

# Caught in the Middle: The Divide Between Conventional and Alternative Medicine

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## ABSTRACT

*This paper begins with a patient perspective from the first author. Faced with cascading health problems, this author describes her gradual embrace of alternative treatments. While these improved her health, they also set her apart and prompted antagonism from those in conventional medicine. She found she was not alone in benefiting from a more open view of healing, and not alone in being buffeted by the opposing medical views. Two invited commentaries from medical professionals follow, as well as the first author's response.*

*Keywords: Alternative Medicine, CAM, Complementary Medicine, Immune Thrombocytopenia, ITP, Personal Health, Seizures, Thyroxine*

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## PATIENT PERSPECTIVE

*By Joan W. Young*

## INTRODUCTION

Growing up in a small US town in the 1950s, my view of healthcare was simple: the doctor was the person you went to when you were ill. You did what he (and it was almost always a he) said, no questions asked. You got better or didn't, but certainly you didn't second guess the decision or the place to go for medical information. I remember asking my mother about a chiropractor after driving by an office

sign. "Oh, they're quacks," she said, without a second thought. In time, I was the one with second thoughts, as I gradually broke from the bounds of my parental messages and the weight of the medical establishment to embrace a more inclusive path to wellness.

My more recent health saga began in 1977, when my ob/gyn felt some lumps in my throat. After various tests and consultations, a surgeon removed most of my thyroid gland. "It won't be a problem," my endocrinologist assured me, "We have a pill that replaces it." He was, of course, talking about Synthroid (thyroxine). The lumps turned out to be benign, the lab report described a touch of papillary cancer, and the huge dose of Synthroid, designed to turn off the pituitary communication and prevent further cancer, perked up my mood. But the

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easy-replacement-no-problem message was a platitude. Seven years later I learned that the hard way when my large Synthroid (thyroxine) dose and complacent thyroid monitoring attitude triggered a seizure. The neurologist prescribed Dilantin (phenytoin), assuring me with another no-problem message. The Dilantin numbed my thinking, dulled my vitality and helped precipitate my job loss. It also fed a growing distrust of the 'doctor knows best' message.

I stopped seeing a neurologist and stopped the seizure meds, then set out to regain my health. This time I was going to look elsewhere, to the fringes of medicine, to places where the medical TV shows and my parents never ventured. I went to a doctor whose idea of a diagnosis involved an extensive medical history and whose 'cure' was to correct nutrition, suggest supplements, heal any gut problems, and give treatments that would make the FDA blanch. I did feel better after addressing the parasite diagnosis and eliminating food sensitivities, but the shots he gave me, the ones that changed T-cell function, the shots I was hesitant to accept, caused suspicion. I was diagnosed with immune thrombocytopenia (ITP) in 1992, a T-cell mediated autoimmune disease. My antibodies were attacking my platelets and I had few of them. Of course I had no way of knowing if those shots were instrumental in my diagnosis, but looking back on some bleeding symptoms, I think my platelet count was sinking for years.

The treatment for ITP brought another round of healthcare horrors. While I was reducing my dose of prednisone and after I received a round of IVIg at double the standard dose, according to my second hematologist, I had another seizure and developed tachycardia. A splenectomy, colchicine, and danocrine all failed to raise my platelet count for more than a few weeks. For months, my mouth was full of blood blisters, my legs were covered in petechiae, and my platelet count rarely went over 10,000. At one point my platelet count registered a zero.

As each treatment failed and I collected all of the side-effects but none of the benefits, I began thinking again of alternative medicine.

Perhaps that approach offered something that could get me off of the merry-go-round of pills for my ITP, more pills for the side-effects, and more pills for the side effects of those pills. I just wanted out of the deadly cycle and have my life back.

After encountering a holistic doctor who was as arrogant as any in the AMA tradition, I found some healers who really knew the meaning of the verb 'to heal.' With the help of a team that included a Reiki therapist, a macrobiotic counselor, a naturopath MD, an Ayurvedic physician, a medical intuitive, and a psychologist, I succeeded in my goal. A year after I was diagnosed and six months after I was bald from vincristine and too weak to walk up stairs, I achieved a normal platelet count that has, with one minor relapse, continued to this day. I was free. And to say that I learned a lot is an understatement.

## DISCUSSION

After almost dying, then finding what I considered a miracle cure, I was enthusiastic about the possibilities of alternative medicine and knew others would benefit from my experience. This was not welcome information to the ITP specialists I contacted. I was called a liar, despite having all my medical records. I was told to run some clinical trials for my 'cure,' which was, of course, a financial and practical impossibility. Although I was dismissed and discounted by some in the medical profession, I knew those who suffered as I did, struggling with failed treatment after failed treatment, would want to know what I learned. I was right.

Using my technical background, I constructed an ITP web site in 1997. In addition to my story I incorporated as much information as I could find about ITP, including the usual treatments for the disease. I also added a discussion group. By the immediate and overwhelming global response it was obvious there was a large, unmet demand for ITP information and sharing. The one big difference from this web site and those for other diseases was that

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