



Radioiodine treatment for thyrotoxicosis

A guide for patients and their carers



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Introduction

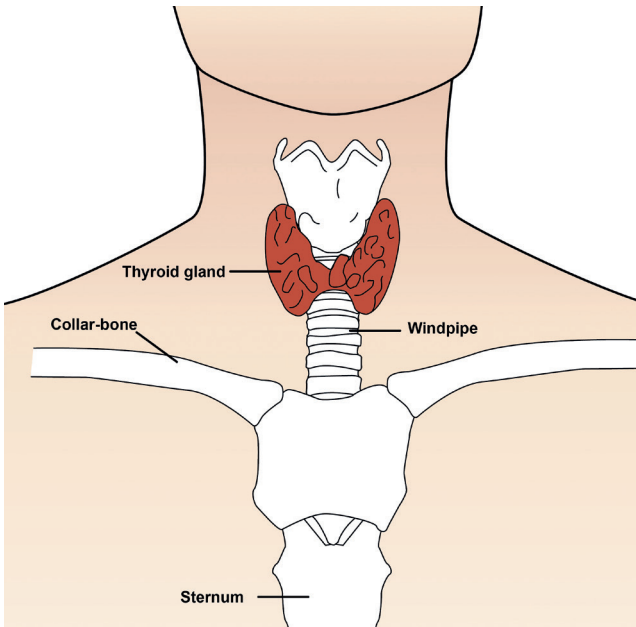
Radioiodine can be used to treat people with an overactive thyroid gland or an enlarged thyroid gland. The Christie treats many people with radioiodine for these two conditions. This information is in two sections. The first part is about radioiodine treatment. The second part explains what you should 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 how fast your heart pumps, 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, you may have diarrhoea and you can sweat more than usual.

You may also feel anxious, and experience muscle weakness.

More information can be found on the British Thyroid Association website at www.btf-thyroid.org

What is radioiodine?

Iodine is a natural element which is found in food. Almost all the iodine 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 overactive or enlarged thyroid gland.

If your thyroid gland is overactive and makes too much thyroid hormone you will feel unwell. You will also have a higher than normal chance of breaking a bone or developing a heart problem. If you have an enlarged thyroid gland, you can develop problems with breathing and swallowing.

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

Within a year after treatment, the thyroid will stop making too much thyroid hormone in most people.

A second treatment may be required in a small number of people. After one or more radioiodine treatments, most people (about 17 of every 20 people) will go on to later have an underactive thyroid which makes too little thyroid hormone.

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

What are the benefits of radioiodine treatment?

Most people (about 18 of every 20 people) who have an overactive thyroid gland will be cured with radioiodine treatment, so that their thyroid hormone levels become normal or lower than normal after treatment. This means that problems related to overactive thyroid symptoms (e.g. higher heart rate, diarrhoea, sweating, anxiety, muscle weakness) will get better. 2 of every 20 people will still have a slightly overactive thyroid gland after treatment that may need further treatment.

Low thyroid hormone levels can be easily treated with tablets containing man-made thyroid hormone (levothyroxine).

Radioiodine treatment shrinks the thyroid gland to half of its current size. This can take up to 2 years.

Are there any alternatives to this treatment?

There are three ways to treat an overactive thyroid gland:

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

Carbimazole and propylthiouracil (see the separate leaflet available in the clinic) are the 2 drugs which are used to control an overactive thyroid. They are typically taken for 18 months with the dose being adjusted to keep the thyroid hormone levels under control. Occasionally, people experience skin, joint or gut symptoms with these tablets.

In a very small number of people (about 1 in 100), the white cell count becomes very low. These effects usually occur within 6 months of starting to take these drugs. The major problem with tablets used to decrease thyroid hormone levels is that the thyroid usually becomes overactive again when the tablets are stopped. About half of people have already become overactive again within 2 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 enlarged 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 man-made 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 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?

You will get two appointments from the radioiodine clinic.

The first appointment is a phone call with the clinic nurse, to answer any questions and check that you are ready to have treatment. This is as important as a hospital appointment, but we want to make it easier for you by having this conversation over the phone instead.

The second appointment is a visit to the clinic, which we may need to change to fit around what you tell us on the phone. Most people have radioiodine treatment in the Nuclear Medicine department straight after this visit to the radioiodine clinic.

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

If you have taken amiodarone tablets or injections in the past 6 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.

If you have had a CT scan recently (in the past 8 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 2 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 7 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 be able to receive radioiodine treatment if you have stopped taking these tablets.

If you are taking levothyroxine, your doctor may ask you to stop taking this as well.

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 7 days before radioiodine treatment.

When you come for radioiodine treatment, your doctor will advise you when you should start taking thyroid tablets again.

Please bring with you any other tablets and medicines you are taking, including any that you do not get on prescription. 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 straightforward. After meeting a doctor in the Endocrinology department (department 63 on the second floor) you will be directed to the Nuclear Medicine department (department 31 on the ground floor).

In the Nuclear Medicine department you will be given a small gelatine capsule to swallow, with a cup of water to help it down. The capsule has no taste. The picture below shows you how small the capsule is by comparing it to a 5p coin.



If you are unable to swallow a capsule, you **MUST** tell the clinic nurse when they call you, or phone the radioiodine clinic before you come to the hospital. There are alternative treatments we can discuss with you.

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 6 months it can be repeated. There is a small chance (about 2 in 20 people) that you will need the 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 increased heart rate 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 2 weeks after radioiodine treatment, and to restart carbimazole or propylthiouracil 1 week after radioiodine treatment.

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

Thyroid eye disease

Smoking and an untreated underactive thyroid increases the risk of thyroid eye disease. There is a chance that following treatment, you may develop eye problems or the eye disease caused by your thyroid problems may get worse. This can happen to about 2 out 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. They may suggest that you take a course of prednisolone tablets. Prednisolone is a steroid treatment.

For more information on thyroid eye disease, see the information leaflet produced by the British Thyroid Foundation www.btf-thyroid.org

Are there any long term side effects of radioiodine treatment?

One year after radioiodine treatment more than half of people (about 17 in 20 people) will have low thyroid hormone levels because they have an 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 **6 months** after radioiodine treatment
- not to father children for **4 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 anyone who is pregnant 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.

If you are aged 12 to 55 and there is any possibility you may be pregnant, we will ask you if you might be pregnant and whether you are breast feeding before you have radioiodine treatment. 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 unborn baby from being exposed to radioiodine.

How may I travel home?

We will give you advice about this when the clinic nurse phones you before your clinic appointment. In general, you may travel alone by driving, cycling or walking.

Usually, you may travel with one other person in a car. Ensure the driver and passenger are as far apart as possible, e.g. with the passenger sitting in the opposite corner from the driver. Your driver should not be pregnant.

It is normally possible to travel by public transport as long as you do not spend more than 1 hour sitting close to the same person on the bus or the train. Sitting more than 1 metre (3 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 2 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 and sweat. The amount of radioiodine in your body will reduce each day, and will disappear over several weeks.

If you sometimes leak urine, please mention this to the clinic nurse who phones you before you come for radioiodine treatment. They will need to give you advice on what to do after 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. The radioiodine treatment is for your benefit, but you will need to take some precautions until the amount of radioiodine in your body is low.

You can avoid this by limiting the time that you spend close to other people. Staying more than 1 metre (3 feet), and preferably more than 2 metres, from other people is usually fine.

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

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.

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. 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 has gone. 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 okay, but sitting next to someone for 2 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, close friends and work colleagues.

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

The dose you are most likely to receive is 600 MBq. The instructions for this dose are listed below in the text boxes. If we need to make any adjustments to these instructions we will discuss this with you before your treatment. **We suggest that you look at and plan for the instructions that you receive before you come for your clinic appointment.** If you need to make extra arrangements you could ask to defer the radioiodine treatment for 1 - 2 weeks.

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 later in the booklet on page 17.

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, avoid close contact from **day 1 to day 25**.

When can I go back to work?

If you go out to work, you will probably need to take some time off. 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. When the clinic nurse calls you, they will ask you about your work so that they 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 – 3 weeks from the day of radioiodine treatment.
- Full-time office worker sharing an office – 2 weeks from the day of radioiodine treatment.
- Half-time shop worker – 1 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 to look after you if you are unwell or disabled unless they are pregnant, but they should follow the instructions as closely as possible.

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 they are aware of the small risk involved, and that they have given their consent. The radiation dose that your partner receives would be about the same as 2 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 them to read and sign the letter which will be included with your appointment letter. It contains some more information for them. Please then bring the letter with you when you come for radioiodine treatment.

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

Travelling abroad by plane or ferry in the next 3 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 3 months of your radioiodine treatment. We can give you a letter stating that you have received radioiodine treatment.

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 during your first appointment, when the clinic nurse calls you. Alternatively, you can:

- Telephone the Nuclear Medicine department on **0161 446 3946**
- Visit our website: www.christie.nhs.uk

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

They produce a useful leaflet 'Antithyroid drug therapy to treat hyperthyroidism'.

The Thyroid Eye Disease Charitable Trust

PO Box 1928, Bristol, BS37 0AX
Tel no: **0844 800 8133**
www.tedct.co.uk

Benefits and finance

Due to your condition, you may have had to stop work and had a reduction in your income. If this is the case, you may be able to get benefits or other financial help.

Personal Independence Payment (PIP) is a social security benefit and has replaced Disability Living Allowance (DLA) for new claimants. It's for people who need help either because of their disability or their illness. You can apply if you are aged 16 or over and have not reached State Pension age. You can apply for DLA if you are under 16.

If you are State pension age or older and need help with personal care or supervision, you could be entitled to Attendance Allowance.

Your carer could get Carer's Allowance if you have substantial caring needs. Find out more today:

- To get a claim pack for Attendance Allowance, call **0345 605 6055** and for PIP call **0800 917 2222**.
- For DLA: If you were born on or before 8 April 1948 call **0345 605 6055**, if you were born after 8 April 1948 call **0345 712 3456**.
- Carer's Allowance: call **0345 608 4321**.
- Contact your local social services department for help with equipment and adaptations, or for an assessment of care needs. Visit www.gov.uk for further information.

Student training

The Christie is a training centre for postgraduate and undergraduate trainees so you may meet students in all areas of the hospital. We train doctors, nurses, radiographers and other therapists in the treatment and care of cancer patients.

Placements at The Christie are an important part of student training, so by allowing them to assist in your care, you will be making a valuable contribution to student education.

Students are always supervised by fully qualified staff. However, you have a right to decide if students can take part in your care. If you prefer them not to, please tell the doctor, nurse, radiographer or other therapist in charge as soon as possible. You have a right to do this and your 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.

If you need information in a different format, such as easy read, large print, BSL, braille, email, SMS text or other communication support, please tell your ward or clinic nurse.

Christie website

For more information about The Christie and our services, please visit **www.christie.nhs.uk**

The Christie is committed to producing high quality, evidence based information for patients. Our patient information adheres to the principles and quality statements of the Information Standard.

If you would like to have details about the sources used please contact **patient.information@christie.nhs.uk**

Notes

Contact The Christie Hotline for
urgent support and specialist advice

The Christie Hotline: 0161 446 3658

Open 24 hours a day, 7 days a week

Visit the Cancer Information Centre

The Christie at Withington **0161 446 8100**

The Christie at Oldham **0161 918 7745**

The Christie at Salford **0161 918 7804**

Open Monday to Friday, 10am – 4pm.

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

The Christie NHS Foundation Trust

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0161 446 3000

www.christie.nhs.uk



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