



GRAVES' DISEASE & THYROID FOUNDATION

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Me, Bush and Graves' Disease by Abigail Trafford

Many thyroid patients face an emotional roller coaster. George and Barbara Bush have given an overactive thyroid a certain cachet. In the public mind, Graves' disease is now seen as a "good-news" ailment, not at all bad to have. So when the President's irregular heart beat was attributed to his thyroid gland, everyone breathed a sign of relief. "Thank God – only a thyroid" problem.

But here's the bad news: it is difficult to live with and adjust to Graves' disease. What's missing in all the upbeat press releases from the White House is the powerful emotional impact the disease has on many patients and the effects of hyperthyroidism on mood and behavior and judgment. And while Graves' is, indeed, curable, it can take months, sometimes years, for people to get their thyroid function back to normal.

The reason I know is that 22 years ago, I was sitting in the doctor's office in Houston when a smiling doctor told me the "good news" that I had Graves' disease. I was a typical patient: female, in my twenties, the mother of two children. Later, I would find out that thyroid problems run in my family on my mother's side. Graves' is more common among women and has a genetic component. While it is caused by excess levels of the thyroid hormone in the blood, the underlying disease is a disorder of the body's immune system.

The disease seemed to come on me quite suddenly. One weekend, I was sick with a wretched flu bug and very sore throat. By Monday, I had severe symptoms: racing heartbeat, jitters, the feeling that the gas pedal in my body was stuck to the floor, and I was spinning out of control. I was terrified. I looked in the mirror and thought: Maybe this is what it's like to flip out.

I immediately went to a doctor, who immediately sent me to an endocrinologist, who immediately smiled his "thank-God-it's-Graves'-disease" smile. He ran some tests, confirmed the diagnosis, treated me with radioactive iodine, which destroys the thyroid gland. After a few months, when my thyroid became underactive because of the radiation, he prescribed daily thyroid pills which I've taken ever since.

Through it all, I functioned as a reporter covering the Apollo moon flights. I went to news conferences and asked questions about the guidance systems on the lunar module, its trajectory and other complex matters. I usually wore dark glasses to cover my bulging eyes, a problem that can occur in Graves' patients. (Barbara Bush, for instance, has experienced problems with her eyes; so far, George Bush has not.)

To the outside world, I was thumbs-up fine. But inside, I

was shaken, a common reaction, especially for those who are otherwise very healthy. Graves' disease strikes on a psychological basis and strikes a population that is not used to the concept of being sick," says an assistant professor of medicine at George Washington University.

"There's no question that the emotions are severely out of whack," says a Washington endocrinologist. Or, as the acting chief of endocrinology at Georgetown University Medical Center describes Graves' patients: "Emotionally, they can be feeling very good and then very bad. There are lots of ups and downs...they cry at TV ads."

Receptionists in doctors' offices can always spot Graves' patients – and usually dislike them. Graves' patients tend to be demanding, anxious, frustrated and rude. They can't sit still; they seem to stare at a person relentlessly. "On a certain level, patients with Graves' make you nervous."

Hyperthyroidism doesn't destroy cognitive functions or reasoning, doctors say, but many people can't focus quite as well. They are easily distracted. They are also very

irritable and unable to stand frustration. "One thing about having Graves' disease is that you can't suffer fools. You make snap judgments and then worry about them all the time" Some women with Graves' find they can't stand the misbehavior of their children. They start doubting that they are "good mothers."

Graves' can play havoc with marriages and work relationships, especially if not diagnosed. Doctors talk about patients who lose their jobs because of their Graves'-linked behavior. Sometimes patients break up their marriages. There are cases in which a couple was able to get back together once the patient has been diagnosed and treated.

The disease can be so disruptive that doctors may ask the patient – who is usually female – to bring in her spouse to talk about the psychological aspect of the disease. "I ask the husband – 'has she been hard to live with?' The answer is always yes. Frequently, the wife bursts into tears," reports one consulting physician.

Even after Graves' is diagnosed and while treatment is taking effect, patients can go through a period of self-doubt and emotional vulnerability.

Doctors describe how patients may feel out of control and guilty about their behavior. They can't figure out whether they are feeling upset due to their thyroid gland or whether they really are in an upsetting situation.

This confusion often leads a sufferer reviewing the past through a Graves' lens and asking the question: When did this all start? In most cases, the thyroid dysfunction probably began only a few months before the symptoms appeared. It's unlikely that a person with noticeable symptoms of Graves' can go for long without knowing that something is very wrong.

But there is no way to document the beginning of hyperthyroidism without a blood sample to measure the levels of thyroid hormone circulating in the body. Once Graves' is diagnosed, a person is likely to think back and replay the tape of recent events. You wonder how much of your metabolism and energy level are a part of your personality and how much an artifact of incipient Graves' disease.

I was always the one to take another run down a ski slope even though the lift was about to close. Like the Bushes, I spent many summer vacations in Maine – and was always up

for exploring another island in a sailboat even though it was getting late in the day. “Always on the go coz,” my many cousins would say as we’d take off on yet another expedition. Was I slightly hyperthyroid all along?

With Bush, his physicians say he was never routinely tested for thyroid function, and there is no way to know when his thyroid levels began to go up without testing past blood samples. According to the White House, the President’s thyroid started to become overactive last month (April, 1991) when he began to lose weight. Three weeks later, he experienced an irregular heartbeat while jogging at Camp David.

Now that he has been diagnosed with Graves’ disease, it is impossible not to wonder whether there were telltale precursor signs of the onset of the disease as long as last August. The White House flatly denies that there was any connection. A few days ago, Bush labeled the idea “just plain oldfashioned malarkey.”

Yet I think back to the days after Iraq’s August 2 invasion of Kuwait and remember the President’s phenomenal pace. As Bush told reporters just before he left Washington August 10 for his long

summer vacation in Maine: “Life goes on. Gotta keep moving; can’t stay in one place all the time.” That was following the photos of Bush in a seemingly nonstop round of sports, including speeding around in his powerboat off the Maine coast.

Earlier last year, I recall his frustration with the press for not enthusiastically joining him on a run at 7 in the morning. I remember Arnold Schwarzenegger, the White House fitness commando who heads the President’s Council on Physical Fitness and Sports, complaining about his trouble keeping up the President and all his physical activities at Camp David. The effects of hyperthyroidism can be so subtle that, looking back, a person often really cannot tell when the levels of thyroid hormone might have started to rise. Each case is different.

By now, I have made peace with my thyroid gland. After 20 years of being “cured” and presumably normal, all I can say is that when I’m in Maine, I still want to explore yet another island – and go “downstreet” for a crab roll and swim in the quarry and then in the evenings have the cousins over to play the banjo and sing. Maybe it will be the same for the President.

“Most people with frenetic personality have a frenetic personality and don’t have thyroid disease,” the GWU consultant says. For the majority of patients, the hyperthyroid effect is a transient one and they are left with their basic personality.

But the cure of Graves’ doesn’t happen overnight. Depending on the severity of the disease and type of treatment, most people take six months to a year to get back to normal. After swallowing the dose of radioactive iodine that targets the thyroid gland, all a person can do is wait and wonder: How much of the gland is gone now? Are the levels of hormone dropping down nicely? There is stored hormone in the gland that continues to be released into the body even after treatment. Have the hands stopped trembling? Still having palpitations? And then emotional questions pop up: Who’s angry and upset when the car has a flat tire – me or my thyroid?

It can take several weeks for the radioactive iodine treatment to work on the gland. It takes several “half-lives” to get the thyroid level in the blood down. So Bush, who talks about his extreme tiredness, probably can expect that to go on for some time.

So, too, can his “slowing down on the mental processes” as he describes his condition.

Some people take three months to feel like their old selves. Some patients take a year or more. Some never seem to regain their former vitality. Sometimes the initial treatment doesn’t work and has to be done again. For most patients with Graves’, there is the prospect that the thyroid eventually will become under-active and the person will be required to take daily thyroid supplements for life. Roughly 30 percent of Graves’ patients become hypothyroid in five years, and 40 percent in ten years.

“I reassure my patients continuously that they will get back to normal,” says the Georgetown University expert. “I tell them to be nice to themselves. They shouldn’t push themselves during this period.”

In the end, a few patients miss their hyperactive thyroid gland. Even after a year they complain they don’t have the high energy that they had before – and liked. “Some people may be used to high energy. They have forgotten what it is like to have normal metabolism.” Doctors speak about “a certain longing”

patients have for the high energy state of an overactive thyroid gland. Some people, they say, can tolerate untreated hyperthyroidism and adjust to a chronically overactive thyroid as long as the signs and symptoms are mild. However, severe, untreated hyperthyroidism can lead to cardiac problems and death.

As for myself, I was pretty lucky and got my body back in a few months. My eyes also got back to normal on their own and my hands stopped shaking.

How affected was my mood and behavior? I recently called up a friend from my Houston days and asked her if she remembered what I was like when I got Graves’. She could not remember anything special, and we went on to reminisce about other things. In fact, I hadn’t ever thought about Graves’ for 20 years until Barbara Bush developed the disease in 1989. By the time I had become like the smiling doctors and murmured to myself: “Thank God it’s only Graves’ disease.”

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