Graves’ Disease in Pediatrics

Graves’ disease is a common cause of an overactive thyroid. It occurs in about 1 in 5000 children and teens. It occurs more often in females than males. This booklet is designed to help you learn more about Graves’ disease. After reading it, please feel free to ask your nurse or doctor any questions you may have about Graves’ disease.

Before we can discuss what it means to have this disease, we need to back up and take a look at the main body organ involved in Graves’ disease: the thyroid gland.

What is the thyroid gland?

The thyroid is a butterfly-shaped gland found in the front of the neck. It is part of the endocrine system. This means it makes hormones and sends them into the bloodstream. Then they can act on certain parts of the body called target organs.

The thyroid uses iodine and other building blocks to make two hormones: thyroxine (called T4) and triiodothyronine (called T3). Your thyroid makes more T4 than T3, but in other parts of the body some T4 is changed to the more active T3.

Thyroid hormones affect almost every tissue and organ system. They act on a number of target organs to aid in growth, body and brain development, and normal metabolism. Thyroid hormone acts like the body’s “gas pedal,” because it affects the rates of growth, muscle contraction, metabolism, and protein building.

The thyroid is controlled by two centers in the brain called the hypothalamus and the pituitary gland. The pituitary gland is a pea-shaped organ at the base of the brain and the hypothalamus lies just above it. When the body needs more T3 or T4, the hypothalamus sends a message (thyroid releasing hormone or TRH) to the pituitary telling it to release thyroid stimulating hormone (TSH). TSH causes the thyroid to raise the body’s level of thyroid hormones. The hypothalamus and the pituitary gland detect this increase and stop sending TSH messages when the thyroid has produced enough of the hormone.

What do hyperthyroidism and hypothyroidism mean?

When your thyroid is working as it should and it makes the right amount of thyroid
hormone, you are **euthyroid** (eu- meaning “normal”). If you produce too much thyroid hormone, it is called **hyperthyroid** (hyper – meaning “too much”). Low levels of thyroid in the body cause you to be **hypothyroid** (hypo – meaning “too little”). You need to know the symptoms of hyper- and hypothyroidism because both may occur in the course of treating Graves’ disease.

**Symptoms of Hyperthyroidism (too much T3 and T4)**

- Feeling hot when nobody else does
- Having moist or sweaty skin
- Diarrhea
- Feeling nervous or restless, having trouble falling or staying asleep
- Short attention span
- Normal or increased growth rate, but decreased weight
- Increased appetite
- Rapid heart beat
- Muscle weakness or tremors
- Irritability
- Fine hair

**Symptoms of Hypothyroidism (too little T3 and T4)**

- Feeling cold when nobody else does
- Cool, dry skin
- Constipation
- Fatigue
- Slowed growth and weight gain
- Poor appetite
- Having a calm or quiet nature
- Coarse, dry, thin hair

**What Causes Graves’ Disease?**

Graves’ disease is an **autoimmune** (auto – meaning “self”) disease. Every person has an immune system which will produce **antibodies** (also called **immunoglobulins**) that help the body fight disease. An antibody connects to a foreign particle in the body and helps destroy it. But when the immune system makes antibodies against things that are not foreign to the body, but are part of the body, autoimmune disorders like Graves’ disease occur.

In Graves’ disease, the body’s immune system makes antibodies that affect the thyroid in the same way TSH would. Like TSH, these antibodies, called **thyroid-stimulating immunoglobulins or TSI**, act as a message that turns the thyroid “on” and tells it to produce thyroid hormones. But, unlike TSH, TSI is not controlled by thyroid hormone levels, and the result is hyperthyroidism.

The reason the body begins to produce antibodies against the thyroid is not fully known. Research seems to suggest that some peoples’ genes make them more prone to making autoantibodies

**What will the doctor do to decide if I have Graves’ disease?**

Your doctor relies on your health history, physical exam, and blood tests to decide if you have Graves’ disease. The list below describes many of the things your doctor may do or order during your clinic visit.

**Look for signs of Graves’ disease by checking for:**

- Weight loss or rapid growth.
- Resting pulse rate of greater than 100 beats per minute.
- Blood pressure with a large gap between the high (systolic) and low (diastolic) numbers.
- Fast reflexes.
- Moist or oily skin and hair.
- Enlarged thyroid gland (called a **goiter**). In hyperthyroidism due to Graves’ disease, the thyroid is enlarged because stimulation of the thyroid by TSI causes it to grow.
- Prominent eyes called **exophthalmos**. This gives you a wide-eyed staring look. This is caused by autoantibodies and is not a result of hyperthyroidism. Other
changes in the eyes may include excess tearing, aching, or burning behind the eye, a feeling as if grit or sand is in the eye, or being bothered by light.

- Nervous system signs such as tremors, feeling restless, muscle weakness, and sleep problems.

**Blood Tests**

Your doctor will also order some lab tests. The main things your doctor wants to measure are

1. **TSH** levels in people with Graves’ are very low because their T3 and T4 are high enough that the pituitary does not need to send TSH to the thyroid to make it produce T3 and T4.
2. **Free T3 and Free T4** tests find that T3 is high when a person is hyperthyroid. T4 may be normal or high. Since Graves’ speeds up the change of T4 into T3, normal levels of T4 can occur with high levels of T3.
3. **TSI** is sometimes, but not always, seen when Graves’ disease is the problem.
4. **Thyroid Scan** gives a picture of how your thyroid uses iodine. It can be used to decide whether it is Graves’ disease or some other cause of hyperthyroidism. This test is rarely used in children.

**How is Graves’ disease treated?**

If hyperthyroidism is not treated, it can be a severe problem. As a result, if patients have symptoms, they should receive medical, radiation, or surgical treatments.

**Drug treatment**

Tapazole® (methimazole) acts on the thyroid to reduce its production of thyroid hormones. As a result, less thyroid hormone is produced. These drugs also slow down the change of T4 to T3.

Another group of drugs called **beta-blockers** (e.g., propanolol), do not act on the thyroid and do not affect thyroid hormone levels, but block the effects of the thyroid hormones in the body. For instance, this type of drug might be used when Graves’ is first diagnosed and the heart rate is very rapid.

In children, most doctors use Tapazole® (methimazole) as the first treatment for Graves’ disease. We will adjust the dose to bring thyroid hormone levels into the normal range. Knowing the signs of hypo – and hyperthyroidism will allow you to tell your doctor that a change in dose may be needed.

About 5% of Graves’ disease patients getting drug treatment have **side effects** such as skin rashes, liver problems, joint pain, and fever. Rarely, problems with white blood cell production can cause high fever and throat or mouth infections. **You must call your doctor or the endocrinology nurse if you have any of these signs or symptoms.** You will need blood tests done to watch for any of these side effects.

Even though drug treatment works well to lower thyroid hormone levels, it does not shrink the size of the thyroid gland or prevent other problems of Graves’ disease such as eye problems. Treatment is often needed for two or more years. But we cannot predict the course of Graves’ disease and sustained use of drug therapy may not be the best option. At that time, we may need to think about other forms of treatment.

**Radioablation**

Radioablation can be used to permanently treat the hyperthyroidism of Grave’s disease. Because iodine is a crucial building block of thyroid hormones, the thyroid will take up radioactive iodine, which then destroys the thyroid cells. The risk of getting cancer or having children with birth defects is **not** increased for patients who have received radioablation, but it is expected that
hypothyroidism will result and this can be treated with thyroid hormone supplement. More than one treatment with radioiodine may be needed.

**Surgery**

Overactive thyroid tissue can also be removed by surgery (thyroidectomy). In the hands of a skilled surgeon, side effects rarely occur. The risks include: not enough of the thyroid gland is removed, damage to the nearby parathyroid glands, or damage to the nerve that controls the vocal cords. To reduce some of these risks, drug treatment may be needed before surgery to lower thyroid hormone levels.

Drugs are most often used as the first type of treatment for children and teens. But each case varies and so will the treatment choices. Either radioablation or surgery can destroy the tissue that is causing too much thyroid hormone to be produced. Because of its ease, lower cost, and safety, radioablation may be the preferred treatment for patients with long-term, unstable Graves’ disease.

Thyroidectomy is the best choice for patients with a large thyroid who have failed medical treatment and do not want radioablation.

After surgery, hypothyroidism would be expected. The patient would then need to be on thyroid hormone replacement. This is a once daily tablet.

All of these treatments control the hyperthyroidism part of Graves’ disease by bringing down hormone levels, but they do not cure the disease. It is best to discuss with your doctor whether drug treatment, radioablation, or surgery would be the best option for you.

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**How long will my Graves’ disease last?**

We cannot predict how long you will have Graves’ disease because each case is unique. Some people respond well to drug treatment and their Graves’ disease goes into remission after the first 18 to 24 months of treatment. For most people, longer treatment is needed. When radioablation is used, symptoms decrease after a few months. With surgery, the results are seen sooner. Since the TSI can persist after hyperthyroidism is gone, ask your doctor what this might mean for you.

**What can I do to help?**

One of the best things you can do is to learn more about the thyroid and Graves’ disease. By knowing the symptoms of hypo – and hyperthyroidism, what your medicines are, and how to use them, you can help us take good care of you.

Follow your treatment plan by taking your medicine as prescribed. Do not miss doses. This is the best thing you can do to ensure success. Regularly scheduled clinic visits and blood tests will also help your doctors and nurses work with you to keep you healthy. Feel free to ask your doctor or nurse any questions you may have. For further information, you can contact these groups.

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The American Thyroid Association
www.thyroid.org
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