neck on the line

The thyroid rests neatly above a woman's collarbone. But when it goes haywire—as it will for tens of millions of us—it can destroy every fiber of our being, from our weight to our mental health. So how come so many women *want* a diagnosis? And why are doctors at each other's throats about how to treat the condition? *WH* investigates.

BY VIRGINIA SOLE-SMITH
PHOTOGRAPHS BY FELIX WONG

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"And though she be but little, she is fierce." The Shakespearean line from *A Midsummer Night's Dream* could describe The Average Woman's Nightmare—the thyroid. That tiny butterfly-shaped gland in our neck seems to be to blame for why so many of us feel like utter crap: Tired. Grumpy. Overweight. Roughly 16 million women will, at some point, have a breakdown of the thyroid, which produces hormones that touch every cell and help regulate our metabolisms, our bowels, our brains. More pointedly, one in 10 women will have hypothyroidism, a sluggish gland that doesn't produce enough hormones to control such functions. Diagnosing the condition is actually simple—a basic blood test determines the amount of thyroid-stimulating hormone (TSH), a substance pumped out by the pituitary gland that regulates thyroid output. Yet doctors have spent decades debating—and are *still* at odds about—what that amount, or number, should be. A normal TSH typically ranges from 0.4 to 4. So why are some physicians treating patients who have a TSH of 2.5—smack-dab in normal range—while others hold off until it balloons to 10?

It's an astonishing question, and splitting hairs over those numbers is just the beginning. Despite widespread attention—Gigi Hadid, Zoe Saldana, and Gina Rodriguez all recently opened up about their hypothyroidism—the condition is still underdiagnosed. An estimated 60 percent of people with the disorder don't know they have it, because its vague symptoms (fatigue, weight gain, depression, menstrual irregularities, and slower thinking) so closely mimic other disorders or generalized stress that doctors and patients routinely brush them off. Ironically, those same ambiguous symptoms lead droves of women with *healthy* thyroids to believe they have a problem—and many fight to be diagnosed with a disease they don't have and are then treated with synthetic hormones they don't need. That sounds unthinkable...until you consider the alternative is often a giant question mark over why they feel so miserable.

There's one last layer to this already complex puzzle: a gray faction of women whose thyroids aren't functioning perfectly but may not be glitchy enough to need treatment. The majority of them are put on medication—even though research overwhelmingly shows there's no benefit in doing so. Succinctly put, "people are being both undertreated and overtreated for thyroid disease," says Martin Surks, M.D., an endocrinologist at Montefiore Health System in New York City.

VOICES FROM THE EPICENTER OF THE EPIDEMIC

The best way to understand the contrary pieces of this knotty issue? Straight from the women grappling with it.

"It felt like I was living in a body that wasn't mine."

During her mid-twenties, Kaitlyn Hoever felt increasingly depressed and exhausted. "I didn't want to see my friends or return their texts," recalls the now-31-year-old entrepreneur in Brick, New Jersey. She was gaining weight even though she worked out religiously and was meticulous about her eating habits. Kaitlyn didn't have a regular M.D. to discuss her symptoms with, so it wasn't until she was 26, and Googling them, that she began to suspect she had an underachieving thyroid. She visited a primary-care doctor, but he was dismissive, saying she just needed to eat less and work out more to lose weight. Kaitlyn begged him to test her thyroid, and her TSH was 20. Another physician later said that, based on her symptom history, she likely had hypothyroidism for at least five years.

Kaitlyn's experience is far from rare. Hypothyroidism's symptoms are often shrugged off, which can have deleterious results. Left untreated, the condition can raise your bad LDL cholesterol, increase your risk for heart disease and infertility, and in rare cases, lead to a life-threatening condition known as a myxedema coma.

Kaitlyn started taking medication just over two years ago. She's since lost much of the weight, and her emotional state and energy levels have mostly returned to normal. Still, it's taken several years to arrive at a treatment plan that works. Finding the right dose is often a dance between symptoms and side effects, says Surks.

When Your Thyroid Works *Too* Hard

Although hypothyroidism is the most common thyroid issue, around one in 50 women have the opposite problem: thyroids that crank out too much of the hormone. And while it's not as controversial, this hyperthyroidism isn't healthy either. Common symptoms include weight loss, diarrhea, a fast heartbeat, and shaky hands or tremors. The majority of hyperthyroid cases are caused by Graves' disease, an inherited autoimmune disorder in which the body produces antibodies that trigger the condition. Hyperthyroidism can be managed with medications that work to tone down hormone production. (Severe cases of hyperthyroidism may require the surgical removal of the gland; those patients then require replacement thyroid hormones to keep things in balance.)

HANRO BRA AND UNDERWEAR

Thyroid not running right? The symptoms might as well be written all over your body.

“I wanted it to be a magic bullet, but it backfired.”

On top of regular light-headedness and incessant thirst, 24-year-old Amy Kincaid’s* first clue something wasn’t quite right was her wardrobe. It was September, but the Hartford, Connecticut, government employee wore her down jacket all day at the office while her colleagues were in T-shirts. Amy’s endocrinologist tested her TSH level; it was 5.7, a touch out of the normal range. Her thyroid wasn’t totally kaput, just mildly out of whack.

Endocrinologists have squabbled over whether to treat this so-called subclinical hypothyroidism, which affects around 5 percent of women, because there’s no definitive point at which thyroid dysfunction begins to trigger symptoms. In other words, a woman with a borderline TSH (typically somewhere between 4.5 and 10) could experience the same—or more, or less—fatigue as someone with an extremely high one. She could see three different endocrinologists and get three different opinions. (*Unless* a woman is pregnant or thinking about it, because hypothyroidism during pregnancy is linked to a higher risk for miscarriage and premature birth. Most moms can stop treatment after the baby is born.)

Some doctors immediately prescribe synthetic hormones to prevent full-blown hypothyroidism, though studies show that only happens in 2 to 5 percent of people who start at the subclinical point. Others dole out meds to ward off future cardiovascular problems, but the research there is decidedly mixed, and the drugs themselves can slightly increase the risk for cardiac arrhythmia (when the heart beats erratically), as well as bone loss. And then there are endocrinologists who do…nothing. One reason: Nearly 40 percent of people with borderline TSH levels will see them inexplicably revert to normal within a few years without any intervention, says Surks. (He suspects the temporary elevation may be the work of harmless viral infections.) But even more compelling is that studies show meds simply don’t ease symptoms for people in this group. They may actually lower a patient’s TSH to a point where she starts experiencing side effects such as insomnia or hot flashes. “We really have no good evidence that treating people with borderline TSH elevations offers any benefit beyond what we see with a placebo,” says David Cooper, M.D., director of the Thyroid Clinic at the Johns Hopkins Hospital in Baltimore.

With so much conflict, most docs err on the side of caution. Consider this: the synthetic thyroid hormone levothyroxine is the top-prescribed medication in the United States, with around 121 million prescriptions filled annually. Amy was given the drug and found it helped her symptoms, but it came with an unwanted and yet fairly common side effect: severe anxiety. So less than a year after starting the meds, she came off them. She’s a rarity in this regard. According to Surks, once a doctor prescribes thyroid medication, that patient often stays on it for life.

That’s why the best approach to a middle-of-the-road TSH is, well, middle-of-the-road. “It’s reasonable to ask your doctor to follow your TSH levels every six to 12 months, to see whether they rise further or stabilize before treating,” says Antonio Bianco, M.D., Ph.D., an endocrinologist at Rush University Medical Center in Chicago and past president of the American Thyroid Association.

The thyroid gland is shaped like a butterfly, and like the winged insect, treatment has gone through a metamorphosis.

ANDERSON ALVES

Inside the World of Shady Supps

Thyroid meds help hypothyroid patients lose weight and feel energized…could over-the-counter thyroid supplements do the same? That line of thinking leads some healthy women to take OTC “natural” thyroid supplements. Bad idea. In a study, nine of the 10 “thyroid support” supplements tested contained dangerous levels of the same synthetic thyroid hormones used in Rx meds. Used in excess, these hormones can cause severe side effects like panic attacks, heart problems, and bone loss. Some of the pills also contained iodine, which can encourage the thyroid to slow down, leading, ironically, to weight gain and fatigue.

“I felt like a zombie, but my doctor wouldn’t treat me.”

Julie Arnold,* a 30-year-old grad student in Philadelphia, struggled with classic symptoms of hypothyroidism—fatigue and an inexplicable 60-pound weight gain—for several years. Yet three doctors refused to treat her because her TSH levels were 1.067, well within the normal range. She was devastated after each visit. Yes, you read that right: She was crushed doctors said she *didn’t* have hypothyroidism. And she’s not the only one.

“There is a lot of misinformation out there, spread by both patients and some doctors, that symptoms like weight gain or fatigue, which are so common in the general population, must be explainable by a thyroid problem,” says Cooper. But research shows weight plays a less significant role in thyroid issues than you might think. “Even in the most severe cases, we only see gains of about 10 to 20 pounds,” says Cooper. (Subclinical hypothyroidism is unlikely to spur any weight gain.) Fatigue is similarly blurry; an underactive thyroid can cause a lack of mental clarity, but depression, anxiety, or menopause are more likely culprits.

Yet the misconceptions persist, driving women to seek testing. Cooper estimates primary-care providers see at least as many patients who think they have thyroid problems but don’t, as those who genuinely do. “If the result is negative, patients will say, ‘Well, if it’s not my thyroid, what is it?’” he says. “Frequently, we have to say, ‘I don’t know.’” That can be hard to hear. “Oftentimes I tell a woman she doesn’t have hypothyroidism, and the reaction is unexpected. While many are relieved, some start crying,” says Bianco.

And then there are women who flat-out refuse to accept that a wonky thyroid isn’t behind their struggles. Blogs written by patients who believe they have a thyroid problem, even though lab tests say otherwise, have huge followings; the most popular racks up 2.8 million page views each month (for comparison, the American Thyroid Association has just 700,000 page views). Though the claims made on these sites are often anecdotal and lack medical evidence, millions of women take them as gospel and visit doctor after doctor until they find someone who will give them medication, often in high doses, says Bianco. Our experts believe these doctors are preying on women who feel sick and discouraged. Often, they run private clinics and charge high prices to perform lots of tests and prescribe lots of meds, but don’t accept insurance, says Cooper.

The fourth physician Julie visited agreed to treat her. She says she’s less tired now, but her weight hasn’t shifted much and her doctor is still working to find a dose that will ease her symptoms without triggering insomnia and numbness in her arms and legs (other common side effects of the drug). And so she waits. ■

Are You at Risk?

Certain factors can up your chances for hypothyroidism. If you experience symptoms and any of the below apply, talk to your M.D. about testing your thyroid levels.

A FAMILY HISTORY
Having a first-degree female relative (mother, sister, daughter) with a thyroid disorder increases your risk of developing one.

HASHIMOTO’S DISEASE
Hypothyroidism is frequently triggered by this autoimmune disorder, which causes the body to produce antibodies to attack the thyroid. “Over the course of several years, the entire thyroid can be destroyed,” explains endocrinologist Antonio Bianco, M.D., Ph.D. But: Testing positive for the antibodies doesn’t guarantee you’ll develop a thyroid disorder. “Over 20 years, only around a third of patients’ condition progresses to the point that they need to take synthetic thyroid hormones,” says endocrinologist Martin Surks, M.D.

OTHER AUTOIMMUNE DISEASES
Type 1 diabetes, multiple sclerosis, and celiac disease slightly raise your odds for Hashimoto’s, and therefore hypothyroidism. Why? Having one autoimmune disorder increases your risk of developing another one.

RADIATION
The radiation used to treat Hodgkin’s disease, lymphoma, or head and neck cancers can destroy the thyroid. Diagnostic X-rays aren’t thought to carry this risk, but some experts suggest that the thyroid be shielded during dental X-rays.

BIPOLAR DISORDER
Researchers are still studying this link, but anti-thyroid antibodies are found more often in individuals with bipolar disorder. One theory: Lithium, a medication used to treat the mental health issue, may interfere with thyroid hormone production, says endocrinologist Jacqueline Jonklaas, M.D., a professor of medicine at Georgetown University in Washington, D.C.

*Name and identifying details have been changed.