

Thyroid Cancer

What You Should Know

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I was just told that my thyroid nodule biopsy was positive for cancer, what happens now?

There are four types of thyroid cancer divided into two categories: differentiated (papillary and follicular) and undifferentiated (medullary and anaplastic). 90-95% of all thyroid cancer is differentiated and most is papillary.

The main treatment for differentiated thyroid cancer is surgery (removing most of the thyroid gland and any involved lymph nodes), radioactive iodine (discussed below) and thyroid hormone therapy (life-long). Cancer treatments like chemotherapy and external beam irradiation are almost never used.

What can I expect from thyroid surgery?

One of the most important parts of thyroid cancer therapy is the surgery. You need this to be done by a very experienced surgeon. Ask your potential surgeon how many thyroid surgeries they do each year (preferably more than 20) and what is the expected rate of complications. Thyroid surgery is done under general anesthesia and usually takes about two hours. You will be in the hospital for about 2 days and should plan on missing work for about a week to recover. Since most of the thyroid gland is removed, you will need to take thyroid hormone for the rest of your life.

Are there any special risks with thyroid surgery?

Two complications that can occur are damage to the recurrent laryngeal nerve and damage to the parathyroid glands. The recurrent laryngeal nerve runs behind the thyroid gland and makes the vocal cords work. Damage to one nerve can lead to a permanent hoarse voice, while damage to both nerves can lead to breathing problems. The risk of damage to one nerve is about 1-2% in the hands of an experienced surgeon and can be as high as 10-20% for a less experienced surgeon. The risk of damage to both nerves is practically zero in the hands of a good surgeon. The parathyroid glands (most of us have four) are located just behind the thyroid and can be accidentally removed or damaged during surgery. If one functioning gland remains, it will work just fine. If all glands are removed or damaged, you won't have any parathyroid hormone (PTH), which helps to maintain blood levels of calcium. Low calcium can lead to numbness and muscle cramps which can be quite severe; this can be treated with vitamin D and calcium, but can be difficult to regulate. The risk of permanent damage to your parathyroid glands is about 1-2% in the hands of a good surgeon.

What is radioactive iodine and why do I need it?

Normal thyroid cells and most thyroid cancer cells concentrate iodine to make thyroid hormone. Basically, no other organ concentrates iodine like the thyroid, so the therapy with radioactive iodine is quite specific.

After surgery (in most cases), you will be taken off thyroid hormone in preparation for radioactive iodine treatment. Your pituitary gland makes a hormone called TSH (thyroid stimulating hormone) that does just that. TSH stimulates thyroid cells (normal and cancer) to make thyroid hormone. In order to make thyroid hormone, these cells avidly concentrate iodine. When your TSH is high enough (measured by a blood test) you are given radioactive iodine which is concentrated in these cells and the radioactivity kills them. Luckily, the killing radiation has a short path and doesn't significantly damage neighboring cells. The radioactive iodine is necessary to kill any remaining thyroid cancer cells as well as any normal thyroid cells to improve our ability to follow you for potential cancer recurrence.

What will I feel when I take the radioactive iodine?

The radioactive iodine is a liquid (about a tablespoon) that tastes like stale water. Most people don't feel anything when they take the radioactive iodine. About 5% of people have a little nausea and 1-2% of people have severe nausea (and vomiting) that can be managed with medicine. Radioactive iodine is also concentrated in the salivary glands, but to a lesser degree than the thyroid. About 1% of people notice tenderness in the salivary glands (around the mouth and upper neck) and it can occasionally be severe, but this can also be treated with medication. Although, the regulations will hopefully change in the near future, as of 1999, you will need to come in the hospital for this treatment because of the amount of radioactivity used. Your stay is usually for 24 hours, and our staff can give you information regarding this stay.

Isn't radioactivity dangerous?

Yes. But when used appropriately, radioactive iodine is quite safe. The major long-term risks associated with radioactive iodine are bone marrow suppression and an increased risk of other types of cancer (bladder, certain types of leukemia). Bone marrow suppression, which can lead to low blood counts of white cells, red cells and platelets, can be seen with very high single dosages of radioactive iodine. The dosages typically used to treat thyroid cancer do not cause bone marrow suppression. Other types of cancer have been seen with very high cumulative dosages of radioactive iodine over a long period of time (repeated treatments). Most patients are kept well below the cumulative dosages known to increase your risk of these other cancers.

How will I feel without thyroid hormone?

Stopping the thyroid hormone is necessary to stimulate the thyroid cells to concentrate radioactive iodine for treatment. You need to be off thyroid hormone for about six weeks to achieve the necessary stimulation. During the first four weeks, you will take a shorter acting thyroid hormone (Cytomel), so you will feel fairly good. The final 10-14 days off all thyroid hormone can be difficult. You may feel very tired, cold, constipated and you may have difficulty concentrating and even controlling your emotions. These symptoms of hypothyroidism (low thyroid) can be quite mild to quite severe depending on the individual. We recommend that you don't drive during these last 10-14 days, because your reflexes can be quite slow. You will be started back on thyroid hormone the day after you receive your radioactive iodine and should expect to start feeling better in a few days, but you probably won't feel normal for 2-4 weeks.

How am I followed to make sure the cancer doesn't come back?

Once you are treated, you will be started back on thyroid hormone and have blood tests in about 2 months to make sure the dose of thyroid hormone is right for you. Between 6 and 12 months, you will need a whole body scan, using a small dosage of radioiodine, to make sure all of the thyroid tissue and cancer was destroyed. There

are now two ways to prepare you for this. One way is the standard withdrawal of thyroid hormone discussed above (6 weeks). The other is a newly approved agent called recombinant human TSH (Thyrogen). Like insulin and growth hormone, Thyrogen is a protein made in genetically engineered cells and purified. It is given as an injection each day for two days to raise your blood level of TSH, which is necessary to stimulate any remaining thyroid cells or cancer cells to concentrate radioactive iodine. On the third day, you are ready to get the small dosage of radioactive iodine for your whole body scan. Ask your thyroid specialist which method (thyroid hormone withdrawal or Thyrogen) is best for you.

Two to three days after you receive the radioactive iodine, a scan will be performed to look for any areas of uptake (indicating persistent tissue). If this is negative, you most likely don't have any cells and can be followed as outlined by your thyroid specialist. If areas of uptake are seen, you will need to be treated with a larger dosage of radioactive iodine. Long-term follow-up is specific for your type of disease, but usually involves a yearly examination and blood tests.

Are any other tests used to follow for thyroid cancer recurrence?

Thyroid cells (cancer and normal) are the only cells in the body that make a protein called thyroglobulin, which can be detected on a simple blood test in people with a normal thyroid gland and patients with persistent thyroid cancer. If only a few thyroid cancer cells are in the body, thyroglobulin can be detected in the blood, making this a very sensitive test. High levels of TSH (caused by thyroid hormone withdrawal or an injection of Thyrogen), stimulate any thyroid cells to make more thyroglobulin, so the most sensitive indicator of the presence of any thyroid cells is a serum thyroglobulin level after TSH stimulation. Thyroglobulin levels are usually measured while you are on thyroid hormone and when a whole body scan is performed.

In some cases, other testing such as a chest x-ray, ultrasound of the neck or CAT scan of the chest can be helpful in locating disease if the thyroglobulin level is high.

What are my chances of being cured?

Your chances of being cured are dependent on the behavior of your original cancer (size, invasion outside the thyroid, metastases to other organs, your age). Luckily, most people with thyroid cancer have a small tumor that is confined to the thyroid, and the chance of complete cure is better than 90%. Thyroid cancer is usually slow growing and may take years (> 10 years) to reappear, so life-long surveillance with yearly examinations is needed.

What if I have the undifferentiated (medullary or anaplastic) cancer?

These are fortunately rare cancers, but can be difficult to treat. You will need to discuss treatment options with your thyroid cancer specialist since the treatment is different than described above for differentiated thyroid cancer.