

British Thyroid Association Patient Information Leaflet 4: Radioactive iodine ablation and therapy

Radioactive iodine (RAI) may be used to destroy any remaining thyroid tissue in the neck after a thyroid operation. This is known as 'RAI remnant ablation' (RRA). Radioiodine "therapy" is the use of radioiodine to treat any thyroid cancer that is known to be left behind after surgery (for instance in the neck or lungs), or that has recurred after initial treatment.

The treatment consists of swallowing RAI usually as a capsule. RAI is used in the treatment of thyroid cancer because under normal circumstances the thyroid gland acts as an iodine store in the body. When we eat iodine in our diet it is taken up by the thyroid gland and used to make thyroid hormones and stored in the thyroid gland. This means that we can use iodine in a radioactive form to target any remaining thyroid cells and destroy them.

You will need to be admitted into hospital and stay in a specially equipped room (sometimes called the iodine suite, isotope room or isolation room) in order to receive RAI. You can ask to see the room beforehand. In some centres photos or a DVD may be available to show the room and facilities.

Is RAI treatment safe?

RAI has been used to treat thyroid cancer safely for over 60 years. There is a very small increased risk of developing a second cancer, but with people living longer, the risk of second cancers is growing for everyone. This has to be balanced against the benefits in treating the thyroid cancer. Your treatment team will discuss these issues with you before the treatment.

The precautions described below are intended to protect other people by reducing unnecessary exposure to radiation, particularly for pregnant women and young children.

Are there any side effects from RAI treatment?

Most patients do not have side effects from RAI treatment. Some patients may experience a feeling of tightness or swelling in the neck and/or feel flushed, which may last for a few days. If this happens please inform the nursing staff immediately. A simple pain-killer can be given to relieve this problem. You may feel pain in the neck region shortly after having RAI, but this is rare. It can be treated very effectively with a short course of steroids tablets.

Sometimes having RAI can result in a temporary taste disturbance. This might not start until you get home. It can last for a few weeks, and usually resolves. Drinking plenty of fluids after the treatment helps to reduce this problem.

Saliva glands will also take up some of the RAI. Sometimes this can result in symptoms. In most cases this is temporary but

in a few cases it may be permanent. You will be advised to drink plenty of fluids during your admission to reduce the risk of these complications as well as to speed up the clearance of the RAI from the body. Some hospitals recommend drinking a tumbler of water every waking hour to flush out the radioactivity. Some hospitals recommend either chewing gum or sucking sweets to encourage the salivary glands to keep working, but there is no evidence that this helps.

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

What if I am pregnant or breastfeeding?

It is very important that you do not have RAI treatment if you are pregnant. If you are of childbearing age you will be asked about your chances of being pregnant. Blood or urine pregnancy tests can be done where there are any uncertainties.

If you are breastfeeding, you should stop this at least six and preferably eight weeks before you have the RAI treatment. You should not start again afterwards.

What about sex, contraception and fertility?

You should use a condom for seven days after RAI.

You should use a reliable form of contraception from the time of your treatment and for six months after. Female fertility should not be affected in the long term even after repeated doses of RAI.

Male patients are advised not to father children for at least four months after RAI treatment. Your fertility should not be affected in the long term, but there may be a small risk of reduced fertility if repeated RAI is needed. In this situation you can be considered for sperm banking. Please discuss this with your specialist consultant or a member of the treatment team as specialist advice and help is available.

What medication/tablets should I take before RAI?

After surgery to remove the entire thyroid gland, you will need to take thyroid hormones in tablet form. The type of tablet that you are prescribed will depend on how you are going to be prepared for your RAI treatment.

Preparing you for RAI treatment

Currently there are two regimes used in the UK to prepare for RAI.

The recommended regime is as follows:

- Following removal of your thyroid gland the thyroid hormone levothyroxine (T4) will be prescribed for you.
- Just before RAI you will be given two injections of recombinant human TSH, also known as Thyrogen™.
- Thyrogen injections will be given into the buttock on two consecutive days. On the third day you will go into hospital for the RAI treatment. You will remain on levothyroxine throughout.

Please contact your oncology team at least one month before your planned date for RAI treatment if you are unsure about your thyroid medication and what is planned for you.

The other regime is as follows:

- Following removal of your thyroid gland thyroid hormone Liothyronine (T3) will be prescribed for you.
- T3 tablets will then be stopped two weeks before your RAI treatment.
- You may feel weak and tired after you stop taking your tablets. This is normal. It will improve once you start taking levothyroxine (T4), usually a few days after you have had your RAI.
- You are advised not to drive after stopping the tablets and to wait until you are fully comfortable with this after restarting your levothyroxine tablets.
- Being without your thyroid hormone replacement may also make you feel cold, especially your hands and feet. Take some warm clothing and bed socks into hospital with you.
- You will usually be started on levothyroxine (T4) on the day you go home.

The instructions about stopping your thyroid medication may vary in different centres. It is important you follow the instructions from your treatment team.

Should I keep taking my other medication/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 with you on admission and show it to the doctor and nurse team.

If you are taking any iodine-containing vitamin or mineral supplements or cod liver oil, you should stop taking them around two weeks before your therapy to help reduce your iodine levels.

What can I eat?

Some studies have shown that reducing iodine intake may improve the effectiveness of the treatment. Therefore, two weeks before coming in to hospital we recommend the following:

- You can eat fresh and frozen fruit and vegetables, fresh and frozen meats, rice, pasta and potatoes, soft drinks, fruit juices, beer, wine, tea, coffee, plain fats and oils (non-dairy), olive oil spread, fresh and homemade bread.

- Avoid eating seafood and fish, cows'/goats' milk, cheese, ice cream, yoghurt, butter, and egg yolks.
- Avoid food from restaurants, fast-food chains and takeaways, and imported processed foods. In the USA and in many European countries iodine is added to table salt and used in baking.
- 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.
- The best way to ensure a lower iodine content in your food is to prepare it from fresh ingredients. Table salt and sea salt with no added iodine may be used. Iodine is rarely added to salt in the UK.

This diet is based on iodine content of foods in the UK. Unlike some other countries YOU DO NOT NEED TO BAKE YOUR OWN BREAD OR DRINK DISTILLED WATER.

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

Do I have to come into hospital for RAI treatment?

Yes, you will probably need to stay in hospital in the RAI or iodine suite for 2–4 days. How soon you go home depends on how quickly the radioactivity leaves your body.

There are different levels/doses. RAI patients who receive the lowest dose may only be in hospital for 24 h.

What happens on admission?

On the ward you will see members of the nursing, medical and nuclear medicine teams who will give an explanation of the treatment and details about the room where you will be staying. You will also have the opportunity to ask any questions that you might have.

You will be asked if there is any chance you could be pregnant. If there is any uncertainty then a pregnancy test will be performed to check that you are not pregnant before proceeding with the RAI treatment.

You will be asked to sign a form giving consent for the treatment if this has not already been done in clinic.

Who gives the capsule?

You will be given the RAI capsule by a member of staff from the nuclear medicine department. The capsule is about the size of a paracetamol capsule. Occasionally the treatment may be given as a liquid (which is colourless and tasteless).

What happens next?

You should not eat or drink anything for 2 h after taking the capsule to allow time for the iodine to be absorbed. After this time you should eat as normal and drink plenty of fluids.

Are there any visiting restrictions?

As the treatment is radioactive, people under the age of eighteen or pregnant women will not be allowed to visit you. Others may visit for a short time. The specific restrictions may vary. Staff will advise on a daily basis what length of visiting time is allowed.

Staff will spend only short periods of time in your room. When they bring in your meals and drinks they may stand behind a screen or in the doorway. You should try to maintain a safe distance of about 3 m. Staff won't stay and chat for long periods of time but do not hesitate to contact them if you need anything.

What happens at meal times?

The nursing or catering staff will bring meals to your room. These meals may be served on paper plates and you may need to use plastic cutlery. When you have finished your meal these should be thrown away in a bin provided. If there is any unwanted food this needs to be sealed in a plastic bag and put in the bin. Sometimes ordinary plates and cutlery are used. These will have to be washed up either in your room or in a special kitchen. A waste disposal unit may be available to dispose of any unwanted food. Each day you may receive a menu to fill in for the next day although this will vary from centre to centre. Hot drinks are usually provided in the morning, mid-morning, lunch time, tea time and night-time. Some units have a fridge where you can store food and drink and/or a small kitchen where you can make your own hot drinks.

What about washing and hygiene?

As you should be drinking more than usual, you should also be using the toilet frequently. All your body fluids are radioactive and you must flush the toilet twice after each use. If you spill or splash urine, please contact the nursing staff. Your sweat is also radioactive, so we advise you take shower daily.

What can I bring in with me to help me relax or pass the time?

- You may take in a mobile phone. Most centres recommend that you take an old phone or a cheap replacement and just exchange the sim card. The phone is often placed in a plastic bag to reduce the direct contact with your hands.
- You may be able to bring DVDs, CDs and books with you; they may need to be monitored for radiation before they can be removed from your room.
- If any items are significantly radioactive they will need to be stored in the hospital for some time after you go home.
- Check with your specialist team regarding the use of laptop and tablet computers. Some centres will provide a lap top.
- If you need earphones, buy a cheap set that can be left behind.

Take travel size toiletries with you and leave your toothbrush behind when you leave.

The usual recommendation is to take your clothes home and wash them once on their own in your washing machine. There is no need to discard your clothes.

Please check your centre's specific recommendations beforehand as these may vary.

When can I go home?

The staff from the nuclear medicine or medical physics department will come to the ward to take radiation measurements each day. They can then work out how much radiation is still in your body and if the level is safe for you to go home. You must stay in your own room until that time.

You will have a whole body scan either on the day you are discharged home or during the first week following the treatment, in which case you will be asked to return to the hospital.

Will I still have any restrictions when I get home?

When you go home you should avoid close contact with babies, young children and pregnant women.

You will also need to limit close and prolonged contact with other people, and stay away from crowded places such as cinemas, theatres, public transport where you may be close to the same person for a prolonged period of time.

The nuclear medicine staff will explain to you how many days you need to limit yourself. This advice varies from patient to patient, is dependant on the dose of RAI who have received and differs for contact with adults and young children.

Medical or nursing staff will organise a new supply of thyroid tablets. If you stopped these during RAI you should restart these on the day you go home.

Will I have to come back to the hospital?

You will need to be seen again in the outpatient department by a member of the thyroid cancer care team. You will either be given an appointment when you leave the ward or this may be sent to you later. When everything is organised, you are free to go home.

How will I be followed up?

You will be followed by the thyroid cancer care team and or your surgeon/endocrinologist at regular intervals to see how you are feeling and check your thyroid hormone levels.

If you are struggling and need emotional support, do let them know, or contact one of the patient support groups listed below.

Another important aspect of thyroid cancer treatment is thyroid stimulating hormone (TSH) suppression.

Your thyroid team will want to keep your thyroid hormone levels at a slightly higher level than would normally be required, by doing this the TSH will be 'turned off' or suppressed.

This will be required for at least the several months following diagnosis and for some patients it may be longer.

It is very important than no one other than your thyroid team such as your GP alters your thyroxine dose. Should this happen please refer them to your thyroid team before making any changes to your medication.

Some centres give out TSH alert cards for patients to carry.

About six to twelve months after RAI you will be called back for a scan (usually a neck ultrasound scan) and a thyroglobulin (Tg) blood test to see if the RAI has been successful. Tg is an important 'marker' for thyroid cancer and you will have ongoing Tg blood tests during the long term follow up period to check for any early signs of recurrence.

Most centres do a 'stimulated thyroglobulin test'. Before the blood test you will be given Thyrogen™ injections to raise the TSH level and asked to follow the low iodine diet. Alternatively you may be asked to stop your thyroid hormone treatment for 2 weeks prior to the blood test.

Will I need RAI treatment again?

Some people need additional RAI doses or surgery to make sure all the remaining thyroid tissue has been destroyed. This does not mean they are not going to be cured. Thyroid cancer is highly treatable and is cured in around 96% of cases. There are people alive now who were diagnosed more than 50 years ago.

Your centre may give you an information leaflet which has more details on how RAI is given in your local centre. Treatment details vary from place to place. Please contact your thyroid cancer care team if you have any questions or concerns after reading this information.

Patient support

Being diagnosed with a rare cancer can make you feel isolated.

You should be introduced to a Clinical Nurse Specialist (CNS) or a named Key Worker either at or shortly after your diagnosis. They are there to help you with any questions or worries you may have.

Talking to others who have been through it can help. Support and information are available through the patient-led organisations mentioned below who have collaborated in writing this leaflet. Together we can give you informational and emotional support to help you through your investigations, treatment and recovery.

Butterfly Thyroid Cancer Trust. Butterfly Thyroid Cancer Trust is the first registered charity in the UK dedicated solely to the support of people affected by thyroid cancer.

Address: PO Box 205, Rowlands Gill, Tyne & Wear NE39 2WX

Tel: 01207 545469

Website: www.butterfly.org.uk

Email: enquiries@butterfly.org.uk

Thyroid Cancer Support Group – Wales. Supporting thyroid cancer patients and families not only in Wales but nationally and occasionally internationally. The group is funding the first national tissue bank specifically for research into anaplastic thyroid cancer.

Address: 'Morcote', Sunlea Crescent, New Inn, Pontypool, Gwent, South Wales NP4 8AD

Tel: 0845 009 2737

Website: www.thyroidsupportwales.co.uk

Email: thyroidgroup@tiscali.co.uk

British Thyroid Foundation. The British Thyroid Foundation is a charity dedicated to supporting people with all thyroid disorders and helping their families and people around them to understand the condition.

Address: 2nd Floor, 3 Devonshire Place, Harrogate, West Yorkshire GH1 4AA

Tel: 01423 709707/709448

Website: www.btf-thyroid.org

Email: info@btf-thyroid.org

Hypopara UK. Hypopara UK is the national patient organisation for people with parathyroid conditions, including post-surgical calcium issues and permanent hypoparathyroidism.

Address: 6 The Meads, East Grinstead, West Sussex RH19 4DF

Tel: 01342 316315

Website: www.hypopara.org.uk

Email: info@hypopara.org.uk

Association for Multiple Endocrine Neoplasia Disorders – AMEND. AMEND provides information and support to families with multiple endocrine neoplasia (MEN) and associated endocrine tumours, including medullary thyroid cancer.

The Warehouse, Draper Street, Tunbridge Wells, Kent TN4 0PG

Tel: 01892 516076

Website: www.amend.org.uk

Email: info@amend.org.uk

RAI is not used in the case of medullary thyroid cancer as it is not effective in this type of cancer.