

**Patient
Information**

Radioactive Iodine Ablation Therapy (RAI) for Thyroid Cancer

Introduction

Following your thyroid surgery, you have been referred to the Gloucestershire Oncology Centre for Radioactive Iodine (RAI) therapy. This leaflet gives you information about the preparation, treatment and aftercare.

What is RAI therapy?

RAI is a treatment that uses radiation to treat thyroid cancer. The radiation comes from a radioactive substance called iodine-131. You take radioactive iodine as a capsule that you swallow with a drink of water. The capsule **contains gelatine**, please let us know if there are any moral or ethical reasons preventing you from proceeding with this therapy.

RAI is usually given for the following reasons:

- To destroy any thyroid tissue that is still in your neck after surgery
- To treat any thyroid cancer that could not be removed with surgery
- To treat thyroid cancer that has come back after your initial treatment

How does RAI therapy work?

The thyroid gland usually takes iodine out of our diet and uses it to make thyroid hormones. When RAI is administered the thyroid cells absorb the iodine and therefore receive a high dose of radiation. This then destroys any remaining thyroid or thyroid cancer cells.

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Department

Radiology

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**Patient
Information**

Is RAI therapy safe?

RAI therapy has been used to treat thyroid diseases for many years. It is generally very well tolerated although like all drugs, it can have side effects.

Temporary side effects:

- Dry mouth and taste changes: The salivary glands take up small amounts of iodine. Some people find sucking sweets helpful after treatment to help you produce more saliva in your mouth.
- Neck discomfort: You may notice a slight discomfort around your thyroidectomy scar. Pain relief will be prescribed if needed during your hospital stay.
- Feeling sick: It is rare for anyone to vomit after RAI treatment; however, you may feel nauseous (sick). We will prescribe you anti-sickness medication if needed.

Other things to consider:

- There could be a very small risk of secondary cancer with this treatment (as there is with all radioactive treatments). If your consultant has recommended RAI therapy to you then the benefits of the treatment are considered to outweigh the risks.
- Fertility and pregnancy: It is essential that RAI is not given to anyone who might be pregnant; therefore appointments are carefully made around menstruation dates. Patients of child bearing potential, under the age of 55, will be asked to give a urine sample so that a pregnancy test can be carried out before treatment. If you think there is a chance that you might be pregnant, please let your team know immediately.
- Radioactive iodine can also pass into breast milk; therefore, the treatment is unsuitable for patients who are breastfeeding. If this affects you, please discuss it with your team.

It is recommended that patients do not conceive for 12 months following treatment and that at least 2 forms of contraception are used after treatment, for example condoms and an oral contraceptive.

**Patient
Information**

Who is in the team?

Consultant Oncologist - You will meet your consultant oncologist before your treatment. They will discuss the details of your treatment with you and ask you to sign a consent form. They may also request a blood test is taken to check your kidney function and that you are on the correct dose of levothyroxine.

Macmillan Thyroid Clinical Nurse Specialist (CNS) - You will hopefully have met, or spoken to, your CNS before your first appointment with the consultant oncologist. The CNS will send you information about your cancer and treatment, and will be your main point of contact should you have any queries or concerns.

Nuclear Medicine Team - You will meet or speak to a member of the team before your treatment. They will arrange your treatment with you and discuss what needs to be done before your treatment begins as well as what you need to do to keep yourself and others safe from the radiation.

What do I need to do to prepare for treatment?

Low iodine diet

This diet is suitable for people who are being treated with RAI. The following information gives you the reasons for limiting foods that are high in iodine and suggests low iodine alternatives.

Why follow a low iodine diet?

A diet which is rich in iodine could interfere with your RAI therapy. A low iodine diet aims to reduce your iodine intake before treatment and helps to increase your body's iodine absorption. It is not possible or necessary to follow a **no iodine** diet.

Where is iodine found?

Iodine is essential for good health and is found in many foods in varying amounts. The richest source of iodine is in foods from the sea.

Patient Information

You have been provided with a list of low and high iodine containing foods in the UK. If you commonly eat foods or use ingredients from overseas, please speak to your team.

It is important to avoid the food colouring E127, which is pink, and is added to foods such as pepperoni, tinned strawberries and pink cakes and pastries.

Iodine is also found in high concentrations (strengths/amounts) in all cough medicines.

How long should I follow a low iodine diet?

We recommend following the low iodine diet for 2 weeks.

After you have received the radioactive iodine treatment, you will need to carry on with the low iodine diet for 48 hours, after which 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 information in this leaflet.

Where can I get further information about the low iodine diet?

You should follow the information in this leaflet and in the Macmillan booklet given to you by your CNS. Levels of iodine in food vary in different parts of the world and so we would advise against seeking further information on the internet.

We have included some meal ideas in this leaflet but should you want any recipes, please contact your CNS.

Foods you can eat freely

- Fresh/frozen fruit
- Fresh/frozen vegetables
- Cooked green vegetables
- Fresh/frozen meat
- Ordinary table salt
- Rice
- Dried pasta
- Potatoes
- White/wholemeal/granary bread

Patient Information

- Non-dairy spread
- Olive oil, vegetable oils and nut oils
- Water, soft drinks, fruit juices and alcoholic drinks
- Tea and coffee without milk
- Milk substitutes such as rice, coconut, almond or soya; please check ingredients and avoid brands that contain carrageenan (seaweed extract).
- Dark/plain chocolate with a minimum of 70% cocoa
- Crisps

Foods that should be limited

- Milk – a maximum of 25ml per day which could be used in tea and coffee (about 5 teaspoons of milk per day)
- Butter – limit to a very thin scraping (one teaspoon or 5g) per day
- Cheese – one ounce or 25g per week
- Egg – one per week

High iodine foods which should be avoided:

- Fish, seafood, seaweed, kelp, laver bread
- Milky coffee and tea, cappuccino, hot chocolate, malted milk drinks
- Cakes and biscuits containing butter and eggs
- Milk chocolate and white chocolate
- Dried fruit
- Oat milk
- Take away– meals and fast food/restaurant foods as ingredients are unknown
- Iodised salt, sea salt and pink Himalayan salt
- Vitamins and mineral supplements, nutritional supplements and cough mixtures (unless prescribed by your medical team, for example calcium and vitamin D)

**Patient
Information**

Meal suggestions

Breakfast

- Toast with non-dairy spread
- Porridge made with water or milk substitute
- Cereals with water or milk substitute.
- Fresh fruit or fruit salad
- Cooked breakfast (without eggs) such as unsmoked bacon, tomatoes, mushrooms etc

Lunch

- Sandwich made with non-dairy spread filled with fresh ham, chicken, unsmoked bacon or Quorn™ and salad (non-processed meats only)
- Salad with olive oil and vinegar (no raw spinach) topped with chicken breast
- Jacket potato 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, chickpeas and vegetables such as roasted peppers, courgettes and 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, Quorn™ or tofu stir fry with vegetables and rice
- Stewed meat with potatoes, carrots and swede
- Chilli con carne with rice and peas
- Sweet and sour chicken and rice
- Risotto (without cheese) with chicken, butternut squash, peas and sweetcorn
- Curry dishes without cream

Snacks and puddings

- Tinned or fresh fruit
- Stewed or poached fruit
- Jelly
- Sorbet
- Dairy free custard or single cream alternative

Patient Information

- Soya dessert or soya yoghurt (check it doesn't contain carrageenan thickening agent)
- Vegetable crudité's and homemade avocado dip or soya plain yoghurt and mint sauce
- Popcorn
- Potato crisps
- Rice cakes
- Dark chocolate

Other things to do in preparation for treatment:

Before your treatment it is important to have a high Thyroid Stimulating Hormone (TSH) level for the treatment to be most effective.

Routinely you will have 2 injections of a form of TSH called Thyrogen. These injections are given into a large muscle (typically your buttock or thigh) on the 2 days before your treatment date. You will need to attend Cheltenham General Hospital for the Thyrogen injections.

You will also need swabs taken for MRSA.

Our Iodine Suites

We have two Iodine Suites which are situated within Lilleybrook Ward at Cheltenham General Hospital.

Both rooms have a kitchenette where you can prepare hot drinks, a fridge, TV (with Freeview), DVD player, DVDs, books, a tablet and a hair dryer.

There is an ensuite bathroom with a walk-in shower. We provide all linen and towels.

There is also a telephone which is free to use— just dial '9' to get an outside line.



Patient Information

Meals will be brought in to you by the nursing staff, but you are more than welcome to bring in sweets and snacks should you wish.

We have a video camera (CCTV) in the main rooms so that the nursing staff can check on you to make sure you are safe. We advise that you therefore get changed in the bathroom.

What to bring in for your stay

Please bear in mind that anything you bring in to your room may become contaminated with radioactive iodine and so it would be appreciated if you could only bring in clothes, books and magazines that can be destroyed after you leave the ward. We recommend bringing an old set of clothes or pyjamas that you are happy to throw away after your treatment. You are welcome to bring your glasses in with you, but ask that you leave mobile phones, tablets/laptops at home.

We also recommend that you bring in only a small quantity of toiletries and enough of your medication, in its original packaging, to last you for your stay in the Iodine Suite.

If there are any changes to your routine medication between your appointment with the oncologist and the time of the treatment, please let a member of the team know as soon as possible as it may affect your treatment.

Your treatment

The length of time you will be in hospital will depend on the dose of RAI that you are having. The Nuclear Medicine Team will advise you how long you should expect to be in hospital before your admission.

On the day of your treatment, we recommend that you have an early breakfast. You need to be treated on an empty stomach - nothing to eat or drink for 2 hours before the treatment. You cannot eat for a further 2 hours after the treatment. You may drink 1 hour after treatment. **If you have diabetes or have food allergies/intolerances, it is important to let us know before your admission.**

Patient Information

When you arrive at Cheltenham General Hospital, please go to the Nuclear Medicine Department situated on the first floor in the Oncology Centre (next to Rendcomb Ward). You will then be seen by a member of the Nuclear Medicine Team who will go through your consent form with you and perform any necessary blood and urine tests. Next you will be taken to Lilleybrook Ward where you will be seen by a nurse and/or doctor before your treatment. The nuclear medicine staff will then show you to your room and help you to settle in. You will be asked to change into the clothes that you will wear while you are on the ward. Your other clothes can be left in the room next to the Iodine Suite.

The treatment comes as a small capsule about the size of a paracetamol tablet which you will be asked to swallow with water.

Once you have had the treatment you must stay in the Iodine Suite until the Nuclear Medicine Team tell you it is safe to go home.

In order to decide when it is safe for you to go home, measurements of radioactivity will be taken at 3 different distances from you. These will be repeated each day and will allow us to calculate when safe levels are reached. This can be between 1 and 5 days depending on the dose given.

We recommend that you drink plenty of fluids and pass urine as frequently as possible for the first 8 hours after taking the capsule. This will help reduce the dose to your whole body and wash away any unused iodine. Some of the radioactive iodine will be excreted from your body via perspiration (sweat) so we recommend that you shower at least once a day.

Visiting

Visiting is restricted while you are on the ward. Staff looking after you will keep their radiation dose down by keeping their visits to your room as brief as possible. However, if you do need assistance from the ward staff, please contact them using the nurse call bell in the room.

If you wish to have visitors, please discuss this with the Nuclear Medicine Team. You are allowed visitors but for their protection they can only stay for 1 hour per day and must be no closer than 3 metres to you.

**Patient
Information**

Discharge from the ward

When your radiation level has fallen to a safe level you will be discharged from the ward. The Nuclear Medicine Team will give you a yellow treatment card before you go home with radiation protection advice on how to keep the people around you safe. You must carry this card with you at all times until all radiation protection restrictions have ended. You may go home by car as the only passenger as long as the driver is not pregnant and you sit behind the passenger seat (maximum distance from the driver).

Radiation protection

After discharge, you should:

- Stay at least 1 metre away from people
- Sleep separately from other people
- Not use public transport
- Avoid routine medical and dental work, including blood samples, for 37 days

For the first 48 hours after discharge you should:

- Wash your hands frequently when preparing food for yourself
- Not prepare food for anyone else
- Flush the toilet twice after use
- Use separate cutlery and crockery from your family and wash separately/put through the dishwasher on their own

The length of time that you need to keep your distance from others will depend on the dose of RAI given and how long it takes to leave your body.

Children under 5 years of age and pregnant people are more sensitive to radiation so you will need to avoid them for a longer period of time.

**Patient
Information**

Post treatment scan

You will be asked to come back to the hospital a few days after discharge to have a scan. This scan tells us where the iodine has been absorbed. You will also have your radiation levels re-measured. The Nuclear Medicine Team will then advise you about how long you should continue to follow radiation protection guidance at home.

Follow up

You will be given an appointment to see your consultant oncologist 2 to 4 weeks after your treatment. They will discuss the results of your scan and make a plan with you for your ongoing follow up appointments.

If you have any concerns or queries outside of your appointments you should contact your CNS using the details at the end of this leaflet.

Contact information

Macmillan Head and Neck/Thyroid Clinical Nurse Specialist

Tel: 0300 422 6785

Monday to Friday, 8:00am to 4:00pm

Nuclear Medicine Team

Tel: 0300 422 4036/4046

Monday to Friday, 9:30am to 3:30pm

If there is no answer, please leave a message and a member of the team will call you back as soon as possible.

Further information

Macmillan Cancer Support

Tel: 0808 808 00 00

Monday to Sunday, 8:00am to 8:00pm

Web: www.macmillan.org.uk

Maggie's Centre

There is a local Thyroid Cancer Support Group that runs on the third Monday of each month. Please contact Maggie's on:

Tel: 01242 250 611 or speak to your CNS

**Patient
Information**

Butterfly Thyroid Cancer Trust

Tel: 01207 545 469

Web: www.butterfly.org.uk

British Thyroid Foundation

Tel: 01423 810093

Helpline available Monday to Thursday, 10:00am to 4:00pm

Web: www.btf-thyroid.org

British Thyroid Association

Web: www.british-thyroid-association.org

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