

Radioiodine for thyroid cancer

Patient Information Series PI 15



Mount Vernon
Cancer Centre

Who can I contact if I have questions?

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

Nuclear Medicine Department: 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 the leaflet: Getting to Mount Vernon Hospital (HHC232) available on the website.

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 first appointment.

If you have not been given a form, this will be discussed with you at your first appointment.

Identification

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

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 2. 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 telephone call

About two weeks before your treatment, you will receive a pre-assessment appointment by telephone. You will be called by a member of the Nuclear Medicine team.

They will go through a questionnaire with you about the treatment and check that you have all the relevant information about your treatment. You will get a chance to ask any questions.

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 one to three 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, women should not have treatment if they 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.

Women are advised not to become pregnant for six months after the treatment.

For men who have been given radioiodine therapy, we recommend that you do not father a child for four 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 pregnancy or fathering a child, 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.

You will receive an injection of Thyroid Stimulating Hormone (Thyrogen) on each of the two days prior to iodine treatment. You will be given appointments to attend Mount Vernon Cancer Centre for these injections which are usually given into the buttock. Apart from mild discomfort at the injection site there are minimal side effects from these injections. If you are having the injections you should continue with your usual thyroid medication.

For certain patients it will be necessary to stop their thyroid medication prior to treatment instead of giving these injections. You will be informed by the doctor if this is the case. Thyroxine (T4) will be stopped for four weeks before your radioiodine treatment. In this four week period you may be asked to change to Liothyronine (T3) for two weeks and then stop for the last two weeks before treatment.

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 two weeks before (and 24 hours after) taking your radioiodine capsule:

- ✓ Do eat fresh meat, fresh 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 four 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 four 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 from 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.

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 do 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.

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 to go home.

How long will I have to stay in hospital?

You will usually have to stay in hospital between one and three 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 - 3 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 will have a scan in the Nuclear Medicine Department.

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 six weeks after your radioiodine treatment.

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 a guest 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).
- Wash the clothes you used in the hospital separately from the rest of the family wash.
- Avoid sharing cutlery and crockery (after washing these items they are completely safe).

- 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 four to six months after the treatment. Some patients may have a radioiodine whole body scan.

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.

If you normally pay for NHS prescriptions

People undergoing treatment for cancer do not have to pay NHS prescription charges if they have a valid medical exemption certificate. To get an exemption certificate, ask your GP for an application form.

Other help and support

People often say that, during their illness, they experience a range of emotions. Many find it to be a stressful, anxious and confusing time.

If you have any questions or concerns about your treatment, are struggling to cope or need some support, please visit the Lynda Jackson Macmillan Centre (LJMC). Please feel free to drop in before, during or after any of your visits to the Cancer Centre.

The team at the LJMC works as part of the overall team caring for you to provide help, support and information in a relaxed setting to help you cope better with your treatment. Your family and friends are also welcome to visit the centre or call the Helpline.

You do not need an appointment to visit the LJMC which is located next to the Chemotherapy Suite by Gate 3. If you are unable to get to the LJMC, you can call the Helpline on 020 3826 2555.

Please see the back page of this leaflet for more information.

This publication has been produced by the Information team at Mount Vernon Cancer Centre. Contributors include health professionals, patients and carers who have expertise and experience in the topics covered by this publication. All our publications are reviewed and updated regularly. If you would like any details of the references used to write this information please contact the Information team on 020 3826 2555.

**Questions or concerns about
cancer and treatment?
Struggling to cope?
Need some support? Need to talk?**

Drop in to the Lynda Jackson Macmillan Centre
or call the support & information helpline

We will listen to your concerns, answer your questions
and guide you to further information
and services to help you

cancer treatment	practical support
side effects of treatment	headwear workshops
day-to-day living with cancer	exercise
benefits advice	diet and nutrition
counselling	health and wellbeing
someone to talk to	talking to family and friends
emotional support	Look Good Feel Better
complementary therapy	self-help courses
relaxation services	life after cancer

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

Opening hours: Monday–Friday 9.30am–4.30pm

020 3826 2555

www.ljmc.org

Supporting people affected by cancer
from diagnosis, through treatment and beyond



Lynda Jackson Macmillan Centre

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