

Patient information factsheet

Radioactive iodine treatment for thyroid cancer

We have given you this factsheet because your doctor has referred you for radioactive iodine (RAI) treatment for thyroid cancer. It explains what RAI is and what the treatment for thyroid cancer involves, so you know what to expect. We hope it helps to answer some of the questions you may have. If you have any further questions or concerns, please contact us using the details at the end of this factsheet.

Before agreeing to treatment, you will have a consultation with a specialist doctor and nurse, where you will have the opportunity to ask any questions you may have.

What is radioactive iodine?

Radioactive iodine (RAI) is a targeted treatment that uses radiation to treat thyroid cancer. The radiation comes from a radioactive form of iodine called iodine-131.

RAI is usually given as a capsule that you swallow.

How does the treatment work?

The cells in the thyroid (a small gland in the neck that makes hormones) usually take in iodine from our diet to make thyroid hormones.

When thyroid cells take in RAI, they get a very high dose of radiation which destroys the thyroid cells (including cancer cells).

Why do I need this treatment?

RAI treatment may be given to destroy any remaining normal thyroid cells left in the neck after surgery or to treat thyroid cancer that could not be removed surgically.

Your doctor will explain to you why they have referred you for this treatment, and the benefits and risks.

Are there any alternatives?

Your doctor will discuss any alternative treatments with you before you decide whether to have RAI treatment.

Is RAI treatment suitable for everyone?

You cannot have RAI treatment if you are:

- **pregnant** – To make sure you aren't pregnant, we may carry out a pregnancy test on the day of your treatment, if applicable.
- **breastfeeding** – If you are currently breastfeeding, you will need to stop breastfeeding at least six weeks before having RAI treatment and you will not be able to breastfeed after the treatment. However, it will be safe to breastfeed if you have more children in the future.
- **unable to look after yourself without support** – For this treatment, you will need to be able to care for yourself while staying in a room alone for a few days. This is because you will be radioactive, and we will not be able to enter the room to help you with normal daily living activities.

How should I prepare for the treatment?

Low-iodine diet

You will need to eat a low-iodine diet for two weeks before your treatment (we will provide separate information about this diet along with this factsheet). You will also need to follow this diet for one to two days after having RAI treatment.

Thyroid-stimulating hormone injections

You will need to have two thyroid-stimulating hormone injections (Thyrogen) into the muscle in your buttocks; one 48 hours before and another 24 hours before having RAI treatment. You will need to have the injections around lunchtime each day.

Depending on where you live, we may arrange for you to have these injections at Southampton General Hospital or at your local hospital, or in some cases, at home.

If we arrange for you to have these injections at Southampton General Hospital, these will be given to you on C4 ward (this is the same ward where you will receive the RAI treatment). If you have any questions about these injections, please call C4 ward on **023 8120 4373** or **023 8120 6691** (24-hour lines).

Medications

You should continue to take your usual medications as normal, including your current dose of thyroxine, before your treatment.

Pre-assessment telephone appointment

A member of the nuclear medicine team will telephone you a couple of weeks before your treatment. During this call, they will explain how to prepare for the treatment and what to expect when you come into hospital. They will also ask you a number of questions, including:

- Who do you live with?
- Do you share a bedroom at home?
- How do you plan to travel to and from the hospital?

Your answers to the questions will help us to personalise your aftercare. This call is also a good opportunity for you to ask any questions you may have.

Items to bring with you

You will need to stay in hospital after having this treatment (usually for one to four nights). For this reason, please bring in an overnight bag with you into hospital.

We recommend packing the following items:

- all the medication that you are currently taking (in its original packaging)
- one set of comfortable clothes to wear for the duration of your hospital stay (day and night) and underwear
- well-fitting slippers and/or outdoor shoes (you will need to wear something on your feet when walking around the room – we can provide slipper socks if you prefer)
- toiletries (for example, shower gel, shampoo, toothbrush and toothpaste)
- any items you need on a daily basis (for example, a walking aid, hearing aids or glasses)
- a mobile phone (without a case) and a charger
- entertainment items (for example, a book or magazine)
- a notebook and pen

Please note that anything you take into the room with you that is soft, such as books and magazines, is likely to become radioactive and may need to be disposed of after your hospital stay. Clothes can either be washed or disposed of. We can give you a hospital nightgown if you would prefer.

What will happen on the day of the treatment?

Before your treatment

You should aim to arrive on C4 ward between 9 and 10am (please see your appointment letter for more details). We will take you to the room we have prepared for you to stay in. You will notice that we have placed cling film around areas that are frequently touched, such as door handles and bed controls.

We will then check you in and complete any necessary paperwork with you. We will then perform a blood test and if applicable, a pregnancy test.

After this, you will be able to go for an early lunch. You will need to return to your room between 1 and 2pm to begin your treatment.

During your treatment

We will explain the treatment to you in more detail and answer any questions you may have. If you are happy to proceed with the treatment, we may ask you to sign a consent form (if you haven't done so in clinic already).

We will then give you the RAI capsule to swallow with a glass of water.

After your treatment

After you have swallowed the capsule, we will take regular readings of your radiation levels over the duration of your hospital stay.

You will need to remain in your room alone (in isolation) until your radiation levels are low enough to go home. When you can go home will depend on the dose of RAI you receive and how quickly it leaves your body. Most people usually need to stay in hospital for a few days. We will let you know when it is safe for you to go home. When you get home, you will then need to follow further radiation safety precautions. We will provide you with specific instructions when you are ready to leave hospital, as this will vary from person to person.

What should I expect during my hospital stay?

We have included some useful information below about what to expect during your hospital stay.

Facilities

Your room will have the following facilities:

- a bed
- a chair
- an ensuite bathroom
- a small window
- Wi-Fi
- a TV
- a kettle
- a small fridge

Food and drink

The ward has a range of low-iodine food available for you to choose from during your hospital stay, including soy milk, and vegan and gluten-free options. If there are any particular foods that you would prefer to have during your hospital stay, please bring these with you into hospital.

We can store cold food in the ward fridge for you and bring this to you in your room.

Bowls, cups and cutlery will all need to remain in your room, and you will need to wash these up yourself between meals. We will provide you with all the necessary equipment to do so.

Personal hygiene

RAI will leave your body in your sweat, saliva, urine (pee) and faeces (poo), so we advise showering a couple of times a day during your hospital stay. We will provide you with some towels to use. Please place any used towels in the linen bag in your room.

Anything made of a soft material will absorb the radiation (for example, mobile phone or electronic device cases, books, magazines and clothes). For this reason, you should not bring any soft material items into your room unless you are happy to throw them away after your hospital stay (except for clothes which can be washed).

Anything made of a hard material can be wiped down after your hospital stay or we can apply cling film to protect it from the radiation.

Clothing

We advise coming into hospital wearing your normal clothes and then hanging them up in the wardrobe in your room. You can then change into the comfortable clothes you have chosen to wear while having your treatment or a hospital gown.

When you are ready to leave hospital, you will need to change back into the clothes you hung up in the wardrobe. We will then bag up your treatment clothes for you to take home, or if you wish, we can discard these for you. You will need to wash these treatment clothes twice in a washing machine, separately from any other items of clothing. We will provide you with more details about washing your clothes before you leave hospital. Once washed, these clothes should only be worn by you for the next six weeks.

Visitors

You may have one adult visitor for 30 minutes a day. Your visitor must not be pregnant and will need to stay outside your room behind a lead screen. Most people stay in contact with family and friends via mobile devices.

Are there any side effects?

RAI treatment is generally well-tolerated with minimal side effects.

Temporary side effects

Some people may experience the following side effects for a few days after having RAI treatment:

- mild nausea (feeling sick) – If you feel sick, please tell the nursing staff so they can give you anti-sickness medication.
- tenderness or swelling around the neck or salivary glands
- taste changes (this side effect may last a few weeks)
- a dry mouth

To prevent the radiation affecting your salivary glands long term, we recommend sucking on tangy sweets or fruit, such as lemons or limes, hourly while you are awake in hospital. This will help to stimulate your saliva flow and clear away the radiation from your salivary glands.

Long-term side effects

Some people may experience the following long-term side effects:

- a persistent dry mouth (this is rare)
- reduced fertility in males (if repeated RAI treatments)
- a very small risk of a secondary cancer developing many years later

If you experience any long-term side effects after having RAI treatment, please contact your clinical nurse specialist (CNS) team for advice.

Fertility

There is currently no evidence to suggest that RAI treatment affects fertility in women. However, it is important that you do not become pregnant for at least six months after having RAI treatment, as there is an increased risk of miscarriage for up to 12 months after the treatment.

Repeated RAI treatment may affect fertility in men. If you need to have RAI treatment more than once, we will offer to refer you to a fertility centre who will be able to provide more information about sperm banking (sperm collection and storage). You should also not conceive a child for at least four months after having RAI treatment, as the risks to the child are unknown. If you are sexually active, you must use condoms even if you or your partner is using another form of contraception.

Radiation safety precautions

You will be radioactive for a short while (usually a few days) after the RAI treatment. While you are radioactive, it is important that you follow the radiation safety precautions below for the safety of yourself and other people. We will let you know how long you need to follow these safety precautions for before you leave hospital. This will be based on the radiation measurements taken during your hospital stay.

While you are radioactive, you should:

- avoid close and prolonged contact with people, especially children (under 18 years of age) and anyone who is pregnant (close contact is considered less than one metre away and prolonged contact is more than 15 minutes). You may have brief close contact (less than 15 minutes) with people. However, if you have young children, you may wish to consider that either yourself or your children stay with family or friends for a few days. It is safe for you to be around pets. You do not have to worry about people you see occasionally or pass in the street.
- shower at least once a day
- wash your hands regularly
- drink plenty of fluids
- not use plastic cutlery or cups
- wash dishes in a dishwasher (if possible)
- sleep alone
- wash your bed sheets in the washing machine separately from other items (this should be done on the Friday after your treatment or two days after returning home, whichever is sooner)
- avoid having sexual intercourse
- take time off work (unless you work from home)

How should I travel home?

Avoid using public transport if you can. If you must travel on public transport, only take short journeys. Try to stay away from children and anyone who is pregnant.

Travelling after RAI treatment

You may set off radiation alarms at airports for a short while after having RAI treatment. If you plan to travel abroad shortly after having RAI treatment, speak to your doctor or the nuclear medicine team first. They will be able to send you a certificate or a letter that explains the treatment you have had.

Will I need any follow-up care?

We will perform a whole body scan a few days after your treatment to check where the RAI has been taken up in your body. This is a painless scan, and it is normal for it to take a few hours. This is nothing to worry about.

You may need to have blood tests after having RAI treatment. We will discuss this with you if necessary.

As RAI treatment takes many months to work, we will arrange for you to have a follow-up appointment with your doctor 8 to 12 weeks after your treatment. Your doctor will discuss the results of your scan and any blood tests you have had with you.

Patient information factsheet

Depending on the results, some people may need more than one RAI treatment. We will discuss this with you if this is the case.

Contact us

If you have any further questions or concerns, please contact us.

Nuclear medicine team

Telephone: **023 8120 6627** (Monday to Friday, 8.30am to 6pm)

Head, neck and thyroid specialist nursing team

Telephone: **023 8120 5788** (Monday to Friday, 9am to 5pm, excluding bank holidays)

Email: hnt@uhs.nhs.uk

Additional support

You can also contact the charities below for additional advice and support:

Butterfly Thyroid Cancer Trust

Telephone: **07399 564463**

Email: amy@butterfly.org.uk

Macmillan Cancer Support

Telephone: **0808 808 0000** (every day, 8am to 8pm)

Useful links

British Thyroid Association

Website: www.british-thyroid-association.org

British Thyroid Foundation

Website: www.btf-thyroid.org

Webpage: www.btf-thyroid.org/low-iodine-diet

Butterfly Thyroid Cancer Trust

Website: www.butterfly.org.uk

Cancer Research UK

Website: www.cancerresearchuk.org

Webpage: www.cancerresearchuk.org/about-cancer/thyroid-cancer/treatment/radiotherapy/radioactive-iodine-treatment

Macmillan Cancer Support

Website: www.macmillan.org.uk

Webpage: www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/radioactive-iodine-for-thyroid-cancer

NHS

Website: www.nhs.uk

Webpage: www.nhs.uk/conditions/thyroid-cancer/treatment

Webpage: www.nhs.uk/conditions/vitamins-and-minerals/iodine

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