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HYPOTHYROIDISM

A BOOKLET FOR PATIENTS AND THEIR FAMILIES



A PUBLICATION OF THE
AMERICAN THYROID ASSOCIATION (ATA)
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AMERICAN
THYROID
ASSOCIATION

ATA | *Founded 1923*

THE AMERICAN THYROID ASSOCIATION (ATA)

The American Thyroid Association (ATA) is the leading organization devoted to thyroid biology and to the prevention and treatment of thyroid disease through excellence in research, clinical care, education, and public health.

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ATA PATIENT RESOURCES

The ATA patient resources are designed to provide up-to-date information for thyroid patients, their families and other interested public communities. The ATA is dedicated to serving as an educational resource for the public by supporting thyroid research and promoting the prevention, treatment and cure of thyroid-related diseases and thyroid cancer.

The information contained in or made available through the ATA Website www.thyroid.org is not intended to replace the services of a trained health professional or to be a substitute for medical advice of physicians. The user should consult a physician in all matters relating to his or her health, and particularly in respect to any symptoms that may require diagnosis or medical attention.

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HYPOTHYROIDISM

WHAT IS THE THYROID?

The thyroid is a butterfly-shaped endocrine gland located in the lower front of the neck below the larynx (the voice box). The thyroid's job is to make thyroid hormones, which are secreted into the blood and then carried to every tissue in the body. Thyroid hormone helps the body use energy, stay warm and keep the brain, heart, muscles, and other organs working as they should. The main hormone made by the thyroid is thyroxine, also called T4 because it contains four iodine atoms. Small amounts of another and more potent thyroid hormone containing three iodine atoms, triiodothyronine (T3), are also made by the thyroid gland. However, most of the T3 in the blood is made from T4, via the removal of an iodine atom, in other body tissues.

Thyroid hormones control the way every tissue in your body uses energy. They are essential to help each cell in your body's tissue and organs work right. For example, thyroid hormone controls the body's temperature, heart rate, blood pressure, and the rate at which food is turned into energy (metabolism).

WHAT IS HYPOTHYROIDISM?

Hypothyroidism is a kind of thyroid disease. If you have hypothyroidism that means you have an underactive thyroid ("hypo-" means "under" or "below normal"). In people with hypothyroidism, the thyroid does not make enough thyroid hormone to keep the body running normally. Common causes of hypothyroidism are autoimmune disease, surgical removal of the thyroid, and radiation treatment.

Low thyroid hormone levels cause the body's functions to slow down, leading to general symptoms like dry skin, fatigue, loss of energy, and memory problems. Hypothyroidism is diagnosed by a simple blood test for thyroid-stimulating hormone (TSH). Hypothyroidism is treated by replacing the missing thyroid hormone with synthetic thyroxine pills, which usually have to be taken every day for life. With daily treatment, most patients recover completely.

WHO CAN DEVELOP HYPOTHYROIDISM?

Hypothyroidism is one of the most common thyroid diseases. It affects people all over the world—of every age, sex, race, and level of wealth and education.

About 2 percent of Americans have hypothyroidism and as many as 10% have mild hypothyroidism. More than half of those with hypothyroidism do not know they have it.

WHAT CONTRIBUTES TO THE RISK OF DEVELOPING HYPOTHYROIDISM?

- Hypothyroidism is more common in women than men; and, much more so in young women than young men. The risk of hypothyroidism increases during pregnancy, after delivery and around menopause.
- Hypothyroidism is more common in whites and Asians than in other races and ethnicities.
- Hypothyroidism can develop at any age, but the risk for developing it increases with age.
- The risk of hypothyroidism is increased in many situations, including:
 - Having another autoimmune disorder, such as type 1 diabetes, rheumatoid arthritis, multiple sclerosis, celiac disease, Addison's disease, pernicious anemia, or vitiligo.
 - Having a close relative, such as a parent or grandparent, with an autoimmune disease.
 - Having had previous thyroid surgery, radioactive iodine treatment, or radiation therapy to the neck or upper chest.
 - Having Down syndrome or Turner syndrome (which are genetic disorders)
 - Having bi-polar disease (manic depression)
 - Taking certain medications, such as lithium, amiodarone, pembrolizumab, nivolumab

SYMPTOMS

Hypothyroidism has a variety of symptoms. Symptoms are something you see, feel and/or experience yourself. Many of these symptoms are often confused with other health conditions.

When your thyroid hormone levels are too low, your body's cells cannot get enough thyroid hormone. This causes your body's processes to start slowing down. For example, the body makes less heat and less energy, causing organs like the brain and bowels to move more slowly. As the body slows, you may notice that you feel colder, you tire more easily, your skin is getting drier, you are becoming forgetful and depressed, and you are getting constipated.

Symptoms of hypothyroidism usually appear slowly over several months or years. However, some people develop symptoms of hypothyroidism quickly over a few months. In general, the lower your thyroid hormone levels become and the longer they stay low, the more severe your symptoms will be.

Subclinical (mild) hypothyroidism may cause mild symptoms or no symptoms at all. Severe hypothyroidism usually causes more severe symptoms.

Some people are very sick by the time they learn their diagnosis, but others whose blood tests show severe hypothyroidism have few if any symptoms. Because the symptoms are so variable, the only way to know for sure if you have hypothyroidism is through blood tests.

COMMON FEATURES OF HYPOTHYROIDISM

- Less energy
- More fatigue, trouble awakening in the morning, need for more sleep, and tendency to fall asleep during the day
- Feeling cold when other people feel warm
- Less sweating
- Drier, itchier skin
- Drier, coarser, more brittle hair
- More hair loss (the amount differs in different people; patients don't go bald but their hair can look thin)
- Loss of appetite
- Mild weight gain (5-20 pounds) and difficulty losing weight (hypothyroidism doesn't cause obesity)
- New or worsening problems with memory, slower thinking
- New snoring
- Muscle cramps and joint aches
- New feeling of pins and needles in the hands and feet (paresthesia)
- New or worsening constipation
- Puffiness around the face (especially the eyes), hands, ankles, and feet because of fluid build-up
- Carpal tunnel syndrome
- Heavier and/or more frequent menstrual periods, worse cramps, worse premenstrual symptoms, milky discharge from the breasts
- Feeling irritable
- New or worsening depression-sadness or not caring about anything
- New or worsening hoarse voice
- New or worsening hearing loss
- Goiter (swelling in the front of the neck, caused by enlargement of the thyroid)
- Slowing of heart rate
- Slightly higher blood pressure
- Higher cholesterol levels
- Growth delay in children

If you have hypothyroidism, you may also have body changes that you cannot feel. For example, you may not know that cholesterol is building up in your blood or that plaque is hardening your arteries, both of which can increase your risk for heart attack. Hypothyroidism does not just cause symptoms; it can make other health conditions worse.

CAUSES

There are many reasons why the cells in the thyroid cannot make enough thyroid hormone. Here are the major causes, from the most to least common:

AUTOIMMUNE DISEASE

The immune system normally protects the body against bacterial and viral “invaders.” In autoimmune diseases (“auto” means “self”), the immune system attacks a normal part of the body. In autoimmune hypothyroidism, the immune system accidentally attacks cells in the thyroid. This causes the cells to become inflamed and damaged, interfering with their ability to make thyroid hormone. When enough thyroid cells have been destroyed, too few are left to meet the body’s need for thyroid hormone.

Autoimmune thyroid disease is more common in women than men. It can start at any age, but becomes more common as people get older. In women, it often begins during pregnancy, after delivery, or around menopause. The cause is likely a combination of an inherited tendency and still unknown triggers. Autoimmune hypothyroidism can begin suddenly, but in most people it develops slowly over years.

The most common form of autoimmune hypothyroidism is called Hashimoto’s disease. This can sometimes cause the thyroid to shrink over time.

SURGICAL REMOVAL OF PART OR ALL OF THE THYROID

Some people with thyroid nodules, thyroid cancer, or Graves’ disease need to have part or the entire thyroid removed. Hypothyroidism results when the entire thyroid is removed or when the remaining thyroid tissue no longer works properly.

RADIATION TREATMENT

Some people with Graves’ disease, nodular goiter, or thyroid cancer are treated with radioactive iodine (¹³¹I). Radioactive iodine destroys the thyroid, which can result in hypothyroidism. Hodgkin’s disease, lymphoma, or cancers of the head or neck are treated with radiation which can destroy the thyroid and result in hypothyroidism.

CONGENITAL (FROM BIRTH) HYPOTHYROIDISM

About 1 in 4,000 babies each year are born without a thyroid or with a partly formed thyroid. A few babies have part or their entire thyroid in the wrong place (ectopic thyroid). In some babies, the thyroid cells or their enzymes do not function correctly or are affected by medications taken by the mother. In others, the thyroid may make enough hormone for a while but later stops functioning as the child gets older or becomes an adult. In the United States, all children are tested at birth for hypothyroidism.

THYROIDITIS

Thyroiditis is an inflammation of the thyroid. It is usually caused by an autoimmune attack (such as Hashimoto’s disease, postpartum thyroiditis or silent thyroiditis) or by a viral infection. Thyroiditis can make the thyroid release its whole supply of stored thyroid hormone into the blood at once, causing there to be too much thyroid hormone for a brief period of time (hyperthyroidism). Once the entire stored hormone has been released, the damaged thyroid is unable to make more and becomes underactive. Most people with thyroiditis recover their thyroid function, but up to one-fourth of people will have permanent hypothyroidism.

MEDICINES

Some medicines can interfere with the thyroid’s ability to make thyroid hormone, leading to hypothyroidism. Lithium is one of the most common medicines that cause hypothyroidism. Other medicines that can cause hypothyroidism are amiodarone, interferon alpha, and interleukin-2. All of these drugs are most likely to trigger hypothyroidism in people who have a genetic tendency to autoimmune thyroid disease. Newer drugs used in the treatment of cancer, such as ipilimumab, pembrolizumab, and nivolumab, can trigger the production of thyroid antibodies and cause autoimmune hypothyroidism.

TOO LITTLE OR TOO MUCH IODINE

The thyroid must have iodine to make thyroid hormone. Iodine comes into the body in foods, mainly dairy products, chicken, beef, pork, fish, and iodized salt. The iodine then travels through the blood to the thyroid. Keeping thyroid hormone production in balance requires the right amount of iodine. People who live in undeveloped parts of the world may not get enough iodine in their diet. Worldwide, iodine deficiency is the most common cause of hypothyroidism, although it is a rare cause in the U.S.

Too much iodine can also cause or worsen hypothyroidism. The major source of too much iodine is dietary supplements containing kelp, a kind of seaweed. Most of these supplements are sold with the false promise of helping people lose weight. Other sources of too much iodine are dyes used in CT scans and medicines like amiodarone.

DAMAGE TO THE PITUITARY GLAND

The pituitary gland tells the thyroid how much hormone to make. If the pituitary gland is damaged by injury, a tumor, radiation, or surgery, it may no longer be able to give the thyroid the right instructions and the thyroid may stop making enough hormone.

PREVENTION

In countries where the diet does not contain enough iodine, taking iodine supplements can prevent hypothyroidism. In the United States and other developed countries, where most people's diet contains enough iodine, there is no known way to prevent hypothyroidism. Though there is much interest in the subject, there is no evidence that consuming more of any one type of food, or eliminating certain components from the diet, such as gluten, will prevent hypothyroidism.

Diagnosing hypothyroidism early by testing newborn babies, pregnant women, and people with symptoms or risk factors is the best way to find hypothyroidism and prevent it from worsening. The biggest risk factor is having relatives with thyroid disease.

DIAGNOSIS

Making a diagnosis is the art or act of identifying a disease from its signs and symptoms. A health care professional considers several factors when identifying or determining the nature and cause of hypothyroidism, including:

- Your symptoms (changes in how you feel), medical history, risk factors, and family history
- A physical exam
- Blood tests: The most sensitive test is TSH. In some circumstances, other tests, such as free T4, free T4 index and total T4 may be helpful.

CHANGES IN HOW YOU FEEL

Hypothyroidism cannot be diagnosed based on symptoms alone. Most hypothyroid symptoms are common complaints that many people with a normally functioning thyroid can have. These symptoms might be clues to conditions that may or may not be related to the thyroid. One way to help figure out whether your complaints are symptoms of hypothyroidism is to think about whether you have always had a symptom or whether the symptom is a change from the way you used to feel (hypothyroidism could be indicated).

MEDICAL AND FAMILY HISTORY

Tell your doctor everything you can at your appointment. This includes information about:

- Your overall health, especially changes in your health.
- Your family's health history, especially if a close relative (such as a sibling, parent or grandparent) has hypothyroidism or another form of thyroid disease
- If you have ever had thyroid surgery
- If you have ever had radiation to your neck to treat cancer
- If you are taking any medicines that can cause hypothyroidism, such as amiodarone, lithium, interferon alpha, interleukin-2, pembrolizumab, ipilimumab, or nivolumab

PHYSICAL EXAM

In addition to listening to your symptoms and your medical history, your doctor will check your thyroid and look for physical signs of hypothyroidism. Severe hypothyroidism can be indicated by findings such as dry skin, swelling, slower reflexes, or slow heart rate. For less severe cases however, few, if any, physical signs can clearly predict hypothyroidism.

THYROID BLOOD TESTS

Your doctor may order one of the blood tests described here:

TSH TEST

TSH (thyroid-stimulating hormone) is the most important and sensitive test for diagnosing and monitoring hypothyroidism. TSH is a simple blood test that measures how much T4 the thyroid is being asked to make. A helpful way to think about it is that TSH tells us how satisfied your body is with the amount of hormone your thyroid is making. An abnormally high TSH test may mean you have hypothyroidism.

WHAT IS TSH (THYROID-STIMULATING HORMONE)?

Your thyroid needs to be told how much thyroid hormone to make. The instructions come from the pituitary gland. The system works like a thermostat and a heater: special cells in your pituitary gland determine the normal T4 range for your body. This is known as your set point. As blood flows through your pituitary gland, these cells measure your T4 levels to determine whether they are at your set point.

The pituitary cells communicate with your thyroid by sending their own hormone, TSH (thyroid-stimulating hormone), into the blood. When your T4 levels are at your set point, the pituitary gland sends out enough TSH to tell the thyroid to keep making the same amount of T4. If the T4 levels get low, the pituitary sends out more TSH to tell the thyroid to make more T4. The lower the T4 levels go, the higher the TSH goes. The opposite is also true: if the T4 levels get too high, the pituitary sends out less TSH, telling the thyroid to make less T4.

In most labs, the normal range for TSH is approximately 0.4 mU/L to 4.0 mU/L, but the exact number at the bottom and top of the range will vary slightly. If the TSH measures above 4.0 mU/L on both a first test and a repeat test, this may indicate hypothyroidism. Most people whose thyroid works normally have a TSH between 0.4 mU/L and 4.0 mU/L. This range may be lower in pregnant women and higher in older people. If your TSH is between 2.5 and 4.0 mU/L your doctor may wish to test your blood for anti-thyroid peroxidase (anti-TPO) antibodies. If you have these antibodies, you may have an autoimmune thyroid disorder which is a risk factor for developing hypothyroidism. If so, you should have the TSH test repeated at least once a year. There is no need to repeat a positive anti-TPO test. Some physicians may want to reevaluate a previously reported negative anti-TPO test in connection with a pregnancy.

Remember: as the T4 falls, the TSH rises (as the thyroid hormone supply falls, the demand increases). As the T4 rises, the TSH falls (as the supply rises, the demand falls).

There is one exception to the rule that everyone with hypothyroidism has a high TSH. If the pituitary stops working properly, it may not be able to send out normal amounts of TSH. In this case, even though the thyroid itself may be healthy, if it does not get enough TSH, it won't make enough T4. This disorder is called secondary, or central, hypothyroidism. Fortunately, it is rare.

T4 TESTS

T4 (thyroxine) is produced by the thyroid gland. The free T4 and the free T4 index are both simple blood tests that help tell how your thyroid is functioning when combined with a TSH test.

T3 TESTS

While T3 tests are often useful to diagnosis hyperthyroidism, T3 testing rarely is helpful in the hypothyroid patient, since it is the last test to become abnormal. Patients can be severely hypothyroid with a high TSH and low FT4 or FTI, but have a normal T3.

BIOTIN INTERFERENCE

Biotin, a commonly taken over-the-counter supplement, can cause the results of several thyroid function tests to look abnormal, when they are in fact normal in the blood. Biotin should not be taken for 2 days before blood is drawn for thyroid function testing. Tell your provider if you are taking any supplements that contain biotin.

WAYS THAT HYPOTHYROIDISM CANNOT BE DIAGNOSED

- Low body temperature is not a reliable measure of hypothyroidism. People with hypothyroidism as well as people who do not have hypothyroidism can have temperature well below 98.6 degrees F.
- Saliva tests for thyroid disease are not accurate.
- Swelling in the base of the neck, or abnormal findings on a thyroid ultrasound such as nodules or swelling. These structural findings do not necessarily mean there are issues with the function of the thyroid. Conversely, even if your thyroid looks normal, you can have thyroid disease. An underactive thyroid may look like a normal thyroid or it may be larger or smaller.

TREATMENT

THYROXINE (T4) REPLACEMENT

Hypothyroidism cannot be cured but it can be treated and completely controlled in most people. Hypothyroidism is treated by replacing the amount of hormone that your own thyroid can no longer make. This makes sure that your T4 and TSH stay at balanced levels. Synthetic thyroxine (also called L-thyroxine or levothyroxine) pills contain the hormone T4 like a healthy thyroid makes naturally.

Like the T4 that your own thyroid makes, each dose of synthetic thyroxine keeps working in your blood for about a week (Thyroxine takes about 4 weeks to clear completely from the body). This lets the T4 levels in your blood stay steady so a constant supply of T4 is available to your body cells.

WHO SHOULD TREAT YOU

Many people with hypothyroidism can be treated effectively by their primary care doctor. You might need to see an endocrinologist or thyroidologist for a second opinion or for regular care if:

- You have congenital hypothyroidism or another unusual cause for your hypothyroidism
- You are pregnant
- You have autoimmune polyglandular syndrome—autoimmune hypothyroidism combined with one or more other autoimmune conditions, such as type 1 diabetes, Addison’s disease, or premature ovarian failure
- You have another condition, like epilepsy, heart disease, or bowel disease that affects the treatment of your hypothyroidism
- You have trouble establishing the right dose of thyroxine
- You have questions and concerns that your regular doctor cannot answer

Most people with hypothyroidism can be treated as outpatients without any hospitalizations.

THYROXINE DOSE FACTORS

When you are first diagnosed with hypothyroidism, your doctor will determine your starting dose of thyroxine based on:

- Weight. The greater the body weight, the higher the dose often will be.
- Age. Older people should start on a low dose and raise it slowly to give their bodies time to adjust, particularly the heart. Because older people’s bodies clear drugs more slowly, they generally stay on lower doses. Special considerations also apply to children.
- Cause of hypothyroidism. If your thyroid has been removed, all of your T4 must be replaced with thyroxine. If your hypothyroidism is caused by autoimmune disease and is still making some T4, you may only need a low dose of thyroxine. If you have had thyroid cancer, you may need a higher-than-usual dose of thyroxine to keep your TSH low to prevent the cancer from coming back.
- Other health conditions. If you have conditions that decrease intestinal absorption such as Celiac disease, Crohn’s disease, or previous bariatric surgery, you may have trouble absorbing thyroxine and may need a higher dose.
- Other medicines. If you take birth control pills, hormone replacement therapy, antidepressants, anti-seizure or anticonvulsant medications, Zoloft®, Tegretol®, Dilantin®, Phenobarbital, proton pump inhibitors to reduce stomach acid production, or dietary supplements, such as calcium, iron or soy, you may need a higher dose of thyroxine. If you take testosterone or niacin, you may need a lower dose of thyroxine.

Your starting dose is your doctor’s best estimate of the amount of thyroxine you need. Your doctor may purposely start you on a low dose to prevent you from getting symptoms of too much thyroxine, like anxiety, restlessness, nervousness, and a racing heart. The doctor may then raise your dose gradually. Over time your thyroxine dose may need to be adjusted.

Because thyroxine is a slow-acting hormone, it may take several weeks before your body adjusts and you start to feel effects. After about 6 to 10 weeks, your body will have adjusted enough that your doctor can test your TSH again to see if any adjustment in the thyroxine is needed.

Every person responds differently to thyroxine, and you may need a higher or lower dose than someone who started out with the same TSH as you. You will eventually reach a stable dose, and you may stay on that dose for many years.

Thyroxine comes in multiple strengths, each with its own pill color. When you get your pills, make sure you have been given the right strength.

Many people have to take two thyroxine pills—sometimes of two different strengths—to get the right dose. If your dose needs to be 163 mcg, your doctor might give you prescriptions for 75 mcg pills and for 88 mcg pills. Taken together, they equal 163 mcg.

Getting the right dose for you is just a matter of taking your pills as prescribed and getting regular blood tests. A small change in your thyroxine dose can make a big change in how you feel and function. If you are on the right dose, all your symptoms caused by hypothyroidism should disappear.

TAKING YOUR THYROXINE PILLS

Taking your treatment correctly each day is very important. Your doctor might prescribe that you take the same dose every day or different doses on different days. Following these instructions allows your doctor to accurately measure how your TSH is responding to treatment.

Thyroxine replaces the hormone that your thyroid can no longer make. Thyroxine is not like an antibiotic that you take for a week or two weeks until your infection is treated. The only way to control your hypothyroidism is to take your pill every day for the rest of your life. If you stop taking your pills for any reason, your hypothyroidism will return.

Some people who have hypothyroidism without any symptoms say that they do not want to take pills because they feel fine. They still need to be treated because their body functions are slowing down even if they cannot feel it.

TIPS FOR TAKING YOUR THYROXINE PILLS

These tips may help you take your pills every day:

- Take your pill at the same time every day—first thing in the morning or last thing at night works well for many people—and make it part of your daily routine. For example, you may remember to take your pill if you take it before or after brushing your teeth.
- For many people, it is easy to forget whether they have taken their daily pill. To keep better track of your pills, store them in a container that has a box marked for each day of the week. Whatever container you use, keep it tightly closed so your pills stay dry.
- Store your pills in the room where you will best remember to take them. As with all medicines, keep thyroxine out of the reach of children.
- Ideally, your pill should be taken with water only. Grapefruit juice and coffee should be avoided. Do not try to swallow your pill without liquid; if it dissolves in your mouth or throat, not enough medicine will be absorbed into your blood.
- Thyroxine can be taken on an empty stomach. Foods and medicines taken at the same time as the thyroid hormone pill can interfere with the body's ability to absorb the thyroxine. If you always take your pill with food, you may need a higher dose than if you always take it on an empty stomach.
- Wait 4 hours after taking thyroxine before you eat foods that contain soy (including soy formula for babies), take calcium supplements, iron supplements, or antacids that contain either calcium or aluminum hydroxide, or take other medicines such as cholestyramine (Questran®), colestipol (Colestid®), or sucralfate (Carafate®).

GIVING THYROXINE TO BABIES

To give thyroxine to a baby, crush the thyroxine pill between two spoons, mix it with a little water or breast milk, and immediately squirt it inside the baby's cheek with a medicine dropper. Then, nurse or bottle-feed the baby. Do not try to crush the thyroxine pill and mix it into a bottle. Thyroxine loses its strength in liquid. Tirosint-SOL® - a liquid solution - can be administered directly from the single-use packaging or mixed with a small amount of water.

GIVING THYROXINE TO CHILDREN WHO CANNOT SWALLOW PILLS

You can give a thyroxine pill to a child the same way as a baby—crush the thyroxine pill between two spoons, mix it with a little water, and immediately squirt it inside the child's cheek with a medicine dropper. Or, put the pill in a small paper cup with just enough water to dissolve the pill and have the child drink the solution. Then, put a little more water in the cup to catch any more bits of the pill and have the child drink that.

WHY YOU SHOULD ALWAYS TAKE THE SAME BRAND OF THYROXINE

The available brands of thyroxine are Synthroid®, Levoxyl®, Unithroid® tablets, Tirosint® gel capsules, and Tirosint-SOL® liquid solution. The U.S. Food and Drug Administration (FDA) regulates all of these brands. All are safe and effective.

Each brand contains the same active ingredient, but each is made a little differently, and there may be small differences in the actual dose amount from brand to brand. If you change from one brand to another, even at the same dose, your body may absorb and respond to it differently. This means that if you switch to a new drug, you need a TSH test 6 to 12 weeks later and your new dose may need to be adjusted.

The American Thyroid Association recommends that once you get used to one brand or formulation of thyroxine, you continue with that brand. The ATA also recommends that you use brand name drug rather than a generic drug, or if a generic is taken, that the same preparation be taken consistently. This is because generic drugs can be substituted with other generic drugs from different manufacturers of levothyroxine each time you get your prescriptions refilled. Make sure the pharmacist gives you the same brand (or the same manufacturer for generics) each time you pick up your pills.

IF YOU MISS A PILL

It is not serious to miss just one pill because thyroxine stays in your blood for a long time. For example, you can take your pill in the afternoon if you remember that you did not take your pill that morning. If today you remember that you did not take yesterday's pill, you can take two pills in one day.

If you are sick and vomit up a pill, do not take an extra pill. Wait and take your next regular dose tomorrow. However, if you vomit up a pill because you are pregnant and having morning sickness, take another pill at a different time when you are less likely to feel sick.

It is much more serious to miss one thyroxine pill every week. This is because your body will react as though you are taking a lower dose than needed. For example, suppose you are prescribed 100 mcg of thyroxine a day; this adds up to 700 mcg of thyroxine a week. If you miss one pill every week, you would only be taking 600 mcg of thyroxine a week, or 86 mcg of thyroxine a day. If you miss two pills every week, you are taking only 500 mcg of thyroxine a week, or 71 mcg of thyroxine a day. If you miss several thyroxine pills, do not try to make it up. Just start over with daily pills and figure out how to best remember to take them.

Keep track of how often you miss your thyroxine pills so you can tell your doctor next time your TSH is tested.

IF YOU BECOME PREGNANT

If you become pregnant, take your thyroxine dose as instructed. Thyroxine is safe for women who are pregnant. In fact, if you are pregnant, you need thyroxine more than ever because it provides T4 for both yourself and your developing baby.

You may need to raise your thyroxine dose by as much as 30 to 50 percent because your body needs more T4 to handle the physical demands of pregnancy. You should see your doctor as soon as you find out you are pregnant or even before becoming pregnant if possible. You and your doctor will work closely throughout your pregnancy to ensure the best possible health for yourself and your baby. Your doctor should test your TSH several times while you are pregnant. After the baby is born, your body returns to needing the same amount of T4 as before you were pregnant.

Many experts recommend that all women get tested for thyroid disease if they are thinking of becoming pregnant or as soon as they learn that they are pregnant. If you are diagnosed with hypothyroidism during your pregnancy, you must begin thyroxine treatment right away and continue treatment and frequent TSH testing until you deliver. Then your TSH levels will determine whether you need to continue treatment.

TREATMENT CONSIDERATIONS

SHOULD SUBCLINICAL (MILD) HYPOTHYROIDISM BE TREATED?

Subclinical (mild) hypothyroidism is defined when T4 level is in the normal range and the TSH is slightly high (usually 4.0 to 10.0 mU/L). Subclinical hypothyroidism usually causes few or no symptoms. Experts have not come to an agreement on whether to treat people, including children, with subclinical hypothyroidism although some Pediatricians believe treating children offers special benefits.

Some doctors treat all people with subclinical hypothyroidism. Some treat only people who have symptoms. Some treat those with anti-TPO antibodies or a high cholesterol. Some do not treat people with subclinical hypothyroidism but instead test them on a regular basis to see whether their TSH rises higher.

Research is still needed on whether people with subclinical hypothyroidism stay healthier if they are treated or whether their health is at risk if they are not treated (for example, it is possible that subclinical hypothyroidism increases people's risk for heart problems).

People with a TSH in the high-normal range of 2.6 and 4.0 mU/L may wish to keep being tested to see whether their levels rise to the level of hypothyroidism.

HOW HELPFUL ARE TREATMENTS COMBINING T4 WITH T3?

A healthy thyroid makes 14 times as much T4 as T3. T4 is turned into T3 by normal bodily processes. When tissue cells remove T4 from the bloodstream, they change some of it into T3. In fact, more than 80% of the T3 in your blood is made from T4 that has been changed by the liver and other tissues outside the thyroid. Underactive thyroids still make both T4 and T3—just not enough. Because the failing thyroid still makes some T3, and because body tissues turn T4 into T3, most hypothyroid patients need to be treated only with T4. In these patients, having the right amount of T4 allows the body to make the right amount of T3.

All brand-name thyroxine pills in the United States contain only T4. However, some researchers have wondered whether a combination of T4 and T3 might be better. Early studies have shown that some people felt better on the combination, but the improvement did not last. Unlike thyroxine pills, which work for a week, the only FDA-approved brand of T3 works in the body for just a few hours. This means that people taking T3 might need several doses a day. Another problem is that taking T3 pills interferes with the body's normal ability to adjust T3 levels, so the T3 levels that the pills give to people cannot match the body's normal patterns. This makes some people feel worse on combined therapy. A T4-T3 combination might be of some help to people who have had their whole thyroid removed and cannot make any T4 or T3 of their own. If people want to try a combination of T4 and T3 pills, the ATA recommends that their doctor prescribes doses that are in a similar ratio to what the thyroid would normally make, and that levels are monitored carefully to be sure the TSH remains normal. Taking too much T3 can seriously harm the heart.

THYROXINE FROM ANIMALS

Before synthetic forms of thyroxine became available, animal thyroid saved many lives. Now, people are safer taking synthetic thyroxine. Some people argue that pills made from animal thyroids are more natural, but these pills pose several dangers.

- Pills made from animal thyroid are not purified. They contain some proteins that do not normally appear in the human bloodstream. Thyroxine made in a lab is exactly the same hormone that a human thyroid makes, but in a pure form.
- The balance of T4 to T3 in animals is not the same as in humans, so the hormones in animal thyroid pills are not natural for the human body.
- The amounts of T4 and T3 can vary in every batch of animal thyroid, making it harder to keep both hormones level.
- Case reports suggest possible allergic reactions tied to components within animal thyroid preparations.

In sum, synthetic thyroxine is much safer than animal thyroid.

THYROXINE AND WEIGHT LOSS

Hypothyroidism can cause a mild weight gain of 5 to 20 pounds, but does not cause obesity. People with hypothyroidism who are started on the right thyroxine dose will not suddenly lose weight, but some may find it easier to lose weight if they try. People who take too high of a thyroxine dose in the hope of rapid weight loss can weaken their muscles and bones and damage the heart—all of which can make it harder to exercise. Worse yet, a high dose of thyroxine can cause increased hunger. So instead of losing weight, people may gain weight.

People with a normal TSH should never take thyroxine pills for weight loss.

INEFFECTIVE TREATMENTS

Chinese herbs, selenium, iodine-tyrosine supplements, kelp (a kind of seaweed), and other herbal remedies high in iodine may claim to treat hypothyroidism, but they do not work. Once the thyroid stops functioning, taking extra iodine or other substances will not help it work better. In fact, taking too much iodine can worsen both hypothyroidism and hyperthyroidism. Worse yet, taking these can prevent people from getting the thyroxine treatment that they really need.

SIDE EFFECTS AND COMPLICATIONS OF TREATMENT

The only dangers of thyroxine are caused by taking too little or too much. If you take too little, your hypothyroidism will continue. If you take too much, you can develop the symptoms of hyperthyroidism—an overactive thyroid. The most common symptoms of too much thyroid hormone are fatigue, the inability to sleep, greater appetite, nervousness, shakiness, feeling hot when other people are cold, muscle weakness, shortness of breath, and a racing, skipping heart. Hyperthyroidism can also cause changes that you cannot feel, like bone loss (osteoporosis) and an irregular heartbeat.

People who have hyperthyroid symptoms should have their TSH tested. If it is below normal, their thyroxine dose needs to be lowered.

People who have had thyroid cancer may need to take higher-than-usual thyroxine doses. This increases their risk for bone loss. If you are being treated with thyroxine following thyroid cancer, your doctor should also monitor your bone density regularly.

Thyroxine pills do not harm the thyroid gland.

FOLLOW-UP

REPEAT BLOOD TESTS

After a change in your thyroxine dose, you will need to have your TSH checked about in 6 to 10 weeks. You may need tests more often if you are pregnant or you are taking a medicine that interferes with your body's ability to use thyroxine. The goal of treatment for hypothyroidism is to get your TSH in the normal range and keep it there. The American Thyroid Association recommends that your doctor try to keep your TSH within a range of 0.5 to 3.5-4 mU/L. Within this range, your body gets the best possible amount of thyroxine and you are likely to feel the best.

On the day of your blood test, you should take your thyroxine the same way and time that you always do - it does not need to be held for the blood test.

Babies must get all their daily treatments and have their TSH levels checked as they grow to prevent mental retardation and stunted growth (cretinism).

NORMAL VARIATION IN TSH LEVELS

TSH levels can vary, even when you are taking the same dose of thyroxine. Do not worry if you get a result of 0.8 mU/L on one TSH test and 1.1 mU/L on your next test. It does not mean that your hypothyroidism is getting worse. Differences in test results are expected:

- TSH levels can vary because the pituitary sends out TSH in pulses rather than a steady stream.
- Labs cannot measure every test exactly the same way. For example, if a lab runs two tests on one blood sample, it may get two slightly different results.
- TSH levels normally go up at night and come down during the day. There is some evidence that T4 levels also vary slightly throughout the day.

BE SURE TO FOLLOW UP WITH YOUR DOCTOR IF...

Once you have established the thyroxine dose right for you, TSH tests are necessary about once a year. You need to make an appointment to discuss with your physician if you:

- Feel a change in your symptoms. If your TSH turns out to be high, hypothyroidism is probably causing your symptoms. But if your TSH is normal, it means something else is causing your symptoms.
- Want to change your thyroxine dose or brand, or change to taking your pills with or without food.
- Gain or lose a lot of weight without changing your diet or exercise routine. For some people, even a change of 10 pounds or less can signal that something is wrong.

- Start or stop taking a drug that can interfere with absorbing thyroxine, or you change your dose of such a drug (see “*How your thyroxine dose is decided*,” above). For example, if you start taking estrogen in a birth control pill or in hormone replacement therapy, you may need to raise your dose. If you stop taking the drug, you may need to lower your dose.
- Are not taking your thyroxine pill every day. It is very important to be truthful when telling your doctor how many pills you have missed. If you have missed pills but say that you have taken them as prescribed and if your TSH test is then high, your doctor may think that your hypothyroidism is getting worse and may raise your thyroxine dose.
- Want to try to stop thyroxine treatment. If ever you think you are doing well enough not to need thyroxine treatment any longer, try it only under your doctor’s close supervision. Rather than stopping your pills completely, you might ask your doctor to try lowering your dose. If your TSH increases, you will know that you need to continue treatment. You should never stop thyroxine treatment on your own. You must take your thyroxine every day, most likely for the rest of your life.

IF HYPOTHYROIDISM IS NOT TREATED OR IF TREATMENT IS STOPPED

BABIES AND CHILDREN

Thyroid hormone is essential for the brain to develop normally. In a healthy pregnancy, the mother’s thyroid supplies the developing baby with thyroid hormone during the first trimester. In the second trimester, the developing baby’s thyroid starts to make its own hormone. Once babies are born, they must depend completely on their own thyroid.

Too little thyroid hormone can keep the brain from developing normally. If the pregnant woman has hypothyroidism, she cannot give her developing baby enough thyroid hormone. If a baby does not get enough thyroid hormones, it cannot maintain normal thyroid hormone levels before or after birth.

Hypothyroidism that begins before birth and through the age of 3, when left untreated, puts babies and children at risk for mental retardation. Untreated severe hypothyroidism slows both brain development and physical growth (cretinism). In the United States and some other developed countries, all babies are tested for hypothyroidism a few days after birth so that they can begin treatment right away if there is hypothyroidism.

HYPOTHYROIDISM CAUSED BY IODINE DEFICIENCY

The body needs iodine to make thyroid hormone. People who live in parts of the world where they do not get enough iodine from their food may develop hypothyroidism. This, in turn, puts babies and children at increased risk of developing hypothyroidism. Worldwide, iodine deficiency is the major cause of hypothyroidism and preventable mental retardation.

PEOPLE OF ALL AGES

No one can predict whether hypothyroidism will worsen. Subclinical (mild) hypothyroidism may never get worse or it may get worse over months or years. If people with autoimmune hypothyroidism also have high levels of anti-TPO antibodies, their hypothyroidism is more likely to worsen, although there is no way to predict how quickly.

SEVERE HYPOTHYROIDISM (MYXEDEMA)

The worse untreated hypothyroidism becomes, the less the body is able to cope with stressors like cold weather, infections or even minor surgery. Severe hypothyroidism is called myxedema. Usually it takes years for hypothyroidism to reach the point of myxedema, but people who do not have a thyroid (because of surgery or radioactive iodine treatment) can progress to myxedema more quickly. In people with myxedema, the body slows to the point that it starts to shut down. At its worst, the person falls into a coma. To survive a myxedema coma, people need good supportive care in the hospital intensive care unit. Myxedema is now rare in developed countries.

KEEPING OTHER PEOPLE INFORMED

TELL YOUR FAMILY

Because thyroid disease runs in families, you should explain your hypothyroidism to your blood relatives and encourage them to get a TSH test. If it is normal, they should be retested if they develop symptoms, or at least every 5 years.

TELL YOUR OTHER DOCTORS AND PHARMACIST

Keep your other doctors and your pharmacist informed about your hypothyroidism and about the drug and dose with which it is being treated. If you start seeing a new doctor, tell the doctor that you have hypothyroidism and you need your TSH tested every year. If you see an endocrinologist, ask that copies of your reports be sent to your primary care doctor.

You do not need to wear a medical alert bracelet, but it would be wise to keep a card in your wallet, or update the health app on your smartphone, listing the following information:

- Your name and contact information
- Your doctor's name and contact information
- That you have hypothyroidism and any other diseases or health conditions
- Your thyroxine brand name and dose

PARTNERSHIP BETWEEN YOU AND YOUR DOCTOR

The more you and your doctor work as a team, the healthier you will be.

YOUR JOBS

Because you will probably have hypothyroidism for the rest of your life, you have to be your own main caretaker. You cannot depend on your doctor to do all the work for you. You have to fill your prescriptions and take your pills every day. You have to make and keep your appointments for blood tests and doctor visits. When you go for visits, you have to tell your doctor how you are feeling and be honest in saying how often you miss your pills. Before you visit your doctor, write a list of all the things you want to ask or tell her or him so you do not forget.

YOUR DOCTOR'S JOBS

Your doctor should explain hypothyroidism to you and how it is treated. She or he should also answer any questions that you have and listen to your concerns. The doctor should take your symptoms into account when adjusting your thyroxine dose and give you your blood test results. Choose a doctor who keeps up to date about advances in the diagnosis and treatment of thyroid disease.

YOUR EMOTIONAL NEEDS

Many people are diagnosed with hypothyroidism after feeling sick for years or believing or being told their symptoms are “all in your head,” “just stress,” or “a normal part of aging.”

Some people are so relieved finally to know what is wrong that they are eager to start treatment so they can begin to feel better. Other people are so exhausted and depressed by the time they are diagnosed that they do not believe they have the energy to work at getting better or may fear they will never feel well again.

It is important to be patient as you begin treatment—patient with yourself and the changes happening in your body, patient with your doctor, and patient with the people who are going through this with you. It can take weeks before the thyroxine begins to make you feel better and months before you and your doctor get the dose exactly right. But for most people, the effort is worthwhile.

LIVING WITH HYPOTHYROIDISM

There is no cure for hypothyroidism, and most people have it for life. Over time, your hypothyroidism may become more or less severe. As a result, your thyroxine dose may need to change. You have to make a lifetime commitment to treatment. You should never stop thyroxine treatment on your own. If you do, your health may get worse.

If you take your pills every day and work with your doctor to establish the correct thyroxine dose, you should be able to keep your hypothyroidism completely controlled throughout your life. Symptoms can disappear and the serious effects of low thyroid hormone will stop and should actually improve. Not all symptoms are due to thyroid hormone levels. If your hypothyroidism is well-controlled, it will not shorten your lifespan.

MANY QUESTIONS ABOUT HYPOTHYROIDISM REMAIN MYSTERIES

For example: Which genes increase people's risk for thyroid disease? What triggers the start of thyroid disease? Why does the immune system attack the thyroid? What is the best way to treat hypothyroidism? These are among the questions that researchers, including members of the American Thyroid Association, are working hard to answer.

MEDICAL TERMS IN THIS BOOKLET

- Addison's disease:** permanent loss of function of the adrenal glands, which make essential steroid hormones for the body
- anemia:** too few of the red blood cells that deliver essential oxygen to the body's cells
- antibodies:** proteins that the body's immune system makes to attack invaders like bacteria and viruses
- anti-TPO antibodies:** in autoimmune thyroid disease, proteins that attack the thyroid peroxidase (TPO) enzymes that help the thyroid make hormone
- autoimmune disease:** any disease in which the body's immune system, designed to protect the body from viruses and bacteria, attacks a normal (healthy) part of the body
- autoimmune thyroiditis:** inflammation of the thyroid, caused by autoimmune disease
- atrophic thyroiditis:** a form of autoimmune thyroiditis in which the immune system's attack on the thyroid causes it to shrink and stop making thyroid hormone
- coma:** unconsciousness from which a person cannot be awakened
- congenital hypothyroidism:** hypothyroidism in a newborn baby
- cretinism:** mental and physical retardation caused by severe congenital hypothyroidism
- deficiency:** a lack; too little
- ectopic:** in the wrong place; an ectopic thyroid is usually in the tongue and/or upper neck
- endocrine gland:** any gland that produces and releases hormones directly into the blood; for example, the thyroid, pituitary, adrenals, and pancreas
- endocrinologist:** a medical doctor who specializes in endocrinology, the treatment of endocrine gland diseases like thyroid disease and diabetes
- enzyme:** protein that helps chemical processes take place within the body but does not get used up in the process; the major enzymes in the thyroid are peroxidases
- feedback loop:** a system in which A effects B, which in turn affects A again
- fetus:** a developing baby
- free T4:** the thyroid hormone T4 that circulates in the blood unattached to a protein and that can be taken up by cells in tissues
- free T4 index:** an estimate of the amount of free T4 in the blood
- gland:** an organ or tissue that makes and sends out a hormone or other substance
- goiter:** an enlarged thyroid, which can cause swelling in the front of the neck
- Graves' disease:** autoimmune hyperthyroidism, usually with goiter and eye symptoms Hashimoto's thyroiditis (also called Hashimoto's disease): autoimmune thyroiditis in which the immune system's attack on the thyroid causes a goiter and, sometimes, hypothyroidism
- hormone:** substance, made by an organ or tissue, that affects the function of one or more other organs
- hyperthyroidism:** an overactive thyroid
- hypothyroidism:** an underactive thyroid
- I-131:** one of several forms of radioactive iodine; low-dose I-131 is used for medical testing and to destroy an overactive thyroid

infiltrate: to deposit an abnormal substance in a tissue

immune system: the body's way of protecting itself from invaders like bacteria and viruses

inflammation: the body's response to injured cells

iodine: chemical element that is an essential ingredient of thyroid hormone

mcg: unit of measure, abbreviation for "micrograms"; thyroxine doses may be measured in mcg (also written as ug); 50 mcg = .05 mg (milligrams)

metabolism: all the processes by which the body makes and uses energy and builds tissues

mild hypothyroidism (also called subclinical hypothyroidism): a T4 in the normal range, but a slightly high TSH of 4.0 to 10.0 mU/L, causing few or no symptoms

mU/L: unit of measure, abbreviation for "milliunits per liter"; TSH levels are measured in mU/L

myxedema: severe hypothyroidism; the brain, heart, lungs, kidneys, and other organs slow to the point that they cannot keep up critical functions like maintaining temperature, heart rate, blood pressure, and breathing

myxedema coma: often-fatal unconsciousness resulting from severe hypothyroidism

nodule: small abnormal mass or lump; nodules in the thyroid are very common, but few are cancerous

paresthesias: feeling of pins and needles in the hands and feet

pituitary gland: from its position in the base of the brain, the pituitary monitors most basic body functions and sends out hormones that control those functions, for example, the rate at which the thyroid makes hormone

polyglandular autoimmune syndromes: combinations of autoimmune diseases affecting both endocrine and non-endocrine organs and usually involving the thyroid

postpartum: after giving birth

premature ovarian failure: before the normal age for menopause, the ovaries' loss of ability to produce estrogen and release eggs, leaving a woman unable to become pregnant

radioactive iodine (also called radioiodine): iodine that has naturally or artificially been made radioactive; see "I-131" above

secondary hypothyroidism: hypothyroidism caused not by damage to the thyroid but by damage to the pituitary gland, preventing it from being able to tell the thyroid to make hormone

set point: the body's preferred level or range for a function; for example, the pituitary gland knows the body's normal T4 range (set point) and works to keep the T4 within that range

silent: not causing symptoms

subclinical ("mild") hypothyroidism (also known as mild hypothyroidism): a T4 in the normal range, but a slightly high TSH of 4.0 to 10.0 mU/L, causing few or no symptoms

supportive care: general medical care, such as nutrition and fluids, to help a person recover when no targeted treatment can improve the person's condition

suppressive treatment: thyroxine dose high enough to keep the TSH below normal

syndrome: a combination of symptoms

synthetic: made in a laboratory

T3: triiodothyronine, a hormone with 3 iodine atoms, made in small amounts by the thyroid and in larger amounts from T4 in other body tissues

T4: thyroxine, the main hormone made by the thyroid

thyroid: a gland, normally in the lower front of the neck, that makes and sends out the hormones T4 and T3 that regulate the metabolism of every cell in the body

thyroid hormones: T4 and T3, the products of the thyroid

thyroiditis: inflammation of the thyroid

thyroidologist: a medical doctor who specializes in the diagnosis and treatment of thyroid diseases

thyroid peroxidase (TPO) enzymes: enzymes within the thyroid that help thyroid cells make hormone

thyroid stimulating hormone (TSH): hormone that the pituitary gland makes and sends into the blood to tell the thyroid how much T4 and T3 to make

thyroxine: T4, the main hormone made by the thyroid; also, pills used to treat hypothyroidism by replacing the missing T4

trimester: three months; the nine months of a pregnancy are broken into three trimesters

TPO: thyroid peroxidase

TSH: thyroid-stimulating hormone

TO LEARN MORE

VISIT THE ATA WEB SITE, WWW.THYROID.ORG, TO LEARN MORE ABOUT HYPOTHYROIDISM. THERE YOU WILL FIND:

- names of thyroid specialists in your area,
- access to “*Friends of the ATA*” newsletter emailed to you with the latest thyroid news updates,
- *Clinical Thyroidology for The Public*, a monthly publication describing the latest thyroid research,
- The most recent guidelines for the management of thyroid diseases and thyroid cancer,
- Links to the *ATA Alliance for Patient Education* — organizations that help patients,
- Current and up-to-date information and education about thyroid disorders.

YOU MAY ALSO WANT TO READ THE FOLLOWING BOOKS ABOUT HYPOTHYROIDISM THAT WERE WRITTEN BY MEMBERS OF THE ATA:

- *The Complete Thyroid Book*, 2nd edition, by Kenneth Ain, M.D. and M. Sara Rosenthal, Ph.D. McGraw-Hill: New York, 2010
- *How Your Thyroid Works*, 4th edition, by H. Jack Baskin, M.D. Adams Press, Chicago IL, 1995.
- *The Harvard Medical School Guide to Overcoming Thyroid Problems* by Jeffrey R. Garber, M.D. with Sandra Sardella White, McGraw-Hill, New York 2005.
- *The Thyroid Gland: A Book for Thyroid Patients*, by Joel I. Hamburger, M.D. Michael M. Kaplan, M.D. (self-published) Southfield, Michigan, 1991.
- *The Thyroid Sourcebook* by M. Sara Rosenthal with a foreword by Robert Volpe, M.D., Lowell House, Los Angeles 1998.
- *Could It Be My Thyroid? The Complete Guide to the Causes, Symptoms, Diagnosis, and Treatments of Thyroid Problems* (Foreword by George H.W. Bush) by Sheldon Rubinfeld, M.D. The Thyroid Society for Education and Research, Houston, Texas, 1996, 2002, 2003.
- *The Thyroid Book A Book for Patients* by Martin I. Surks, M.D. (self-published) 1993, 1999.
- *Your Thyroid: A Home Reference*, 4th edition, by Lawrence C. Wood, M.D., David S. Cooper, M.D., and E. Chester Ridgway, M.D. Ballantine Books, New York, NY, 2006.



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HYPOTHYROIDISM

A BOOKLET FOR PATIENTS AND THEIR FAMILIES

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