc. also bring in a china mug.

We advise you to drink plenty of water during your stay in hospital, as radioiodine primarily leaves your body in your urine. As you should be drinking more than usual, you may also be using the toilet more frequently. We ask that male patients sit to use the toilet to avoid contamination of the surrounding area.

You must always flush the toilet twice and wash your hands afterwards.

Your sweat will also be slightly radioactive, so please shower frequently.

You can bring laptops and books to entertain yourself during your stay. Wi-Fi will be available in your room. You may also bring your mobile telephone. Radiographers can also provide hair dryers and tablets if required.

During your ward stay we ask that you don't leave your feet bare, so please wear something on your feet at all times – either socks, slippers, or shoes.

You can take home your clothes and any items that you bring in to hospital with you. You may like to bring in your own hand

and bath towels to use during your stay. These will need to be washed in the usual way when you get home.

The fire alarm is usually tested every Thursday morning. If it sounds at any other time, the nurses on the ward will tell you what to do.

Going home from hospital

Radiation protection precautions on discharge from hospital

When you are ready to go home, we ask that family members **DO NOT** enter your room as you leave, as the room will be contaminated with radioactivity.

The radiographers will explain to you any restrictions you must follow when you go home, and they will give you a yellow radiation protection precautions card. The aim is to protect other people – especially pregnant women and children – from exposure to radiation.

The radioactivity in your neck will be measured prior to you being discharged from the hospital.

The restrictions you are given will be different from other people, as the rate at which the radioiodine is excreted from the body may vary between patients.

Most patients will have continued taking thyroid medication during treatment, but if you have stopped your thyroid medication, you should restart it the day after discharge from hospital.

Returning to work following treatment

How quickly you are able to return to work will depend on your job and how closely you work with people, especially women who are or who may be pregnant, and small children.

If you withdrew from your thyroid medication, it may take a few days for you to return to your usual pre-treatment self.

Two months following treatment

You will be given an appointment to attend the hospital as an outpatient to see your doctor and have a blood test. The doctor will discuss with you the plan for further monitoring. This is likely to be an ultrasound scan of your neck nine to 12 months after treatment, with a 'stimulated' blood test four days later in the Bristol Haematology and Oncology Centre (BHOC). The stimulated blood test is done by having two further Thyrogen injections, as outlined below:

- **day one** – neck ultrasound followed by a thyrogen injection
- **day two** – a second Thyrogen injection
- **day five** – stimulated blood test.

The doctor may decide to undertake a 'tracer dose and scan' as an alternative option to the above. In this case, radiographers will provide further information for you.

Will I need radioactive iodine treatment again?

Some people may have one treatment with radioactive iodine, and others may go on to have more.

If needed, repeat treatments are usually given six months apart.

Clinical trials

Your consultant may tell you about any 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.

If you need further information

If you require any further information or have any questions about your treatment, please contact the molecular radiotherapy unit at the BHOC on **0117 342 2694**.

If no-one is available, please leave a message on the answer machine and we will return your call. Please ensure you leave your full name and contact telephone number. You can also contact us by email at: **BHOCmolecularRT@nhs.net**.

Useful contacts

The BHOC information and support centre offers information and support. It is situated on the ground floor and is open Monday to Friday from 9.00am to 5.00pm.

They can also give you information on the organisations below, and assist you in accessing the low-iodine cookbook if you don't have a computer at home.

Thyroid Cancer Support West

Website: www.thyroidwest.co.uk

E-mail: thyroid.west@gmail.com

Butterfly Thyroid Cancer Trust

PO Box 205,
Rowlands Gill,
Tyne & Wear
NE39 2WX

Telephone: **01207 545469**

Website: www.butterfly.org.uk

British Thyroid Foundation

Suite 12, One Sceptre House,
Hornbeam Square North,
Hornbeam Park,
Harrogate, HG2 8BP

Telephone: **01423 810093**

Website: www.btf-thyroid.org

Macmillan Cancer Support

89 Albert Embankment
London
SE1 7UQ

Freephone: **0808 808 0000**

Website: www.macmillan.org.uk

Schedules for treatment

You will be offered one of three schedules for treatment depending on your diagnosis and clinical need.

The treatment schedules are:

1. 1.1GBq of radioactive iodine, no changes to your thyroid medication, with thyrogen injections. Usually patients go home the same day, very occasionally staying overnight.
2. 3.7GBq of radioactive iodine, no changes to your thyroid medication, with thyrogen injections. Usually patients stay in hospital for one night, but occasionally two nights.
3. Other dose of radioactive iodine, no changes to your thyroid medication, with thyrogen injections. With higher doses, the hospital stay can be two or three nights.

GBq = Gigabecquerel. This is a unit of measurement for radioactive isotopes.

Treatment schedule

- continue to take your thyroid medication throughout treatment
- follow the low iodine diet for two weeks before treatment
- in the morning two days before treatment (usually Monday morning) you need to visit your GP for the first Thyrogen injection
- in the morning one day before treatment (usually Tuesday morning) you need to visit your GP for the second thyrogen injection
- on the day of treatment, please report to ward D603 on level 6 of the BHOC to be admitted as an inpatient.

You will be given radiation protection advice to follow to limit any exposure to your friends and family. This will be written on a small yellow card, which you will be asked to carry with you until you return to hospital for your scan.

A follow-up appointment will be booked before you leave, so that you know when you are returning to see us next.

A radioactivity measurement and whole body scan will be carried out a few days after treatment has been given. The scan detects the absorption of the radioiodine into your thyroid tissue. We also measure the radioactivity remaining in your neck. This is done in the molecular radiotherapy unit by radiographers before the scan is done. As a result of this, further radiation protection advice may be given.

Notes

Please note that if for any reason you would value a second opinion concerning your diagnosis or treatment, you are entirely within your rights to request this.

The first step would usually be to discuss this with the doctor or other lead clinician who is responsible for your care.

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

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.uhbristol.nhs.uk/research-innovation

For access to other patient leaflets and information please go to the following address:

www.uhbristol.nhs.uk/patients-and-visitors/information-for-patients/

Hospital switchboard: 0117 923 0000

Minicom: 0117 934 9869

www.uhbristol.nhs.uk



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

For this leaflet in large print or PDF format, please email patientleaflets@uhbristol.nhs.uk.