

# Graves' Disease

## *Mental Health and an Insidiously Foggy Existence*

Written and All Research Performed  
by

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So Little Attention is Given to this Dangerous Illness

“Irritability and affective symptoms can be prominent in the insidious onset of the illness. Bearing in mind these aspects of the illness, it is surprising that the psychological and social impact of hyperthyroidism has received so little attention” (Jadresic, 1990).

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## Dedication

“Everything can be taken from a man or a woman but one thing: the last of human freedoms to choose one's attitude in any given set of circumstances, to choose one's own way.”

Viktor E. Frankl, author  
Man's Search for Meaning

## Epigraph

“Persons who have experienced a thyroid imbalance may continue to suffer adverse effects even after their thyroid levels have returned to normal. Patients who do not feel the same as they used to, despite normal blood levels, are often those who have experienced lengthy cycles of stress-imbalance-stress. These longtime sufferers often describe symptoms similar to those who were affected by an enormous trauma, such as being the victim of a crime or a combatant in war. For this reason, physicians consider the aftermath of thyroid imbalance a form of post-traumatic stress syndrome. This sounds serious – and it is. Beyond the suffering the patient experiences before diagnosis and into the midst of the cycle, the healing must continue even after the disorder has been corrected.”

Ridha Arem, M.D., author  
The Thyroid Solution

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## Foreword

### **Living with Thyrotoxicosis**

By Elda Hoke Jenkins, R.N., M.S.  
American Journal of Nursing/May 1980

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(Author's note: Thyrotoxicosis and hyperthyroidism are conditions where too much thyroid hormone is in the body. Graves' disease is an illness that results in too much thyroid hormone in the body.)

It has taken me from adolescence to middle life to learn how to live with my thyroid disorder. My problems started when I had to cope with my mother's thyroid illness.

She would start housework at six in the morning and often continue past midnight, whistling incessantly, singing, "jawing," scolding, threatening, or crying. Her emotional changes, triggered by anything from a broken dish to Roosevelt's bank holiday, made hard depression days harder.

By the time I was 14, my mother was a trembling shadow all bones. She couldn't even hold a pencil. She opened doors and windows in winter to cool herself. Finally, she was confined to bed. Father told us we were to be quiet because she could bear no noise. We cooked for her so she could gain weight, and we gave her her iodine drops.

My brothers and I did the housework and spent what seemed like endless hours washing sweaty bed linen, spoon-feeding her, and keeping her bedroom clean.

Despite her enforced bed rest we were harassed by the supervision my mother maintained. Dad backed her up in the true disciplinary tradition of those times. We tried to avoid "The Bedroom" whenever possible.

The family doctor came several times a week, and after a while Dad told us we had done a good job. Mother was well enough to have an operation that would remove some of her thyroid gland.

The one time I was allowed to visit her in the hospital, no one told me it was because they thought she was dying. When I saw her encased in a tent, somehow I knew. I blamed myself because I had not spent more time with her. But Mother did pull through, and our family was happier than ever.

At 15, I was scrawny, restless, laughed as easily as I cried, and ate more than my two brothers. Remembering the difficult days before my mother "got well," I made a secret vow never to be like her.

Looking back, I understand now that my childish vow was a denial of my genetic predisposition to thyrotoxicosis. This denial was one of the maladaptive mechanisms

I created during my struggle to deal with my thyroid disorder.

In later years, without recognizing the symptoms for what they were, I learned to contend with some of my discomforts. Aspirin, hot tubs, and swimming relieved the soreness of my muscles. Eye makeup camouflaged orbital edema, and a low-salt diet arrested the edema. Alternating hot and cold packs relieved the feeling of being "all eyes." Stroking my eyes or the sides of my neck reduced the feeling of "taking off."

Full activity drained off excessive energies. My insomnia enabled me to extend my day for more creative activities than working and keeping house.

Between those complaints and multiple traumas to my spine, I came under the care of a variety of physicians, and each suggested different reasons for my complaints: maladaptation to physical trauma, alcoholism, collagen disease, and premenopausal syndrome. My coping mechanisms led professionals down blind allies, thus delaying the diagnosis of hyperthyroidism. To me, their diagnoses were better than exposing my childish vow with all its guilt.

There were numerous false accusations of alcoholism. Once, when I was hospitalized for a diagnostic workup, a resident physician told me to go buy a bottle and not waste his time. On another occasion, a medical director with whom I had made daily rounds when I was an instructor called me to his office. "Your drinking is compromising your job," he said. I didn't try to defend myself. I knew I wasn't an alcoholic, but I was confused by their misperception of me.

After that, I left teaching and relieved a private duty nurse on the night shift in a nursing home. On my fourth night there, the patient told me my services were no longer required because I was an alcoholic. I tried to manage a job, but tremors, inattentiveness, and lability increased.

I became weak. I could prepare a simple meal, but I was too tired to eat it. I lived in a clouded state, unable to exercise judgment.

It was not until I returned to my father's home that the cause of my problems was identified. "She's toxic with thyroid!" my father said. My internist confirmed "my father's diagnosis."

A physical examination documented a 45-pound weight loss in less than six weeks, a protein-bound iodine concentration (PBI) of 18.5 mcg./100 ml., and an ECG showing atrial fibrillation and flutter, Radioactive iodine uptake and thyroid scan further substantiated the diagnosis.

I refused hospitalization. Compassionately but reluctantly, the internist agreed to home care with administration of propylthiouracil (Propacil) and bed rest.



On that drug, perhaps for the first time in my life, I emerged from thyrotoxicosis into a euthyroid state. There were three choices for treatment—to continue with the medication, to have an operation, or to receive treatment with radioactive iodine.

Because of my age and a thyroid scan that showed an enlarged gland, isotopes appeared to be the treatment of choice. My internist and I again agreed to treatment on an outpatient basis.

Treatment with isotopes was like being on a roller coaster. It meant leaving the calm while I abstained from the Propacil. Abstinence for more than two weeks was necessary to increase the uptake of iodine by the cells and to allow time for the breakdown of thyroid, I cells from the radioactive iodine.

During this period, the resurgence of thyroid symptoms was unbearable for me. Finally, however, after two years and several treatments, I was euthyroid again. Life was to be enjoyed. I had a new job, and my next thyroid workup was scheduled for a year hence. I thought I was well and would never become toxic again, although I might develop hypothyroidism from the treatments. But, I found that the behavior I had developed in a hyperthyroid state was ineffective in a euthyroid world. It took me over a year to adjust to a slower pace.

At the end of that year, I was referred to an endocrinologist with whom I could not communicate. He saw me only as the area between my sternum and my chin. One day at work he gave me a prescription that read: "Animal thyroid 60 mg. O.D." There had to be a mistake, I thought. But all he said was, "Do you want to go myxedematous and die? That's your choice."

I began taking the animal thyroid as he had prescribed. My medical follow-up was by telephone and when he told me, "You are quite capable of adjusting your own thyroid dose," even the telephoning stopped.

After I had gotten up to 180 mg. of animal thyroid, I developed hyperactive gastrointestinal symptoms. At work, I collapsed with abdominal pain from an ulcer. When gastroscopy confirmed that the ulcer had healed, the specialist referred me back to the same endocrinologist. I refused the referral.

After some time, I developed an eye infection and corneal ulcers. The ophthalmologist referred me for a thyroid workup with the same endocrinologist. His business letter informed me that my workup was normal for 180 mg. of animal thyroid.

Gradually, feelings of uselessness returned. The tachycardia, fatigue, and insomnia were constant; my judgment and insight were clouded.

In desperation, I saw the endocrinologist again. He adjusted the thyroid to 120 mg. and placed me on short-term sodium phenobarbital (Luminol). Tachycardia and insomnia disappeared. He took me off the thyroid drug to do more tests. In less than 10 days, I

became myxedematous. Now the world was a cold, inert place for me, almost devoid of life and especially of feelings. He put me back on 120 mg. of thyroid and my next uptake was normal.

On the job, I was assigned to a less tension-producing situation. My entire work life, because of my thyroid condition, had placed me in the position of being overqualified for jobs-used by employers to solve problems-falling apart under stress and being assigned to less stressful situations, only to be called upon when there was trouble.

Finally, I sought psychiatric help. I knew I was depressed and toxic, but I didn't know how to handle either. I had nightmares that a butterfly carried me in a container that always broke in flight, plunging me toward earth. I would be rescued by another butterfly and then dropped again. I would wake screaming.

It was six weeks before I was able to call a different physician. He saw me at regular, frequent intervals. He examined me, and we talked openly. He took another scan and reviewed it with me. This scan had a relatively low uptake but no cold areas. The butterfly nightmare vanished. He agreed that I had too much thyroid "on board," and would wean me from the animal thyroid gradually, but I would have to allow him a year, maybe two. He explained endocrine disturbances, my need to stabilize routines, and lose weight. He took as much interest in my behavioral problems as he did my physical. I had never experienced this with a physician before.

My sister was the first to notice that my actions and responses were much slower than before. I often had to bring myself to a full stop in order to view a situation and decide on options. This was misinterpreted in my employment evaluation. I was "not carrying my share of the workload."

My slow thinking was confusing to my son and his family. When I told them to plan visits in advance, they were offended until they began to understand that I needed time to organize so that plans for a holiday would be in keeping with what I was capable of doing. I could no longer do anything quickly.

Shifting gears also was difficult. My endocrine system resisted rapid changes, either the necessary speeding up for emergencies or the slowing down needed when the emergency was over.

Overnight, the medical service I was working on became chaotic. Our census suddenly changed from 28 to 46 with no increase in staffing. We had acquired a diverse group of patients, few capable of functioning independently. Simultaneously, there was a new rotation of interns.

As team leader, I started out one evening reassuring my team that we would "keep it cool," set our priorities, and do our best. By nine, I had had it. I knew I had to go home. Shame engulfed me and I cried. The supervisor arranged for me to go home. By midnight, without drugs, I went to sleep.

The next evening, the supervisor and I discussed my reaction. She recalled earlier days when the same events would have challenged me. When I explained, she began to understand. From then on, the members of my team supported me when I felt a bit shaky. By the end of the first six months of the stabilization program, I had learned that I could function only by pacing myself.

I could say without hesitation that I experienced grief as my metabolic rate became normal. When I was hyperthyroid but not physically debilitated, I was known as a person who worked hard with pleasure. I had a country house and three gardens. I was a gourmet cook, I made my own clothes and did my own interior decorating, all in addition to working 40 hours a week. And I was always available to help in emergencies. I was self-reliant. That was a difficult image to give up.

After a year, I was on 60 mg. of animal thyroid every other day and went from a size 18 dress to a 12. My physician continued to check me every three months. I learned to respect how easily one can slide from a euthyroid to an abnormal state. I no longer permit it to control me. I control it.

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Jenkins, Elda Hoke. "Living with Thyrotoxicosis." American Journal of Nursing (May, 1980) 80(5):956-958. PUBMED ID: 6901470.

## Preface

I researched this topic and organized excerpts from my results into this paper because I needed accurate information about this illness directly from authoritative and reliable sources. These authoritative and reliable sources are from research articles in medical journals and books on the topic written by physicians who regularly work with patients who suffer from dysthyroid illnesses.

Originally, in 2004, I read everything I could find on thyroid disease. Only later, did I reduce that information to the essentials presented here. When I began my research in May 2004, I only knew that a serious ailment was affecting me and I needed information. There was no thought about eventually preparing this booklet. At that time, I experienced awful symptoms and was frustrated that I had not received this vitally important information from any other source.

When I began my research, the hyperthyroid condition rendered me incapable of adequately interpreting and reducing the information. This paper was born when I later decided to organize the excerpted information into one document so that it would be readily available to me for reference. I wanted access to the unaltered information directly from sources of authority. I needed to use this information while interacting with individuals from the medical community to ensure that I was receiving informed medical care.

My need to communicate information about my condition also motivated this paper. I needed others to understand the dysthyroid-induced mental and physical condition that has been present in me since the late 1980s. This was and continues to be an educational project of great personal significance since the information contained in the research directly affects my well-being and quality of life. Not only does this research inform my medical care, it allows me to more meaningfully communicate information about my experience and condition.

After several months of healing, I realized that other thyroid patients could use this information. At that point, I added a narrative that expresses my personal experience with Graves' disease, a hyperthyroid condition. It is my hope that the combination of medical research and personal narrative will provide a more complete look at the hyperthyroid condition.

I do not need medical training to understand this condition's devastating impact; I live with it. I continue to search for answers in medical literature and hope that, until there are more answers and help for this condition, this compilation of research may help others battling this condition find the information they need.

There is much more work to do on this subject should I choose to do so. This printing represents my intention to summarize my thoughts and library research to date. I hope

someday to produce a more complete and thoughtful work. There is indeed much more that must be said.

## **Acknowledgments**

The Ruth Lilly Medical Library located within the Indiana University Medical School which is located on the campus of Indiana University - Purdue University at Indianapolis. The use of these vast resources has significantly helped me to begin to heal physically and mentally through this ordeal. Further, knowledge from these resources has equipped me to call attention to this thyroid disease that so insidiously affects and effects the entire human condition. Thank you, indeed!

Those who reviewed my writing in this document made it more readable while allowing my words and thoughts to remain. Much more work on this document is required in content, composition and style before it is in a form that more meaningfully communicates my experiences.

## Introduction

Since the late 1980's I have experienced a dysthyroid condition. In January 1990, I was diagnosed with Graves' disease—an autoimmune disease that causes the thyroid gland to produce too much thyroid hormone. This condition is called hyperthyroidism and it causes the body to function in very dangerous ways. After I was diagnosed, I was treated with radioactive iodine to kill my thyroid function. This treatment was successful. Soon thereafter, as expected my body went into a hypothyroid state and I began the life-long regimen of supplemental thyroid hormone medicine. For the next fourteen (14) years until May 2004, the condition was mismanaged. As a result, I have never felt healthy again. The closest I have been to feeling healthy was when I began using thyroid hormone T3 in February 2005, a full fifteen years after radioactive iodine treatment.

During a routine physical examination in May 2004, I had some blood work to determine the health of my thyroid condition. My new family doctor informed me that I was being prescribed too much thyroid hormone replacement medicine and it would need to be immediately reduced or I could suffer injury. This exam was the beginning of the end of my oppression. My thyroid medicine was further reduced after an examination by an endocrinologist and more blood work in July 2004. The medicine dose would eventually be reduced by nearly a third from 300 mcg to about 228 mcg per day. Curious about these dramatic and sudden reductions, I retrieved my medical record laboratory reports from previous doctors. From this information, I learned that—for more than a decade—doctors had prescribed too much thyroid medicine. As a result, I had been hyperthyroid for more than a decade.

Hyperthyroidism is a serious illness that affects the entire life of the thyroid patient. Too much hormone causes the body to overheat, throws brain chemistry out of balance, and causes a variety of physical ailments. In at least one medical study it was reported that about one third of the persons studied indicated being prescribed psychotropic drugs at least one time during their experience with Graves' disease. In other more serious cases patients have been admitted to a psychiatric hospital. These adverse conditions severely affect an individual's interpersonal relationships and career. Hyperthyroidism is truly an insidiously destructive condition. It destroyed a large part of my adult life.

My spiritual life of daily prayer and meditation died within a few short years of the radioactive iodine treatment. My eleven-year marriage that began three days after treatment with radioactive iodine never developed into even a friendship and as a result, was destroyed. I lost fifteen years that are typically considered some of the most productive years of an adult's life. I lost numerous social contacts in the community. For fifteen years, I lost the opportunity to live and genuinely enjoy life. My life was a repetition of wasted opportunities, wasted time, wasted money, and wasted resources. I lost fifteen good years because of the insidious effects of hyperthyroidism as a result of Graves' disease due directly to physician's prescribing too much medicine. This disease's onset was mysterious, its adverse effect on my body and brain chemistry was certain, its

treatment was mismanaged for more than a decade, and my prognosis for a full recovery is less than one hundred percent.

It seems clear now that I was fighting a serious thyroid disease. However, the cognitive affects of this condition ensured that I didn't know I was in a fight. After the initial radioactive iodine treatment, I began the standard life-long regimen of supplemental thyroid hormone medicine. The doctor told me there was nothing more to it. Yet, as a result of the medical community's lack of information about this condition and, most importantly, insufficient blood diagnostic equipment sensitivity, for the past fifteen years, my life has been one miserable disaster after another.

After radioactive iodine killed my thyroid function, I experienced a subsequent problem that is the primary focus of this document. The physician prescribed too much thyroid hormone replacement medicine and as a direct result, I was hyperthyroid for over ten years.

Throughout this period I saw a doctor almost every year, was married to a doctor whose father was a doctor and I knew several doctors who knew that I had been treated for Graves' disease. Yet, my problem of hyperthyroidism was not detected until May 2004. At least two times since 1990, I have experienced the vicious cycle of imbalance-balance-imbalance. This cycle had the worst affect on my brain chemistry. I could not begin healing until my system was back in balance in October 2004. My recovery can take as much as two and a half years and full recovery is impossible.

I experienced dramatic changes in my body and brain chemistry and recognized that the best I was receiving from the medical community was mismanaged care that only deepened and prolonged my condition. I spent weeks in the local medical library finding my own answers. This document includes a narrative of my experiences and excerpts from medical journals that relate to my experiences with this condition.

The first part of this document describes how doctors discovered, treated, mismanaged, and—to the degree possible—corrected my condition. This part reads more like a list of events that took place rather than as a detailed report of the gut-wrenching despair that was my experience with thyroid disease. Citations provide author and year (Smith, 2001) for the related excerpted material located in Part II of this document.

Part II consists of excerpts from medical journal research articles and books by physicians that describe the different aspects of Graves' hyperthyroid disease. This document includes excerpts from only a portion of the more than 200 journal articles and the few books that I have referenced in the bibliography.

Perhaps the worst part about the disease is that the patient doesn't realize all of the changes that are occurring in their bodies and in their brain. As a result, the disease adversely affects every aspect of their physical, mental, social, and professional lives. My experience with a prolonged hyperthyroid condition is that it has had an absolute, profoundly adverse, and insidious impact upon my body and brain chemistry. It resulted



in an utterly miserable and unconditionally desolate quality of life for more than a decade and destroyed the most productive years of my adult life.

As of February 2005, after four months of healing, I was prescribed hormone T3 and have experienced more improvement for which I am indeed grateful. The best that I can expect is an improved condition since; for me, complete healing is impossible. Whatever healing is to take place, we won't know for certain until sometime after April 2007 – two and a half years after the initiation of the October 2004, healing process.