

## GRAVES' DISEASE & THYROID FOUNDATION

Educate \* Encourage \* Empower

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### Playing on One String: Day to Day Life With Graves'

by Kimberly Dorris

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*With assistance from (and many thanks to) our Graves' patient communities on Facebook and Twitter, our local support groups, and the GDATF's online support forum.*

What do Graves' patients have in common with violin virtuoso Niccolò Paganini? For starters, we've all had the experience of living with a chronic illness. Paganini is believed to have lived with Marfan syndrome, a genetic connective tissue disorder. In fact, the long fingers and flexible joints associated with Marfan syndrome might have contributed to Paganini's unparalleled skill on the violin.

One unconfirmed – but oft-repeated – legend surrounding Paganini was that he was in the middle of a performance when one of the four strings on his violin snapped. The virtuoso continued playing, improvising to ensure the melody continued on his remaining three strings. But then another string broke! Again, Paganini continued unfazed. He made the needed adjustments to continue on his remaining two strings until the third string snapped. Paganini paused for a moment, held up his violin, then proclaimed “And now - Paganini and one string!” Then he finished the piece on one string to a rousing ovation from the audience.

Which brings us back to Graves' disease. There you are, playing the beautiful melody of your life on all four strings. And then Graves' disease shows up.

Energy: SNAP!  
Memory: BING!  
Mood: TWANG!

Each patient's journey is unique, and your own snapped strings might include Vision, Sleep, Concentration, Appearance, or other issues. But here we all are, left with a single string – and a need to learn to improvise.

The GDATF has reached out to our communities on Facebook, Twitter, our online support forum, and in local support groups for coping tips to make that improvisation a little easier. Read on for more!

**Memory.** The presentations archived on the GDATF's YouTube channel (screen name GravesAndThyroid) provide a wealth of information. One of our most popular presentations is “The Emotional Aspects of Graves' Disease” by Dr. Ira Lesser from the Department of Psychiatry at Harbor-UCLA Medical Center. Dr. Lesser notes that studies on Graves' and memory have been mixed. In fact, one theory is that attention is compromised, which makes recall difficult. Still, memory issues are a common complaint that we hear from our members. We asked our Facebook community if they had experienced specific memory issues:

- Forgot someone's name +57
- Lost keys/wallet/etc. +46
- Forgot what I was doing or saying +45
- Forgot passwords +31
- Forgot an appointment +28
- Forgot to take perishable groceries out of the car +16
- Forgot lab paperwork +15
- Forgot location of an appointment +12
- All of the above +7

About five years after my diagnosis, I went in for labs. The lady at the desk asked, “Do you have some paperwork for me?” I looked at her blankly. Then it dawned on me that she was talking about the EXACT SAME PAPERWORK that I’d brought to...oh...around 25 previous visits at that EXACT SAME LAB. As Tommy Lee Jones said in MiB 2, “This one is an example of go home and do it again.”

M.T. recommends laying out lab paperwork the night before, rather than trying to collect everything during the morning rush. She puts lab documents with her purse, as she always has purse in hand when she leaves the house!

Our online community stressed the importance of tracking appointments and to-dos in order to keep life running reasonably smoothly.

- Track everything in my phone. +14
- Track everything in writing in a planner. +10
- Leave myself notes. +8

M.B. noted that the act of physically writing something down was more powerful in terms of recall than typing a to-do into a phone.

The GDATAF’s Founder, Nancy Hord Patterson, Ph.D. is generally not a fan of sticky notes (“You’re going to lose them”), but a couple of cautions if you can’t kick the habit: first, try to keep notes all in one place. Your post-it won’t help if you can’t put your hands (or eyeballs) on it when it’s time to act. Second, avoid the temptation to use acronyms. Something like “PMFLQF” might make perfect sense at the moment you are writing or typing – but the meaning might turn out to be elusive when you really need it.

**Mood Swings.** Emotions can be difficult to manage when thyroid levels are out of balance. In many cases, these issues resolve when thyroid levels return to normal. In other cases, mood issues linger. Sometimes, another underlying disorder exists that needs separate treatment. (Again, I highly recommend Dr. Ira Lesser’s “The Emotional Aspects of Graves’ Disease” for more info on this topic.)

Mood swings can strain both work and family relationships. “Graves’ Rage” is not a medical term, but is certainly a state that many patients can identify with! We asked our community how they would respond if that annoying neighbor, co-worker, or family member started to set them off.

- Try to find a way to take a break for a few minutes. +13
- Oops! I lose it again. +8
- Take some deep breaths and carry on. +5
- Explain to the other person what is going on. +2

Taking a few minutes to disengage from the situation was by far the most popular response. One commenter suggested a nap as the best solution! A support group member, C., suggested that movement during the break

can make a difference. Consider walking around your office building or around the block.

**Work Issues.** Speaking of work, you probably need ALL of your strings to do your job successfully. So how can you improvise? When we asked our community members how they handled work-related issues, the majority revealed that they were up front with their teammates regarding their health challenges.

<input type="checkbox"/> I continued at my job - and was open with all my co-workers about my diagnosis.	+40
<input type="checkbox"/> I continued at my job - and only told my supervisor and/or direct reports.	+11
<input type="checkbox"/> I continued at my job - and did not share my diagnosis.	+8
<input type="checkbox"/> I quit my job.	+5
<input type="checkbox"/> I took medical leave from my job.	+4
<input type="checkbox"/> I reduced my hours.	+1
<input type="checkbox"/> I changed jobs.	

The Job Accommodation Network (<https://askjan.org/>) can be a helpful resource when it comes to finding temporary accommodations to help deal with workplace issues. JAN is one of several services provided by the U.S. Department of Labor's Office of Disability Employment Policy (ODEP). Its development has been achieved through the collaborative efforts of ODEP, West Virginia University, and private industry throughout North America.

Accommodation suggestions from JAN include flexible schedules, working from home (if feasible), scheduled rest breaks, control of worksite temperature, and possible transfer to a less stressful position.

**Your Morning Routine.** For those of us who aren't morning people to start with, adding a

chronic illness to the mix can make dragging our tired bodies out of bed feel like an Olympic sport. But wait – there's more! Hypothyroidism (which will occur following surgery or RAI – and less commonly, can also happen spontaneously in patients taking antithyroid medications) can increase the degree of difficulty in the face-the-day-athlon. Most doctors (check with your own doc for specific instructions) recommend waiting 30-60 minutes after taking replacement hormone to eat breakfast or drink coffee. We asked our community members how they deal with this wrench in their morning routines. A surprisingly large number of community members were fairly chipper about this new wrinkle. My own heart lies with the tired/hungry/grumpy group.

<input type="checkbox"/> I take the meds as soon as I get up - it's really not a problem.	+21
<input type="checkbox"/> I set the alarm an hour early to take the meds and then go back to bed.	+10
<input type="checkbox"/> I wake up (not by alarm), take my medication, and go back to sleep.	+11
<input type="checkbox"/> I take the meds at night.	+7
<input type="checkbox"/> I take the meds as soon as I get up - and then spend the next 30-60 minutes tired, hungry, and grumpy.	+5
<input type="checkbox"/> I take my meds in the morning as I walk out the door to go to work .	+1

**Appearance changes.** Dr. David Granet from University of California San Diego Shiley Eye Institute commented on living with thyroid eye disease: “We found levels of depression and anxiety that rival cancer and AIDS...not looking like yourself hit people even worse than double vision.” Many patients completely withdraw from work and social situations, because the appearance change so profoundly affects how they interact with the world and vice versa.

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Eye changes are distressing for many patients; others deal with excessive weight loss, weight gain, or a visible thyroidectomy scar. (An experienced surgeon will place the incision in a natural crease to minimize visibility.)

When we asked our community how they handle comments about their appearance, the vast majority said they took the high road and took the time to explain that their first priority was to return to good health. Others said that they ignore the comments. J. noted, “[I] act like it doesn’t phase me and cry at home.”

Having a community that truly understands what you are going through is invaluable – as is hearing from patients who are success stories. If you haven’t already, please consider joining the GDATF’s closed Facebook group or the [www.gdatf.org](http://www.gdatf.org) online forum.

In order to join the Facebook group, visit our Facebook Page at <https://www.facebook.com/GDATF/>. Select "Groups" - which will be in the same spot as "Photos", "Events", etc.; this will be in a slightly different spot depending on whether you are connecting via mobile or desktop. Select "Join" to join the group; you will then receive a notification message asking if you agree to abide by the group guidelines. Respond "Yes" - and we will approve your memberships as quickly as possible. (Approvals can take up to one business day).

To join the online forum, visit [www.gdatf.org](http://www.gdatf.org) and click the “register” button towards the top right-hand side of the screen. The system will send a verification e-mail to your chosen e-mail address; once you click on the link, you are ready to post. Your first post must be manually reviewed and approved by a facilitator, which can take up to one business day. Unfortunately, this step is needed to

keep spammers from clogging up the bulletin board.

A few communities have in-person local support groups, and we are always looking to expand our support group offerings! If you might be interested in starting a local group, the first step is to contact the GDATF at 877-643-3123 or [info@gdatf.org](mailto:info@gdatf.org). We can update you on the requirements for becoming a support group leader as well as the application process. A key part of the application process is to determine if a potential leader is ready to take on this role. Our founder notes that the time commitment – and the mental, physical, and emotional energy – required to lead a support group varies from “considerable” to “monumental”. If you are currently dealing with other life events that are placing significant demands on your time and energy (including a new Graves’ diagnosis), it’s probably not the optimal time to try and tackle one more commitment. If you need support, but are not yet ready to take on a leadership role, you can visit one of our online groups or contact a patient advocate via phone or e-mail at 877-643-3123 or [info@gdatf.org](mailto:info@gdatf.org).

A few other random observations as our single-string performance plays on...

- Treatment for Graves’ disease is not “one size fits all.” In fact, the American Thyroid Association notes, “Once the diagnosis has been made, the treating physician and patient should discuss each of the treatment options, including the logistics, benefits, expected speed of recovery, drawbacks, potential side effects, and costs. This sets the stage for the physician to make recommendations based on best clinical judgment and allows the final decision to incorporate the personal values and preferences of the patient. The treatment selection should also take into

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account the local availability and the associated costs. Whenever surgery is selected as treatment one should consider the use of expert high-volume thyroid surgeons with on average lower risk of complications; lack of that expertise should be considered against the known risk of alternative choices. Long-term continuous treatment of hyperthyroidism with ATDs may be considered in selected cases.”

- If your insurance company permits, have your labs done before your office visit. Then you can spend your time with your endocrinologist discussing the results and ensuring that your questions are answered. When dosing changes are explained after the fact over the telephone, misunderstandings can easily occur.
- Ask your doctor’s office for hard copies (or electronic copies) of your lab reports. This will allow you to compare your levels to your lab’s “normal” reference ranges – and keep track of them over time. Different labs can use different “normal” ranges, so the actual numbers are only useful in the context of your lab’s range. Are you right in the middle? At the upper end? The lower end? And where are you compared to your last set of labs?
- If your symptoms change significantly – but your next appointment is still weeks away – ask your provider about getting a new set of labs ordered. If your schedule is flexible, ask if the office can place you on a cancellation list for a quicker appointment.
- If your nightly ZZZs are becoming more and more elusive, consider getting labs done. But we can all benefit from healthy sleep habits, such as having a routine to

wind down an hour before bed, avoiding screen time and caffeine/nicotine/alcohol too close to bedtime, and sleeping in a dark, cool room. Google “sleep hygiene”, and you’ll find great info from institutions like Harvard Medical School and the Centers for Disease Control. Just stay away from those dodgy sites.

- Speaking of dodgy websites, use extreme caution with websites and Facebook Pages that offer “natural” cures for Graves’ disease. Although some patients assume that “natural” or “alternative” therapies are risk-free, this is not the case. If an unproven therapy fails to adequately control hyperthyroidism, there is a risk of bone/muscle wasting, heart problems, and a potentially fatal complication called thyroid storm. For those who are interested in learning about specific supplements, the National Center for Complementary & Integrative Health has a helpful web site that looks at alternative therapies from a science-based perspective: <https://nccih.nih.gov/>
- Time management experts often discuss the four “Ds” when evaluating a new task that comes in: Do, Dump, Delegate, or Delay. Consider these options in relation to your energy management. If there are tasks that drain you physically, mentally, or emotionally, can you use one of the four “Ds” to reclaim your energy? And on the flip side, prioritize activities (and people!) who bring you energy and joy.

**Humor and Healing.** As those strings started snapping, your sense of humor might have been the first one to go. But if you can find a way to patch it together with some glue or duct tape, a sense of humor is an excellent companion on this unpredictable journey. As we were discussing memory issues on

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Twitter, member Kim Mills @kdmills204 asked us to “add humor as a tip.”

“I rely heavily on lists and my family,” she noted. “It’s difficult. People worry and can’t understand my lack of recollection. Graves’ is a daily battle.” Then she added:

“My hubby just read my last tweet, hugged me, and said, ‘it’s gonna be OK’. Then he said, ‘My name is Dave.’”



**Reclaiming Your Strings.** Paganini started his musical career with a violin made by Giuseppe Guarneri. But you don’t need an instrument crafted by a world-famous Italian luthier to become a master of improvisation.

Favio Chavez, an environmental engineer in the poor town of Cateura, Paraguay started a project to make musical instruments for kids out of trash from the local landfill. (The Recycled Orchestra of Cateura now tours all over the world). One of his masterpieces is on display at the Musical Instrument Museum in Phoenix, AZ: a violin made out of a metal canister, recycled wood, and a fork!

So even if Graves’ disease has snapped one, two, three, or maybe ALL of our strings, we can still learn and adjust and improvise – and continue playing the melody of our own lives.

Play on, Graves’ warriors.

Play on.

## References:

“The Emotional Aspects of Graves’ Disease”. Presented by Dr. Ira Lesser, Chair, Department of Psychiatry, Harbor-UCLA Medical Center. Presented on October 27, 2012 at the Graves' Disease & Thyroid Foundation Patient & Family Conference - A Bridge to Wellness XIX.

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