



Radioiodine treatment for thyrotoxicosis

A guide for patients and their carers

We care, we discover, we teach



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Introduction

Radioiodine can be used to treat people with an overactive thyroid gland or a large thyroid gland. The Christie treats many people with radioiodine. Many doctors send their patients to The Christie for radioiodine treatment. This information is in two sections. The first part is about radioiodine treatment. The second part explains what you should and should not do after radioiodine treatment.

Radioiodine treatment

What is thyrotoxicosis?

Thyrotoxicosis describes the situation which occurs when your thyroid gland is over-active and makes too much thyroid hormone.

The thyroid gland is in the neck in front of the windpipe. When healthy, the thyroid gland is small and cannot be easily felt.

Usually, thyroid hormone keeps bodily functions occurring at the correct rate. These bodily functions include heart pumping, bowel activity and skin production of oil.

If your thyroid gland is over-active and makes too much thyroid hormone, your heart rate can increase, your stool frequency can increase and you can sweat more than usual.

What is radioiodine?

Iodine is a natural element which is found in food. Almost all iodine which you get from your food goes to your thyroid gland. This iodine is used to make thyroid hormone. Radioiodine is a form of iodine which gives off radiation.

Why use radioiodine treatment?

We use radioiodine in small doses to treat an over-active or large thyroid gland.

If your thyroid gland is over-active and makes too much thyroid hormone, you have a higher than normal chance of breaking a bone or developing a heart problem. If you have a large thyroid gland, you can develop problems with breathing and swallowing.

If you swallow radioiodine, almost all of the radioiodine will go to your thyroid gland and give off radiation to the thyroid gland. This means that the thyroid gland will shrink and make less thyroid hormone.

Your doctor will discuss with you the reasons for this form of radioiodine treatment. If there is anything you do not understand, please ask.

The benefit of radioiodine treatment is that the thyroid will stop making too much thyroid hormone in most people (about 17 in every 20 people) after one treatment within a year. A second treatment may be required in a few people (about 3 in every 20 people). After one or more radioiodine treatments, most people will go on to later have an under-active thyroid which makes too little thyroid hormone.

What are the benefits of radioiodine treatment?

Most people who have an overactive thyroid gland will be cured with radioiodine treatment. This means that the over-active thyroid symptoms (palpitations, diarrhoea, sweating etc) and the other over-active thyroid problems (risk of bone fracture and heart problems) will be controlled. One year after radioiodine treatment about 5 in every 20 people will have normal thyroid hormone levels and about 12 in every 20 people will have low thyroid hormone levels

– an underactive thyroid gland. With time, most people (about 17 in every 20 people) develop low thyroid hormone levels.

Low thyroid hormone levels can be easily treated with tablets containing natural thyroid hormone.

Radioiodine treatment shrinks the thyroid gland to half of its current size. This can take up to two years.

Are there any alternatives to this treatment?

There are three ways to treat an overactive thyroid gland:

- tablets (carbimazole or propylthiouracil)
- surgery; and
- radioiodine.

Carbimazole and propylthiouracil (see the separate leaflet available in the clinic) are the two drugs which are used to control an over-active thyroid. They are typically taken for 18 months with the dose being adjusted to keep the thyroid hormone levels under control. A few people experience skin, joint or gut symptoms with these tablets and the white cell count becomes very low in a very small number of people. These effects usually occur within six months of starting to take these drugs. The major problem with tablets used to decrease thyroid hormone levels is that the thyroid usually becomes over-active again when the tablets are stopped – about 7 in every 20 people have already become over-active again within two years of stopping tablets.

Modern thyroid surgery is extremely safe and effective. It is an option for people who would prefer this form of treatment. Thyroid surgery is used mainly for people with large thyroid glands (goitre) or for people with an

overactive thyroid gland which did not respond to other treatments. The surgeon usually removes the whole gland. This means that treatment with tablets containing natural thyroid hormone (levothyroxine) is needed for life.

Radioiodine treatment has the advantage of permanently curing an overactive thyroid in most people without the need for an operation.

What happens if I don't have radioiodine treatment?

If your thyroid gland makes too much thyroid hormone, you have a higher than normal chance of breaking a bone or developing a heart problem. This can lead to stroke. If you have a large thyroid gland, you can develop problems with breathing and swallowing.

If you do not have radioiodine treatment, it is important that you are treated either with tablets (carbimazole or propylthiouracil) or with surgery.

Is radioiodine treatment dangerous?

No. Radioiodine has been given to millions of people since it was introduced in the early 1940s. We know that it is both safe and effective.

The rest of your body will receive a smaller amount of radiation than your thyroid. Other people may be exposed to an even smaller dose if they come into close contact with you. We will help you to keep this as low as possible.

Will I have radioiodine treatment on my first visit?

Most people have radioiodine treatment at their first visit to the radioiodine clinic.

If you are pregnant or are breastfeeding you should not have radioiodine treatment. You can have radioiodine treatment once you are no longer pregnant and you are no longer breastfeeding.

If you have taken amiodarone tablets or injections in the past six months, this will interfere with radioiodine treatment. Amiodarone is often used to treat irregular heart rhythms. Your doctor may decide that you should come back on another day to have radioiodine treatment when you are no longer taking amiodarone tablets.

If you have had a CT scan recently (in the past 12 weeks) which involved an injection, your doctor may decide that you should come back on another day to have the radioiodine treatment. The injection that is used for CT scans is usually an iodine-based dye that can interfere with radioiodine treatment.

Before you have radioiodine treatment, more tests may be needed to make sure that radioiodine treatment is suitable for you. If the doctor decides that you need some more tests, you may have to wait for the results or you may have to come back on another day to have the radioiodine treatment.

If you have radioiodine treatment, there are some preparations that you should make and some precautions that you should take.

Can I eat and drink before my radioiodine treatment?

Yes. You can eat and drink as normal before radioiodine treatment. There is no need to have a low iodine diet before radioiodine treatment. We recommend that you do not eat or drink anything for two hours after radioiodine treatment. This is to make sure that the radioiodine is absorbed.

What about my tablets?

Tablets used to treat an overactive thyroid gland (carbimazole or propylthiouracil) should usually be stopped seven days before radioiodine treatment. This increases the chance that the radioiodine treatment will work.

Please follow the instructions in the appointment letter carefully because you will only receive radioiodine treatment if you have stopped taking these tablets.

We do not recommend that you take any tablets, such as vitamin or mineral supplements, which contain iodine or kelp (a seaweed, which contains iodine). If you do take tablets containing iodine or kelp, you will need to stop taking them at least seven days before radioiodine treatment.

When you come for radioiodine treatment, your doctor will advise you when you should start taking thyroid tablets again. We usually recommend that you start taking thyroid tablets (carbimazole or propylthiouracil) again seven days after radioiodine treatment.

Please bring with you any other tablets and medicines you are taking, including any you have bought from a chemist. Show them to the doctor who examines you. You should be able to continue taking them, but we would like to check.

How is radioiodine treatment given?

Having radioiodine treatment is very easy. After meeting a doctor in the endocrine department (department 63 on the second floor) you will be directed to the nuclear medicine department (department 31).

In the nuclear medicine department you will be given a small drink (less than half a cupful) containing the radioiodine diluted in water. It looks and tastes just like water. You will drink the liquid through a straw and will then drink some further water to make sure that you have taken the full dose.

It is likely, in the future, that the radioiodine will be given in a small capsule, which you will swallow with water.

How long does the radioiodine take to work?

It can take between a few weeks and several months for the radioiodine to decrease thyroid hormone levels and to decrease thyroid gland size. If radioiodine treatment has not worked within six months we can repeat the radioiodine treatment. There is a small chance (about 3 in 20 people) that you will need radioiodine treatment to be repeated.

Are there any short term side effects of radioiodine treatment?

Most people notice no ill-effects from radioiodine treatment and feel entirely well afterwards. There is a small chance that you may develop the symptoms of an overactive thyroid (such as palpitations and sweating). This usually happens 5 to 10 days after the radioiodine treatment. For this reason we ask most people to take propranolol tablets for two weeks after radioiodine treatment, and to restart carbimazole or propylthiouracil one week after radioiodine treatment.

There is a small chance that you may develop, or experience worsening, of eye symptoms. This can happen to about 3 of every 20 people who have radioiodine treatment. This can be prevented by steroid treatment. Your doctor will discuss this with you before you have radioiodine treatment – he or she may suggest that you take prednisolone tablets for a few months. Prednisolone is a steroid treatment.

A very few people experience discomfort in the neck after radioiodine treatment. This is usually mild and usually disappears after a few days.

Are there any long term side effects of radioiodine treatment?

One year after radioiodine treatment more than half of people (about 3 in 5 people) will have low thyroid hormone levels (underactive thyroid gland). With time, more people develop low thyroid hormone levels.

An underactive thyroid gland can be easily detected by blood tests. You should, therefore, have your blood thyroid hormone levels checked regularly by your doctor.

An underactive thyroid gland can be easily treated with tablets containing natural thyroid hormone (levothyroxine). This should prevent the symptoms of an underactive thyroid such as weight gain and tiredness.

Are there any extra risks in having children after radioiodine treatment?

No. Many years of experience of using radioiodine treatment shows no effect on children of patients who have had radioiodine treatment. However, we strongly advise you:

- not to become pregnant for **six months** after radioiodine treatment
- not to father children for **four months** after radioiodine treatment.

Precautions you need to take

Can someone come with me to the hospital?

Yes, but please do not bring anyone under the age of 18 or pregnant women with you. This is very important.

Should I tell anyone if I am pregnant or breast feeding?

Please contact us immediately if you are pregnant or breastfeeding.

Radioiodine treatment cannot be given if you are pregnant or breastfeeding.

Before you have radioiodine treatment, we will ask you (if you are female and aged 12 to 55) whether you might be pregnant and whether you are breast feeding. We may also ask you to have a pregnancy test. If you are pregnant, radioiodine treatment must be delayed.

These precautions are to protect your baby.

How may I travel home?

This may depend on the amount of radioiodine you have been given and also on the length of the journey. We will advise you about this.

In general, you may travel alone by driving, cycling or walking.

Usually, you may travel with one other person in a car as long as you are the only passenger and that you sit in the back seat on the opposite side of the car to the driver. Your driver should not be a pregnant woman.

It is normally possible to travel by public transport as long as you do not spend more than one hour sitting close to the same person on the bus or the train. Sitting more than one metre (three feet) from other people is usually fine.

How long will the radioiodine stay in my body?

Within a few hours, most of the radioiodine will be taken up by your thyroid gland. This means that the vast majority of the radiation effect will take place in the thyroid. Other parts of the body will take up much smaller amounts of radioiodine.

The radioiodine will gradually leave your body, mainly in your urine. You should drink plenty of fluids during the first two days after your radioiodine treatment, so that you go to the toilet more often. Drinking plenty of fluids and emptying your bladder regularly will help to remove the radioiodine that has not been taken up by your thyroid. Very small amounts of radioiodine will also leave your body in saliva, faeces and sweat. The amount of radioiodine in your body will reduce each day. How long it takes to disappear depends on how much you are given and is usually several weeks.

If you sometimes leak urine without meaning to, please mention this to the doctor when you come for radioiodine treatment.

Will the radioiodine affect other people?

For a while after receiving radioiodine treatment, anybody who comes into close contact with you will get a small amount of radiation. You can avoid this by limiting the time that you spend close to other people. Staying more than one metre (three feet), and preferably more than two metres, from other people is usually fine.

Things that you touch, such as books, coins or the telephone, do not become radioactive.

The radioiodine treatment is for your benefit, but you will need to take some precautions until the level of radioiodine in your body is low.

The advice we give you is to protect your family and other people from radiation. You may continue:

- to cook for other people at home
- to use the telephone
- to have usual contact with pets.

When can I go back to work?

You will need to take some time off work. We can provide you with a certificate stating this. The length of time that you need to take off work will depend mainly on how close you are to other people while at work and on the kind of work that you do. It also depends on the amount of radioiodine that you receive. We will ask you about your work so that we can give you the right advice. The following examples will give you a rough idea of the amount of time that you will need to take off work.

- Full-time nursery nurse – three weeks from the day of radioiodine treatment.
- Full-time office worker sharing an office – two weeks from the day of radioiodine treatment.
- Half-time shop worker – one week from the day of radioiodine treatment.
- Lorry/van driver working alone – no time off work is needed.

What about my partner?

If you follow the information and restrictions listed in this booklet, the amount of radiation that your family receive will be below the national limits for members of the public.

It is appropriate for an adult family member (except for a pregnant woman) to look after you before the time periods shown later have passed if you are unwell or disabled.

If sleeping separately is difficult, then you and your partner may both choose to share a bed before the suggested times have passed. Because your partner will receive a higher amount of radiation by doing this, we must be sure that he or she is aware of the small risk involved, and that he or she has given his or her consent. The radiation dose that your partner receives would be about the same as two years of naturally occurring radiation (which everyone receives).

If you and your partner choose to continue to share a bed after radioiodine treatment, please ask him or her to read and sign the letter which will be included with your appointment letter. It contains some more information for him or her. Please then bring the letter with you when you come for radioiodine treatment.

More information is available via the phone numbers listed later in this booklet.

Travelling abroad in the next three months?

There are sensitive radiation detectors in airports and ports. These are present to help maintain national security by preventing radioactive materials entering or leaving the country. Please tell us if you plan to travel abroad within three months of your radioiodine treatment. We can give you a letter stating that you have received radioiodine treatment.

What are the precautions that I should take when I get home?

When you are ready to go home, you will receive a card with some instructions. Although the amount of radiation that other people will get will be small, it is best to keep it as low as possible. You will reduce the amount of

radiation your family and other people get if you follow the instructions on the card.

Please follow the instructions on the card for the number of days stated on the card. Day 1 is the day that you have your radioiodine treatment.

The main precaution is to limit the time you spend close to other people until most of your radioiodine is used up. During this time, it is possible to be close to other people for a few minutes, a few times a day. So hugging every now and then is OK, but sitting next to your child for two hours watching a film is not.

We hope that these precautions don't make the time following your radioiodine treatment too hard for you. We would rather you have the information in advance, so that you can discuss it with your family and with your work colleagues.

If you look after children either at home or work please discuss this with us.

The instructions that you receive will depend on the amount of radioiodine that you receive. Most patients receive **low** or **medium** dose radioiodine treatment. **We suggest that you look at and plan for the instructions for the medium dose radioiodine treatment, before you come for your appointment.** If it is then decided that you need **high** dose radioiodine treatment, you could ask to defer the radioiodine treatment for a week or two if you need to make extra arrangements.

For **low** dose radioiodine treatment (400 MBq)

From Day 1 to Day 4

- Don't share crockery (plates, bowls, cups etc), cutlery (knives, forks, spoons etc) or toothbrushes with others. Rinse your crockery and cutlery after use, then wash with other people's.
- Avoid sexual contact and open-mouth kissing.
- Avoid preparing food that involves a lot of handling of food that cannot be washed. Examples include making pastry or bread. If you really want, or need, to continue to prepare such food, wear thin plastic gloves during food preparation.
- Flush the toilet twice after use, and pay extra care with hand-washing afterwards.
- Make sure that no-one else uses your towels and face-cloths.

From Day 1 to Day 11

- Try to stay more than an arm's length away from other people, and limit the time you spend close to them.
- Sleep in a separate bed – please see the “What about my partner” section earlier in the booklet.

Advice about contact with children and pregnant women

If you are a main carer for young children, the amount of time you normally spend close to them probably depends on their age. For this reason, the periods of restriction below depend on the children's age.

- For children more than 5 years old, avoid long periods (more than a few minutes, a few times a day) of close contact (less than an arm's length) from **Day 1 to Day 11**.
- For children aged between 3 and 5 years, avoid close contact from **Day 1 to Day 16**.
- For children aged less than 3 years old, and for pregnant women, avoid close contact from **Day 1 to Day 21**.

For **medium** dose radioiodine treatment (550 MBq)

From Day 1 to Day 4

- Don't share crockery (plates, bowls, cups etc), cutlery (knives, forks, spoons etc) or toothbrushes with others. Rinse your crockery and cutlery after use, then wash with other people's.
- Avoid sexual contact and open-mouth kissing.
- Avoid preparing food that involves a lot of handling of food that cannot be washed. Examples include making pastry or bread. If you really want, or need, to continue to prepare such food, wear thin plastic gloves during food preparation.
- Flush the toilet twice after use, and pay extra care with hand-washing afterwards.
- Make sure that no-one else uses your towels and face-cloths.

From Day 1 to Day 14

- Try to stay more than an arm's length away from other people, and limit the time you spend close to them.
- Sleep in a separate bed – please see the “What about my partner” section earlier in the booklet.

Advice about contact with children

If you are a main carer for young children, the amount of time you normally spend close to them probably depends on their age. For this reason, the periods of restriction below depend on the children's age.

- For children more than 5 years old, avoid long periods (more than a few minutes, a few times a day) of close contact (less than an arm's length) from **Day 1 to Day 14**.
- For children aged between 3 and 5 years, avoid close contact from **Day 1 to Day 20**.
- For children aged less than 3 years old, and for pregnant women, avoid close contact from **Day 1 to Day 25**.

For **high** dose radioiodine treatment (800 MBq)

From Day 1 to Day 4

- Don't share crockery (plates, bowls, cups etc), cutlery (knives, forks, spoons etc) or toothbrushes with others. Rinse your crockery and cutlery after use, then wash with other people's.
- Avoid sexual contact and open-mouth kissing.
- Avoid preparing food that involves a lot of handling of food that cannot be washed. Examples include making pastry or bread. If you really want, or need, to continue to prepare such food, wear thin plastic gloves during food preparation.
- Flush the toilet twice after use, and pay extra care with hand-washing afterwards.
- Make sure that no-one else uses your towels and face-cloths.

From Day 1 to Day 16

- Try to stay more than an arm's length away from other people, and limit the time you spend close to them.
- Sleep in a separate bed – please see the "What about my partner" section earlier in the booklet.

Advice about contact with children

If you are a main carer for young children, the amount of time you normally spend close to them probably depends on their age. For this reason, the periods of restriction below depend on the children's age.

- For children more than 5 years old, avoid long periods (more than a few minutes, a few times a day) of close contact (less than an arm's length) from **Day 1 to Day 16**.
- For children aged between 3 and 5 years, avoid close contact from **Day 1 to Day 22**.
- For children aged less than 3 years old, and for pregnant women, avoid close contact from **Day 1 to Day 27**.

Agreeing to treatment

If you decide to have radioiodine treatment we will ask you to sign a consent form. Signing this form indicates that you:

- have read this booklet describing radioiodine treatment (or have had someone read it to you)
- are aware of the risks, benefits and alternatives to radioiodine treatment and are aware of the need to take precautions after radioiodine treatment so as to keep the amount of radiation that other people get as low as possible
- have been given an opportunity to discuss any concerns that you may have
- agree to have radioiodine treatment.

You can always ask for another opinion from another doctor who specialises in treating thyroid disease. You can ask your own consultant or your GP to refer you. You may withdraw your consent at any time before you receive radioiodine treatment. Should you decide to withdraw your consent then a member of your treating team will discuss the risks, benefits and alternatives with you.

Further information

If you have any questions, or if there is anything about the radioiodine treatment you do not understand, please ask either when you are seen at the clinic, or by telephone to:

- Endocrinology Hotline on 07768 703100, or
- Nuclear medicine department on 0161 446 3946
- www.christie.nhs.uk/our-services/endocrinology/patient-information.aspx

Christie leaflet: Taking Carbimazole or Propylthiouracil (PTU)

The British Thyroid Foundation

2nd Floor, 3 Devonshire Place, Harrogate,
North Yorkshire, HG1 4AA

Tel no: 01423 709707 or 01423 709448

www.btf-thyroid.org

The Thyroid Eye Disease Charitable Trust,

PO Box 1928, Bristol, BS37 0AX

Tel no: 0844 800 8133

e-mail: ted@tedct.co.uk

www.tedct.co.uk

Christie Website

Many Christie booklets are available via the website

www.christie.nhs.uk

Student training

Many hospitals train postgraduate and undergraduate trainees so you may meet male and female students in all areas. We train doctors, nurses and other therapists in radioiodine treatment and in the care of people with cancer and other conditions. Students are always supervised by fully qualified staff. However, you have the right to decide if students can take part in your care. If you prefer them not to, please tell the doctor, nurse or other therapist in charge as soon as possible. You have a right to do this and your radioiodine treatment will not be affected in any way. We also try to respect the concerns of patients in relation to the gender of their doctor and other health professionals.

We try to ensure that all our information given is accurate, balanced and based on the most up-to-date scientific evidence. If you would like to have details about the sources used please contact patient.information@christie.nhs.uk

Benefits and finance information

You may have had to stop work and had a reduction in your income. You may be able to get benefits or other financial help. You may be entitled to Personal Independence Payments but new claims cannot be made for Disability Living Allowance. People over 65 may be able to claim Attendance Allowance. Find out more:

- Disability Living Allowance, call the Disability Benefits Helpline on 08457 123 456
- Attendance Allowance, call 0845 605 6055
- Personal Independence Payment (PIP), call the PIP Claim line on 0800 917 2222
- Carer's benefits, call the Carer's Allowance Unit on 0845 608 4321
- Contact The Christie at Withington general and benefits advisers on 0161 446 8538 or 8539. The Christie at Oldham has a benefits advice session on Thursday afternoons phone 0161 918 7745
- Contact your local social services department for help with equipment and adaptations, or for an assessment of care needs
- Macmillan Cancer Support has an advice line on 0808 808 00 00
- Useful websites: www.macmillan.org.uk or www.gov.uk

You may be able to claim travel costs for petrol and parking or public transport but not taxi fares if you receive: income-related Employment Support Allowance, Income Support, Universal Credit, Guaranteed Pension Credit or hold a valid tax credit exemption card. You may also be able to qualify for help if you are on a low income and have a valid HC2 or HC3 certificate. For advice please contact the general and benefits advisers.

The Christie Clinic

A private patient partnership between HCA International and The Christie NHS Foundation Trust

Private cancer care at The Christie Clinic

Patients with private medical insurance can access a full range of cancer treatment at The Christie Clinic. The partnership with The Christie NHS Foundation Trust and HCA International allows The Christie to invest in enhancing NHS services.

We work with a number of consultants who will be personally dedicated to your care.

If you wish to use your private medical insurance or pay for your treatment yourself there are three simple steps:

- 1. Check your insurance cover.** There are a variety of insurance policies all offering different levels of support.
- 2. Make an appointment.** There are no waiting lists. An appointment can be easily scheduled to suit you.
- 3. For more information or advice:**
 - Speak to your consultant about continuing your treatment as a private patient.
 - Call us on 0161 918 7296 if you have any queries about our services, insurance issues or self-pay quotations.
 - Email us: info.christieclinic@hcahealthcare.co.uk

For the visually impaired: Large print versions of Christie booklets are available, please contact Patient Information on 0161 446 3576 or you can download these from the Christie website at www.christie.nhs.uk.



Visit the Cancer Information Centre:

The Christie at Withington Tel: 0161 446 8100

The Christie at Oldham Tel: 0161 918 7745

The Christie at Salford Tel: 0161 918 7804

Open Monday to Friday, 10am to 4pm.

Opening times can vary, please ring to check before making a special journey.

The Christie NHS Foundation Trust,
Wilmslow Road, Manchester,
M20 4BX, United Kingdom

T. 0161 446 3000

F. 0161 446 3977

Web: www.christie.nhs.uk



The Christie Patient Information Service
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