Radioiodine therapy

This leaflet has been written to provide information for patients and their relatives. We hope this will answer your questions, but it may give rise to others which we are happy to answer.

The multi professional team that will be caring for you consist of a nuclear medicine physicist, oncology consultant, nurse specialist and ward staff.

We hope you find this helpful and welcome your comments, should you have any.

What is radioiodine?

There are several radioactive forms of iodine. The one we use is called Iodine-131 (\(^{131}\)I) and it is used to treat thyroid cancer and other thyroid diseases.

Iodine is part of everyone’s diet and is necessary for the normal working of the thyroid gland. This gland is situated in the neck and controls the speed at which many bodily processes take place. Like ordinary iodine, radioiodine is taken up by the thyroid cells but the radioactivity destroys them. The treatment is painless.

How do I prepare for treatment?

Some patients will stop thyroxine (T4) tablets six weeks prior to radioiodine treatment. It is usual to have short-acting liothyronine (T3) at 20mcg twice a day for one month and then to have two weeks without thyroid hormone replacement. You should obtain a prescription from your GP for the T3 if you do not already have the tablets.

It is important that you follow the instruction regarding stopping the thyroxine medication given to you by your consultant. Please contact the hospital if you are unsure about your thyroxine medication. During this time it is usual to experience symptoms such as dry skin, dry hair, feeling lethargic and depressed all of which can interfere with daily life.

Some patients are unable to stop thyroid hormone replacement and are given an injection of a substance called “recombinant human thyroid stimulating hormone” (rhTSH) on the two days prior to radioiodine. The injection is given into muscle (usually the buttock). The injections can sometimes be given at home or occasionally patients need to come to hospital to have them administered.

The most common side effects associated with recombinant thyroid stimulating hormone are nausea and vomiting, headache, fatigue and dizziness but these are usually mild. Less common side effects include lack of energy, back pain, flu-like symptoms, fever, rash, shivers and a tingling sensation. Rare side effects include palpitations, joint and muscle pain, shortness of breath and water retention.

How is radioiodine given?
The radioiodine is in capsule form and administered by a physicist. The treatment itself involves simply swallowing the capsule. The whole procedure takes only a few minutes.

It is usual to give an anti-sickness tablet half an hour before you receive the radioiodine. This is as a precaution, although most people do not feel sick as a result of the treatment.

### Are there any side effects?

Possible early side effects associated with radioiodine treatment are neck discomfort (some swelling 24 to 48 hours after treatment), taste abnormalities, nausea, acute inflammation of the salivary glands and radiation induced gastritis and cystitis. Side effects vary from person to person; you may have none or several of the side effects described. They are however rare, generally minor and usually temporary. Medication can be given to relieve some of these symptoms.

Late side effects associated with radioiodine are very rare and include a dry mouth, dry eyes and secondary carcinomas or leukaemia.

Please do talk through any of your questions with the consultant or a member of the treatment team.

### What if I become, or am likely to become, pregnant or father a child?

Women are advised not to become pregnant or be breast feeding for six months after radioiodine treatment and diagnostic radioiodine scans. It is very important that you do not have radioiodine if you are pregnant or if you think that you might be. Please let the medical staff know if you are unsure before you have your treatment as a pregnancy test will be undertaken. You should use a reliable contraceptive until all your treatment has finished. In the long-term your fertility will not be affected although there may be a small risk if repeated doses of radioiodine treatment are needed.

If you are breast feeding you should stop this before you have radioiodine treatment.

Men are advised not to father a child for four months after radioiodine treatment and diagnostic radioiodine scans. In the long term your fertility should not be affected but there may be a small risk if repeated radioiodine treatment is needed.

If you do become pregnant or father a child, you will receive counselling from your doctor about the possible risks to your unborn baby.

### What happens on admission?

On the ward you will be greeted and your details will be registered. You will then be issued with a hospital name band to wear with your hospital registration number and a few details on it. One of the nursing staff will take your blood pressure, pulse and temperature as a routine procedure.

You will be given an explanation of the treatment and details about the room you will be staying in. There are two iodine rooms adjacent to each other which have their own en-suite shower and toilet facilities. If you have any concerns about your privacy and dignity we are here to help. Please discuss it with a member of the thyroid team prior to your admission.

You will have the opportunity to ask any questions that you may have. Your doctor will then come and examine you and check that you have stopped taking your thyroid tablets or had...
“recombinant human thyroid stimulating hormone” (rhTSH) injections prior to treatment. Failing to prepare appropriately would interfere with the absorption of the radioactive iodine.

You will be asked to sign a form giving consent for the treatment, if you have not already done so.

You will have blood tests taken to measure thyroid hormone and thyroglobulin levels.

**How long will I be in hospital?**

If you are having a standard dose you will probably need to stay in for three nights. Most patients leave after their nuclear medicine scan on day four. If you are having a low dose then you will only stay for one night, and you will be able to leave after your scan on the afternoon of day two.

You will be asked to drink more than usual during your stay in hospital to help flush any remaining radioactive substance out of the body. Radioactivity also leaves the body in your stools, so it is important that you have your bowels opened regularly. If you do become constipated, please ask the nurse for something to relieve the problem.

**What precautions are taken about the radioactivity?**

The radioiodine leaves the body in urine, stools, saliva and perspiration. Some of the radioactivity may get into your clothing, bedding and anything that you put into your mouth.

Crockery and cutlery will be provided for personal use during your stay. These have to remain in your room so please wash these utensils after your meals using the cleaning materials provided. Anyone entering your room will wear disposable overshoes and other protective clothing and will minimise time spent with you.

- There is an en-suite shower room inside your room and you will be asked to take a daily shower. It is advisable to use hospital towels. Please notify the nurses if your bed linen needs changing. Disposable hand towels are provided, please let the staff know if you run out of these.
- Rinse your toothbrush and washcloth thoroughly after use. You should wash your hands before knitting or reading.
- Do not chew pencils or knitting needles or lick postage stamps or envelopes as traces of radioiodine may be transferred to these items on your saliva.
- Being confined to the bedroom and en-suite can be a lonely experience. Ward staff are instructed to have minimal contact with you because of the radioactivity. It is best to try and prepare yourself for this and bring a few things to do. There is a telephone in the room for incoming and internal calls. The TV is free and allows external calls. DVD players are available on request.
- It is advisable to bring some extra food to supplement the hospital menu, but bear in mind that you will need to adhere to the low iodine diet for 48 hours after treatment. There is a fridge and food storage space in the room. Please discuss any concerns with the staff.
- Once the radioactivity has reached a safe level you may go home. The safe level in your particular case depends on who shares your home and how you intend to return.
What do the physics staff do?
The physics staff are trained in the handling of radioactive substances and in all the radiation aspects of your treatment. A physicist will explain the procedures to you before giving you radioiodine. The physicist will make daily measurements of the radioactivity remaining in your body. They will inform you and the nursing staff when the level of radioiodine has become low enough for you to go home.

Is radioiodine dangerous to others?
In this treatment, radiation will be used for your benefit. There is a possibility that it could be harmful to those with whom you come into contact. To reduce this risk you will be cared for in a single room with your own en-suite facilities. Staff will not be able to stay with you for any longer than is necessary to attend to your needs. If you need special nursing or emergency medical care this will of course be provided. There is a call button by your bed and in the toilet.

May I have visitors?
You are allowed visitors but there are some restrictions. Visitors are not permitted on the first day of your treatment. On subsequent days adults can visit for half an hour. Children under 18 years of age and pregnant women should not visit you because they are particularly vulnerable to the effects of radioiodine. You should not give your visitors anything at all. Please ask the ward staff if you are in doubt about this. Visitors should not eat or drink while near you, nor should they use your toilet facilities.

Will I have any tests while I am in hospital?
When you are admitted you will have a blood test and an examination by a doctor to check your general state of health.

Before you leave you will be scanned in the nuclear medicine department.

What is the nuclear medicine scan?
The scan shows the position of any radioactivity in your body and it helps to measure the progress of the treatment. For the scan to be performed it is necessary for you to lie on a flat surface while the scanner takes pictures of you from above and below. Usually you are free to go home after the scan.

Before any scans you will be asked to have a shower and put on clean clothes. Before you leave the room you must put on a pair of disposable overshoes.

It is possible that your belongings, particularly your clothing and washing things may have become slightly radioactive. While you are having the scan the physicist will check your belongings. Please leave them on the bed and try to separate your clothing and washing things from other belongings.

Are there any restrictions when I get home?
Before you go home you will be seen by the physicist and any restrictions will be explained. You may need to take some time off work and avoid public transport and places of entertainment. You will probably be asked to avoid close contact with other people, particularly children, for a few days. The details will be given to you on your yellow card (the yellow card is issued with the exact details of radioactivity levels and instructions on what the restrictions are for the patients when they are at home).

When you get home wash any clothing, flannels or towels used during your stay separately from the rest of the family’s laundry. This is only necessary for the first wash.

**What may I eat before my radioactive iodine treatment?**

A diet that is rich in iodine can reduce the effectiveness of the treatment. Therefore, **two weeks** before you come into hospital we recommend that you follow the Low Iodine Diet guidelines and advice below:

**Low Iodine Diet**

<table>
<thead>
<tr>
<th><strong>Low iodine foods you can eat freely</strong></th>
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<tbody>
<tr>
<td>✓ Fresh/frozen fruit and vegetables, including potatoes</td>
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<tr>
<td>✓ Cooked green vegetables like spinach and broccoli</td>
</tr>
<tr>
<td>✓ Fresh/frozen meat</td>
</tr>
<tr>
<td>✓ Ordinary table salt and sea salt</td>
</tr>
<tr>
<td>✓ Rice and dried pasta</td>
</tr>
<tr>
<td>✓ Fresh bread (including fresh sliced bread)</td>
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<tr>
<td>✓ Non-dairy spread such as Vitalite or Pure or Flora non-dairy</td>
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<tr>
<td>✓ Olive oil, vegetable oils and nut oils</td>
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<tr>
<td>✓ Water, soft/fizzy drinks, fruit juices &amp; alcoholic drinks</td>
</tr>
<tr>
<td>✓ Tea and coffee without milk</td>
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<tr>
<td>✓ 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)</td>
</tr>
<tr>
<td>✓ Dark/plain chocolate with a minimum of 70% cocoa</td>
</tr>
<tr>
<td>✓ Crisps</td>
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**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 yoghurt, 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
- Take away 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 yoghurt
• Dairy free custard or single cream alternative
• Vegetable crudities and homemade avocado dip (guacamole) or soya plain yoghurt & mint sauce
• Nuts (maximum 30g/1oz per day)
• Sweet or salted popcorn
• Potato crisps or rice cakes
• Dark chocolate

What do I need to bring into hospital with me?
Each room has a telephone, kettle and fridge. The following list of items may be useful:
• Toothbrush and toothpaste
• Washcloth
• Soap
• Shaving kit
• Hairbrush
• Boiled sweets
• Fruit squash or other drinks
• Enough books, magazines or games to last your stay
• Mobile phone use is permitted within the room

Please do not bring towels, they will be provided

Will I have to come back for another treatment?
Some patients need two or more treatments. Your course of treatment depends on your individual case and your hospital doctor will discuss this with you when you return to the outpatient clinic. This attendance is usually about six weeks after your radioiodine dose and occasionally earlier if your doctor wishes to monitor your medication.

Where can I get help?
Contact numbers are listed below for you to call if you still have unanswered questions or problems with regard to your disease or treatment. You can also contact us if you experience any unexpected problems or side effects.

If you think of a question write it down in the space given below when it occurs to you and have the list to hand when you visit the clinic or call it.

If you are planning to travel abroad shortly after radioactive iodine treatment please discuss this with your consultant.

Contact numbers:

**Thyroid specialist nurse – Inge Harrison**
Monday, Tuesday, Wednesday: 01223 348796

**Nuclear medicine physics team**: 01223 217139

**Ward A5 – Weekends/Emergencies**: 01223 216312

**Thyroid Secretary – Hazel Henniker-Horn**:
Mon-Fri: 01223 596182

We are now a smoke-free site: smoking will not be allowed anywhere on the hospital site. For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.

Other formats:

If you would like this information in another language, large print or audio, please ask the department where you are being treated, to contact the patient information team: patient.information@addenbrookes.nhs.uk.

Please note: We do not currently hold many leaflets in other languages; written translation requests are funded and agreed by the department who has authored the leaflet.