



## It kills thyroid cancer, but is radiation safe?

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By Steve Sternberg and Anthony DeBarros, USA TODAY

BALTIMORE — Soon after Holly Russell-Milstein took her thyroid cancer medicine at Johns Hopkins University here on Oct. 18, she went into self-imposed isolation in a row house a short walk from the hospital.

The medicine, iodine 131, is a proven cancer fighter. But it's also radioactive, and in higher doses, can cause cancer. Russell-Milstein — like thousands of other thyroid cancer patients in the USA each year — worried that the radiation might pose a risk to her family.

For two weeks after her treatment, Russell-Milstein, 29, chose to isolate herself rather than go home. Her doctor told her that if she stayed away from her four children and followed precautions, it would be safe to return to her family in McLean, Va. But Russell-Milstein says she couldn't accept the consequences if the doctor was wrong.

"How can you have any peace of mind when you know you're potentially putting your family at risk?" asks Russell-Milstein, who returned home Oct. 30, in time for Halloween. "I'd rather live in a box under a bridge than come home to my small children."

Many other patients echo her concerns, even as I-131 is being used to treat a broadening spectrum of cancers. The isotope works so well in treating thyroid cancer — the five-year survival rate is 97% — that researchers worldwide have begun using it in treatments of lymphoma and cancers of the liver, colon and prostate.

"It's an exciting time" for radioactive iodine treatment, says Russell-Milstein's doctor, Paul Ladenson, director of endocrinology at Johns Hopkins Medical Institutions.

Doctors and scientists, however, disagree over the risks of secondhand exposure to I-131. Two years ago, the National Academy of Sciences reported that no amount of ionizing radiation is safe. However, an analysis done for USA TODAY suggests the risk is relatively low and that a hug from a radioactive mom is unlikely to sow the seeds of thyroid cancer in her child.

"Chances are, if you get a cancer, it's not going to be related to this exposure," says Owen Hoffman, an independent risk analyst for the consulting firm SENES in Oak Ridge, Tenn.

Hoffman calculates that the additional lifetime cancer risk for an infant girl — infants are most vulnerable to radiation exposure — is 2 in 1,000. For a boy, it would be 1 chance in 1,000. For adults, he estimates, the risk falls to a few chances in 10,000.

Even so, Hoffman says he can't totally discount the risk of illness from secondhand exposure to I-131.

"Every exposure poses a risk," he says. "These levels of radioactivity pose a risk far greater than the Environmental Protection Agency would accept for public exposures at Superfund sites."

A USA TODAY survey, the first to examine the scope of thyroid cancer survivors' concerns nationwide, finds that more than half of patients who received I-131 were treated and released rather than kept in



hospitals. The survey also finds that 85% of outpatients worried about exposing their family members to radiation.

Not only are patients radioactive for several days after treatment, the objects they touch may become radioactive. Although patients excrete the bulk of their radiation in three days, traces may linger in the body for as long as two weeks.

A decade ago, I-131 patients didn't have to worry much about exposing family members to radiation. Most patients were kept in the hospital for several days until radiation detectors indicated it was safe to send them home. In 1997 the Nuclear Regulatory Commission relaxed its rules, allowing doctors to give I-131 to outpatients.

That decision marked a tipping point for thyroid cancer patients. Many hospitals eliminated their radiation isolation rooms. Some doctors began treating patients in their offices. Health plans tightened restrictions on I-131 treatment so much that insurance often won't cover hospitalization.

Now, with thyroid cancer diagnoses increasing, more patients are raising concerns about the safety of outpatient I-131 treatment. The issue has sparked controversy among patients in support groups and in Internet chat rooms. Doctors' conflicting opinions add to the confusion: Some say it's almost always safe to release patients treated with I-131. Others disagree.

### **'Only two things can go wrong'**

Ladenson says he rarely admits I-131 patients to the hospital. Before the NRC changed its rules, he says, "I admitted two patients a week. Now I admit two patients a year," those who are so sick that they need whopping doses of the isotope.

To demonstrate the safety of low-dose I-131, he scanned his own thyroid with a radiation counter moments before Russell-Milstein's treatment to show that he had no ill effects from the six treatments he had performed that week.

Then, wearing only standard doctor's attire — a white coat over a shirt and necktie — the white-haired specialist produced a lead-like canister with hands sheathed in purple hospital gloves.

"There are only two things that can go wrong with this treatment. You can give the wrong dose to the wrong person, or you can drop the container on your foot. It's made of tungsten and extremely heavy."

Inside the canister, nested like Russian dolls, was a plastic cylinder containing a large capsule of I-131. Russell-Milstein retrieved the vial, held it to her lips and tossed down the capsule. Ladenson handed her a Styrofoam cup. She washed the pill down with water.

Russell-Milstein's first question after she took the pill concerned the safety of those around her.

"It's safe to be around people for a brief period," Ladenson answered. "You don't want to sit on a couch with your daughter for two hours."

Russell-Milstein wouldn't see her daughters for 12 days. She was determined to protect Alanna, 9, Ava, 7, Amelia, 4, and especially Ariela, 2, who was too young to understand that hugging Mommy might be risky. "She's all over me," Russell-Milstein laments.

To guard against contaminating her rented row house, Russell-Milstein brought her own bedding and lined the floors with plastic runners. She covered doorknobs and other surfaces with contact paper. She even wrapped the TV remote control in a plastic bag.



"I guess it's better if you stay away for two weeks and come home healthy, than if you stay here sick," she recalls Alanna saying.

A common thread runs through online thyroid cancer support groups. Members complain about people who describe the disease as a "good" cancer, because of its very high survival rate. "Some people actually think that you are 'milking it,' " wrote one irate member of a Yahoo thyroid cancer chat group.

Thyroid cancer has a mild reputation because I-131 treatment is so effective for most forms of the disease. The approach exploits the thyroid gland's hunger for iodine, a key ingredient in the thyroid hormone that regulates the body's energy use. Because thyroid tissue soaks up any iodine it finds, I-131 is drawn directly to the cancer, wherever it has spread.

"It's like the ultimate magic bullet," says Robert Udelsman, a thyroid cancer expert and surgeon at Yale University. "Radioactive iodine goes straight to thyroid cells and kills them. If only we had such a wonderful magic bullet for other cancers, we'd have a lot fewer cancer deaths in this country."

Doctors likely will be using I-131 more often as time goes by. Although it is still relatively rare — just 1.5% of all cancers — thyroid cancer's incidence has doubled during the past 30 years, possibly because of improved diagnosis, research indicates.

Doctors now diagnose about 34,000 new cases a year, twice as many of them in women as men. "About 90% get treated with radioactive iodine. You're probably talking about 28,000 patients a year," says Douglas Van Nostrand, director of nuclear medicine at Washington Hospital Center in Washington, D.C., and a co-editor of *Thyroid Cancer: A Guide for Patients*.

The median age of diagnosis for women is 46. That means many of those needing I-131 treatment are likely to be women with young children. Kids are particularly sensitive to radiation, according to studies of survivors from the atomic bombings in Hiroshima and Nagasaki during World War II, and the 1986 meltdown at the nuclear power plant at Chernobyl, where escaping I-131 gave 5,000 children thyroid cancer.

### **Risks and uncertainties**

Chernobyl released vastly greater amounts of radiation than the maximum of 500 millirems a bystander might receive from an I-131 patient. No one knows precisely how much damage the much smaller dose could do, because it's virtually impossible to conceive of an ethical, large-scale experiment that involves exposing people to radiation.

The studies done so far are small and don't mirror reality, says Peter Crane, a thyroid cancer survivor and former NRC lawyer who is challenging the agency's decision to relax its rules on outpatient treatment with I-131.

To reduce the risk of secondhand I-131 contamination, the congressionally chartered National Council for Radiation Protection and Measurement recently released more than 200 pages of guidelines for treating patients with radioactive therapies. They advise I-131 patients to:

- Avoid holding children for more than 10 minutes a day for 21 days after treatment.



- Sleep alone for a full week after treatment or 24 days if your bedmate is pregnant.
- Try to stay as far from other people as possible, "to the extent that's reasonable."

Jean St. Germain of Memorial Sloan-Kettering Cancer Center in New York, chairwoman of the committee that wrote the recommendations, says she and her co-authors tried to clear up the confusion.

"If you have a patient who isn't able to follow instructions, who is mentally challenged or is a young mother with three children, maybe this is not the best person to send home" from the hospital, she says.

The USA TODAY survey, carried out with the help of the Thyroid Cancer Survivors' Association, discloses how patients react to the risks and uncertainties of I-131 therapy. The survey drew 914 responses from the group's 5,000-plus members. Because respondents weren't chosen randomly, the survey isn't scientific, but it offers a window into the world of thyroid cancer care:

- Eighty-six percent of the outpatients said they went directly home after being treated. Two percent used public transportation, potentially exposing others to radiation. About 4%, rather than going home, checked into hotels or other accommodations, potentially posing a risk to guests or cleaning staff.
- Ninety-one percent were warned of radiation's risks, which means nearly 1 in 10 were not. Many respondents also commented that they were given confusing or conflicting information.
- Nearly half of all patients surveyed experienced nausea after treatment and 8% threw up, a side effect of I-131. Many of those reported they believed the vomiting, or the cleanup that followed, posed a radiation risk to others.

Just as revealing were the stories of hundreds of patients left to grapple on their own with the complexities and uncertainties of outpatient radiation treatment.

Ellen Hodge, 53, of Glendale, Ariz., says she and her husband were so worried that I-131 would harm his thyroid that he drove her home from treatment wearing a lead-lined dentist's X-ray apron — not knowing it doesn't block I-131 gamma rays. Hodge sat as far away from him as she could in the family's dual-cab pickup.

Millie Hughes, 36, of Blue Ridge, Ga., says her husband slept in an RV in the front yard. Her son, Taylor, 11, and daughter, Austin, 12, stayed with Hughes' mother, who would regularly drop off food. One day, she waited in the car and sent Taylor to the front door with a meal for his mom. "He's my son, he wants to see me, but he can't," Hughes says. "That was horrible. I just shut the door, called my mom and said, 'Let's not have that happen again.' "

Then there's Aileen Schlissel, 45, of Las Vegas. The mother of two young children, Schlissel rented a time-share apartment for a week to avoid irradiating her family. She decided to treat the week as a vacation, renting movies and buying chocolate. What she didn't count on was becoming violently ill from I-131. Her doctor told her to go to the emergency room.

"When I got there, I said, 'I can't stand here, I'm radioactive.' One of the woman behind the counter was pregnant. She looked at me like I had three heads. And I threw up in the lobby." That wasn't the worst part of her experience.



"What floored me," she says, "is that not only was I radioactive, I was all alone."

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