



Lynda Jackson Macmillan Centre

support & information at Mount Vernon Cancer Centre

... supporting people affected by cancer...

This leaflet forms part of a series of publications produced by the Lynda Jackson Macmillan Centre (LJMC).

If you would like further information about any aspect of cancer and its treatments, please drop in to the centre or call the Helpline.

The LJMC is staffed by healthcare professionals and trained volunteers and is part of the Mount Vernon Cancer Centre.

Services offered at the LJMC include:

- Drop-in centre for support and information
- Telephone helpline
- Benefits advice*
- Complementary therapies*
- Relaxation classes
- Counselling*
- Look Good...Feel Better™ beauty workshops
- Self-help courses

* These services are available to NHS patients under the care of an oncologist based at Mount Vernon Cancer Centre.

The **Lynda Jackson Macmillan Centre** is situated between the Cancer Centre and Gate 3 (White Hill)

Opening hours: **Mon-Fri: 9.30am-1.00pm & 2.00-4.30pm**

Mount Vernon Cancer Centre, Northwood, Middlesex HA6 2RN

Telephone Helpline: **020 3826 2555**

Website: www.ljmc.org

a patient's guide

Radioiodine for thyroid cancer

Patient Information Series PI 15



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East and North Hertfordshire **NHS**
NHS Trust



Consent

It is a legal requirement to have a signed Consent Form from you before the start of your treatment.

If you have already been given one of these forms, please bring the completed form with you when you come for your pre-assessment visit.

If you have not been given a form, this will be discussed with you at your pre-assessment visit.

Identification

Please note that it is a legal requirement for the staff to check your name and details against your treatment sheet and your hospital name band each time you attend.

You must wear your name band at all times whilst in hospital.

This leaflet has been written by the staff in the Nuclear Medicine Department, with oncologists and health care professionals at Mount Vernon Cancer Centre, as well as patients and carers at the Lynda Jackson Macmillan Centre.

If you have difficulty reading this size of print, a version of this leaflet, or any of our leaflets, can be produced for you in a larger print.

If you have any questions please contact the Nuclear Medicine Department.

Nuclear Medicine Department:
tel: 020 3826 2263

Mon - Fri: 8.30am – 4.30pm

Mount Vernon Cancer Centre is at:
Mount Vernon Hospital,
Rickmansworth Road,
Northwood,
Middlesex
HA6 2RN.

A map of Mount Vernon Hospital can be found on the website: www.ljmc.org

For more information see our
Helpful Hint no. 232 - Getting to Mount Vernon Hospital

Will I have to have more than one treatment?

Some patients will have more than one treatment. The scan and the blood test are used to decide how effective treatment has been and if any more therapy is needed.

The doctor in charge of your treatment will see the results of your scan. You will be contacted about more treatment, other medication or for an out-patient appointment.

Are there any long-term effects?

There are usually no long-term effects from the radioactivity from the iodine. As this radioiodine treatment aims to stop your thyroid gland from working, it will stop it from producing any more thyroid hormone.

This hormone will need to be replaced by taking thyroxine tablets. Your doctor will explain this to you.

Can I change my appointment once made?

The radioiodine has to be ordered specially for each patient when the appointment is booked. The special room on the ward has to be booked weeks in advance.

Because of these special arrangements we ask patients to give us at least three weeks notice if they need to cancel or change their treatment appointment.

Of course, we will understand if there are situations such as illnesses which are beyond your control.

A patient's guide to radioiodine treatment for thyroid cancer at Mount Vernon Cancer Centre

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Introduction

This leaflet is written for patients who are being offered radioiodine treatment for thyroid cancer. Whilst it cannot deal with every issue, it does answer some of the most commonly asked questions.

If anything in this leaflet is unclear please contact us using the telephone number on page 15. Our staff will be pleased to help you.

What is radioiodine therapy?

Radioiodine is a radioactive form of iodine; it releases radiation in the parts of the body where it is absorbed.

As the thyroid gland needs iodine in order to work, it attracts any iodine in your body.

This provides an easy way to get the radioiodine to the place it is needed, so the treatment is effective.

Radioiodine therapy is often used as treatment after surgery to remove the thyroid gland. If there is any thyroid tissue left after surgery, it will take up (absorb) the radioiodine and the radiation will stop it working.

Pre-treatment attendance

About two weeks before your treatment, you will need to attend Mount Vernon Hospital for a pre-assessment appointment in clinic. At this visit you will be seen by the ward doctor, a nurse and a member of the nuclear medicine team. You will get a chance to see the treatment rooms and be able to ask questions.

- wash the clothes you used in the hospital separately from the rest of the family wash
- avoid journeys on public transport which last longer than one hour. Journeys by air will always take longer and must be avoided. Please be aware that some security scanners at airports, railway stations etc. may be so sensitive that they may be able to detect that you have had radioiodine therapy months after your treatment

Before you go home you will be given a yellow sheet with details of your treatment. You should carry this with you for six months.

Will I have to stay off work after the treatment?

Although the treatment will not make you feel ill, you will have to stay off work for a few days because of the radioactivity passing through your body. If you work with children or pregnant women, this length of time will be longer.

The Nuclear Medicine staff at the hospital will explain how long you must stay away from work. These arrangements are made in order to be absolutely safe and should not cause you or anybody around you any anxiety.

When will I know how well the treatment has worked?

The treatment works slowly over a period of weeks. Usually you will be given a follow-up appointment for an ultrasound scan and a blood test about 4 - 6 months after the treatment. Some patients may have a radioiodine whole body scan.

Will I have restrictions when I get home?

Yes. At home you will need to take some precautions and follow some restrictions. This is to protect other people. These are very important for children and pregnant women.

Staff will discuss these with you. They will give you your instructions in writing. You will be told before you go home, the exact number of days that these restrictions apply to you. It is normally about one week, but can be longer if you have contact with children or pregnant women.

The restrictions you must follow are:-

- avoid contact with children and pregnant women. If you have small children who need constant attention, you may need someone else to look after them during the time you have to take precautions. They do not have to be sent away, if someone else can attend to them. They can still see you, but they will need to be kept at a distance from you for the restricted time
- avoid staying in a hotel or boarding house, as there may be children and pregnant women present
- avoid having close contact with other people as much as possible. For example, at home if you are watching the television don't sit beside anyone. Sit in a separate chair
- you should not share your bed with another person
- you should abstain from any sexual activities and open mouth kissing, for 14 days
- avoid places of entertainment such as the cinema or restaurants, where you are close to other people for periods of more than one hour
- avoid dental appointments and non-urgent visits to the GP (family doctor)

Where is the treatment given?

The treatment is given at Mount Vernon Hospital in the Iodine Suites in Ward 11, where you will need to be an inpatient for about 1 to 5 days - see table on page 11.

A member of staff from the Nuclear Medicine Department will come to your room on the ward to give you your treatment.

Will I have to sign a consent form?

Yes. As for all medical procedures, you will be asked to sign a form giving your consent to this treatment. It is very important that you understand what you are giving consent to. If you are worried or unclear about any aspects of this treatment, please ask the team treating you.

What about conception, pregnancy and breast-feeding?

As with all procedures involving radiation, you should not have treatment if you are pregnant. You must tell the staff if there is **any chance** of you being pregnant. Also you must not have this treatment if you are breast-feeding.

You are advised not to become pregnant for 6 months after the treatment. For men who have been given radioiodine therapy, we recommend that you do not father a child for 4 months after the treatment.

Your follow-up may require that these restrictions are extended for a year or more. It is therefore very important that you discuss with the doctor, any plans for a pregnancy, before starting the treatment.

What must I do to prepare for treatment?

Before you are admitted, you must stop certain medications and follow the dietary instructions opposite.

Medications:

At your first consultation the doctor will advise you about your medication. You will also receive a letter with this advice.

To allow the radioiodine to work, you will need to stop any thyroid medication.

If you are taking T₃ (liothyronine) this will be for 2 weeks before your radioiodine treatment.

If you are taking T₄ (thyroxine) this will be for 4 weeks before your radioiodine treatment. In this 4-week period you may first be asked to change to T₃ (liothyronine) for 2 weeks and then stop for the last 2 weeks before treatment.

When you are not taking your tablets, it is normal to feel increasingly tired. You may feel cold and put on a small amount of weight.

Some patients may be eligible for (rhTSH) injections (Thyrogen). This allows you to carry on taking your thyroid medication. Not all patients are suitable, or able to have these injections. Your doctor will advise you.

How long will I have to stay in hospital?

You will usually have to stay in hospital between 1 and 5 nights, depending on how much of the iodine your thyroid tissue absorbs and the prescribed dose. See the table below:

Prescribed Dose	Typical length of stay	Scan
1.1 GBq	1 night	✗
3.7 GBq	2 - 3 nights	✓
5.5 GBq	2 - 5 nights	✓

The staff from the Nuclear Medicine Department will come to your room every day to take measurements of radioactivity. They can then work out how much radioactivity is still in your body and if the level is safe for you to go home. You will be required to stay in the iodine room until that time.

Before going home you may have a scan in the Nuclear Medicine Department, see table above.

This is a simple procedure. You will be asked to lie on a couch and a special camera will be used to look at where the radioiodine has been absorbed.

If you have stopped taking your thyroid medication, you will be advised to start taking thyroxine when you are discharged. You will usually have a blood test before your follow-up clinic appointment to check the dose of thyroxine.

The follow-up clinic appointment is usually 6 weeks after your radioiodine treatment.

If you are allowed any visitors, they must report to the nurse in charge when they arrive. Pregnant women and children under 18 years **must not** visit you.

The room has a telephone with a direct line, so that you can have calls from family and friends. The telephone numbers of the radioiodine treatment rooms are listed below. Please give the correct number to your family and friends so they can call you.

Ward 11: Iodine Suite 1 - tel: 020 3826 2047
Iodine Suite 2 - tel: 020 3826 2048

It is possible for you to make calls from the telephone in your room, via the operator. Please note that you will be charged for these calls.

It is important that nothing is taken out of your room. Your meals will be brought to you on disposable paper plates and you will be asked to wash the cutlery yourself.

You may bring in items such as DVDs and books, but they will have to be monitored for contamination before you take them home with you. It is advisable to bring in a separate change of clothes and shoes which can be kept for wearing home when you go home.

Dietary instructions:

A diet that is rich in iodine may reduce the effectiveness of the treatment. Therefore we advise you to follow a

low iodine diet:

- [a] For 2 weeks before (and 24 hours after) taking your radioiodine capsule:
- ✓ Do eat fresh meat, vegetables, fresh fruit, pasta and rice (these are low in iodine).
 - ✗ Do not eat any fish, seafood, kelp, fish-oil tablets and iodised salt.
 - ✗ Stop taking 'over the counter' medicines such as cough mixtures, vitamin tablets and complementary medicines which contain iodine. If in doubt read the labels or check with the pharmacist.
 - ✗ Avoid food that is artificially coloured red using E127 which is rich in iodine. This is in glacé and maraschino cherries. Food coloured by spices is allowed.
 - ✗ Dairy products contain some iodine, so cut down on egg yolk, cheese, butter, yoghurt, milk and milk products. You do not have to cut these out altogether but have as little as you can.
- [b] For 4 hours before your treatment:
- You may drink water, black tea or black coffee but it is very important that you do not eat anything for at least 4 hours before your treatment. On the day of treatment, please have a light breakfast before 6.30am.
- [c] For 24 hours after your treatment:
- Carry on avoiding all the food and medications listed in section [a] above.

Are there any side-effects from this treatment?

Usually, there are not any side-effects from this treatment. Sometimes a patient will get a sore throat but this should last for only a few days. If this happens, drink plenty of fluids and tell a member of the ward staff who will ask your doctor to prescribe something soothing for your throat.

Sometimes patients develop swelling (inflammation) of the salivary glands and a dry mouth. This can happen a few days, or even months, after the treatment. These side-effects usually settle down after a few days. Lemon sweets may help prevent this. You can have these 24 hours after treatment.

How is the treatment given?

The treatment is usually given as a small capsule, which is about the same size as an antibiotic capsule. You will be given some water to help you swallow it, and a hot drink afterwards to enable it to dissolve in your stomach.

You should drink plenty of fluids during the 48 hours after the treatment. You will be asked to pass urine frequently. This will flush the excess radioactive iodine out of your system. Water is provided, but you may bring your own drinks with you if you wish.

Sometimes, the radioiodine may be given as a drink which is colourless and tasteless.

Will I be radioactive after the treatment?

Yes. During the first 24 hours after the treatment, some of the radioiodine is taken up by any remaining thyroid tissue. The rest is excreted from your body, mostly through your urine. But also through your saliva, sweat and faeces.

For this reason there are certain precautions to take that will reduce the radiation dose to other people. **Pregnant women and children under 18 cannot visit under any circumstances.**

It is important to restrict the length of time that you are close to other people. You should also observe a high level of personal hygiene, this reduces the risk of contamination.

Whilst you are in hospital

Whilst you are in hospital having this treatment, the staff looking after you will wear protective clothing, such as: aprons, gloves and overshoes. They will spend only short periods of time in your room, because of the nature of your treatment.

They may stand behind a lead door and you should try to remain on the opposite side of the room. Please do not expect them to stay and chat for long periods of time. Please contact them if you need anything.

The room you will stay in on the ward is purpose built for radioiodine patients and to make your stay easier it has special facilities to help you. These include:

television / DVD

private bathroom (with shower, sink and toilet)

fridge

telephone

You will have to stay in this room for all of your treatment. Visitors are not allowed except for special reasons, which will need to be discussed before your treatment with the Nuclear Medicine Department staff.