Could you have thyroid eye disease? P. 10

Are you on an emotional rollercoaster? Here's help! P. 22

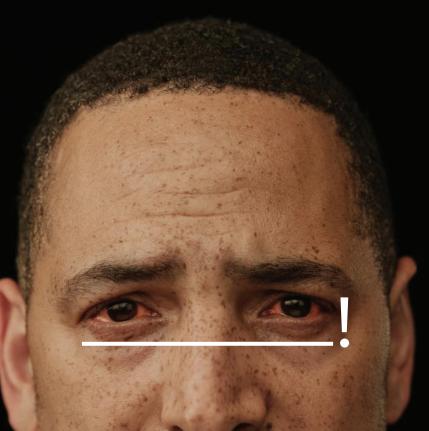
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"My future finally looks bright!"

Graves' Disease

Bulging eyes. Double vision. Dryness. Dentist Layla Lohmann feared she'd have to live with the symptoms of thyroid eye disease until an amazing treatment came along.

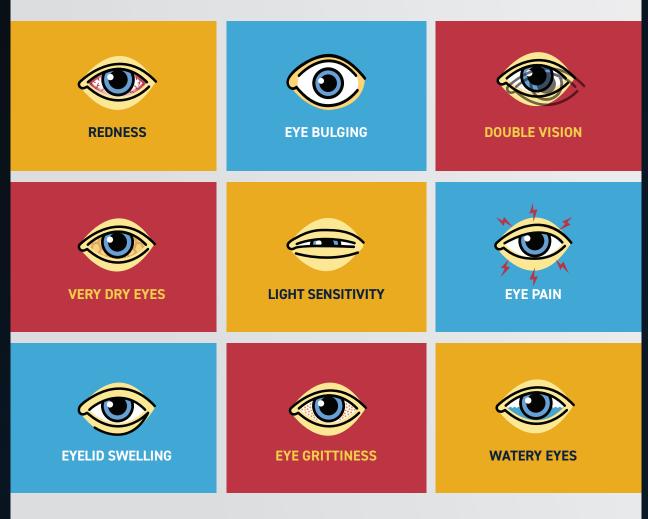


Many people with Graves' disease could develop **a different** condition called **Thyroid Eye** Disease (TED).

If you have Graves' disease and are experiencing eye symptoms such as redness, pain, or itchy eyes, it may be Thyroid Eye Disease (TED).

AMGEN

Many people with Graves' disease could develop a different condition called Thyroid Eye Disease (TED). Are you experiencing any of the following symptoms?



If yes, learn more and take action: SymptomsOfTED.com





To find a TED Eye Specialist, use the camera on your smart phone to scan the QR code or visit **FindTEDdoctors.com.**

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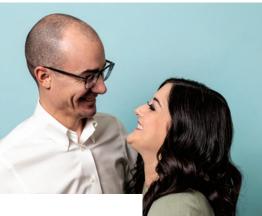
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After more than 20 years living with Graves' and thyroid eye disease, Layla Lohmann finally found an effective treatment. Now she's sharing her story in the hope she can help others find relief, too!

THE BASICS

5 Graves' and thyroid eye disease what you need to know Get the facts on these linked conditions

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Up to 1 in 2 people with Graves' disease develop thyroid eye disease, a progressive condition that can damage vision and steal daily joy. Thankfully, new treatments can help stop it in its tracks.

When June turned

37, an amazing thing happened—she began to drop weight without trying.

"I thought maybe I had won the reverse genetic lottery," laughs the Upstate New York property manager. "But I was so focused on everyone complimenting how I looked, I never stopped to think the weight loss might be the sign of a medical problem."

Things took a turn when June also began experiencing heart palpitations, unexplained sweating and waking up all hours of the night.

"I finally told my doctor what had been going on, and a few tests later I was diagnosed with Graves' disease,

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THE BASICS

which my doctor explained meant my immune system was attacking my thyroid, causing it to overproduce hormones."

While it took some time, eventually June was able to manage the condition with medication.

"And it seemed like literally the morning after I got that situation under control, I woke up and felt like someone had rubbed sand in my eyes. Unfortunately, it progressed. My eyes were red and looked like they were bulging. I was also seeing double."

June went to her eye doctor, who diagnosed her with thyroid eye disease (TED), an autoimmune disease common in people with Graves'. She told her about a new treatment specifically approved to treat TED, which is given by infusion—and June agreed to try it.

"Thankfully the medication worked, and my eyes started to feel better by the second infusion. This process has been a journey, but I'm grateful to these medications for helping me feel like my old self again!"

What is Graves' disease?

In Graves' disease, the immune system attacks the thyroid, the small, butterflyshaped gland at the base of the neck. As a result, the gland goes into overdrive, producing more hormones than the body needs. Because thyroid hormones help control many functions throughout the body, the symptoms can include everything from anxiety,

irritability, hand tremors and weight loss to increased perspiration, trouble sleeping, frequent bowel movements and sexual problems.

TED: a common companion

Like June, about half of people with Graves' disease go on to develop a condition called thyroid eye disease (TED), also known as Graves' ophthalmopathy. TED is also an autoimmune disease, but instead of the thyroid being under attack, in this case, it's the muscle and fat tissue behind the eyes. As a result, inflammation and scarring occur, which can lead to eye changes, such as bulging eyes (proptosis), misaligned eyes (strabismus) and double vision (diplopia).

Other symptoms of TED include:

- Dry, gritty eyes
- Red, swollen eyes and eyelids
- Watery eyes
- Eye pain
- Sensitivity to light
- Eyelids unable to close properly (retraction)

TED can come on strong

TED often starts suddenly, causing symptoms like redness, dryness and swelling, and can quickly get worse, setting the stage for scarring and serious vision damage. This is known as the acute phase of TED, which can last anywhere from six months to two years. The acute phase of TED



is followed by a chronic or "inactive" phase, but that doesn't mean the disease has gone away. In fact, if it's left untreated, TED can flare again when exposed to a trigger like stress or cigarette smoking.

Understanding your options

First and foremost, it's important to understand that TED is a separate disease from Graves', so it requires its own treatment—preferably in the acute phase. That's the best way to minimize scarring and prevent serious eye damage. Today's treatments can

relieve the symptoms of TED, and one medication is now FDA approved to address TED at the source. Current options include:

Eye drops or gels. These can relieve the dry, gritty feeling that comes with TED, and in the case of eyelids that won't close (retracted eyelids), lubricated gels can keep eyes moist.

Steroids. Although steroids can help bring down swelling, over the long term, they can cause weight gain and increase the risk of infection. So it's

common to start at a high dose and slowly taper off.

Orbital radiotherapy (ORT). With this treatment, radiation is aimed at the inflamed area behind the eye to help reduce bulging and other symptoms.

Assess your TED risk Take this quick quiz and review with your healthcare provider.

- Do you have Graves' disease?
 ☐ Yes ☐ No
- Have you been prescribed radioactive iodine for a thyroid disorder?
 Yes No
- 3. Are you female? □ Yes □ No
- 4. Do you smoke? ☐ Yes ☐ No
- 5. Are you older than 40? □ Yes □ No
- 6. Do you have a family history of Graves' or Hashimoto's disease?
 ☐ Yes ☐ No

Surgery. When TED is in the chronic phase, these surgeries may be performed: 1) Orbital decompression to help the eyelids close better, minimize bulging, ease eye pain and potentially improve double vision; 2) Strabismus surgery to help correct double vision and improve forward vision; 3) Eyelid repositioning surgery to help relieve dryness; 4) Face sculpting to help the eyes and face look better.

Monoclonal antibody. One

treatment has been FDA approved to treat TED at the source. It works by blocking the IGF1 receptor, a protein that allows the overgrowth of fat and muscle behind the eye. As a result, the bulging, redness, pain and swelling go down. The drug can improve double vision (in some cases, making it go away) and even help improve physical appearance so surgery isn't needed. The medication is given by infusion, once every three weeks, for a total of eight infusions.

If you have Graves' disease, keep reading to learn more about TED so you're alert to the signs and symptoms and, if needed, can get treatment. June, for one, couldn't be more grateful: "TED tried to steal my happiness. It feels great to look and feel like me again."



Who is on your Graves' disease care team?

- **Primary care provider.** An MD, PA, or NP, this provider can coordinate and monitor your overall care, prescribe medications and refer you to specialists, such as an ophthalmologist, an endocrinologist and a thyroid eye disease specialist.
- **Ophthalmologist.** This MD can provide a baseline eye exam, diagnose TED, monitor the progress of your TED and determine if you need to see a thyroid eye disease specialist.
- **Thyroid eye disease specialist.** An ophthalmologist or oculoplastic surgeon who specializes in TED, this physician can diagnose TED, do a baseline eye exam, conduct other tests, help develop a TED treatment plan and determine how often you should be checked.
- Endocrinologist. An MD who specializes in treating hormone conditions, this physician can help you manage your Graves' disease. They will work with your TED specialist or ophthalmologist to make sure your treatments won't have any negative interactions.
- Oculoplastic surgeon. These ophthalmologists specialize in plastic and reconstructive surgery of tissues around the eyes, including the eyelids, eyebrows, forehead, cheeks and bony cavity around the eye.
- Mental health professional. Psychiatrists, psychologists and social workers can help you deal with the emotional effects of living with TED, which is associated with high rates of depression.

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Watch for signs of TED

If you have Graves' disease, you are at high risk for a condition called thyroid eye disease. Fill out and review this worksheet with your healthcare provider.

Do your eyes often feel...

- dry and gritty
- like there's something stuck in them
- watery

Have you noticed any of the following changes in the way your eyes work, such as...

- increased sensitivity to light
- blurry vision
- double vision

Have you felt any eye discomfort, such as:

- eye pain or pressure behind the eye
- discomfort or pain when you look left or right, or up or down
- swollen eyelids
- red, swollen eyes
- redness in the whites of your eyes



- bulging of one or both eyes
- 📕 eye pus
- one eye moves slower than the other
- trouble reading street signs or subtitles
- inflammation in the inside corner of your eye

Have you noticed vision changes, such as...

- inability to see colors
- vision loss

Have eye symptoms had an impact on your ability to do everyday activities, such as...

- walking
- driving
- cooking
- watching TV
- working
- reading
- going up and down stairs

Track your symptoms

Because TED is a progressive disease, it's important to monitor your symptoms and keep your doctor in the loop.

Monitor your eye pain or discomfort

In the last three months, how much have you been bothered by these symptoms?

Pain or pressure behind the eye		
Discomfort when I look up or down, or left or right 📕		
Swollen eyelids		
Red, swollen eyes.		
Whites of my eyes are red		
Bulging eyes.		
Eyes don't move at the same time		
Trouble reading signs or subtitles on TV		
Inflammation in the corner of your eyes		

Monitor how your eyes feel

In the last three months, how often have you noticed...

My eyes are dry and gritty	
It feels like there's something stuck in my eye	
My eyes are watery	

Monitor how your eyes work

In the last three months, how often have you noticed...

Blurry vision		
Sensitivity to light		
Double vision		
Difficulty seeing colors		
Difficulty with vision in general		

Monitor how your eyes look

Have you noticed the following? Check all that apply.

- My eyelids are pulled back
- My eyes point in different directions
- My eyelids droop

Could You Be at Risk for Thyroid Eye Disease (TED)?

Share your results with a TED Eye Specialist.

Find one at FindTEDdoctors.com

Identifying TED early before serious eye damage occurs is critical. It is not completely understood why some people develop TED and others do not. Doctors have identified certain factors that put people at greater risk for developing TED. Check off any risk factors you may have below and share the results with a TED Eye Specialist, a doctor experienced in treating TED.

Do you have Graves' disease?

 Many people with Graves' disease could develop a different condition called Thyroid Eye Disease (TED).



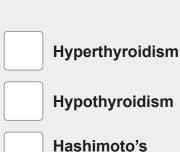
Do you have another type of thyroid disease?

- In one study, 60% of patients with hyperthyroidism developed TED
- In another study, 6% of patients with Hashimoto's disease had TED
- Up to 10% of patients with TED have Hashimoto's disease. hypothyroidism or normal thyroid levels

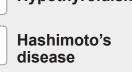


Have you been prescribed radioactive iodine for a thyroid disorder?

- Radioactive iodine is used to treat Graves' disease and other thyroid conditions
- In one study, the risk of developing TED (or making it worse) was shown to be 20% after radioactive iodine treatment



Hypothyroidism





Women are about 5x more likely than men to develop TED

Are you female?

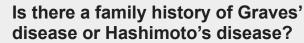
- Do you smoke? • People who smoke are up to 8x more likely to develop TED
- In one study, smoking worsened TED in 40% of patients



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What is your age?

• The risk of developing TED increases in a person's 40s



 40-50% of patients with thyroid disorders reported another family member with a thyroid disorder



Share your TED risk factors with your doctor.

Learn more about Thyroid Eye Disease at ThyroidEyes.com To take the full risk assessment, scan QR code or visit RisksOfTED.com

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Years



"My future finally looks bright!"

Bulging eyes. Double vision. Dryness. Dentist Layla Lohmann feared she'd have to live with the symptoms of thyroid eye disease—until an amazing treatment came along. —BY BETH SHAPOURI

Today, Layla Lohmann's eyes feel

good—she's able to go outside without having to avoid sunny days, she's waking up without feeling like there's grit in her eyes and she's free of headaches caused by double vision. But it wasn't long ago that the wife, mom and dentist thought these symptoms were just "a part of life" and one more thing she had to deal with.

Layla's journey with thyroid eye disease (TED) began when she was 12-yearsold following a diagnosis of Graves' disease, a condition where the immune system attacks the thyroid and causes an overproduction of thyroid hormones. One of the first symptoms of her Graves', in fact, were the telltale bulging eyeballs associated with TED, which is when that same immune malfunction that causes the body to attack the thyroid also attacks the muscle and tissue behind the eyes.

At the time, there was little doctors could offer Layla to treat the TED, but they did opt to remove her thyroid when she was 15. "I mistakenly believed that removing my thyroid would cure both conditions, so even though I was still experiencing severe dry eye, redness and tenderness after the surgery, I just chalked it up to allergies."

"I needed a better answer!"

Fast forward to 2015, Layla was married to husband David and pregnant with her son, Lucas, when her eye symptoms took a sudden turn for the worse, including debilitating headaches and double vision.

"That's when my doctor explained how TED works—that even though my thyroid was gone, the immune malfunction that caused my Graves' was still active in my body and was attacking my eyes."

Luckily, after she gave birth, the symptoms subsided, making it a bit more bearable for Layla with the help of steroids and eye drops. And her downward vision wasn't impacted, which was very important for her career as a dentist.

But while her ophthalmologist assured her the eye symptoms would not likely surge again even with another pregnancy, that turned out to be untrue. In fact, she says, "The first sign I had that made me suspect I might be pregnant again was that the double vision suddenly returned!"

While her symptoms decreased again after she gave birth to Nora, they still disrupted her day-to-day life. "I didn't enjoy going to my son's soccer games because being outside in the sun hurt my eyes." Not only did she hate missing out on those moments, she says, "It really opened up how I felt as a kid where people would call me lazy for staying indoors and not participating in things."

So she went back to her doctor and asked if there was anything else she could try. And that's when he mentioned there was a new biologic medication that had recently been approved to treat TED.

"I said, 'Sign me up!' " laughs Layla.

"I couldn't believe the difference"

Layla started the infusions and by the third round, to her amazement, she suddenly found relief.

"I was in shock! It eased symptoms I didn't even realize I was having, like the dry eye in the mornings, because I'd lived with them so long I thought they were normal and everyone felt that way. For the first time in 26 years, my eyes weren't bothering me!"

That's why Layla was dismayed when production of the drug (among others) was ceased in 2020 so manufacturers could concentrate on producing the COVID-19 vaccine. Even after it was put back on the market, she found she had to battle her insurance for continued access when her symptoms would return.

Frustrated, Layla decided she needed to take action and became a patient advocate with the TED Community Organization to fight not just for her own access to her medication but for other patients, too.

"I'm a healthcare provider with resources, and if this is what I have to go through to get access to this medication, I can't imagine somebody who doesn't have my support. That's why I'm fighting these battles," she says.

"Now I'm looking forward"

Today, Layla is continuing to get infusions of the medication, and is still working to help others gain access to the drug that she says "changed my whole life."

"I'm in a good place right now. I go to my son's soccer games, I go outside and play with my kids. It's been so empowering—this medication has just been a game-changer."



Get the upper hand on TED, like Layla did!

Ask your healthcare provider if her tips could work for you.

Find help for access

If you're having trouble getting your insurance company to cover your medication, Layla suggests contacting patient advocacy groups like the Patient Access Network Foundation (panfoundation.org) or asking the manufacturer of the drug your doctor recommends if they have any patient liaisons. She explains these advocates are great because, "While I'm taking care of my kids, my husband, and myself, this person was taking care of me and trying to get me the medication that I need!"

Communicate with your kids

Children often don't have a filter, which means kids of people who have TED sometimes hear things about their mom or dad's eyes at school. For her son, who is now 8, she says letting him know he doesn't have to protect her is important. "I try to talk to him to normalize it," she explains. "I say, 'Mommy's eyes sometimes pop out, and people will say things to you. If anyone makes you feel uncomfortable, just let me know, and we'll talk it out together.' "

Try tinted glasses

Layla finds wearing blue light-blocking tinted glasses indoors to help on the days when her eyes are feeling sensitive to help reduce glare. This has been an upgrade from when she used to wear sunglasses indoors! "People just thought I was trying to be cool!" she laughs.

"TED DOESN'T DEFINE US!"

From self-care makeup tricks to soothing ice packs, Suzy and Christine are sharing how they manage to thrive despite thyroid eye disease. See if their tips could help you! —BY BETH SHAPOURI

"BE PATIENT AND RESEARCH!"

SUZY GERNSTEIN

Overwhelmed from juggling her role as a mom to her then 2-yearold son, Harvey, and her job as a makeup artist, Suzy Gerstein first took the symptoms she experienced in 2014 as simple fatigue.

"I wasn't sleeping," she recalls. "It was easy to chalk things up to being tired, but I knew other members of my family had had thyroid issues, so that possibility was also on my mind."

When she developed a lump in her throat and stopped being able to fully close her eyelids, she knew something serious was going on and visited her doctor.

That resulted in a triple whammy diagnosis:

Graves' disease, thyroid eye disease (TED) and thyroid cancer.

She had surgery to remove her thyroid and a year after being pronounced cancer-free, she underwent her first eye surgery.

Today, seven eye surgeries later, she says, "I'm finally happy with how it's healed."

Along the way, she's also come to redefine beauty and is giving herself more grace. "I look at a recent picture and I'm like, Okay, I like her more. She's got some scars, but she's earned them. There's a beauty to that."

Here, Suzy shares the other methods she used to get control of her TED.

Think gentle with eye

makeup. Suzy found staying away from waterproof eyeliner especially along the inner line of her eyes—helped ease her eye issues, as does skipping mascara some days. To take her makeup off at night, she exclusively uses micellar water, which is gentle and easily removes anything she's applied. "It feels nice and refreshing, and I don't have to tug at my eyes, which is a big no-no." Her favorite: Micellar Cleansing Water All-in-1 Waterproof Makeup Remover (\$12.99, Ulta.com).

Find ways to destress.

After her diagnosis, Suzy had to teach herself how to slow down. "There was a time I disliked massages because I literally couldn't sit still for that long and just relax. I would be crawling out of my skin!" But she kept at it and found she loves the art of Gua Sha massage (in which the skin is scraped with a special tool) as well as acupuncture. "I also used to fight breath work and meditation, but now I get it. It really is important to treat your whole self and your wellbeing, especially when battling a chronic illness."

Ask for help. If Suzy had to do it all over again, she says she'd lean more on others. "I would have had more childcare and more familial support,"



she says. These days she's gotten better at speaking up when she needs a break, and she's found the people around her eager to help. "People want to be there for you—let them! Tell them how! You think you're being a burden, but actually they are grateful. It probably makes you feel good to help people—this is true for the others in your life!" ►



"SEEK YOUR OWN JOY!"

CHRISTINE GUSTAFSON

Today, Christine Gustafson is the founder of the TED Community Organization, but in 2009, she was simply a patient with both Graves' disease and TED. And the day-to-day reality of living with bulging, swollen eyes was taking its toll.

"I was actually frightening little children!" she recalls. "I felt very isolated and alone." In fact, it would be another 12 years before she met another patient in her shoes.

She underwent her first eye surgery to correct the bulging in 2012 and has since had six more, including decompression surgery, in which the space behind the eyes is cleared out to allow the eyes to move back.

Luckily, her last surgery in 2022 was a success not only are her eyes symmetrical, but she now has nearly 20/20 vision and no longer sees double. That same year she decided to pay it forward by founding the TED Community Organization to create "a one-stop place for education, support and community" after trying to help a fellow patient she met online find educational resources. "It became clear that this was a great need and something I could help with," she explains. She says of her fellow patients, "We need each other. We seem to do better in a community!"

Here, Christine shares some of the advice she wished she'd had when first diagnosed.

Plan for discomfort.

Having strategies onhand can be a lifesaver when eye discomfort from TED hits. Christine now makes sure she always has the following stocked up in her house: "soothing eye drops, ice packs that I can put over my eyes to ease swelling and pain medication."

Find support.

"Embarrassment and loneliness are primary to a TED diagnosis. Connecting with the TED community is a very important way for those affected by the condition to overcome these sizable roadblocks to a solution," she says. That's, after all, why she started the TED Community Organization. To find out more, visit *tedcommunity.org.*

Health m Monitor

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Answers to your questions about Graves' disease and TED

for the first time recently. She told me about a new medication that could help reduce the appearance of my bulging eyes. I was going to have surgery to fix them, but could this medicine help me avoid surgery instead? A: Teprotumomab is a new medication approved for the treatment of TED. It blocks one of the receptors that is responsible for the inflammatory reaction in the eve socket. Clinical trials have found reduction of bulging eyes (proptosis) in 83% of patients who were treated with teprotumomab during the active phase of their disease. We do not yet know if this medication will reduce the need for surgery. Your doctor will discuss risks and benefits of medical and surgical treatment, and help

AVOIDING SURGERY

Q: I saw a TED specialist

APPEARANCE CONCERNS

your case.

Q: As my TED progresses, I am avoiding the mirror more and more. And when I occasionally catch sight of myself accidentally, it's painful. I don't recognize

you decide what is best in

myself. I hate what I see. It's traumatic. How can I cope with the changes? A: We know that TED not only affects eye health but also quality of life. Aside from problems with the function of the eyes, such as eye pain, light sensitivity and double vision, many patients feel concerned and depressed about the profound change in their appearance. Discussing these feelings with other TED patients in online groups and exploring options for rehabilitation of your normal appearance with your oculoplastic surgeon can be helpful. Medical treatment or reconstructive surgery aimed at restoring predisease appearance is generally not considered cosmetic and therefore covered by medical insurance plans in most cases.

OUR EXPERT:

Lilly Wagner, MD Assistant Professor of Ophthalmology Consultant, Ophthalmic Plastic and Reconstructive Surgery; Mayo Clinic; Rochester, MN

Anxious? Embarrassed? Down? You can get off the emotional roller coaster

Thyroid eye disease and Graves' disease come with a lot of difficult symptoms, but some of the toughest are emotional—things like embarrassment over bulging eyes, anxiety about the future and even an increased risk for depression. If you're facing these challenges, you're far from alone—and luckily, there are ways to help you cope. Read on to learn more, and hopefully discover a few methods that can help you get back to feeling your best, inside and out! -BY NANCY MORGAN



BATTLING DEPRESSION? Try this...

Focus on small gains. Making a delicious meal, taking a walk, tidying a drawer or calling a friend can give you a sense of accomplishment and help you feel good about yourself.

Do something that gives you pleasure—or that used to! And if you can't do it today, plan for it so you have something to look forward to. Easy things you don't have to plan for might include listening to music, tending to indoor plants or taking photos.

Become an early riser. People who reported greater exposure to morning light (between 8 AM and noon) not only fell asleep more easily and slept more soundly, but they were also less likely to report feelings of depression, according to a study in *Sleep Health*.



STRUGGLING WITH ANXIETY? Try this...

Breathe! When you notice signs of anxiety, such as racing thoughts, irritability or excessive worry, inhale deeply then silently count to five. Hold your breath for two counts, then slowly exhale. By slowing your breathing rate and pattern, you can stimulate the body's relaxation response.

Bring yourself back to the present moment. If your mind starts racing, reassure yourself with a mantra: *I am* going to be okay. Or try to put things in perspective: *I'm feeling anxiety that* might be caused by my Graves' or TED; *I'm going to breathe through it.*

Get classical. If you're able to tune out for a few minutes, try listening to some Bach or Vivaldi. Classical music can slow your heart rate, lower levels of stress hormones and prompt the release of dopamine, a feel-good hormone that counteracts anxiety. Researchers credit the tempo: At 60 to 100 beats a minute, it's similar to a normal heart rate.



FEELING A LOSS OF CONFIDENCE? Try this...

Wear these sunglasses. Ones made for "light sensitivity." These usually feature blue or pink-colored lenses and are made for people with, say, migraines whose eyes can be sensitive to indoor light. If your confidence loss is due to TED, they will allow you to shield your eyes with lenses that are light enough to wear indoors.

Get a "mini" makeover. Maybe it's a new pair of earrings, a daring new shade of lipstick or a funky hairstyle. Small changes to our appearance can go a long way toward rebuilding selfesteem, according to research out of California State University.

Keep this in mind. People who are self-conscious tend to feel others are focusing on them, according to research in the *Journal of Experimental Psychopathology*. But the vast majority of the time, others are thinking about themselves—not your appearance!

Health Monitor Living



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Can this treatment correct my bulging eyes and other symptoms of TED, such as double vision and strabismus?

Is my TED in an acute or chronic phase?

Are there any emergency symptoms I should watch out for? When should I make my next appointment to see you?

to see

What treatment do you recommend and why?



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On treatment and need help covering the cost?

Ask your healthcare provider about patient assistance programs or call the manufacturer of the treatment you have been prescribed. Many pharmaceutical companies offer copay assistance programs that can make treatment more affordable.