CONDITION

Thyroid cancer - medullary carcinoma

Medullary thyroid carcinoma is a cancer that begins in the thyroid's calcitonin-producing C cells.

WHAT IT IS
Cancer of the thyroid's calcitonin-producing C cells

BODY SYSTEM
Hormone system

MAIN SYMPTOMS
Neck lump, swollen lymph nodes, hoarseness, trouble swallowing

WHAT CAUSES IT
Acquired mutations or inherited RET mutations

HOW IT IS DIAGNOSED
Needle biopsy, calcitonin testing, and tumour pathology

MAIN TREATMENT
Surgery, with targeted medicines for some advanced cancers

CAN IT BE CURED?
Sometimes - surgery cures some localised cancers

IS IT AN EMERGENCY?
Sometimes - if breathing becomes difficult

LONG-TERM OUTLOOK
Best when confined to the thyroid and completely removed

Overview

Medullary thyroid carcinoma, or MTC, is a type of thyroid cancer. It begins in specialised thyroid cells called C cells . These cells make calcitonin, a hormone involved in controlling calcium levels.

MTC is different from the more common papillary and follicular thyroid cancers. Those cancers begin in cells that make thyroid hormones. This difference affects how MTC is tested, treated, and monitored.

Some MTCs develop without an inherited cause. These are called sporadic cancers. Others are caused by an inherited change in a gene called RET . Inherited MTC can occur by itself or as part of multiple endocrine neoplasia type 2, known as MEN2. MEN2 can also cause tumours in the adrenal or parathyroid glands.

MTC often starts as a thyroid lump. It may spread to nearby lymph nodes in the neck or, in more advanced cases, to organs such as the liver, lungs, or bones.

Surgery can sometimes cure MTC when it is found before it has spread and can be removed completely. If it cannot be cured, treatment may control its growth and relieve symptoms.

Symptoms

MTC may not cause symptoms at first. It may be found after you notice a lump or during a scan performed for another reason.

Possible symptoms include:

A neck lump is much more likely to have a non-cancerous cause than to be MTC. It still needs assessment if it is new, growing, or persistent.

Advanced MTC can release large amounts of calcitonin and other substances into the blood. This may cause frequent watery diarrhoea or, less often, flushing of the face and upper body. These symptoms do not usually occur in small, localised tumours.

Cancer that has spread may cause symptoms related to the affected area. Bone spread can cause persistent pain. Lung involvement may cause breathlessness or coughing. Liver involvement may cause abdominal discomfort, although it may cause no symptoms initially.

- A lump or swelling in the front of the neck
- Enlarged lymph nodes along the side of the neck
- A hoarse or changing voice
- Difficulty swallowing
- Pressure or discomfort in the neck

Causes and risk factors

Cancer develops when genetic changes allow cells to grow without normal control. In MTC, these changes often affect signalling pathways that tell C cells when to grow.

Most cases that are not inherited develop after birth because of changes within the tumour cells. These changes are not present throughout the body and are not passed to children.

Inherited MTC is usually caused by a harmful change in the RET gene . RET provides instructions for a protein involved in cell growth. A harmful inherited RET change can cause MEN2.

MEN2 may involve:

A person with a harmful RET change has a one-in-two chance of passing that change to each biological child. This does not mean every affected family member will develop the condition at the same age or with the same severity.

A family history of MTC, MEN2, or phaeochromocytoma increases the chance of an inherited cause. However, an inherited RET change can still be found when the family history seems unremarkable. For this reason, genetic testing is generally offered to everyone diagnosed with MTC.

- MTC, sometimes beginning at a young age
- Phaeochromocytoma, an adrenal gland tumour that can release stress hormones
- Overactive parathyroid glands in some forms of MEN2

Diagnosis

Assessment usually begins with an examination and a thyroid ultrasound. Ultrasound shows the size and position of a thyroid lump and whether nearby lymph nodes look unusual.

A fine-needle aspiration may be performed. This uses a thin needle to collect cells from the lump. The cells are examined under a microscope. Tests for calcitonin in the sample may help when the findings are unclear.

Blood tests usually measure calcitonin and carcinoembryonic antigen , or CEA. CEA is a protein that can be released by MTC. High levels can support the diagnosis and help estimate the amount of cancer present, but neither test should be interpreted alone. Other conditions and medicines can sometimes affect the results.

The diagnosis is confirmed by examining tumour tissue. This may come from a needle sample or from tissue removed during surgery.

CT, MRI, bone imaging, or other scans may be needed if tests suggest that the cancer extends beyond the thyroid. Not everyone needs every scan.

A blood test can look for an inherited RET gene change. Genetic counselling can help you understand the result and what it may mean for relatives.

If MEN2 is possible, testing for phaeochromocytoma is important before thyroid surgery. An unrecognised phaeochromocytoma can cause dangerous changes in blood pressure during an operation. Calcium and parathyroid hormone tests may also be used to check the parathyroid glands.

Treatment and management

Treatment depends on where the cancer is, whether it has spread, its genetic features, and your general health. Your preferences also matter.

Surgery is the main treatment when MTC can be removed. This usually means removing the whole thyroid, called a total thyroidectomy . Nearby central neck lymph nodes may also be removed. If tests show cancer in lymph nodes along the side of the neck, a wider lymph node operation may be needed.

After total thyroidectomy, you will need thyroid hormone tablets for life. These replace the hormones that the thyroid previously made. Unlike treatment for some other thyroid cancers, the dose is not normally intended to suppress thyroid-stimulating hormone, because MTC cells do not arise from thyroid hormone-producing cells.

Radioactive iodine does not usually treat MTC. C cells do not take up iodine in the way that other thyroid cells do.

Calcitonin and CEA are checked after surgery. Levels that become very low or undetectable suggest that all detectable cancer may have been removed. Persistent or rising levels can mean that MTC cells remain, but a blood-test rise alone does not always mean treatment should begin immediately.

If MTC cannot be removed or has spread, management may include monitoring, further surgery, focused radiation, or medicines. Slowly growing cancer that is not causing symptoms may be watched with blood tests and scans.

Medicines called tyrosine kinase inhibitors block growth signals used by cancer cells. Vandetanib and cabozantinib are options for some people with progressive, advanced MTC. Selpercatinib is a more selective RET inhibitor used for appropriate RET-mutated cancers. These treatments can slow or shrink cancer, but they are not usually considered curative.

Targeted medicines can cause significant side effects, including diarrhoea, high blood pressure, tiredness, skin problems, liver-test changes, or changes in heart rhythm. The risks differ between medicines and require regular monitoring.

External-beam radiation may be considered for cancer that cannot be fully removed, threatens an important structure, or causes symptoms in a specific area. Treatment for bone spread may include focused radiation, surgery, or bone-strengthening medicines.

Complications

MTC can grow into nearby structures or spread through lymph channels and the bloodstream.

Possible sites include neck lymph nodes, liver, lungs, and bones.

Pressure on the voice-box nerves can cause hoarseness. Pressure on the windpipe or swallowing tube can make breathing or swallowing difficult. Hormones released by advanced MTC may cause persistent diarrhoea, dehydration, and weight loss.

Thyroid surgery also has possible complications. These include bleeding, infection, voice changes from nerve injury, and low calcium if the parathyroid glands are affected. Low calcium may cause tingling around the mouth, muscle cramps, or spasms. Some problems are temporary, while others require long-term treatment.

Treatment complications should be reported promptly. Many can be managed by adjusting treatment, adding supportive care, or treating the specific side effect.

Prevention

Most sporadic MTC cannot currently be prevented. There is no routine screening programme for people without a personal or family risk.

An inherited RET gene change cannot itself be prevented. However, identifying the change before cancer develops can make prevention or very early treatment possible.

Children and adults who carry certain harmful RET changes may be offered thyroid removal before MTC develops or while it is still very small. The timing is based on the specific RET change, calcitonin results, age, and specialist assessment. It is not the same for every family.

When an inherited change is found, genetic counselling and testing can be offered to close biological relatives. Relatives who do not carry the family's RET change do not need MEN2 surveillance related to that change.

Living with it and what to expect

After surgery, follow-up usually continues for life. It commonly includes calcitonin and CEA blood tests, thyroid hormone tests, physical examinations, and scans when needed.

Calcitonin and CEA trends matter more than a single result. Specialists may calculate how quickly the level doubles. A short doubling time can suggest faster-growing cancer, while levels that change slowly may support continued monitoring.

If surgery removes all detectable cancer and markers stay low, you may need only periodic follow-up and daily thyroid hormone replacement. Many people return to their usual work, family life, and activities after recovery.

Persistent calcitonin does not always mean you will feel unwell or need immediate treatment. Some remaining cancers grow slowly for years. Treatment is more likely when scans show meaningful growth, the cancer threatens an organ, or symptoms develop.

Advanced MTC has a less predictable course. Some people live with controlled cancer for years, while others have faster progression and need several treatments. Changes in treatment may be guided by scans, symptoms, tumour genetics, and how well side effects are tolerated.

Genetic results can affect relatives as well as you. Genetic counselling may help with family communication, testing decisions, and planning for children. Emotional support is also available if ongoing tests or uncertainty become difficult to manage.

When to get medical help

Arrange a routine medical assessment if you develop a new thyroid or neck lump, persistent hoarseness, enlarged neck glands, or ongoing trouble swallowing. These symptoms have many possible causes, but they should be checked.

If you have been treated for MTC, contact your care team between planned appointments for new or worsening symptoms. These include persistent diarrhoea, unexplained weight loss, new bone pain, increasing neck swelling, or side effects from treatment.

Seek urgent medical care for:

Call emergency services if breathing becomes severely difficult, neck swelling is affecting the airway, or you collapse.

- Rapidly increasing neck swelling
- New noisy breathing or worsening shortness of breath
- An inability to swallow liquids
- Severe diarrhoea with dizziness, faintness, or very little urine
- Tingling and muscle spasms after thyroid surgery

Common questions

Is medullary thyroid cancer curable?

Sometimes. Cure is most likely when the cancer is limited to the thyroid and nearby tissue and can be removed completely. Cancer that has spread to distant organs is not usually curable,

but treatment may control it.

Is medullary thyroid cancer hereditary?

It can be. Some MTCs are caused by an inherited RET gene change, while others arise from genetic changes found only in the tumour. Genetic testing helps distinguish between them.

Does a high calcitonin level mean the cancer is growing?

Not necessarily from one result. Calcitonin can reflect the amount of MTC present, but the pattern over time is more useful. Levels may remain detectable and stable for long periods. Scans and CEA results add further information.

Why does radioactive iodine not work for MTC?

Radioactive iodine works when cancer cells absorb iodine. MTC begins in C cells, which do not normally absorb iodine. This makes radioactive iodine ineffective for most MTC.

Will my family need genetic testing?

If you have a harmful inherited RET change, close biological relatives may be offered testing for that specific change. If no inherited change is found, relatives usually do not need MEN2 testing based only on your MTC diagnosis.

Can medullary thyroid cancer come back after surgery?

Yes. It can return in the neck or appear elsewhere, sometimes years later. Lifelong blood-test follow-up helps detect changes before they cause symptoms.

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