

Northern Centre for Cancer Care

Initial Radioiodine (I131) Treatment for Thyroid Cancer

This information sheet has been designed to provide you with useful information regarding your admission for Radioiodine (I131) treatment. This leaflet explains:

- Where you will have your treatment
- How your treatment is given
- Special precautions that will need to be taken
- Possible side effects
- Discharge arrangements
- Low iodine diet (Appendix1)
- Patient specific information (Appendix 2)

Why am I having I131?

Your consultant will have discussed the reasons why you have been advised to have I131; including what would happen if you chose not to have this treatment. You will also have been given an information pack in clinic and provided with an opportunity to visit the Nuclear Medicine Department and Ward 35 where you will be having your 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.

I131 is often used to destroy any remaining normal thyroid tissue or microscopic deposits of thyroid cancer after surgery to the thyroid gland. In many studies this has been shown to reduce the risk of the cancer returning and improve survival (Mazzaferri 1997, Mazzaferri & Kloose 2001). I131 can also be used to treat cancer that has returned and still achieve a cure.

It is important to remember that the long-term survival for most patients with papillary or follicular thyroid cancer is excellent.

Where will I have my treatment?

After deciding on the date for your admission, you will receive a letter from Nuclear Medicine Department regarding your admission and whole body scan. On the day of admission you will need to attend Nuclear Medicine Department for blood samples. For females with childbearing capacity a sample of blood will be taken to exclude pregnancy. Pregnant women and those who are currently breast feeding must not be administered radioiodine treatment.

After you are reviewed in nuclear medicine you can make your way to ward 35. You will be met by the ward clerk or one of the nursing staff and then shown to the radioiodine suite. The nurses and doctor will then admit you to the ward, taking blood pressure, pulse and temperature.

Am I nursed in a special room?

Yes, you will usually be nursed in a cubicle that has been specially adapted to care for patients receiving I131. Pictures of the treatment cubicle can be found on the following website www.butterfly.org.uk.

Why do I need to be nursed in a special room?

I131 is a form of internal radiation therapy and once you receive your treatment special precautions must be taken. This is because your bodily fluids will contain the radioactive material and radiation, similar to x-rays, will be emitted from your body. The levels of radioactivity in your body will decrease quickly over a period of days as most of the material is eliminated from the body in your urine. For a few days we care for you in the radioiodine suite to reduce other people's exposure to radiation. Regulations state that members of the public should not receive radiation doses greater than one millisievert (1mSv) in any year as a result of medical exposure to others (Statutory Instrument 1999). To put these risks into context a person living in Newcastle is exposed to two millisieverts (2mSv) of background radiation a year.

What is in the radioiodine suite?

The suite has the following facilities:-

An en-suite bathroom, which includes a wash basin, toilet and shower.

We would advise that you bring travel size toiletries (e.g. soap, shampoo, bath gel, bath gel, toothpaste, tooth brush and make up) as these can be discarded with minimal wastage, when you are discharged from hospital. Disposable razors, sanitary items and top-up items are available on request. Towels are also available but you may wish to bring your own. We are happy for you to use hospital towels as bath mats.

While you are in hospital we would advise that you undertake the following measures in order to help remove unwanted radioactive iodine from your body.

- Have a shower each day.
- Drink between two to three litres of fluid a day (After your capsule)
- Empty your bladder regularly e.g. every three to four hours, while also being careful not to splash urine outside the toilet basin.
- Empty your bowels each day.

A small kitchen area. You may be asked to share your kitchen facilities with another patient who is having the same or similar treatment.

Meals will be placed on the bench in the entrance of your cubicle. A sink, washing up liquid and bowl are provided in the kitchen to enable you to wash your own cutlery and crockery, as this needs to remain in your room. Unwanted food should be disposed of using the waste disposal unit in the kitchen sink.

There is a small refrigerator in your cubicle and you may wish to bring a supply of mineral water, squash or fruit and other items that you are able to eat while on a low iodine diet. Although tea and coffee making facilities are available in your room, including a kettle, please advise the ward staff if you require any additional supplies of tea, coffee, milk or sugar. You will have been advised by your Consultant to eat a low iodine diet for two weeks before and 48 hours after your treatment (Appendix 1). Although in most cases you will be able to select your meals from the ward menu this may be influenced by any additional special dietary requirements you may have e.g. vegetarian. Please contact the ward before your admission if you have any additional dietary requirements which they will need to take into account during your stay.

Patient line. Unfortunately this is not available in your cubicle. There is however a TV and DVD player in your cubicle which you do not need to pay to view. There is no telephone service.

Loan equipment. A hairdryer and CD player are available for you to use while you are in hospital. Please feel free to bring your own CDs from home.

When will I have my treatment?

Your treatment will be given to you in your room on the afternoon of your admission, usually at about 3pm.

How is I131 treatment given?

The nurses will ask you to eat and drink nothing for two hours before and after your treatment. The Nuclear Medicine staff will give you a capsule, similar in size to an antibiotic capsule and ask you to swallow it with a drink. It is very important not to bite it.

What will happen after I have had my treatment?

You must stay in the radioiodine suite. The usual stay is three days and each day the Nuclear medicine staff will take a radiation measurement, using a hand held monitor, to help us to determine how much radioactive iodine is left in your body. These measurements are used to help us decide when you can leave hospital. 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. On the day of your admission the nurse will discuss ways in which we can provide 24-hour surveillance and establish how regularly you would like us to check on your condition, during the day and night. We will however try to ensure that one nurse is responsible for your care each day.

What are the visiting arrangements?

Visiting hours are usually between 2pm and 4pm or 6pm and 8pm. However Ward 35 Sister has agreed to open visiting for radio iodine treatments due to the restrictions set. Under 18s and pregnant women should not visit, as they are more sensitive to the effects of radiation.

The daily radiation dose rate measurements, recorded by the Nuclear medicine staff, are used to calculate how long your visitors may stay each day. Visiting is usually restricted to about 30 minutes per visitor on the first day of treatment but this will increase during the period of your stay. The Nuclear medicine staff will provide you with information regarding daily restriction and this will be recorded on a white board outside your room.

Although visitors may enter your suite they must stay in the blue area marked on the floor, which is inside the first door leading to your suite. It is important that you do not give your visitors anything to take out of your room.

Will I experience any side effects with I131 treatment?

When you stop your thyroid hormone you can feel lethargic, weak and tired and we would advise that you take sufficient rest. We would also advise that you do not drive or operate machinery when you stop taking your thyroid hormone replacement (T3 & T4) and for the first two or three weeks after your I131 treatment as it takes a few weeks for your thyroxine levels to return to normal. When your thyroxine levels are low (hypothyroid) you can feel very cold, particularly at night, and it is worth bringing some warm clothes into hospital with you, including bed socks.

Although side effects with I131 are uncommon, patients can say that their mouth, throat or neck feels 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 I131 capsule.

How can I try to prevent myself from becoming bored?

You or your visitors can bring in items from home e.g. books (not library books), magazines, newspapers games and jigsaws. Although sewing and knitting are permitted, items should not be passed onto anyone else for several weeks.

What will happen on the day I am due to leave hospital?

On the day you are due to leave hospital, we will ask you to take a shower and place hospital towels into the laundry bag provided. You can take your own clothes and towels home with you. Just wash them separately when you get home in order to remove any traces of radioactive iodine.

A member of staff from the Nuclear medicine department will visit you on the ward in the morning to record your radiation dose rate measurement. As you will still have a small amount of radioactive iodine in your body this measurement will be used to provide you with personalised information which will be given to you in the form of a yellow card. You will probably be advised to avoid close, prolonged, contact with other people for another day or two (Eg: Sleep in a separate bed from a partner) and to avoid close, prolonged, contact with small children and pregnant women for a few days.

You will also be advised to avoid having any blood samples taken for 4 weeks after your treatment, unless they are absolutely necessary. You will be given a letter containing this information which you must give to your GP.

If you are planning any long distance travel, especially by air, in the next month or so, please discuss this with your Nuclear medicine team.

The nursing staff will give you some thyroid hormone replacement tablets that have been prescribed by your consultant. As these should be started 48 hours after you take your I131 capsule, you will need to begin taking them on the day that you go home. They will also give you a letter for your GP with information regarding your treatment and contact details. Your follow up will be approximately eight weeks later and will be arranged prior to your discharge. You will be asked to return to the hospital a week after your treatment to have a body scan, which will take approximately 50 minutes to complete.

Going back to work

If you're planning on going back to work it is important to discuss this with nuclear medicine department to establish when you will be safe to do so. You may also still feel very tired after radio iodine treatment if you have stopped taking your thyroid hormones. You will need to discuss with your GP to assess how you feel and whether you are fit for work.

What if I experience any problems when I go home?

If you experience any problems within seven days of leaving the hospital then we would advise that you contact either the Thyroid Nurse Specialist or your consultant's secretary during normal working hours. At all other times please contact your GP.

Thyroid Nurse Specialist	0191 213 7112
Dr Mallick's Secretary	0191 213 8467
Ward 35	0191 213 7035
Hospital Switch Board	0191 233 6161

Family planning

Men - If you are considering have a family in the future please tell your doctor as this treatment can sometimes make some men infertile. If your partner is of childbearing age we would advise that you use contraceptives for 4 months after your treatment as I131 may harm a developing baby.

Women - As I131 may harm a developing baby if you are of childbearing age we would advise that you use contraceptives before and for 6 months after your treatment. You should inform your hospital doctor if your period is late and you think you may be pregnant either before, or within 6 months of having had your treatment.

If you have any further questions regarding your forthcoming admission please do not hesitate to contact your Thyroid Nurse Specialist or your consultant's secretary or the staff on the ward.

More information...

Butterfly Thyroid Cancer Trust is the first registered charity in the UK solely dedicated to the support of people affected by Thyroid Cancer. The charity has a network of thyroid cancer patients who can offer information, support and encouragement to others affected by the disease. A member of the organisation is usually available in the oncology Thyroid Clinic.

Telephone: 01207 545469

Email address: enquiries@butterfly.org

www.butterfly.org.uk

The British Thyroid Foundation is a patient-led charitable organisation dedicated to helping those with thyroid disorders.

<http://www.btf-thyroid.org/>

The British Thyroid Association is a Society of Health Care professionals who care for patients with thyroid disease in the United Kingdom who also provide information to patients via their website.

http://www.british-thyroid-association.org/patient_info.htm

Cancer BACUP is a registered charity providing information about all aspects of cancer as well as emotional support for cancer patients and their families.

Telephone: 0808 800 1234

<http://www.cancerbackup.org.uk/Home>

The Northern of England Cancer Network provides basic and easy to understand information on subjects of interest to cancer patients, their families, friends and carers.

<http://www.cancernorth.nhs.uk/home>

They have also set up a number of **Patient Information Centres** with a Centre Manager and trained volunteers to give support and advice. The Cancer Information Centre is based at the Northern Centre for Cancer Treatment and is situated in the main patient waiting area.

Telephone: 0191 2563596 during office hours (answer phone service at all other times).

National Cancer Institute coordinates the United States National Cancer Program which conducts and supports research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and the families of cancer patients. Their website offers the general public and health professionals consumer-oriented information on a wide range of topics

<http://cancer.gov/cancertopics>

References

Mazzaferri E.L (1997) Thyroid remnant I131 ablation for papillary and follicular thyroid carcinoma. Thyroid. 7; p265-271.

Mazzaferri E.L & Kloose R.T. (2001) Current approaches to primary therapy for papillary and follicular thyroid cancer. Journal of Clinical Endocrinology and Metabolism. 86; p1447-1463.

Statutory Instrument (1999) No 3232 The Ionising Radiation Regulations 1999. London. HMSO. <http://www.legislation.hmso.gov.uk/si/si1999/19993232.htm#6>

Information produced by M. Vincent in collaboration with Medical, Nursing and Medical Physics staff together with ButterflyNorthEast March 2005. Updated December 2009 by J Burton in collaboration with the above.

Updated March 2011 by N J Armstrong.

Review date: March 2013.

Appendix 1

RECOMMENDED DIET FOR TWO WEEKS BEFORE APPOINTMENTS FOR THYROID TESTS AND TREATMENTS

To ensure the effectiveness of the treatment and/or the result of the diagnostic test we recommend a well balanced diet that is low in Iodine. Therefore for two weeks before your appointment please follow the advice given below.

<u>DO EAT</u>	<u>TRY NOT TO EAT</u>
<ul style="list-style-type: none">• Fresh and frozen fruit and vegetables• Fresh and frozen meats• Rice, pasta and potatoes• Soft drinks, fruit juices, beer, wine, tea, coffee and soya milk• Plain fats and oils (non-dairy)• Olive oil spread• Fresh and homemade bread <p>The best way to ensure to make sure of the iodine content is to prepare your food from fresh ingredients listed in the box. Table salt and sea salt with no added iodine may be used. Please do not stop taking any of your regular medicines without speaking to your Thyroid Team.</p>	<ul style="list-style-type: none">• Seafood and Fish• Cow's / goat's milk, cheese, ice cream, yoghurt and butter• Egg yolks• 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 takeaways

Appendix 2

Patient Specific Information

Date when you need to change to from T4 to T3 (if applicable)

____/____/____

Date when you need to start your low iodine diet

____/____/____

Date when you need to stop T3

____/____/____

Date when you need Thyrogen injections (If applicable)

____/____/____ ____/____/____

Date of admission. To attend Nuclear medicine first then ward 35 at 10am

Date ____/____/____

Date of post treatment whole body scan

Date ____/____/____