What to expect when it’s TIME to receive

RADIOACTIVE IODINE (IODINE-131)

Learn about the step-by-step process, including preparation, treatment day, and the days and weeks following.

THIS GUIDE was developed to educate you on what you can expect if your doctor has prescribed radioactive iodine to treat your thyroid cancer. It covers how you will prepare for the procedure, what happens on the day you receive radioactive iodine, possible side effects, and precautions you will need to take afterward.

It’s natural to have some anxiety about receiving radioactive iodine. But radioactive iodine is generally well tolerated and there is little evidence that it can cause significant harm.1 Radioactive iodine has been used to successfully treat patients with differentiated thyroid cancer (papillary or follicular thyroid cancers) for decades and can play an important role in your treatment.1,2

We encourage you to talk to your doctor if you have questions or concerns about radioactive iodine.
What is radioactive iodine and HOW DOES IT WORK?

To understand what radioactive iodine does, it is helpful to learn about how the thyroid gland uses regular iodine that comes from food. Thyroid cells have “iodine pumps” that absorb iodine as it enters your body and use it to produce thyroid hormones that regulate the body’s metabolism.

Thyroid cells absorb radioactive iodine in the same way—except that the radioactivity destroys any remaining normal or cancerous thyroid cells left behind after surgery. Radioactive iodine also destroys remaining thyroid cancer cells anywhere in the body, including those that may have “escaped” (metastasized) and could have become more aggressive and unresponsive to later treatment.1,3

Diagnostic whole-body scan

After surgery you will be given a very small dose of radioactive iodine (iodine-123 or iodine-131) to perform a scan of your whole body called a radioiodine scan or I-131 scan. This scan is used to determine if there are remaining thyroid cells or thyroid cancer to be destroyed, and to help your doctor determine the dose of radioactive iodine to give you for treatment.

Making thyroid cells more receptive to radioactive iodine

Your doctor will raise your level of thyroid-stimulating hormone by either stopping your thyroid hormone replacement therapy or giving you recombinant thyroid-stimulating hormone injections. If your thyroid hormone replacement therapy is stopped, you may temporarily experience symptoms of hypothyroidism.

You are put on a low-iodine diet

To make thyroid cells more receptive to radioactive iodine, you will be asked to follow a low-iodine diet for approximately 2 weeks before treatment and 1 to 2 days afterward. A diet of less than 50 micrograms of iodine per day is recommended and involves avoiding high-iodine foods, such as iodized salt, fish, red dye #3, and dairy products. Your doctor may have specific recommendations for a low-iodine diet.

Dental care

The radiation in radioactive iodine can affect your dental health if it causes a reduction in saliva, so you should make sure your teeth and gums are in the best possible condition at the time of treatment. Schedule a cleaning and tell your dentist that you will be receiving radioactive iodine.

Anti-nausea medication

Nausea can be a common side effect of receiving radioactive iodine, but it can be prevented with medication your doctor may prescribe beforehand. Talk to your doctor about receiving anti-nausea medication.

Breastfeeding

Radioactive iodine should not be used if you are breastfeeding or nursing. Talk to your doctor about your specific situation.
How to prepare

ON TREATMENT DAY

Follow these steps to help your treatment go smoothly:

- Follow your doctor’s instructions on what you can eat or drink, including medications
- Bring with you, for therapies administered in the hospital:
  - Photo identification and health insurance information
  - Foods such as sugarless gum, lemons, and sour candies to help ease dry mouth by stimulating your salivary glands.
  - Water or other drinks to help you stay hydrated and pass the remaining radioactive iodine through your urine
  - A sufficient supply of any medications you are taking. Discuss with your doctor
- Reading material that you can leave behind, such as newspapers or magazines
- Do not bring unessential personal items with you, such as:
  - Additional clothes to wear
  - Jewelry, watches, books, or phone
- Talk to your doctor about whether or not you should take medication to reduce the possibility of nausea
- Make sure you have made arrangements for transportation following your release from the hospital or treatment center

What to expect after

RADIOACTIVE IODINE (IODINE-131) TREATMENT

It may take several months for radioactive iodine to have its full effects on any remaining thyroid cells, both cancerous and non-cancerous. This is what usually happens in the first few weeks after your treatment:

The first 24 hours:

- You will take radioactive iodine by mouth in either liquid or capsule form
- Depending on the dose you are given and other factors, you may be treated as an outpatient and sent home or admitted to the hospital to be kept in isolation for a period ranging from a few hours to one or more days
- If hospitalized, you will remain in your hospital room with the door closed and will be unable to receive visitors until it is safe to release you from isolation
- If you are sent home immediately following your treatment, follow your doctor’s instructions carefully
- Follow instructions on maintaining a low-iodine diet and drinking fluids to stay hydrated to help pass the remaining radioactive iodine through your urine
- You may use the telephone to communicate with family and friends

The days and weeks afterward:

- Follow your doctor’s instructions on avoiding close contact with people in the days following I-131 treatment
  - Length of the isolation period will depend on whether you have small children at home, encounter pregnant women, and other factors
- During the isolation period recommended by your doctor:
  - Sleep alone (or at least 6 feet away from your partner) for several days
  - Use separate bath linens and wash these and underclothing separately for 1 week
  - Use separate eating utensils or disposable eating utensils; wash utensils separately for 1 week
  - Do not prepare food for others
  - Rinse the sink and tub thoroughly after using them; shower every day to help remove the radiation excreted through perspiration
  - Wash your hands with soap and plenty of water every time you use the toilet; flush the toilet each time you use it and wash the toilet seat

continued
Radioactive iodine is considered relatively safe and well tolerated among systemic cancer therapies and early side effects last for a short time, usually go away on their own, and are very manageable. Potential side effects may vary depending on the dose of radioactive iodine you receive.

Common early side effects include:
- Nausea and upset stomach, which can be managed with medication
- Swelling and tenderness of the salivary glands, which can be treated with anti-inflammatory and pain medications
- Temporary taste changes

Possible long-term side effects after receiving radioactive iodine:
- Intermittent obstruction of saliva flow (12% of patients)
- Dry mouth (5% of patients)
- Blocked tear duct (5% of patients)

While there is potential risk of developing another cancer after receiving radioactive iodine, it is very small. In a large study, the absolute risk of developing a secondary cancer after an average of 15 years following radioactive iodine therapy increased marginally from 0.68% to 0.8%. Overall, the risk of developing any secondary cancer is less than 1%.

Potentially side effects of RADIOACTIVE IODINE (IODINE-131)

The days and weeks afterward (cont.)
- In 1 to 2 days after receiving radioactive iodine, you will begin taking thyroid hormone pills
- You will remain on the low-iodine diet for 1 to 2 days after your treatment
- You may be advised to take laxatives in order to reduce the amount of radiation exposure in your intestinal tract
- Discuss with your doctor how long you should wait before attempting to become pregnant after your treatment (usually at least 2 months for males and 6 to 12 months for females)
- If you need to travel by plane or other transportation after receiving radioactive iodine, carry an information card or letter of explanation from your doctor for at least 3 months

Home dental care
- Radioactive iodine changes the amount of your saliva, so follow-up care with your dentist is important
- If you notice a change in taste or saliva, use toothpaste and mouthwash without alcohol, phenol, or whitening agents
- Baking soda is a good option for dental care and may be used 4 to 5 times daily
- Floss daily

Post-therapy scan
- Within 2 to 7 days after radioactive iodine treatment, a whole-body image will be taken using a radiiodine scan (I-131 scan)
- In 98% of patients, the scan will show a small amount of remaining thyroid cells, since surgery and radioactive iodine are unlikely to remove 100% of the thyroid
- This scan will provide information about the location of any thyroid cancer that was not removed during surgery (eg, when thyroid cancer has spread outside the neck area)