Hull University Teaching Hospitals NHS Trust

Queens Centre for Oncology & Haematology

ADMISSION FOR RADIO IODINE ABLATION TREATMENT A guide for patients and carers



January 2021

Great Staff - Great Care - Great Future

This leaflet has been designed in preparation for your admission for radio iodine ablation treatment, providing useful information including what preparation is required and what precautions you may need to take prior to your treatment and post treatment.

IMPORTANT DATES

BEGIN LOW IODINE DIET	
FIRST THRYOGEN INJECTION	
SECOND THYROGEN INJECTION	
ADMISSION FOR RADIO IODINE TREATMENT	

What is Radioiodine?

Radio iodine (R.I) is a radioactive form of iodine. The aim of this is to slow down thyroid cell activity decreasing their capability to produce. Radio iodine ablation is a common form of treatment for thyroid disorders. This form of treatment has been used for over 50 years.

I-131 is a radioactive form of the iodine we eat every day in our diet. The thyroid gland concentrates iodine from the blood and stores it there until it is used by the gland to make thyroid hormones. If we administer radioactive I-131, the radiation emitted by the iodine will destroy the cells around it. For that reason it is often used to destroy any remaining normal thyroid tissue or microscopic deposits of thyroid cancer after surgery to the thyroid gland.

I-131 can also be used to treat thyroid cancer that has returned. You will be required to take a low iodine diet prior to treatment. Your consultant will have discussed the reasons why you have been advised to have

I-131 including what would happen if you chose not to have this treatment. If you have any further questions then you should discuss these with your consultant, or one of their team, before you come into hospital for your treatment.

Low iodine diet

This diet is suitable for people who are to be treated with radioactive iodine. This information leaflet explains the reasons for limiting foods that are high in iodine and suggests low iodine alternatives.

Why follow a low lodine Diet?

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

Where is iodine found?

lodine is found in many foods in varying amounts. It is essential for good health. The richest sources are foods from the sea. Eggs and dairy products also contain iodine. 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 duration of two weeks is sufficient.

Please start your diet on	•

After you have received the radioactive iodine treatment you can return to your normal diet.

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 your dietitian.

If you are taking nutritional supplements please contact your dietitian.

Low iodine foods you can eat freely

- ✓ Fresh/frozen fruit
- ✓ Fresh/frozen vegetables
- ✓ Cooked green vegetables
- ✓ Fresh/frozen meat
- ✓ Ordinary table salt and sea salt
- ✓ Rice
- ✓ Dried pasta
- ✓ Potatoes
- ✓ Fresh bread
- ✓ Non-dairy spread such as Vitalite or Pure or Flora non-dairy
- ✓ Olive oil, vegetable oils and nut oils
- ✓ Water, soft drinks, fruit juices & alcoholic drinks
- ✓ Tea without milk
- ✓ 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 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
- Egg one per week

High iodine foods which should be avoided

- ✗ Fish, seafood, seaweed, kelp, laver bread
- ➤ Dairy produce such as milk, butter, margarine, cheese, yoghurt, ice-cream etc
- ➤ Egg and foods that contain egg yolk for example custard, mayonnaise, fresh egg pasta, egg fried rice
- * Milky coffee and tea, cappuccino, hot chocolate, malted milk drinks
- Cakes and biscuits containing butter and eggs
- * Milk chocolate and white chocolate
- Dried fruit
- 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, topped with fruit, honey or syrup
- 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 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

Snacks & Puddings

- Tinned or fresh fruit, stewed or poached fruit
- Jelly
- Soya dessert or soya yoghurt
- Dairy free custard or single cream alternative
- Sorbet
- Meringue
- 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

Thyrogen injection

What is thyrogen – thyrogen is a recombinant human thyroid stimulating hormone (rhTSH). This means it is similar to natural TSH but is made in a laboratory. You have been prescribed this as a pre-therapeutic stimulation prior to ablation of thyroid tissue remnants.

Thyrogen is administered via an injection into the buttock 48 hours and 24 hours prior to your radio iodine ablation treatment. These injections will be organised for administration by the Head and Neck CNS team.

Once your injection has been prescribed by your consultant, you will need to collect the prescription and pack for the district nurse from the pharmacy at Boots chemist in the Queens centre CHH. Information leaflet on thyrogen will be provided.

Where will treatment be given?

You will be given your treatment in an isolation room which has been specially adapted for patients who have been administered radioactive drugs. This room is called the lodine Suite and is based on Ward 31 in the Queen's Centre for Oncology and Haematology at Castle Hill Hospital.

Once you have had your treatment, both you and your body fluids will contain radioactive material. This material will be giving off radiation similar to X-rays and as a result people around you could get a radiation dose that they do not need.

Also, as your thyroid gland has been removed, there is very little other tissue in your body which will trap the I-131. Almost all of the iodine will pass out of your body over the first few days after your treatment. Most of the I-131 will pass out in your urine, but some will be excreted in your sweat and saliva and it is very important that other people do not come into contact with this.

The lodine Suite has been set up in a way that limits the amount of radiation anyone can receive from you to below the legal limits. It is also easily cleaned so that our staff can remove the iodine from the surfaces and materials in the room between patients.

The suite is set-up to keep you as comfortable as possible during your stay. As well as the standard hospital bed and equipment, the room has an en-suite shower and toilet, a small kitchen area with a kettle and sink, a refrigerator and entertainment equipment. The window in the room looks out over the valley to fields in the background.



The Iodine Suite, Queen's Centre for Oncology and Haematology

The room has been kindly decorated which was donated by the butterfly thyroid cancer trust. The TV and stereo in the Iodine Suite are both free of charge and will receive the majority of free TV stations and non-digital radio stations. The stereo also has a CD player and you are welcome to bring CDs from home to listen to during your stay. Ward 31 also has portable DVD players which you may use to watch your own DVDs.

The room has a telephone which will receive in-coming calls. The ward staff will be able to give you the number of this telephone to pass to your family and friends, on admission. It will also allow you to contact the ward staff if you need anything whilst you are in the room.

What do I need to bring with me?

As the I-131 will be excreted in your sweat, there is the potential that anything you bring into hospital may become too radioactive to take home with you. We ask that you only bring in the minimum of what you will need during your stay so that we do not have to store large amounts of personal belongings.

It is likely that we will need to dispose of your toiletries, so please only bring tester or travel-sized bottles. Razors and toothbrushes also get heavily contaminated so please use disposable versions rather than electric shavers or toothbrushes.

You may find that the room feels cold because you have low levels of thyroid hormone. For this reason you may want to bring in warm clothing and / or bed socks. You will also need a clean set of clothing to travel home in. This should be put in the wardrobe in the room and not used until you are advised that you can go home.

Whilst you are in the room you will need to wear slippers or shoes to avoid contaminating the floor. You can bring your own from home or if you prefer, we can supply disposable slippers.

When will I have my treatment?

On the day you are due to have your treatment you will be asked to arrive on Ward 31 for 08.30am. Once you are at the ward, you will be booked in and a doctor will come to talk to you about your health. You will also have some routine checks including blood pressure and heart rate; swabs will be taken to test that you are not carrying an infection such as MRSA (Methicillin-Resistant Streptococcal aureus). A small sample of your blood will also be taken so that we can test to see what your thyroid hormone levels are.

Once the staff on the ward are happy that you are booked in, the Nuclear Medicine team will come down to start your therapy. This is normally before 11.00am.

What happens when I receive my treatment?

When you are ready for your treatment, a member of staff, normally a Medical Physicist will come to the ward to discuss the procedure with you. The staff member will ask questions about you, your life and your family. This is to make sure that it will be safe for you to have the treatment and so that we can give you the right advice about radiation protection after your treatment. The member of staff will also explain the protection advice and can answer any questions you or your family may have about the treatment. If you have any family members or friends with you, at this point they will normally be asked to leave until visiting time the next day.

If you are a female patient, we may ask to test a sample of your urine to be sure that you are not pregnant. The results of this test will be known straight away and we will tell you the result in private.

Once both you and the member of staff are happy that the treatment is right for you, you will be given the I-131 capsule to swallow with a drink of water. This capsule is similar in size and shape to an antibiotic capsule or a paracetamol tablet and has no taste. It is important that you swallow the capsule whole and do not chew it.

After you have swallowed the tablet, the staff will leave you for about an hour to let the I-131 get into your bloodstream.



The yellow I-131 capsule next to a paracetamol tablet

What happens after my treatment?

Once you have had your treatment you will need to stay in the room for up to four days. During this period of time a member of the Nuclear Medicine team will come every day to see you and to monitor how radioactive you are. These measurements will be used to decide when it is safe for you to go home. The team will normally know the day before your discharge if it will be satisfactory for you to leave.

Due to the possible long-term risks associated with being regularly exposed to patients receiving radiation therapy, the nursing staff will reduce the amount of time they spend with you after you have received your treatment. This does not mean that they will not come and help you if you need anything but they will limit the time they spend with you if it is not urgent.

Can I have visitors?

You may have visitors from the <u>day after</u> you receive your tablet, provided the visitors are:

- Over 18 years of age
- Not pregnant (or possibly pregnant)
- Able to follow the instructions on the door to the room

Daily visiting times on Ward 31 are between 1.30pm and 3.30pm in the afternoon and between 6.00pm and 8.00pm in the evening. Although the visiting periods are two hours long, each visitor will only be allowed to stay for a maximum of an hour per day. You can have more than one visitor at a time, and more than one visitor per session. If your visitors cannot come during the normal visiting hours, the ward staff may agree for them to visit at other times.

When visitors come to see you, they must follow instructions which will be posted on the door. Briefly, these instructions are that:

- the visitor must not pass the yellow and black tape on the floor
- they must wear gloves and aprons when they come into the room
- they must not eat or drink in the room
- they must not take anything away from the room after their visit

Your visitors may bring items in for you such as books, newspapers and food.

How can I occupy myself?

You or your visitors can bring things to entertain yourself such as books, puzzles, CDs and DVDs. You are also allowed to use electronic equipment in the suite including mobile phones, laptops and portable games consoles. However if they become contaminated with I-131 you may not be able to take them home with you again afterwards.

Although sewing, knitting and other handicrafts are permitted, you may not be able to pass them on to others for a while after your stay.

What happens when I am discharged?

When it is safe for you to be discharged, you will be asked to have a shower and to change into your clean going home clothes. We will ask you to put any clothing you have worn during your stay into a bag and to put the bag and the rest of your belongings onto the bed. We will then move you to the day room whilst we check for contamination with a sensitive radiation monitor.

Most belongings can be taken home with you after your stay but some may need to be used only by you for a while. It is likely that your clothing will need to be washed twice, separately from the rest of the laundry when you get home. In some cases items may be too contaminated to let you take them home when you go – normally these items are books or items made of plastic, such as toothbrushes. If the item is small and disposable like a toothbrush we will normally remove it for you. If the item is more valuable or has sentimental value we will store it in a secure location and tell you when it is safe to come and collect it.

We will never stop you using personal items like false teeth, glasses or walking sticks. We will also not place restrictions on important items of jewellery like wedding rings.

When we have finished checking all of your belongings we will bring them to you in the day room. We will tell you if there are any instructions about your belongings and also give you the instructions in writing. We will explain any rules on what you may or may not do when you get home; this is likely to include a few days where you will be asked to avoid contact with other people. You will be given the opportunity to ask questions and given our contact details in case questions come up later.

Finally, we will let the ward staff know that it is safe for you to be discharged. The ward staff will normally give you a discharge letter for your doctor and a supply of the medication you will need once you return home.

Are there any side effects from I-131 Treatment?

Although side effects with I-131 are uncommon, patients' mention that their mouth, throat or neck sometimes feel swollen or sore. If this happens it usually occurs on the second or third day of your stay. Please tell the nursing staff if you experience any side effects as they can provide advice and may give you some medication to ease any discomfort.

Sometimes people find that their sense of taste is slightly altered but this usually improves several days or weeks after your treatment. Citrus fruit sweets, which encourage the production of saliva, can often help but these should only be used 24 hours *after* you have taken your I-131 capsule.

It is very important that I-131 is not given to women who are pregnant or breastfeeding as this can result in a very high dose of radiation to the baby. For this reason we ask that women who are breast feeding stop doing so and move to feeding the baby with formula milk.

After you have had the therapy, we advise both men and women to avoid conception for six months.

If you think that you might be pregnant, if you are breast feeding, or if you are planning to have a child within the next six months, you must contact this department as soon as possible before this appointment

Why do I need to follow the precautions?

Following your ablation treatment visit (treatment with high dose radioactive iodine) we recommend you take certain precautions in order to reduce radiation exposure to others. Whilst there is no evidence that exposure to these low levels of radiation has caused anyone definite harm, a sensible precaution is to keep radiation doses as low as possible. These precautions will help to achieve this.

What are the precautions based on?

The precautions are based on three principles which are explained fully later in the leaflet:

 Distance – the further away you are from other people, the less radiation they will receive. Even an increase of a few meters will greatly reduce the exposure

- 2. **Time** the radiation exposure to others depends on how long you remain close to them. You should try to minimize the time spent in close contact with other people.
- 3. **Hygiene** good hygiene decreases the likelihood that other people will become contaminated with the radioactive iodine that leaves your body. Since most of the radioactive iodine leaves the body in urine, good toilet hygiene and hand washing will reduce the possibility of contamination

How long do I have to follow the rules for?

The exact times during which you need to follow the precautions will be given to you when you attend for your treatment. However, generally we ask you to observe the following precautions for <u>nine days</u> following your treatment:

- Avoid non-essential medical or dental treatments
 By this we mean that non-urgent visits (such as a routine blood test or dental checkup) should be postponed if possible
- Avoid non-essential close contact with other people
 This does NOT mean that you have to completely avoid other people, only to
 restrict the time you spend close to individuals. This may require you not to sit
 next to one person (e.g. whilst watching television) for more than one hour per
 day. You should not share the same bed with other people, including children
- Avoid public places of entertainment (such as pubs, the theatre etc.) or travelling long distances with other people
 The purpose of this is to avoid long periods of contact with another person, for example when sitting next to the same person for a few hours at the cinema or in a restaurant. Journeys of over one hour where you will be in close contact with others (in a car or on public transport) should be avoided
- Rinse the bathroom sink, bath and shower thoroughly after use. Do not share towels or face cloths
 Small quantities of radioactive iodine may leave your body in sweat and saliva so we would like you to take precautions to stop this radioiodine being passed onto others
- Keep the toilet especially clean. Flush it after each use and wash your hands thoroughly. Wipe up any spilled urine with a tissue and flush it away

Since most of the radioactive iodine leaves your body in your urine, good toilet hygiene and thorough hand washing will reduce the possibility of contamination

Drink plenty of fluids and empty your bladder frequently
 This will help speed up the elimination of the excess radioiodine in your body.
 This is the radioiodine that has not been taken up by the remaining thyroid tissue and is therefore not needed for the treatment

We also ask you to take the following precautions for <u>up to 17 days</u> following your treatment

Avoid prolonged close contact with children under 5

We do NOT expect you to avoid all contact with children, only to restrict the amount of time you spend with them. If you have young children at home you should restrict the amount of time you spend cuddling them or having them sit on your knee to less than an hour per day. If this is likely to be difficult it may be worthwhile asking a relative or friend to look after them for this period

Avoid radiation sensitive work

Following your treatment the radiation in your body may interfere with radiation sensitive work (e.g. work with fast photographic films or involving radiation measurements). If you have any concerns about this you should discuss them with us before you attend for treatment

When can I return to work?

Depending on the nature of your job you may need to take some time away from work before returning. If you work with pregnant women, small children or work with radiation or radiation measuring equipment, this may be for three or more weeks. The details will be discussed when you attend for treatment, however please contact us for more information before your appointment if you wish. You will be issued with a sickness certificate to cover this period if required.

Pregnancy, breastfeeding and planning a family

It is very important that radioiodine is not given to women who are pregnant or breastfeeding as this can result in a very high dose of radiation to the baby. For this reason we ask that women who are breast feeding stop doing so and move to feeding the baby with formula milk.

After you have had the therapy, we advise both men and women to avoid conception for six months.

If you think that you might be pregnant, if you are breast feeding, or if you are planning to have a child within the next six months, you must contact this department as soon as possible before this appointment

Sources of Information and support

Macmillan Welfare Support contact number	Free phone: 0808 8080000 www.macmillan.org.uk
Benefits advice (Wilson centre)	(01482) 300303
The British Thyroid Association	www.british-thyroid-association.org
The British Thyroid Foundation	www.btf.thryoid.org
Butterfly Thyroid Cancer Trust	www.butterfly.org.uk

Should you require further advice on the issues contained in this leaflet, please do not hesitate to contact the Nuclear Medicine Department or the Head and Neck CNS Team (01482) 622125 (01482) 461085

General advice and consent

Most of your questions should have been answered by this leaflet, but remember that this is only a starting point for discussion with the healthcare team.

Consent to Treatment

Before any doctor, nurse or therapist examines or treats you, they must seek your consent or permission. In order to make a decision, you need to have information from health professionals about the treatment or investigation which is being offered to you. You should always ask them more questions if you do not understand or if you want more information.

The information you receive should be about your treatment, the alternatives available to you, and whether it carries risks as well as the benefits. What is important is that your consent is genuine or valid. That means:

- you must be able to give your consent
- you must be given enough information to enable you to make a decision
- you must be acting under your own free will and not under the strong influence of another person

Information about you

We collect and use your information to provide you with care and treatment. As part of your care, your information will be shared between members of the healthcare team, some of whom you may not meet. Your information may also be used to help train staff, to check the quality of our care, to manage and plan the health service and to help with research. Wherever possible we use anonymous data.

We may pass on relevant information to other health or social organisations that provide you with care. All information is treated as strictly confidential and is not given to anyone who does not need it. If you have any concerns please ask your doctor, or the person caring for you.

Under the General Data Protection Regulation and the Data Protection Act 2018 we are responsible for maintaining the confidentiality of any information we hold about you. For further information visit the following page: Confidential Information about You.www.hey.nhs.uk/privacy/data-protection

If you or your carer needs information about your health and wellbeing and about your care and treatment in a different format, such as large print, braille or audio, due to disability, impairment or sensory loss, please advise a member of staff and this can be arranged.

This leaflet was produced by the Head and Neck Clinical Nurse Specialist team, Oncology Department, Hull University Teaching Hospitals NHS Trust and will be reviewed in **January 2024.**

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