



GRAVES' DISEASE & THYROID FOUNDATION

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A Role for Self-Care in Evidence-Based Medicine

By Kimberly Dorris, Executive Director

“Are there any alternative treatments for Graves’ disease?” At the Graves’ Disease & Thyroid Foundation, it’s a question we get a lot. While there is definitely a role for self-care practices as we navigate this chronic illness journey (read on for more), the short answer is “no.” The GDATF Board of Directors includes two doctors and a nurse practitioner, and our organization is committed to sharing evidence-based information with our community members. We also want doctors who refer their patients to us to have confidence that the information we provide is sound and that we won’t try to give medical advice. And in the worst-case scenario, we certainly don’t want a patient trying something potentially harmful because they heard about it at a GDATF forum or event.

Those of us who are diagnosed with Graves’ disease are presented with three treatment options to

control hyperthyroidism: antithyroid medications, radioactive iodine, or surgery. Most patients do well, even though the vast majority of them aren’t on social media posting things like, “My levels are normal! Thanks, methimazole! I’m going to Disneyland!” Still, all three options come with potential side effects and complications. And they all sound really scary – especially when you are at the starting line of this journey, and you haven’t slept and can’t think straight and can barely manage to make cereal for dinner.

That’s when it can seem tempting to chase after purported “natural” cures that dangle all the benefits of good health, supposedly without the risk of treatments developed by so-called “Big Pharma.” But it’s important to understand that “Big Wellness” is a multibillion-dollar global industry that remains largely unregulated. And make no mistake: going down this path does come

with risk. Some supplements may have unreported ingredients. Others can lead to side effects. Still others can interact with your existing medications.

Part of the allure of Big Wellness is that you can “take charge of your health.” But the unspoken flip side is that if your health isn’t optimal, it’s your own fault. With some medical conditions, there’s a direct connection with lifestyle choices. For example, smoking is known to increase the risk of developing severe thyroid eye disease, and smokers don’t respond as well to treatment. But when it comes to autoimmune diseases in general, the world’s foremost researchers are still trying to unravel the complex interaction between genetics, environmental factors, and viral illnesses that lead one person to develop Graves’ disease and another Hashimoto’s thyroiditis and still another rheumatoid arthritis or lupus or MS. So it’s not a personal failure if your TSH is still too low or

your T3 and T4 are still too high or if your antibodies are still raging. A single lab report isn't a bad report card that will be sent home to your parents. Instead, think of the results as point-in-time feedback that will help you and your doctor guide your next steps with regard to treatment choices and medication dosing.

My Graves' Journey

When I started my own Graves' journey in 2007, I was under the care of an endocrinologist, and I kept up with labs, appointments, and medication changes under her guidance. But like many patients, I hoped for a solution that would cure my disease, but also perhaps didn't involve freaking out and calling my doctor every time I got a sore throat. (Sore throat, especially with fever, can be a sign of agranulocytosis, a rare but serious side effect of antithyroid drugs where levels of a specific type of white blood cell become dangerously low.) So I went searching for that solution. At one point, I was on a super restrictive diet that cut out gluten, sugar, eggs, dairy, soy, and my will to live. I'm kidding about the will to live. Mostly. But it was exhausting, and I don't

believe it made a difference in the course of my disease.

Around this time, I also visited a practitioner who came recommended by an MD, so I expected this person had some credibility and wouldn't be selling snake oil out of the back of a wagon. After I gave up several vials of blood and my credit card digits, I was told that I had elevated mercury, which was likely the root cause of my Graves' disease. I was also told that the mercury could be removed – but the treatment was very expensive, not covered by insurance, and involved needles. (I'm not a fan.) I decided to take a pass.

A few months later, I was at an annual wellness visit with my primary care doctor and told the physician's assistant that I had elevated mercury. "Sure, we can check for that," she said. "But have you had tuna in the last 24 hours?" Had...I...what??? I brought tuna to work with my lunch almost every day! (In my defense, it was 2007, and I didn't have the knowledge about fish and mercury that's more commonplace today.) I shared this with the PA, who suggested that we do the test later after I'd laid off the tuna for a while. And guess what? When we retested, my mercury problem had

disappeared. My Graves' disease, however, had not.

The important point here is that I remained under the care and guidance of my endocrinologist – including taking my medication as directed – while embarking on this little walkabout. The stakes are much higher for patients who completely abandon conventional treatment options. When your supplement of choice – or even the old wellness standby "diet and exercise" – doesn't control your hyperthyroidism, the consequences can include bone loss, muscle wasting, heart problems, and a potentially fatal complication called thyroid storm. As GDATF Founder and Chair Emeritus Nancy Hord Patterson, Ph.D., recalls, "I talked frequently with one grandmother several years ago whose grown grandson refused to have treatment, other than diet. His levels and symptoms continued to increase, and he eventually died of a painful – and avoidable – thyroid storm." Deaths due to untreated Graves' disease are both heartbreaking and preventable.

Diet and Supplements: What We Know and What We Don't Know

Even when they are under the care of an endocrinologist, we still get questions from patients about diet and supplements to potentially support their healing journey. But the challenge is that we don't have a lot of good research in this area. Some endocrinologists will regularly test Vitamin B and Vitamin D levels and will recommend supplementation as needed. For a patient who has experienced bone loss, calcium supplementation might be recommended. Some studies have indicated that selenium might be beneficial in mild thyroid eye disease — but the studies have been conducted in areas known to be selenium-deficient. So is there a benefit to additional selenium that goes above and beyond correcting a deficiency? The jury is still out. And it's important to not go overboard with selenium. One or two Brazil nuts gives you the full recommended daily allowance. Side effects of chronic and excessive selenium intake include a garlic odor in the breath, metallic taste in the mouth, hair loss, brittle nails, skin rash, nausea, diarrhea, fatigue, irritability, and nervous system

abnormalities. (1) Ironically, many of these side effects mimic the symptoms of hyperthyroidism!

Be especially wary of so-called “Thyroid Support” supplements. The name alone sounds alluring. Who wouldn't want “thyroid support?” But most of these products are loaded with iodine, which can exacerbate hyperthyroidism. And even worse, a 2013 study found unreported T3 and T4 in nine out of ten products tested: in some cases, at levels used in prescription thyroid hormone replacement for patients who are hypothyroid. (2) As explained by The Cleveland Clinic, “The trouble is that you don't always know what's in those bottles. And that disclaimer on vitamins — *This statement has not been evaluated by the Food and Drug Administration. This product is not intended to diagnose, treat, cure, or prevent any disease* — it's there for a reason”. (3)

The bottom line on supplements is to make sure that your endocrinologist (or your primary care doctor) knows everything that you are taking or planning to take, so that they can advise you on dosing, timing, and potential interactions. For example, calcium and iron supplements can interfere with the

absorption of thyroid hormone replacement, so if you are hypothyroid, it's typically recommended to space these four hours out from levothyroxine. Biotin can falsely skew thyroid labs, so most doctors recommend stopping for a period of time prior to having blood drawn. For general information, the National Institutes of Health Office of Dietary Supplements and the National Center for Complementary and Integrative Health can help you learn more about risks and benefits of supplements — including what we know and what we don't know.

In terms of diet, credible information is even harder to come by. We hear from some patients who follow a Mediterranean food plan. Some go vegan. Or on the opposite end of the spectrum, Paleo. Others give up gluten. (One caution about a gluten free diet is to avoid going overboard with processed foods just because they are gluten-free.)

For a thoughtful read on thyroid issues and diet, check out the Medscape article ‘Thyroid Diet’: What's the Evidence? by Angela M. Leung, MD, MSc and Gonzalo J. Acosta, MD. (4) (Medscape login might be required to view, but setting up an account should be free.)

As the authors explain, *“truth be told, there is a lot of information out there that may sound compelling. However, the evidence is usually low quality.”* As mentioned earlier, excessive intake of iodine can exacerbate hyperthyroidism. Although doctors rarely recommend a low iodine diet for Graves’ (except sometimes in preparation for a radioactive iodine uptake and scan test), it’s still important to be cautious with foods that are loaded with iodine. This can be a challenge, as iodine isn’t typically listed on nutrition labels. Think twice before polishing off an entire package of seaweed snacks!

The Three-Legged Stool

While you won’t see social media posts from the GDATAF touting the latest hot new herb or influencer trend, is there room for a discussion of self-care in our evidence-based programming? The answer is a resounding yes! Dr. Herbert Benson (who sadly passed away in 2022) founded the Benson Henry Institute for Mind Body Medicine at Massachusetts General Hospital. In an address to the GDATAF’s 2011 Patient & Family Conference in Boston, MA, he described his approach to overall wellness and well-

being as a three-legged stool. (5) One leg is pharmaceuticals. One leg is surgery and other procedures. (*“Many of us would not be here today, were it not for the first two legs of the three-legged stool,”* Dr. Benson told the group.) But you need a third leg to keep the stool from toppling – and that third leg is self-care.

So what might the third leg of your stool look like? Everyone’s list will look a bit different, but consider:

- Optimizing nutrition (a registered dietician can be helpful here) to focus on whole foods like fruits, vegetables, whole grains, legumes, and lean sources of protein. Consider your personal tastes and your budget, as well as how much time and energy you have available for food preparation.
- Prioritizing sleep and practicing good sleep habits. If you suspect obstructive sleep apnea, get tested.
- Exercising (once a doctor clears you for activity — use caution if hyperthyroidism is still uncontrolled).
- Reducing stress (as much as any of us can).
- Taking a rest day when needed.

- Analyzing your workload. We all have things we must “Do.” But are there things you can “Dump or Delegate?”
- Giving up smoking. Seek help with cessation if needed.
- Reducing alcohol consumption if needed.
- Reducing exposure to endocrine-disrupting chemicals. Plastics are a huge culprit, so The Endocrine Society recommends minimizing consumption of processed foods as much as possible, using filtered as opposed to bottled water, and not exposing canned or plastic-packaged foods to heat, for example, from microwave use or leaving foods in a hot car. (6)
- Prioritizing activities that bring you peace and joy such as hobbies, personal interactions, meditation, etc..
- Other practices like massage — but ask about risks and contraindications and make sure that your provider is appropriately credentialed.

As you build out your self-care plan, don’t neglect the medical/ surgical legs of your stool! Be sure that the point person on your team is an experienced MD or DO. Other professions or internet influencers (with books and

advertisements and sponsored posts for sale) might claim to offer expertise, but there's just no substitute for years of medical training.

It's also important to have a doctor who keeps up with the latest medical guidance. As research evolves, practices can change. For example, it used to be common practice to give antithyroid medications for only 12-18 months before the meds were withdrawn. Today, antibody testing is recommended prior to withdrawing ATDs, and long-term use of ATDs is more common. The GDATAF hosted a webinar featuring Dr. David Cooper and Dr. Eve Bloomgarden to discuss this approach. (7) In addition, the use of T3 in patients who are hypothyroid and feel unwell on T4 monotherapy is also becoming more accepted. As Dr. Cooper noted in a recent webinar co-hosted by the GDATAF and the American Association of Endocrine Surgeons, "It used to be that people who did that, like me, were considered kind of crazy and outside the realm of medical practice. But now it's being more accepted to do this". (8)

Here's what your medical/surgical legs might look like:

- Working with your doctor to determine the treatment option that's right for you. For hyperthyroidism due to Graves' disease, that involves making a choice between antithyroid medications, RAI, or surgery. If you are hypothyroid, work with your doctor to find a medication and dosage that keeps your levels within the normal range and your symptoms at bay.
- Taking medications exactly as directed, and reporting any side effects to your doctor.
- Following up with lab tests and office visits as recommended by your doctor.
- Working with your doctor to test for deficiencies – such as Vitamin B or Vitamin D – and if needed, supplementing as directed.
- Asking your doctor about selenium (although see the previous note – don't go overboard!)
- Keeping up with your doctor's recommended vaccination schedule.

Graves' disease and Hashimoto's thyroiditis are roadblocks that none of us expected or planned for. But with a balanced three-legged stool, we can still live full lives with joy and purpose.

And if you make it to Disneyland (or some other fabulous place), tag us on social media (at @gdatf for FB/Twitter or @gdatfofficial on Insta) so we can share. Somewhere out there is a patient who is just starting this journey (and perhaps making cereal for dinner), and your success story could provide much-needed hope and inspiration!

A prior version of this article appeared in the Graves' Disease & Thyroid Foundation's Spring/Summer print newsletter. This version was posted in October 2025, and will be updated with any new advances regarding our understanding of diet and supplements.

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