

Admission for radioiodine treatment

Information for patients with
thyroid cancer



Who is this leaflet for?

This leaflet is for patients who are due to have radioiodine treatment for thyroid cancer. It explains what the radioiodine treatment involves and aims to answer some of the most commonly asked questions and concerns.

Although the following information cannot deal with every issue and is not meant to replace discussions between you and your medical team, it is hoped that you can use this as a guide to help you with what is discussed.

What is radioiodine treatment?

Radioiodine is the name given to a particular type of radioactive iodine (iodine-I¹³¹) which is used in the treatment of thyroid cancer. Radioiodine treatment for thyroid cancer has been widely used all over the world for more than 60 years.

Your doctor has prescribed radioiodine as part of your treatment for thyroid cancer. This involves swallowing a small capsule containing radioactive iodine, which is absorbed into any thyroid cells that remain after your surgery. Radioiodine slows down the activity and reduces the ability to grow of the remaining small amount of normal thyroid tissue and also any thyroid cancer cells.

This radioiodine treatment will make you radioactive for a short time, therefore you will need to be admitted into hospital and stay in your own specially prepared room for between 1 and 3 days, depending on the dose received. Although the radioiodine is unlikely to make you feel unwell there are some possible side effects, which if you do experience any, are usually mild and short-term.

What are the benefits of radioiodine?

Your doctor will have a discussion with you about what this treatment involves including the benefits and the risks. When you have had all of your questions answered you will be asked to sign a form giving your consent for the radioiodine treatment.

Radioiodine given after a thyroid operation has been shown to reduce the risk of thyroid cancer returning.

Another benefit is that it allows for close monitoring of your blood test results during your follow up with the thyroid team doctors.

Radioactive iodine can also be used as a therapy for this cancer if it returns. It is important to remember that thyroid cancer is highly treatable and cured in around 96% of cases. Even patients who cannot be cured can live for decades with few problems.

Is having radioiodine safe?

Radioiodine has been used in the treatment of thyroid cancer for over 60 years and has been very well researched. This treatment is regularly reviewed and current evidence suggests there is a very small increased risk of developing a second cancer. This tends to be later in life for patients who have received higher doses of radioiodine, but with people living longer, the risk of second cancers is growing for everyone.

It is important to balance this risk against the benefits in treating your thyroid cancer.

You will also be asked to follow some simple precautions which are intended to protect people, with whom you come into close contact, by reducing unnecessary exposure to radiation particularly for small children and pregnant women. These precautions are explained in more detail later in this leaflet.

How is radioiodine given?

It is given as one small capsule which is swallowed with water. This capsule is similar in size and shape to an antibiotic capsule and is taste free. It is important for you to swallow the capsule whole and not to chew it. Please let us know as soon as possible if you have any difficulty in swallowing capsules or tablets.

Why do I need to come into hospital for radioiodine?

For up to three days after you have taken the radioiodine capsule the radiation levels within your body are at their highest. During this time it is necessary for you to stay in your own specially prepared room with your own en-suite shower, wash basin and lavatory.

This is to ensure that the people around you do not have unnecessary exposure to radiation.

Not all of the radioiodine is taken up by your thyroid cells and during the first three days most of it will pass out through your bodily fluids, mainly in your urine. A much smaller amount will also be present in saliva, tears, nasal secretions, sweat and faeces.

External radiation is also emitted from the radioiodine in your body and is at its highest rate whilst you are in hospital.

Once the radioiodine has been administered you will need to remain within your hospital room. If you need urgent medical care in this time, we can safely do this. In the unlikely event of a ward emergency you would be able to leave your room and be evacuated. Once the radioactivity in your body has fallen to an acceptable level you can go home.

Are there any side effects?

Radioiodine treatment is generally well tolerated – however some people can experience the following side effects in the first few days:

- discomfort in the front of the neck, which can be relieved with simple pain killers such as ibuprofen or paracetamol
- as salivary glands will take up some of the radioiodine, it may cause them to swell slightly with some soreness. This can also be relieved with simple pain killers
- a temporary change in your sense of taste, which may cause foods to taste less flavoursome. This should gradually improve over 4-6 weeks
- a feeling of nausea, which can be relieved with anti-sickness medication
- soreness inside the nose is possible a couple of weeks afterwards (as if you have a cold). This gets better quickly.

Side effects in the months following treatment tend to occur in patients who have received higher doses of radioiodine and may include:

- a temporary dry mouth due to a reduction in the amount of saliva produced

- rarely, a permanently dry mouth can occur
- recurrent salivary gland swelling and pain.

How can these side effects be kept to a minimum?

Whilst you are in hospital it is advisable to:

- drink plenty of fluids during your admission. As a guide aim for a tumbler of water every waking hour
- regularly empty your bladder
- avoid constipation. It is advisable to take a laxative if you have not had a bowel movement within 24 hours of taking the radioactive iodine
- chew gum or suck a sour sweet (a sugar-free variety is advised) once every waking hour following your radioactive iodine to encourage your salivary glands to keep working. Although this is recommended at this centre, it remains open to international debate if the use of gum or sour sweets actually helps.

Can I have radioiodine treatment if I am pregnant or breastfeeding?

No. You must inform us if you are pregnant or if you think that you may be pregnant. You also must inform us if you are breast feeding or have recently stopped breast feeding.

Pregnant women or women who are breastfeeding **cannot** have radioiodine as it will harm the unborn baby or a baby who is being breast fed.

As a precaution, women up to the age of 55 years will be asked about the possibility of being pregnant and a routine urine pregnancy test performed. If there is any doubt your radioiodine treatment will need to be rebooked. If you are breastfeeding you will need to have stopped for at least eight weeks before your radioiodine treatment and not start again afterwards. You will be able to safely breast feed babies from future pregnancies.

Women who are sexually active are advised to use an effective form of contraception during the weeks before radioiodine treatment through to six months afterwards.

Will my fertility and any future pregnancies be affected by radioiodine?

Female fertility should not be affected in the long term even after repeated doses and it does not affect future pregnancies or the health of these children.

How long should I wait before I become pregnant?

Following radioactive iodine it is important to avoid becoming pregnant for a minimum of six months.

If you miss a menstrual period or have a concern that you might have become pregnant during the six months after your radioiodine please contact a member of the Thyroid team or your GP without delay.

Can I father children after radioiodine?

Men are advised to use a reliable form of contraception from the time of your treatment until four months afterwards. Male fertility should not be affected in the long term.

If repeated radioiodine is needed there is a small risk of reduced fertility, and in this situation there is the option of sperm banking. Please discuss this with your consultant as specialist advice and help is available.

What about sexual activity?

Male and female patients are also advised to use a barrier form of sexual protection, such as a condom, for 7 days after having radioiodine treatment. This is in addition to your usual contraceptive.

Is there any preparation for radioactive iodine?

Yes. There are two main parts to your preparation: a low iodine diet and Thyrogen injections.

What is a low iodine diet?

Some studies have shown that reducing iodine intake may improve the effectiveness of this treatment. Therefore for 10 days before coming into hospital until after the radioiodine has been given, we advise a low iodine diet.

Eat freely	Fruit	Rice	Water	Olive oil
	Vegetables	Pasta	Juice	Non-dairy spread
Limit	Meat	Bread	Black tea /	Crisps
	Table salt	Potatoes	coffee	
	Milk substitutes eg rice, coconut, almond or soya milk			
Limit	Milk (25 ml per day)		Cheese (25 g per week)	
	Butter (5 g per day)		Egg (one per week)	
Avoid	Fish / seafood, seaweed, kelp, laverbread			
	Sea salt / Himalayan salt / iodised salt			
	Supplements containing iodine			
	Cough mixture			
	Foods that contain eggs / dairy, e.g. cakes, custard, milk/white chocolates, mayonnaise			
	Foods coloured with E127 eg glacé cherries			

Please do not feel anxious about the diet. It is not necessary to limit yourself other than what has been listed. Radioactive iodine treatment was used successfully in the UK for many years before the diet was introduced.

What are Thyrogen injections?

The levothyroxine dose that you are taking keeps your TSH (thyroid stimulating hormone) level low. To help ensure the effectiveness of the radioiodine your TSH level needs to be raised and this is achieved by administering Thyrogen. Thyrogen is a manufactured thyroid stimulating hormone (TSH).

Thyrogen is given as two separate injections into the buttock muscle, the first at 48 hours and the second at 24 hours before the radioactive iodine is given.

You will be asked to attend the Nuclear Medicine department, on the two days prior to your treatment for the Thyrogen injections. Please allow 30 minutes for these appointments, which are usually on a Monday and Tuesday morning.

Please continue to take your levothyroxine as prescribed throughout your radioiodine treatment.

Female patients will be asked about the possibility of being pregnant and a routine pregnancy test performed before the first Thyrogen injection is administered.

Does Thyrogen have any side effects?

Like all medicines Thyrogen can cause side effects, although not everybody gets them. The most commonly reported side effect is nausea (affects one person in 10). Less commonly reported side effects are headache, tiredness, vomiting, dizziness, weakness and diarrhoea.

Can I drive after Thyrogen injections?

Some patients may feel dizzy or have headaches after administration of Thyrogen which may affect the ability to drive and use machines.

What happens after the Thyrogen injections?

On day 3, which is usually a Wednesday, you will come into hospital to have your radioiodine treatment. Please report to Nuclear Medicine first before going to the ward.

Should I keep taking my other medication and tablets?

If you are taking any other medication such as calcium supplements and Vitamin D tablets for hypoparathyroidism or any other medication you should carry on doing so.

Please bring a small supply of your medicines with you on admission and show it to the doctor and nurse team.

What should I bring into hospital with me?

Due to the treatment you are having, any personal possessions you bring with you may become contaminated with radioiodine. Covering them with cling film or using the supplied gloves will protect them.

If contamination occurs a moist wipe may be able to remove it. However, please bear in mind that some items that are significantly radioactive will need to be stored in the Nuclear Medicine department for a short time after you go home.

Any clothing or footwear which is worn during your radioiodine admission will need to be laundered separately on a long cycle in a washing machine as soon as you return home.

Because of this please bring in a minimum of items for your 3-day radioiodine admission, for example:

- a small number of toiletries preferably travel sized eg soap, shampoo, toothpaste and make up
- towels can be provided, although you may bring your own if preferred
- disposable tooth brush, to leave behind
- disposable razors
- a change of clothes. It is a good idea to bring in comfortable clothing which can be layered
- slippers which are machine washable or disposable
- sour sweets and chewing gum (sugar free is advised)
- fruit, sweets, and other food and drink that do not need to be stored in a fridge
- Levothyroxine and all other tablets and medicines that you are taking
- a small amount of cash
- spectacles if worn. If you wear contact lenses it is best not to use them whilst having this treatment
- throwaway books and magazines
- throwaway games, playing cards or jigsaw puzzles
- mobile phone
- tablet or laptop computer.

Will I be able to smoke during my admission?

The Royal Cornwall Hospital has a strict no smoking policy in all areas and you will be unable to leave your room to smoke. This includes electronic cigarettes. Please see your GP to arrange for nicotine patches or gum if you think this might help. Alternatively your medical team can refer you to the Cornwall and Isles of Scilly Stop Smoking Service. Please ask if you would like to be referred.

Will I have a television in my room?

Your room has a bedside entertainment and telephone unit. You can use this to access various free and paid-for services, including radio, TV, movies, internet, phone and text message facilities, games and hospital information. This is operated by Premier Bedside.

What happens on the day of my radioiodine admission?

1. At the arranged time, which is usually a Wednesday morning, please report to the Nuclear Medicine department.
2. Here the duty doctor will see you to take some notes regarding your admission for this treatment, check your medication and answer any questions you might have.
3. Female patients up to the age of 55 years will be asked about the possibility of being pregnant and a routine urine pregnancy test performed.
4. You will then be shown to your room on the ward and introduced to the staff looking after you.
5. The Nuclear Medicine team will then come to the ward to administer your radioiodine capsule. You are welcome to have an adult family member or friend with you until this point.

What happens when I have my radioiodine capsule?

Before having this treatment the Nuclear Medicine team will ensure that all of the necessary checks have been completed, confirm that you have no further questions and go through the form you have signed giving your consent for this treatment with confirmation that you still wish to proceed.

What happens at meal times?

Throughout the day meals and drinks will be brought to your room. These are served using disposable tableware and should be thrown away in the yellow bin after use. Seal any unwanted food in a plastic bag and placed in the yellow bin.

Each day you will be asked to complete a menu for your meals the next day and it is important you let us know of any dietary requirement that you may have, for example gluten or lactose free.

May I have visitors?

You are allowed visitors but there are some restrictions.

- No one may visit you for the first 24 hours following treatment.
- After that visits are limited to 30 minutes a day for each of your visitors. Visiting hours: 2pm to 4pm and 6pm to 8pm.
- The distance between you and your visitors must be kept to a maximum.
- Visitors may sit on the ward side of the white screen at the entrance to your room.
- You cannot have physical contact with your visitors or hand them anything such as food or drink.
- Visitors must not eat or drink during their visit.
- Visitors cannot use your en-suite facilities.
- It is important that any visitors are 18 years or older, and pregnant or breast feeding women do not visit.

How can I help with the radiation precautions whilst in hospital?

Staff will spend only short periods of time in your room. When they bring in your meals and drinks they will stand at the doorway behind the white screen. They won't stay and chat for long periods of time but do not hesitate to contact them if you need anything.

There are a number of precautions that you can take to help:

- where possible, try to maintain a distance of 3 metres (9 feet) from staff and visitors
- wash your hands regularly with running water and soap rather than using a hand sanitiser
- wrap items such as a laptop or mobile phone in plastic or handle them with examination gloves provided by the hospital
- if you use examination gloves, after removing them it is important to wash your hands using running water
- if possible have a daily shower and wash your hair
- please take care not to splash water outside of the hand basin when washing and particularly when brushing your teeth

- thoroughly rinse your wash cloth and toothbrush
- please use soft tissues rather than handkerchiefs and dispose of them in the bin provided
- empty your bladder regularly and empty your bowels each day
- if you are constipated please inform the nursing staff
- after using the lavatory please flush twice
- to help avoid splashes men are advised to sit down when urinating.

When will I be able to go home?

Throughout your admission the Nuclear Medicine team will come and see you twice a day and monitor how much of the radioactive iodine remains in your body.

These measurements are used to confirm when it is safe for you to go home, which is usually two days after your admission (usually a Friday). They are also used to work out how long you need to follow contact restrictions with other people when you go home.

How may I travel home?

If possible please return home in a private car or taxi, without additional passengers. Please sit diagonally opposite the driver in the rear seat. If this is not possible you may be able to return home by public transport and we will advise you about this.

What are the contact restrictions?

There are some simple precautions we ask you to take that will ensure the radiation dose to other people will be below the national limits for members of the public:

- try to keep more than 2 meters (6 feet) apart from other people
- limit time spent at an arm's length with people as much as possible
- avoid crowded places such as shops, cinemas and restaurants
- avoid using public transport
- sleep alone
- avoid sexual contact and open-mouth kissing

- avoid making meals for other people that involves a lot of handling of the food during its preparation
- reserve cutlery for your own use and wash it separately after use
- flush the lavatory twice after use. Men should urinate sitting down to reduce the risk of spillage.
- take extra care with washing your hands after using the toilet. Bathroom hygiene is the main way of avoiding contamination of other people
- make sure no one else uses your towels and facecloths.

When you are ready to go home, we will give you a letter listing the dates that apply to your particular circumstances for when these precautions end. Please keep this letter with you until the very last date is reached. Usually these precautions would be for 5-7 days with adults and for 7-10 days with children and pregnant women. If you plan to go abroad you will need to keep the letter for 80 days to show airport staff.

What if I have young children at home?

If you live with young children it may not be possible for you to return home to them straight away. We would suggest that either you or your children stay with a relative for a time after you are discharged.

As well as mainly leaving your body in your urine, the amount of radioiodine inside you will also reduce each day by natural radioactive decay. How long it takes to reduce to a level that allows you to return to your children varies from person to person. We will take measurements after treatment to help us give you more specific advice.

If you live with a pregnant woman we will advise you about the precautions you should take.

What follow-up will I need?

Within a few days after your treatment the Nuclear Medicine department will arrange for you to have a whole-body scan. This is to assess where in your body the radioiodine has settled and to monitor your progress. A follow-up outpatient's appointment will also be arranged for around 4-6 weeks after your treatment.

Any questions?

If you have any concerns or need advice please do not hesitate to contact the Specialist Thyroid Radiographers in Nuclear Medicine on:

01872 252330 or 01872 252346

Radiographers: Christine Histon or Joy Williams.

Further information

Butterfly thyroid cancer trust

www.butterfly.org.uk

01207 545 469

MacMillian Cancer Support

www.macmillian.org.uk

0808 8080000

British Thyroid Foundation

www.btf-thyroid.org.uk

01423 709707 or 709448

British Thyroid Association

www.british-thyroid-association.org

01423 810093

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