



Admission for radioiodine treatment

A guide for patients and their carers



Contents

Introduction	3
Important dates	3
What is radioiodine?	3
What are the benefits of treatment?	4
Why do we mention precautions?	4
Is there any preparation for the treatment?	4
What about my tablets?	5
May I eat and drink normally?	6
Meal suggestions	8
Should I tell anyone if I am pregnant or breast feeding?	10
What shall I bring into hospital with me?	11
Which ward will I be staying on?	12
What other things do I need to know?	12
How is the treatment given?	13
What are the alternatives and side effects?	13
What must I do during my stay in hospital?	14
May I have visitors?	15
How long will the radioiodine stay in my body?	15
How long must I stay in hospital?	15
How may I travel home?	16
Are there any precautions when I go home?	16
What should I do at home?	17
When may I go back to work?	18
Information about husbands/wives/partners or other relatives	18
Can I go travelling?	19
Will I have to have another scan or treatment?	19
Sources of information and support	20
Benefits and finance	21
Student training	22

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 'A patient's guide 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.

Important dates

Start low iodine diet	
First Thyrogen injection	
Second Thyrogen injection	
Admission and treatment date	
Finish low iodine diet	

What is radioiodine?

Radioiodine is a common, well accepted 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 radioiodine as treatment for your thyroid cancer. Radioiodine 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 we have answered all of your questions, 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. This is to protect other people from the remaining radioactivity. It makes sense to reduce everyone's exposure to radiation – including your own friends and 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?

Most people are suitable for an injection of Thyrogen (Recombinant TSH). This is given so that you do not have to stop taking your thyroid hormone tablets. The team will prescribe these injections when you attend your outpatient appointment. You will be asked to collect these injections from the hospital pharmacy after your appointment and store them in your fridge at home. We will make arrangements for a community nurse to administer these injections on the 2 consecutive days prior to your admission.

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

Thyroid hormone tablets (levothyroxine and liothyronine) would affect the radioiodine treatment. If you are not suitable for a Thyrogen injection, then you will 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 4 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

Stop taking vitamin or mineral supplements 2 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 radioiodine, we will ask you to follow a diet low in iodine.

Why follow a low iodine diet?

A diet which is rich in iodine could interfere with your radioiodine treatment. A low iodine diet aims to reduce your iodine intake before your treatment and helps to maximise your body's uptake of the radioiodine when you receive your treatment. It is not possible or necessary to follow a no iodine diet.

Where is iodine found?

Iodine is found in many foods in varying amounts. It is essential for good health. The richest sources are foods from the sea as well as dairy produce and eggs. In some countries iodine is added to salt. This does not happen in the UK, therefore it is fine to use ordinary table salt, but best to avoid imported food items

How long should the low iodine diet be followed for?

The diet is for a short time only. Evidence suggests that a duration of two weeks is sufficient.

You can return to your normal diet 24 hours after you have received the radioiodine treatment.

What if I eat something high in iodine by mistake?

Eating a high iodine food accidentally is unlikely to affect your treatment. Just carry on with the low iodine dietary advice provided here.

Should I look on the internet for further information?

No, most internet information suggests avoiding all foods that contain salt. This is not necessary in the UK.

If you have any questions or queries please contact the thyroid cancer clinical nurse specialist. If you are taking nutritional supplements please contact your dietitian.

Low iodine foods you can eat freely
✓ Fresh/frozen fruit and vegetables, including potatoes
✓ Cooked green vegetables like spinach and broccoli
✓ Fresh/frozen meat
✓ Ordinary table salt and sea salt
✓ Rice and dried pasta
✓ Fresh bread (including fresh sliced bread)
✓ Non-dairy spread such as Vitalite or Pure or Flora non dairy
✓ Olive oil, vegetable oils and nut oils
✓ Water, soft/fizzy drinks, fruit juices & alcoholic drinks
✓ Tea and coffee without milk
✓ Milk substitutes such as rice, coconut, almond or soya milk (please check labels for ingredients and avoid brands that contain carrageenan which is a seaweed derivative)
✓ Dark/plain chocolate with a minimum of 70% cocoa
✓ Crisps

Foods which should be limited

- ✗ Milk – limit to a maximum of 25ml per day which could be used in tea and coffee (i.e. about 5-7 teaspoons of milk per day)
- ✗ Butter – limit to a very thin scraping (one teaspoon or 5g) per day
- ✗ Cheese – one ounce or 25g once per week
- ✗ Dairy produce like yogurt, dairy ice cream etc. (limit to one portion per week)
- ✗ Egg – one per week only
- ✗ Egg containing products like mayonnaise, custard, fresh egg pasta, egg fried rice, pancakes, Yorkshire puddings etc.

High iodine foods which should be avoided

- ✗ Fish, seafood, seaweed, kelp, laverbread
- ✗ Raw green vegetables like spinach or broccoli
- ✗ Cakes and biscuits containing butter and eggs
- ✗ Milk chocolate and white chocolate
- ✗ Takeaway – meals and fast foods/restaurant foods (as ingredients are unknown)
- ✗ Iodised salt and Pink Himalayan salt if imported/bought outside the UK
- ✗ Vitamins and mineral supplements, nutritional supplements and cough mixtures (unless prescribed by your medical team, for example vitamin D)

Meal suggestions

Breakfast

- Toast with non-dairy spread and marmalade, jam, honey, Marmite
- Porridge made with water or milk substitute (specific brands cannot be suggested as ingredients might be

changed over time by the producer), topped with fruit, honey or syrup

- Cereals with water or milk substitute
- Fresh fruit or fruit salad or grapefruit cocktail
- Cooked breakfast (without eggs) such as bacon, sausages, tomatoes, mushrooms, hash browns, baked beans, toast

Lunch

- Sandwich made with non-dairy spread filled with ham, chicken, bacon or Quorn and salad
- Salad (such as cucumber, lettuce, tomato, avocado, sweetcorn, peas) with olive oil and vinegar (no raw spinach or raw broccoli) topped with chicken breast
- Jacket potato (without butter) with baked beans or chilli con carne
- Beans or tinned tomatoes on toast
- Soup (without cream, butter or milk) with bread
- Couscous with meat, chicken or chickpeas and vegetables such as roasted peppers, courgettes, tomatoes

Dinner

- Spaghetti bolognese
- Pork or lamb chops with potatoes and vegetables
- Steak served with roasted mushrooms, grilled tomatoes, chips or jacket potato
- Roasted meat, vegetables and roasted potatoes with gravy
- Chicken, meat, Quorn or tofu stir fry with vegetables and rice
- Stewed meat (chicken, beef, lamb or pork) with potatoes, carrots and swede

- Chilli con carne with rice and peas
- Jacket potato (without butter) with baked beans, ham or chicken and salad
- Sweet and sour chicken with rice
- Risotto (without cheese) with chicken, butternut squash, peas and sweetcorn
- Curry dishes without cream

Snacks & puddings

- Tinned or fresh fruit, stewed or poached fruit
- Jelly, sorbet, meringue
- Soya dessert or soya yogurt
- Dairy-free custard or single cream alternative
- Vegetable crudités and homemade avocado dip (guacamole) or soya plain yogurt & mint sauce
- Nuts (maximum 30g/1oz per day)
- Sweet or salted popcorn
- Potato crisps or rice cakes
- Dark chocolate

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?

All women of childbearing age (15-55 years) will have a pregnancy test as part of the routine workup for treatment. If you are pregnant, or even if you think you might be, the treatment must be delayed. Please contact us immediately for advice.

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 1 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 4 months. 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.

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 Wi-Fi network accessible in your room.

Which ward will I be staying on?

Adults will be staying on the Brachytherapy and Molecular Radiotherapy Unit (BMRU). Children and young adults will be admitted to the Palatine Treatment Unit. You will have your own room and bathroom. This room is comfortable and has a telephone and television. You must use your room's 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.

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 Palatine Treatment Unit, 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/vaping 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. Alternatively, 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.

- You will be asked to fill in a questionnaire about a week before your treatment. This will make your hospital stay as trouble free as possible and help us understand your home circumstances so we can provide advice on your discharge. 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 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 and no visitors 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 but also in your sweat and saliva. In addition, the natural decay of radioactivity means that 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 2–4 days, but we cannot guarantee this.

Your family circumstances are important. If you live with young children it may 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 short period after you are discharged. We will be able to advise you on how long you should stay apart from them when we know 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, until your radioactivity level is low enough to return home.

How may I travel home?

We will talk with you about this and our advice 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, especially children. You may need to take some time off work, avoid public transport and certain social activities.

The precautions card will divide certain activities into three groups, with specific dates for each group. These dates are personalised to you, and consider the amount of radioiodine left in your body, as well as your personal circumstances.

By completing the pre-treatment questionnaire, you will help us to set these dates appropriately.

- The first date tells you when you are able to return to work. This will depend on the type of job that you do, and the contact that you have with certain groups, i.e. children, adults or pregnant women.
- The second date informs you for how long you should avoid prolonged contact with other adults, including sharing a bed and certain activities in crowded places, such as visiting the cinema, pubs or restaurants and using public transport.
- The third date advises you about any further restriction in close contact if you are a main carer for young children.

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 crowded public places where you will have prolonged close contact with other people, such as 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, for example 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.
- 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 3 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. At this visit we will also arrange for a follow-up scan and blood test to be carried out 9-12 months after your radioiodine treatment. Your doctor will discuss this with you in advance.

Some people need more than 1 treatment. The treatment may need to be repeated until all the remaining thyroid tissue has been destroyed.

Sources of information and support

The British Thyroid Association

www.british-thyroid-association.org

The British Thyroid Foundation

www.btf-thyroid.org

Thyroid Cancer Survivors Association

www.thyca.org

Macmillan Cancer Support

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**. You can also view all patient information on The Christie website in many languages by using the BrowseAloud function.

Contacts

Thyroid cancer clinical nurse specialist

Tel: **0161 446 8041** or **07919 488152**

or call **0161 446 3000** and ask for them 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.

Benefits and finance

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.

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 16–64.

People aged 65 or over who need help with personal care or supervision 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**.
- For benefits advice, contact Maggie's centre on **0161 641 4848** or email **manchester@maggiescentres.org**
The Christie at Oldham has a benefits advice session on Thursday afternoons, call **0161 918 7745**.
- 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.
- Macmillan Cancer Support can give advice on helping with the cost of cancer 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.

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.

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** or visit the cancer information centres at Withington, Oldham or Salford.

We try to ensure that all our information given to patients 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**

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

Wilmslow Road
Manchester M20 4BX

0161 446 3000

www.christie.nhs.uk

The Christie Patient Information Service
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