

Radioactive iodine therapy – information for patients

Introduction

This leaflet tells you about the treatment known as radioactive iodine therapy. It explains what is involved and some of the common complications associated with this procedure that you need to be aware of. It is not meant to replace the discussion between you and your consultant but helps you to understand more about what is discussed.

What is radioactive iodine therapy?

This form of treatment consists of swallowing radioactive iodine as a capsule. The iodine is absorbed by the thyroid gland. A very small dose of radiation is then concentrated in the thyroid cells and destroys them.

Is radioactive iodine therapy safe?

Radioactive iodine (also known as RAI) therapy has been used to treat thyroid cancer for over 50 years and is extremely safe. There has been extensive research into this method of treatment. The treatment is meant to destroy any thyroid cells that may not have been removed during surgery. Whilst no one can say that any treatment is 100% safe, there is very little risk of developing other cancers from receiving radioactive iodine treatment. This small risk applies to the use of doses larger than are usual for thyroid cancer treatment.

If you are unsure or have any questions, please talk these through with your consultant or a member of your medical team. The precautions which are described in this booklet are intended to protect other people who still have a thyroid, particularly pregnant women and young children.

Are there any side effects from radioactive iodine therapy?

Most patients do not experience side effects from radioactive iodine treatment. Some patients may experience a feeling of tightness in the throat and/or feel flushed (when your skin feels warm and red); this usually lasts for no more than 24 hours. If this persists please inform the nursing staff. An anti-inflammatory drug may be given to relieve these symptoms. Some patients may lose their sense of taste slightly. This can happen up to two weeks after the treatment and should last only 3–5 days. Drinking plenty of water and sucking citrus fruit sweets after the treatment helps to wash out your salivary glands and reduces this. Please talk through any questions with the consultant or a member of your medical team.

What if I am pregnant or breastfeeding?

It is very important that you do not have radioactive iodine therapy if you are pregnant or think there it is highly likely that you may be. Please let your medical team know if you have any concerns that you may be pregnant before you have any treatment.

It is important not to become pregnant whilst having investigations for thyroid cancer. You should use a reliable contraceptive method until all treatment has finished and you have had approval from your specialist consultant. Radioactive iodine may also affect a woman's ovaries. In the long term your fertility will not be affected, though there may be a small risk of infertility if repeated doses of radioactive iodine therapy are needed, this will be further discussed in your

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appointments. If you are breast feeding, you should stop this before you have the radioactive iodine treatment.

I am a male patient; will the treatment affect my ability to have children?

Male patients are advised not to try for a family for a certain period of time following radioactive iodine therapy. In the long term your fertility should not be affected, but there may be a small risk of infertility if repeated radioactive iodine therapy is needed, this will be further discussed in your appointments. If you wish to try for a family after the end of your treatment, please discuss this with your consultant or a member of your medical treatment team as specialist advice and help are available.

Before having radioactive iodine therapy what medication/tablets should I take?

Following the removal of your thyroid gland you will have been given thyroxine medication to take (called T4 or T3 tablets).

Most centres now prescribe Thyrogen injections which are administered as an outpatient 48 hours and 24 hours before your radioactive iodine therapy, this means that you can continue to take your T4 medication throughout.

Alternatively your Consultant may advise you to stop taking this medication four weeks prior to having your radioactive iodine therapy.

- If you are taking T3 tablets, this may be stopped for two weeks before your radioactive iodine therapy
- If you are on T4 tablets, this may be stopped four weeks before your radioactive iodine therapy. In this four week period your specialist may first change you to T3 tablets and then stop your tablets altogether for the last two weeks before your treatment. You are likely to feel weak and tired when you are not taking your tablets. This is normal and will disappear once you start taking them again. This will usually be a few days after you have had your therapy

It is important that you follow the instructions given to you by your specialist centre staff, regarding stopping your thyroxine medication, as it may vary in different centres.

Please contact your specialist centre at least one month before your planned start date for radioactive iodine treatment if you are unsure about your medication.

Should I keep taking my other medication/tablets?

If you are taking any other tablets you should continue to do so. You should bring a supply with you on admission and show them to the medical team. If you are taking any vitamin or mineral supplements or cod liver oil, you should stop taking those around three weeks before your radioactive iodine therapy to help reduce your iodine levels. A diet which is rich in iodine can reduce the effectiveness of the treatment. Therefore, two weeks before coming in to hospital we recommend the following:

- Continue to eat fresh meat, vegetables, fresh fruit, pasta and rice. These are low in iodine
- Try to cut down on dairy produce such as eggs, cheese, milk and milk products, as they all contain some iodine

You should completely avoid:

- Foods artificially coloured pink or red such as canned and glace cherries, canned strawberries, spam, salami, certain pastries and sweets. The colouring material E127 is rich in iodine so look on the labels when buying food. Food coloured by spices is allowed
- Cough medicine, iodised table salt, or sea salt as these contain iodine
- Fish, kelp and all seafood
- Vitamin supplements which contain iodine

Low-iodine recipes can be found at www.thyca.org/

Do I have to stay in hospital for radioactive iodine therapy?

If you are prescribed the lowest dose, this may be given as a day case. For those requiring a medium dose you are likely to need to stay in hospital for three to four days. How soon you go home depends on how quickly the radioactivity leaves your body. On the ward you will be greeted and your details will be registered. You will then be issued with a hospital name band to wear, with your hospital registration number, name and date of birth. One of the nursing staff will take your blood pressure, pulse and temperature as a routine procedure. The treatment will be explained to you and you will also be given details about the room you will be staying in. You will have the opportunity to ask any questions that you might have.

Your doctor will then examine you and check you have received the Thyrogen injections or stopped taking your thyroid tablets prior to the treatment, as this interferes with the absorption of radioactive iodine. You will have been sent information regarding your thyroid medication with your appointment letter. If you have not already done so, you will be asked to sign a consent form for the treatment.

Who will give me the medicine?

The Nuclear Medicine (or Medical Physics) department within the hospital is responsible for issuing the radioactive iodine treatment. One of their staff will come to the ward to give you the capsule (which is about the size of an antibiotic capsule).

What happens next?

For the first two hours after taking the capsule you should refrain from eating and drinking, to allow time for the iodine to be absorbed. After this time you should eat as normal and drink as much as possible so that you pass urine frequently. This will flush the excess radioactive iodine out of your system.

Will there be restrictions on visitors?

As the treatment you have received is radioactive, no young children or pregnant women are allowed to visit. Others may visit for a short time (around 10 minutes at a time), it is advised you do not have any visitors for the first two days after treatment.

Because you are radioactive, staff will spend only short periods of time in your room. When they bring in your meals and drinks they may stand behind a lead screen and you should try to remain on the opposite side of the room. Do not expect them to stay and chat for long periods of time, but do not hesitate to contact them if you need anything.

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What will happen at meal times?

The nursing staff will bring you meals in 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 disposed of in the bin provided. If there is any unwanted food this needs to be sealed in a plastic bag and disposed of in the bin. Alternatively, if 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 will receive a menu to fill in for the next day or you may decide to treat yourself to a take away or ask a relative or friend to bring food in for you.

Drinks are provided in the morning, mid-morning, lunch time, tea time and night time. If you do not receive your meal for whatever reason, please ring the nursing staff and they will provide you with one. Drinking lots of fluid results in using the toilet frequently. All your bodily fluids are radioactive so you must double-flush the toilet after use, if you spill or splash urine please contact the nursing staff. We will advise you take a bath or shower daily as your sweat is also radioactive. This may sound a little strange and alarming at first but please remember this is very low dose of radiation and it is for your treatment and long-term recovery. You will soon be free of radiation and back home.

Can I bring things into the hospital to help me pass the time?

You can bring DVD's, books, clothes and toiletries with you. These items may need to be monitored for contamination before they can be removed from your room. Rarely may it be necessary for us to keep some of your belongings if they are contaminated. They will be returned to you once they are no longer radioactive.

When can I go home?

The staff from the Nuclear Medicine or Medical Physics department will come to the ward to take measurements, 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 the iodine room until that time. Before going home you will have a whole body scan.

Will I still have any restrictions when I get home?

The nuclear medicine staff will explain to you the restrictions you must observe when you go home; for example, avoiding crowded places and limiting the number of people you come into contact with. They can work out exactly over how many days you will need to restrict yourself. The restrictions you are given may differ from other patients as some patients may be lower or higher in their radioactivity. Your radioactivity will be at an acceptable level when you go home. These restrictions are to protect other people, especially pregnant women and children. If you had been instructed to stop taking your thyroxine medication, nursing staff will organise a new supply of thyroid tablets for you to take home and you will be told when to restart them.

Will I have to come back to the hospital?

You will need to be seen again in the outpatient department by your consultant. You will either be given an appointment when you leave the ward, or this may be sent to you within two weeks of your discharge. If you do not receive a letter please contact your consultants secretary.

Will I need to have radioactive iodine treatment again?

The treatment may need to be repeated until all the remaining thyroid tissue has been destroyed. Most people will need one dose of radioactive iodine only (ablation dose) while others may need further treatment.

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Please remember that this is a very low dose of radiation and all these procedures are in place to protect you and others in case they need to have radiation treatment in the future. The aim is to keep everybody's exposure to a minimum.

Please contact your specialist treatment centre staff if you have any questions or concerns after reading this information. Together we can help you through your investigations, treatment and recovery.

It is important that you make a list of all medicines you are taking and bring it with you to all your follow up clinic appointments. If you have any questions at all, please ask your surgeon, oncologist or nurse.

It may help to write down questions as you think of them so that you have them ready. It may also help to bring someone with you when you attend your outpatient appointments.

Local sources of further information:

Sandwell and West Birmingham Hospitals NHS Trust

The Courtyard Centre
Sandwell General Hospital
Lyndon, West Bromwich, B71 4HJ
Tel: 0121 507 3792

University Hospitals Birmingham NHS Foundation Trust

The Patrick Room, Cancer Centre
Heritage Building (Queen Elizabeth Hospital Birmingham)
Edgbaston, Birmingham B15 2TH
Tel: 0121 371 3539

About this information

This guide is provided for general information only and is not a substitute for professional medical advice. Every effort is taken to ensure that this information is accurate and consistent with current knowledge at the time of publication.

Please use the space below to write down any questions you may have and bring this with you to your next appointment.

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Information for Patients

Oncology

Queen Elizabeth Hospital Birmingham
Mindelsohn Way, Edgbaston
Birmingham, B15 2GW
Telephone: 0121 627 2000

If you require this information in another format, such as a different language, large print, braille or audio version please ask a member of staff or email patientexperience@uhb.nhs.uk.