



Admission for radioiodine treatment

A guide for patients and their carers

We care, we discover, we teach



Contents

Introduction	1
What is radioiodine?	1
What are the benefits of treatment?	2
Why do we mention precautions?	2
Is there any preparation for the treatment?	2
What about my tablets?	2
May I eat and drink normally?	4
Should I tell anyone if I am pregnant or breastfeeding?	5
What shall I bring into hospital with me?	6
Which ward will I be staying on?	7
What other things do I need to know?	7
How is the treatment given?	8
What are the alternatives & side effects?	8
What must I do during my stay in hospital?	9
May I have visitors?	10
How long will the radioiodine stay in my body?	10
How long must I stay in hospital?	11
How may I travel home?	11
Are there any precautions when I go home?	12
What should I do at home?	13
When may I go back to work?	14
Information about husbands/wives/partners or other relatives	14
Can I go travelling?	15
Will I have to have another scan or treatment?	15
Sources of information and support	16
Benefits and financial information	17
Student training	18
Contacts	19

**Please read this booklet carefully
and bring it with you when you
come to The Christie.**

Introduction

We hope that this booklet will answer any questions you may have about radioiodine treatment. Please read the booklet 'Welcome to The Christie' which gives you some general information. However, when you have treatment with radioiodine, there are some extra preparations and precautions which we would like to explain. If you have any further questions please ask the staff.

What is radioiodine?

Radioiodine is a common form of treatment for thyroid disorders that has been used all over the world for more than 50 years.

"Radioiodine" is the name given to a radioactive form of iodine. This slows down the activity of thyroid cells and reduces their ability to grow.

As your doctor will have explained to you, you will have radioactive iodine as treatment for your thyroid cancer. Radioactive iodine is given to you in capsule form and is absorbed in any thyroid cells that remain after your surgery.

What are the benefits of treatment?

The treatment is intended to destroy any thyroid cells that remain after your surgery. Your doctor will have discussed with you what the treatment will involve and the benefits and risks. When you have all your questions answered, we will ask you to sign a consent form.

Why do we mention precautions?

Because the iodine is radioactive, you will be radioactive for a while after the treatment. You will have to stay in hospital, in isolation, until the amount of radioactivity has fallen to an acceptable level.

When you go home, there are some precautions which we have to advise you to take, to protect other people from the remaining radioactivity. It makes sense to reduce everyone's exposure to radiation - including your own family.

Is there any preparation for the treatment?

Yes. There is important advice in the following sections about your medication and diet in the period leading up to your treatment. Your hospital doctor will discuss these with you before treatment begins.

What about my tablets?

Thyroid hormone tablets (levothyroxine and liothyronine (tetroxin)) would affect the radioiodine treatment, so you **may** be asked to stop taking these for some time before and during the treatment. **If** you are asked to stop, your hospital doctor will tell you which tablets you should stop taking and when. You must not take any of these tablets from this date until you are advised to re-start. You may

feel tired or weak when not taking the tablets. This is to be expected and you will feel better once you start taking them again. This will be four days **after** your treatment.

If you have stopped your thyroid hormone tablets, you may experience the following symptoms which are expected and will resolve when you resume the thyroid hormone tablets:

- tiredness
- puffy hands and face
- hair thinning
- constipation
- poor concentration
- feeling cold.

Some people may be suitable for an injection of Thyrogen (Recombinant TSH). This is given so that you do not have to stop taking your thyroid hormone tablets.

Your hospital doctor will discuss all this with you, and it is important to follow the instructions the doctor gives.

Stop taking vitamin or mineral supplements two weeks before treatment, but tell your hospital doctor about this. If you are taking calcium tablets, do not stop taking these unless you are directed to by your doctor.

If you do feel tired, do not drive or operate machinery.

Please bring with you **all 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. Please bring enough with you for the time you are in hospital.

May I eat and drink normally?

Because you are going to have radioactive iodine, we will ask you to follow a diet low in iodine. **You will need to stay on this diet for about two weeks before having your treatment.** Limiting iodine in your diet will reduce the iodine stores in your body, so that when you get radioactive iodine, your thyroid will be “hungry” for iodine and will absorb more radioactive iodine.

You can resume your normal diet 24 hours after your radioiodine treatment.

Do eat

- ✓ Fresh and frozen fruit and vegetables
- ✓ Fresh and frozen meats
- ✓ Rice and pasta
- ✓ Most drinks (except milk)
- ✓ Plain fats and oils such as Sunflower or vegetable oil (non-dairy)
- ✓ Fresh and home-made bread
- ✓ Cola, lemonade, sodas, fruit juices and squashes.
- ✓ Wine and beer

The best way to make sure of the iodine content is to prepare your food from fresh ingredients yourself. Food prepared from any fresh meats, fresh poultry, fresh or frozen vegetables and fresh fruits should be fine, but do not add any of the ingredients listed in the other box.

Try not to eat

- ✗ Sea salt and iodised salt
- ✗ Seafood, fish
- ✗ Egg yolks
- ✗ Milk and dairy products - butter, cheese, ice-cream, yogurt, cream and milk.
- ✗ Long life (part-baked) bread
- ✗ Soya-based products
- ✗ Foods artificially coloured pink with a red food dye (E127), such as **glacé cherries, canned strawberries, salami, and red sweets**
- ✗ Some cough mixtures and health foods (such as seaweed, kelp, cod liver oil, vitamins and mineral supplements) contain iodine. If the label lists iodine, do not take the supplement while on this diet
- ✗ Avoid food from restaurants, fast-food chains, and take aways.

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

Yes please. This is very important.

Women will be asked :

Are you or may you be pregnant?

Are you breast feeding?

You will be asked this before you have the treatment.

If you are pregnant, or even if you think you may be, the treatment must be delayed. Please contact us immediately in advance if you think you are pregnant.

If you are breastfeeding, you must have stopped completely before you have the treatment.

These precautions are to protect your baby.

Also, we must advise you not to become pregnant until at least one year after you have had the treatment.

In general, the treatment should not affect your fertility.

Men are advised not to father a child for at least a year.

If you are sexually active it is very important that you use effective birth control after treatment.

What shall I bring into hospital with me?

Because of the treatment you are having, any personal possessions you bring in with you may become contaminated with radioiodine. This can happen because some of the radioiodine passes out of your body in sweat and saliva. Provided that the items are only used by you, in the first few weeks after you go home, that is fine. It is possible to remove any contamination from some items (for example, mobile phones, laptops) just with a moist wipe. Some other items may need to be stored for up to a few months here at The Christie, before they are returned to you. Nuclear Medicine staff will talk to you about the need for this.

You may wear your own clothes and nightwear. If you do choose to do this, we would recommend that you wash these separately from other clothes, as soon as you get home. Alternatively, we can provide some comfortable clothes for you to wear whilst you are in hospital. Night clothes and towels will be provided.

There will be a small locker in your room. Please do not bring large amounts of money or valuables. You may bring fruit, sweets, biscuits and squash, books, games, mobile phones and tablet or laptop computers. There is a free WiFi network accessible in your room.

Which ward will I be staying on?

Adults will be staying on the Brachytherapy and Molecular Radiotherapy Unit (BMRU). Young people and children will be on the Young Oncology Unit (YOU). You will have your own room and bathroom. You must use this bathroom and toilet during your stay, as some of the radioiodine is passed out in urine. Nobody else may use the bathroom during this time.

The room is comfortable and has a telephone and television.

Before your treatment a member of staff from the Nuclear Medicine Department will visit you to discuss your treatment and radiation protection issues. They will be able to explain more about your stay on the BMRU or YOU, and answer any questions about what you can and cannot do afterwards.

After the treatment, you must stay in your room for a few days. You will read a bit more about this later on.

What other things do I need to know?

- If you wear contact lenses it is best not to use them whilst you are having the treatment. Please bring some glasses with you.
- The Christie has a strict no smoking policy in all areas. You cannot leave your room any time during your treatment. Please see your GP to arrange for nicotine patches if you think this will help. Or your medical team can refer you to The Christie Smoking Cessation service. Please ask if you would like to be referred.
- There is a telephone in your room for making and receiving calls if you do not use a mobile phone. Local calls to landlines are free.

- We will need to plan ahead to make your treatment as trouble-free as possible, and to understand your home situation. To get this information, we will go through a questionnaire with you, or send one to you for you to fill in and return to us, at least one week before your treatment starts. Please make every effort to complete it.

How is the treatment given?

Having the treatment is very easy.

Staff from the Nuclear Medicine Department will bring the treatment to you in your room.

The staff will ask you to swallow a small capsule about the size of an antibiotic capsule, with a cup of water to help it down. It has no taste. If you are unable to swallow a capsule you **MUST TELL** the Nuclear Medicine Department (0161 446 3945) **before** you come to hospital. They will contact you to discuss alternative ways of giving you the iodine.

What are the alternatives and side effects?

Are there any alternatives to this treatment?

In some cases further surgery may be possible and your doctor will discuss this with you.

What happens if I don't have this treatment?

Without this treatment the risk of recurrent cancer would be significant and it may be difficult for your doctor to monitor your cancer through blood tests.

Are there any side effects?

There is a possibility that your neck will swell or your throat

may be sore after the treatment. Your mouth may feel dry because of reduced production of saliva, and the taste of food may change. These effects are usually mild and short-term.

If you do feel sick at all while you are in hospital, or have any other problems, please tell the staff on the ward straight away.

Symptoms such as sore throat and dry mouth may take several weeks to settle down. Your salivary glands (under your lower jaw) may swell during treatment, or some weeks after treatment. These symptoms usually settle down in time.

Longer-term side effects such as reduced saliva production and permanent dry mouth are rare, but your doctor will discuss these with you in advance.

For the period when you stop taking thyroid hormones, you may temporarily experience some weight gain, water retention (puffiness in face and limbs) and tiredness.

What must I do during my stay in hospital?

- Drink plenty of fluids (3 litres per day).
- Flush the toilet twice after use. To avoid any urine splashes we ask gentlemen to sit down when using the toilet.
- If you are constipated please inform the nursing staff.
- Wash your hands before eating, reading or handling items.
- Tell the nurses straight away if you have any incontinence.
- Please use soft tissues rather than handkerchiefs, and flush them down the toilet.

Although you are in a room on your own, the nursing staff will be in regular communication. The nurses will be able to observe you on a TV monitor while you are in your bedroom. They will bring and clear away your meals, but will not make your bed. They are always available if you feel unwell.

May I have visitors?

You are allowed visitors but there are some restrictions.

Following your treatment, you should not have close contact with other people. No one may visit you for the first 24 hours after treatment. After that visits will be limited to 30 minutes a day for each of your visitors. There are no set visiting hours.

You should ask your visitors to stand behind the white shield, or to sit on the opposite side of the room to you during their visit. Visitors must not sit close to you. You should not have physical contact with your visitors or hand them anything such as food or drink. Visitors may not use your bathroom or eat or drink any of your food.

It is important that children under the age of 18 and pregnant women do not visit you during your stay.

How long will the radioiodine stay in my body?

The radioiodine will gradually disappear from your body, mainly in the urine. Also, because radioactivity decays naturally, the amount remaining inside you will reduce each day. How long it takes to disappear varies from person to person. During your treatment we will be making measurements to see how much radioiodine is left in you. This will help us to predict when you can go home.

How long must I stay in hospital?

The time you must stay in hospital will depend on how long the radioiodine stays in your body and who you live with. The average stay is two to four days, but we cannot guarantee this.

Your family circumstances are important. If you live with young children it will not be possible for you to return home to them straight away. If possible, we would suggest that either you or your children stay with a relative for a time after you are discharged. We will be able to advise you on how long you should stay apart from them, when we see how quickly the radioiodine is leaving your body. If you are unable to make arrangements to stay elsewhere you may have to remain in hospital longer, until your radioactivity level is low enough to return home.

How may I travel home?

We will advise you about this. It will depend on how much radioiodine is left in your body when you go home. Generally, you may go home by private car or taxi. If you do, you should sit in the rear seat furthest from the driver.

You may be able to go home by public transport, depending on the amount of radioiodine remaining in your body and on the length of your journey. If it is not advisable for you to use public transport, we will inform you so that alternative transport may be arranged.

Are there any precautions when I go home?

When you are ready to go home, we will give you a card with some instructions about contact with people and especially children. We hope that these precautions don't make life too hard for you. We would rather you have the information in advance, so that you can discuss it with your family if necessary. You may need to take some time off work and avoid public transport and certain social activities.

The instruction card will give advice on precautions in three sections, with specific dates for you. The time periods for which precautions will apply may need to be increased from those suggested below, depending on the outcome of the measurements we take after your treatment.

- The first date is the time you can start to take further journeys on public transport and mix with adults. For most patients this will be between 2 to 5 days after your treatment. See the list in the next section for other advice which applies at and around home until this date.
- The second date is the time when you can resume sleeping in the same bed as your partner. For most patients this will be 5 to 10 days after your treatment. Please see the "Information for husbands/wives/partners" section later in the booklet.
- The third section applies if you live with and care for young children. The date here will depend on the ages of your children, but are normally 7 to 14 days after your treatment. You will be given further advice before your treatment, and we will take measurements after treatment to help us to give you more specific advice.

What should I do at home?

Further precautions to follow until the first date on your card:

- try to stay more than an arm's length from other people and limit the time you spend close to them as much as possible
- avoid public places like shops, cinemas, pubs, restaurants and public transport (after the journey home)
- avoid sexual contact and open-mouth kissing
- avoid food preparation that involves a lot of handling of food that cannot be washed – like making pastry – or wear thin plastic gloves during food preparation
- reserve cutlery for your own use and wash it separately after use
- flush the toilet twice after use. Men should urinate sitting down to reduce the risk of spillage. Take extra care with hand-washing afterwards. Bathroom hygiene is the main way of avoiding contamination of other people
- make sure that no-one else uses your towels and facecloths
- wash your towels and underwear separately from other washing.

When may I go back to work?

In most cases you will be able to go back to work 7 days after your treatment, if you feel well enough.

However, if you:

- work closely with children, for instance as a teacher or nurse, or
- think that a small amount of radiation might affect your job, please let us know, as you may have to stay away from work for longer. If in doubt, please discuss this with us.

Information about husbands/wives/partners or other relatives

If you follow the information and precautions listed in this booklet, the radiation exposure of all your family will be below the national limits for members of the public.

It is permissible for an **adult** family member (except for a pregnant woman) to look after you **before** the time periods shown on your card have passed, for example to look after you if you are unwell or disabled. Also, if sleeping separately is difficult, then it may be that you both choose to share a bed before the suggested times have passed. Because your husband/wife/partner might then receive a higher radiation exposure from doing these things, we must be sure that they are aware of the small risk involved, and that they have given their consent.

If your partner or other family member is or might be in this position, please discuss this with your hospital doctor when you attend the clinic before your treatment. More information is available via the phone numbers listed in the contacts section.

Can I go travelling?

Once you have passed the first date on your card you are able to use public transport. However if you are planning to travel abroad, please tell us.

- We need to ensure that it is safe for you to sit close to someone for the length of your flight. Aeroplane seats are closely packed so we like to check that everything is safe.
- Many airports and ferry terminals now have radioactivity detectors as part of their security systems. In recent times there have been a few cases where people treated with radioiodine have triggered these detectors even though the level of activity in them is well within safe levels. We are happy to provide a letter explaining your treatment that can be produced in the event of any problems. You will need one of these letters if you are likely to travel abroad within the next three months.

Will I have to have another scan or treatment?

A few days after your treatment we may arrange for you to have a whole-body scan. This is to see where in your body the radioiodine has settled and to monitor your progress. If you live with young children we may take another reading to assess when it will be safe to be with them full-time.

Your next appointment, 3 months after your treatment with radioiodine, is to make sure that all is well. All patients have a further scan which will be carried out 8-12 months after radioiodine treatment. Your doctor will discuss this with you in advance.

The treatment may need to be repeated until all the remaining thyroid tissue has been destroyed. Some people need more than one treatment.

Sources of information and support

The British Thyroid Association

www.british-thyroid-association.org

The British Thyroid Foundation

PO Box 97, Clifford , Wetherby, West Yorkshire LS23 6XD

Tel: 0870 7707933

www.btf-thyroid.org

Thyroid Cancer Survivors Association

www.thyca.org

Macmillan Cancer Support

89 Albert Embankment, London SE1 7UQ

Freephone 0808 808 00 00

www.macmillan.org.uk

Cancer information in your language

If English is not your first language, you can speak to a nurse at Cancer Research UK through a qualified interpreter. The service is free and over 170 languages are available on 0808 800 4040.

For the visually impaired: Large print versions of the 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.

Benefits and financial 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.

No new claims for Disability Living Allowance can be made after April 2013 but you may be entitled to Personal Independence Payments.

People over 65 may be able to claim Attendance Allowance.

Find out more:

- Disability Living Allowance or Attendance Allowance, call the Disability Benefits Helpline on 08457 123 456
- Personal Independence Payment (PIP), call the PIP Helpline on 0845 850 3322
- Carer's benefits, call the Carer's Allowance Unit on 0845 608 4321.
- contact The Christie at Withington general and benefits adviser on 0161 446 8539. The Christie at Oldham has a benefits advice session on Thursday afternoons phone 0161 918 7745.
- contact your local social services department
- Macmillan Cancer Support has an advice line on 0808 808 00 00 or www.macmillan.org.uk

Student training

The Christie is a training centre for postgraduate and undergraduate trainees so you may meet male and female 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 the 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.



Please note:

mobile phones can interfere with the treatment equipment. Please look out for signs letting you know if it is safe to use your mobile phone. If you do have one with you, you may need to turn it off.

We hope that this booklet answers most of your questions.

If you have any more questions, or if there is anything about the treatment you don't understand, please ask.

Contacts:

Thyroid cancer clinical nurse specialist

**Tel: 0161 446 8041, or 07919 488152,
or call 0161 446 3000 and ask
for her to be bleeped.**

Nuclear Medicine Department

Tel: 0161 446 3946 / 3945

Clinical Oncology secretary

Tel: 0161 446 3331

Emergency contact for precautions

**Call 0161 446 3000
and ask for Nuclear Medicine contact**

Christie Website
www.christie.nhs.uk

Many of The Christie booklets and a list of UK help groups are available on The Christie website, the address is above. You can also access other patient information sites in the UK such as Macmillan Cancer Support and Cancerhelp UK via the Christie website.

The Christie Clinic

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

Do you have Private Medical Insurance?

Patients with Private Medical Insurance or those who choose to pay for their care can access a full range of treatment at The Christie Clinic. This includes initial consultation, diagnostics, surgical, chemotherapy and radiotherapy treatments in one place.

The Christie Clinic is the Private Patient facility within The Christie NHS Foundation Trust. We work with The Christie NHS Foundation Trust as a joint partnership with HCA International. The partnership means that a share of the profit from The Christie Clinic is invested back into the NHS for the development of care and future service enhancement.

We value our patients as individuals so care is tailored to provide the best possible clinical outcomes; we work with a number of expert consultants who lead this tailored care plan. This consultant will be in charge of your care for the duration of your treatment.

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:** In some instances your insurance company may suggest that you have your care and/or some aspects of your treatment on the NHS. It is your choice. You have paid your premiums. If being treated in the NHS you choose to exercise your private medical insurance or wish to pay privately you may of course do this, but your consultant would guide you as to the best clinical option. Arranging a referral back into

the NHS for your treatments such as radiotherapy may cause some delays in beginning your treatment.

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 accessing our services or if you need a quotation if paying for treatment or if you have private medical insurance and wish to clarify any points.
- Email us: info.christieclinic@hcahealthcare.co.uk

We care for patients at all stages of illness so it's not too late to consider private treatment.

Find out more about us and our services at www.thechristieclinic.co.uk



Visit the Cancer Information Centre:

The Christie at Withington Tel: 0161 446 8100

The Christie at Oldham Tel: 0161 918 7745

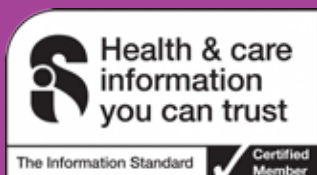
The Christie at Salford Tel: 0161 918 7804

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
January 2014 - Review January 2017