

Radioactive Iodine Treatment (Radioiodine)

Information for patients



Leeds Cancer
Centre

This leaflet aims to help you and your family understand more about your radioactive iodine treatment (also called radioiodine ablation).

It will be given to you in addition to the information you will receive from your Clinical Oncologist (who is a specialist doctor in cancer treatment). His/her team will be caring for you during your treatment. This team may include Nuclear Medicine Therapy Team, nurses, social workers and dietitians.

Each person's treatment will vary, so the information given is a general guide. The healthcare team looking after you will explain your treatment and the side-effects in detail. If you hear any words or phrases that you do not understand, please ask your doctor or a member of your healthcare team what it means. It does not matter how many times you ask.

If you have any special needs (physical, religious, cultural, emotional or medical), please inform a member of staff so every effort can be made to meet your individual needs.

What is radioiodine?

This form of treatment consists of swallowing radioactive iodine usually in the form of a capsule. The iodine is taken up by the thyroid gland. The small dose of radiation is then concentrated in the thyroid cells and destroys them.

Why am I having radioiodine treatment

Your clinical oncologist will have discussed the reasons why you have been advised to have radioiodine treatment. This will also have included what would happen if you chose not to have this treatment. Radioiodine 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 aim of treatment is to destroy any thyroid cells that may have escaped surgical removal; there is usually some normal thyroid gland remaining after the 'thyroidectomy'. This is because the thyroid gland is next to the nerves to the voice box so some thyroid tissue is left behind to avoid damaging these nerves at surgery.

Is radioiodine safe?

Radioiodine has been used to treat thyroid cancer for many years and is extremely safe. There has been extensive research into radioiodine treatment. While no one would say that any treatment is 100% safe, there is very little increased risk of developing other cancers. If you are unsure or have any questions please ask your specialist consultant or a member of the Nuclear Medicine Therapy Team.

The precautions that are described later in this leaflet are intended to protect other people who still have a thyroid gland and particularly pregnant women and young children. It is important to avoid exposing other people to unnecessary radioactivity.

Do I have to come in to hospital for radioiodine treatment?

Yes, you will need to stay in hospital for 3-5 days. Radiation similar to x-rays will be given off from your body during this time. The levels of radioactivity in your body will reduce quickly over a period of days as most of the material is removed from your body in your urine. We care for you in a special room to reduce other people's exposure to radiation. Radiation regulations state that members of the public should not receive radiation doses greater than one millisevert (1mSv) in any year as a result of medical exposure to others. To put these risks into context a person living in Leeds is exposed to two milliseverts (2mSv) of background radiation a year.

Are there any side effects from radioiodine treatment?

Most patients do not have side effects from radioiodine treatment. Radioiodine has very little effect on other parts of your body since other cells do not absorb iodine as well as thyroid cells.

- Some patients may experience a feeling of tightness in the throat, neck swelling and/or feel flushed which usually lasts for no more than twenty four hours. If it happens, it usually occurs on the second or third day of your stay. If this causes discomfort please inform the nursing staff and a painkiller tablet can be given to relieve this problem.
- Rarely patients experience nausea and an anti-sickness tablet is routinely offered to prevent this happening.

- Sometimes patients develop swollen salivary glands (similar to patients with mumps), a dry mouth, taste changes and lose their sense of taste slightly for a while.
- Very occasionally patients can develop dry eyes and tear duct narrowing.

Sometimes side-effects can occur months later.

- The swollen salivary glands and dry mouth can happen a few days or months after the treatment and usually returns to normal. Drinking plenty of water (up to twice as much as usual) for three days after the radioiodine helps to wash out your salivary glands and reduces this problem.
- It is very important that you do not get constipated both in the weeks leading up to your radioiodine and in the first few days after radioiodine. We recommend eating fruit and vegetables and asking your local chemist for laxatives if constipation is a problem.



Female patients

What if I'm trying to get pregnant, I'm pregnant or I'm breast feeding?

It is very important that you do not have radioiodine treatment if you are pregnant or think that there is a good chance that you may be.

You should not get pregnant for six months after your treatment. It is also important not to become pregnant for six months after your follow up radioiodine scan. This scan is usually 9-12 months after treatment if needed.

Please let your medical staff know if you are unsure before you have any treatment.

The reason for this follow up scan is to see if you need to be admitted for more radioiodine. We strongly advise you not to get pregnant until all the radioiodine treatment and scans are finished and you have had the go ahead from your specialist consultant. Meanwhile you should use a reliable contraceptive. If you are breast feeding, you should stop this at least eight weeks before you have the radioiodine treatment.

Will it affect my ability to have children or alter my periods?

Long-term fertility will not be affected. Your periods may stop or be erratic for some months after surgery, radioiodine and alteration in thyroid hormone tablets.

Some patients describe an early menopause but this can occur with or without radioiodine.

Male patients

Will it affect my ability to have children?

Male patients are advised not to try for children (get their partners pregnant) for four months after radioiodine treatment. You should use a reliable contraceptive for four months. Long term your fertility should not be affected but there may be a very small risk to fertility if repeated radioactive iodine treatments are needed. Specialist advice and help is available if you would like to discuss these issues further. Sperm banking can be arranged before the radioiodine treatment.

What if I have children at home?

Children are more sensitive to radiation and therefore the laws regarding radiation are stricter. If you have children at home, they will not be able to visit while you are in hospital. When you go home there may be restrictions on how much physical contact you can have with them. For this reason it is recommended that you make arrangements for your children to stay in a different place from you for at least the first week after you are discharged from hospital.

If you have any queries surrounding this please do not hesitate to discuss these with your medical team or the Nuclear Medicine Therapy Team. We do not want you to be away from your children for any longer than is necessary. Arrangements can be made for you to be monitored during your first week out of hospital to see if you can have contact sooner.

Before having radioiodine treatment

In the past we have been required to ask patients to stop taking their thyroid hormone tablets for two weeks before treatment. You may have read this in booklets or on the internet. This can cause distressing side effects. We are now able to offer an alternative before you come for your radioiodine treatment. You will have two Thyroid Hormone (TSH) injections. These will be given to you two days before your treatment. This will help the radioiodine to work by encouraging it to enter the thyroid cells.

Should I keep taking my other medications/tablets?

If you are taking any calcium or vitamin D tablets you should continue them. If you are taking any other vitamin or mineral

supplement please stop taking them two to three weeks before your treatment to help to reduce your Iodine level. If you are taking any tablets you should mention these to the Nuclear Medicine Therapy Team, who will give you advice on whether they should be continued during radioiodine treatment.

Before my radioiodine treatment what should I eat?

A diet that is rich in iodine may **reduce** the effectiveness of the treatment. Therefore two weeks before having the radioactive iodine and while you are in hospital, we recommend a low iodine diet. Diet information is included on page 16 of this booklet.

How will I know when to come into hospital?

A member of the Nuclear Medicine Therapy Team will contact you, usually by telephone to discuss the date of your admission for treatment. You will be invited to have a look at the room you will be staying in on the ward and to ask any questions about the treatment. This visit usually occurs after your first appointment to see your oncologist or about two weeks before your treatment.

If you have any queries about your admission to hospital for radioiodine, please contact:

The Nuclear Medicine Therapy Team on **0113 206 8324**.
(Monday - Friday - an answerphone is available for messages).

Will I need radioiodine treatment again?

The treatment may need to be repeated until all the remaining thyroid tissue has been destroyed. Most people require one radioiodine dose but sometimes more than one admission for radioiodine therapy is needed. Thyroid cancer cells in other parts of the body often absorb iodine in a similar way to normal thyroid cells in the neck and therefore this is usually a very effective way of treating the disease, even if it has spread. It is very rare for thyroid cancer to spread beyond the neck.

Your stay in hospital

What is the iodine room like?

The iodine room is a bedroom with an ensuite shower, toilet and basin reserved for your exclusive use. There are no telephones in the treatment rooms so please bring a mobile phone with you if you have one.



There is a kettle, refrigerator (for you to store food and drink), television (with FreeView channels), radio, CD and DVD player. Meals will be brought to your room. There is a call bell for nursing staff who are always near at hand.

What happens when I come in to hospital for radioactive iodine treatment?

You will be asked to arrive at the hospital in the morning on the day of admission. We would be grateful if you could have your blood taken in the Outpatients Department on Level 1 before going to the ward.

Please give the laboratory staff the blood form that was sent to you by post with your admission information. If you forget to bring the form in to hospital please ask the ward doctor to write another form for thyroglobulin and TSH.

On the ward you will be greeted by one of the staff. You will then be seen by the ward doctor. It is better for you to arrange your own transport when you are ready go home again. If you are unable to do this please let the nurse know when you arrive and we will then be able to arrange transport for you. If you have any questions or anxieties please let any of the staff know and they will be happy to help you.

After you have been seen please expect to spend some time waiting before you are given your radioiodine capsule. Lunch is served at around 12 noon and the iodine is usually given at approximately 1.30pm. About one hour before the iodine is given the nurse will give you an anti-sickness tablet.

Who gives the capsule?

The Nuclear Medicine Therapy Team within the hospital is responsible for dealing with the radioiodine treatment. One of their staff will take you to your iodine room to give you the capsule (which is about the size of an antibiotic capsule). It is very important not to bite the capsule. We advise eating lunch and taking the anti-sickness tablet at least one hour before the radioiodine.

What happens next?

For the first one to two hours after taking the capsule you should refrain from eating and drinking to allow time for the iodine to be absorbed. After this time you should eat normally (continuing to avoid iodine rich substances).

Radioactivity is lost from your body in urine, saliva, sweat and by opening your bowels.

During your time in the iodine room:

- Drink up to twice your normal amount so that you pass urine frequently and open your bowels regularly. Please can you flush the toilet twice after use. If you spill or splash urine please contact the nursing staff.
- Try not to get constipated and if necessary ask the nurses for laxatives.
- Take two showers a day to wash any small amounts of radioactivity from your skin. It is not necessary to wash your hair every time you have a shower. Once a day is sufficient.

The sooner the radioactive iodine is flushed out of your body the fewer restrictions you will have when you go home.

Are there any restrictions for visitors?

As the treatment you have received is radioactive no children (under 16 years) or pregnant women are allowed to visit because the risk of radiation is greatest for them. Others may visit for a restricted time. Because you are radioactive, staff will spend only brief periods of time in your room. When they bring in your meals and drinks you should remain on the opposite side of the room. Do not expect them to stay and chat for long periods of time but do not hesitate to call them if you need anything. All visitors should stay behind the line marked on the floor of your room. Please do not give your visitors anything to take out of the room.

Daily visiting time is between 12noon to 8pm.

There is usually no objection to visitors outside these hours. Please speak to the nurse in charge. Please note your visitors may not be able to spend the whole visiting time with you.

What happens at meal times?

The ward staff will bring your meals into your room. The waste food is removed by the domestic staff. Each day you will receive a menu to fill in for the next day.

Drinks are provided in the morning, mid morning, lunch time, tea time and night time. There is a kettle in the room to enable you to make hot drinks. If you do not receive your meals, for whatever reason, please ring the call bell and you will be provided with one.

What should I bring into hospital?

- Please make sure you have a plentiful supply of your own medicines, including thyroxine tablets, to bring into hospital.
- Comfortable 'old' clothes to be worn during your stay (It is better to bring old clothes because if they become radioactive they may have to be stored away at home for several weeks).
- Please bring slippers or comfortable shoes to wear in the room as well as the shoes you are going home in.
- Please bring your own towels. If they become radioactive they may also have to be stored away at home for several weeks.
- Shampoo, soap, brush, comb, toothbrush and toothpaste.

- Shaving kit (preferably disposable).
- Books (but not library books).
- Mobile phone.
- Hair dryer.
- You can bring a laptop if you wish free wi-fi is available in the hospital. Pay per view TV is available with internet. You will need to pay in advance which can be done on level 0 Bexley Wing (near the transport office).
- There is a shop on Level 0 in the Atrium where your visitors may buy newspapers, magazines etc for you.
- CDs, DVDs (but not hire tapes).
- Other activities; games, jigsaws, sewing, knitting etc.
- Mineral water or squash.
- Fruit, biscuits, tea bags, coffee and sugar if required.
- Fresh clothes to be worn on discharge: these can be kept in the wardrobe or in a suitcase in your room to avoid them becoming radioactive.

At the end of your stay we will monitor all your belongings for radioactivity and give you advice on washing your clothes and handling the other items. They will not be damaged by the radiation.

When can I go home?

The Nuclear Medicine Therapy Team will come to the ward every day (except at weekends) to take measurements. These are used to calculate how much radiation is still in your body, how long visitors may stay each day and when it reaches a safe level to go home. You must stay in the iodine room until that time.

Before going home you will have a whole body scan (shown here in the pictures). This scan shows the position of any radioactivity in your body. It takes 1-1½ hours and is painless.



Please wear your clean clothes for the scan, though not jeans or clothing with metal buttons or studs.

You will need to see your doctor approximately six weeks after leaving hospital in the out-patient department when you will be given your scan result. You will either be given an appointment when you leave the ward, or have one sent to you later by post.

Will I still have any restrictions when I get home?

The Nuclear Medicine Therapy Team will explain to you the restrictions you must observe when you go home, for example avoiding crowded places and limiting the people you come into contact with. They can work out exactly how many days you need to restrict yourself. The restrictions you are given may vary from other patients as some people may be lower or higher in their levels of radioactivity. You will be at an acceptable level of radioactivity to go home.

These restrictions are to protect other people, especially pregnant women and children.

Diet information for radioiodine patients

A diet that is rich in iodine may reduce the effectiveness of the treatment. Therefore for two weeks before and while you are in hospital we recommend a low iodine diet.

Do eat:

Fresh (rather than canned) meat, vegetables, fruit, pasta and rice. These are low in iodine. Normal table salt or sea salt can be added to food but avoid iodised salt to which iodine has been added (see below).

Avoid:

- Sea food (including fish, prawns and other shellfish, tinned salmon, tuna and crab paste).
- Seaweed, watercress and kelp (a health food).
- Vitamin supplements and cough medicine that contain iodine.

- Cows and goats milk, egg yolks, cream, ice cream, cheese, butter and yoghurt contain iodine so we recommend avoiding them as much as possible. Soya milk contains much less iodine than cows milk and a pint per day of soya milk can be drunk during the time of the low iodine diet.
- Iodised salt (salt to which iodine has been added) is rarely used in the UK.



The list of food to avoid on low iodine diet sheets differs from place to place. In the USA, iodine is added to salt but is not in the UK. Some studies show that less strict diets could produce similar results. It is a controversial area and can be confusing to read about.

On the ward you will be able to choose from the menu provided taking into account the above advice. There is a file in the room with all the available menus. Foods are highlighted on the menus to help you with your choices.

We suggest that you write '**low iodine diet**' on the top of your menu to alert the hospital caterers to your needs.

Also try to eat lots of fibre (fruit and vegetables) to avoid constipation.

Useful addresses for support and information

The Nuclear Medicine Therapy Team

Leeds Cancer Centre, Nuclear Medicine Department Level 1,
Bexley Wing, Leeds LS9 7TF

Tel: 0113 206 8324 **website:** www.leedsth.nhs.uk

Clinical Nurse Specialist

Leeds Cancer Centre, Level 3, Bexley Wing, Leeds LS9 7TF

Tel: 0113 206 7724

Leeds Cancer Support

Leeds Cancer Support complements care provided by your clinical team. We offer access to information and a wide range of support, in a welcoming environment for you, your family and friends. We can be found in the information lounges in Bexley Wing and also in the purpose built Robert Ogden Macmillan Centre.

The Sir Robert Ogden Macmillan Centre

The Centre is on the St James's Hospital site and offers a variety of support services including counselling, support groups and complementary therapies. These therapies include Reiki, relaxation and visualisation, hand and foot massage and many others. You can just drop in for a coffee and a chat anytime.

Contact numbers for Leeds Cancer Support:

Information Lounge Level -2 Radiotherapy Department
Open from 8.00am - 6.00pm **Tel:** (0113) 206 7603

Information Centre Level 1 Outpatients Department

Open from 10.00am - 4.00pm. Tel: **(0113) 206 8816**

Sir Robert Ogden Macmillan Centre

Open from 10.00am - 4.00pm. Tel: **(0113) 206 6498**

All the above services can be emailed on:

leedsth-tr.cancersupport@nhs.net

Maggie's Centre

If you or someone you love has cancer you may have lots of questions. Maggie's is a warm, welcoming place where you can meet people who are experiencing similar things to you.

You may also be able to find support groups specific to your needs and get advice and information from their professional staff. You don't need an appointment and all support is free.

Open Monday to Friday 9.00 am - 5.00pm. Tel: **(0113) 427 8364**

Address: St James's Hospital (next to the multi storey car park), Alma Street, Leeds LS9 7BE

Email: leeds@maggiescentres.org

Website: maggiescentres.org

Thyroid cancer groups

Butterfly Thyroid Cancer Trust UK

This is a voluntary support group based in Newcastle, for patients affected by thyroid cancer. It is a patient led group and they are happy to receive calls and emails from Leeds patients.

Tel: 01207 545 469 website: www.butterfly.org.uk

The British Thyroid Foundation

This group deals mainly with patients that are hypo and hyperthyroid. We advise asking to speak to the thyroid cancer expert for information and support.

Address: Suite 12, One Sceptre House, Hornbeam Square
North Hornbeam Park, Harrogate, HG2 8PM

Tel: 01423 810093 **website:** www.btf-thyroid.org

AMEND (Association for Multiple Endocrine Neoplasia Disorders)

Support group for patients with medullary thyroid cancer.

Address: 31 Pennington Place, Southborough, Kent, TN4 0AQ

email: jo.grey@amend.org.uk

General cancer information services

Macmillan Cancer Support

Information and support for people affected by cancer.

Freephone: 0808 808 0000, 9am to 6pm Mon to Fri.

A textphone service for deaf and hard of hearing people on
18001 0808 808 0000

Website: www.macmillan.org.uk

If more information is required:

Guidelines for the management of thyroid cancer and patient information booklets (similar to the Leeds information leaflet) may be downloaded from:

The British Thyroid Association website:

www.british-thyroid-association.org/patient info

Medline (search the medical literature):

www.medlineplus.gov/



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