

Living Well with Migraine Disease and Headaches

Chapter 1: Introduction, My Life with Migraine Disease and Headaches

The first time I remember having a Migraine attack was when I was six-years-old. At the time, I didn't realize what it was. There were these spots floating around in my vision that I couldn't see through. Then my head started hurting so badly that I began crying. Crying just made it worse. It was a summer day, and the light coming through the window in my bedroom hurt my eyes, so I closed the curtains and buried my face in my pillow. I couldn't stay that way long because I needed to vomit. My father brought a large bowl from the kitchen so I didn't have to get up. Vividly, I remember him wiping my face with a cold cloth and gently rubbing my back until I fell asleep. My mother had these "headaches," too. At the age of six, I didn't really understand them, but I knew my mother would sometimes be in bed with her headaches for days. My parents have told me that the pediatrician said I was "high-strung" and had Migraines like my mother. All they could do was try to give me aspirin and hope I'd go to sleep.

There are many things about my childhood that I understand far better now that I know more about Migraine disease. My mother and an aunt who babysat my brother and me would frequently insist that I go outside in the summer to play. Playing outside on hot summer days often gave me "headaches," so I preferred to stay inside and read. During recess at school, I didn't want to jump rope or do other physical things in the sun. I wanted to sit quietly in a shady spot. That behavior brought criticism from my family and ridicule from other children. As a result, I was pretty much a lonely child with few friends. I did well academically, and I was far more comfortable with adults than with other children.

Through grade school and junior high school, my Migraines were infrequent. When I did get one at school, some teachers would insist that I stay in class, but allow me to put my head down on my desk. They usually rethought that strategy once I'd vomited in their classrooms. Other teachers would send me to the nurse's office. Depending on the nurse, I'd either be told to lie down there or my parents would be called to come get me. One junior high school physical education teacher accused me of faking to get out of her class. My father went to school and took care of that problem very quickly.

By the time I was in high school, the other kids were old enough that not all of them were so insensitive to someone who was ill. I was able to make more friends. Since my Migraines weren't very frequent, I was actually able to have some social life. My parents had also gotten to the point of letting me stay home from school, without questions, when I didn't feel well.

College in the early 70's was a different situation entirely. Some doctors still thought Migraines were psychological or a "woman's thing" and were very patronizing. Triptans were still years in the future, so doctors either told me to take aspirin or, if I were lucky, wrote me a prescription for pain medication. I spent my first semester of college at a large university, and the professors (for the most part) didn't consider a "headache" reason enough to miss a class session, let alone an exam. More than once, I was accused of having partied too much the night before or of using drugs. At the end of that semester, I transferred to a smaller branch of the university, where I found the professors to be far more understanding and accommodating. It helped that the campus nurse was also a Migraineur. I could go to the infirmary when I needed to, and she'd help me. She not only took care of me, she'd send an assistant to take notes to the professors of any classes I was missing, telling them where I was. One professor, who didn't allow exams to be made up,

actually sent his graduate assistant to the infirmary with the exam I was missing to allow me to do the exam orally since I couldn't read it with my Migraine. Such were the advantages of a smaller college and, I'm told, of having a high grade point average.

When I was in my early 20's, my Migraines gradually became more frequent and more severe. My family doctor sent me to an ENT (Ears, Nose, and throat specialist). That brilliant man (yeah, right) examined me, then said, "Congratulations. You're an intellectual. You have Migraines." I didn't know it at the time, but that was the beginning of 20 years of going from doctor to doctor seeking help. I don't know what it was. Maybe it was his tone of voice, but I knew this doctor was not going to be any help to me. My family doctor, when he got the report from the ENT, wasn't any help either. He just told me that "lots of women have Migraines. All you can do is take your pain pills and live with them." So, that's what I did, for then.

A few years later, I changed family doctors. I kept insisting there had to be something that could be done about my "Migraine headaches." He sent me to see a neurologist. The neurologist did his thing with the light in my eyes, checking my reflexes, and that was it. Then he said, "OK. You have Migraine headaches. What do you want me to do about it?" Duh!! I wanted him to do something to help me! His advice? "Have a baby." He said that having a baby sometimes helped. Yes, well, I was divorced and living alone. That wasn't going to happen any time soon. At my insistence, my family doctor sent me to a different neurologist. He ordered x-rays of my head and neck, and I thought maybe I'd found a doctor who was going to help me. So much for that thought. When I went back to see him after the x-rays, he said, "They're Migraines. That's what everyone else has told you. Now that we've done the x-rays, you can quit worrying. They're just headaches." When I said they weren't like other headaches I sometimes had, he said, "No Migraines are worse, but if you'd quit worrying about them, you wouldn't have so many. Have you considered seeing a psychiatrist?" I replied, "I'm sick, not crazy." He answered, "I didn't say you were crazy, but you bring a lot of your headaches on yourself worrying about them and other things." I wasn't as gutsy then as I am now, so I didn't fire him on the spot, but I never went back either.

Over the years, I'd had to go to the emergency room for my Migraines, but not often. When I was 28, I had to go to the ER with one, and they asked if I had a history of high blood pressure. I didn't, but there is a history of it in my family. My blood pressure was high that day, but they said it could have been high because of the Migraine and advised me to follow up with my family doctor. As it happened, I had just changed family doctors to go to a new one whose office was across the street from where I worked. When I went to follow up with him, I was diagnosed with hypertension. At the same appointment, he introduced me to a new Migraine medication, Midrin. Midrin worked better than other medications I'd tried, but never worked as well for me as it does for some Migraineurs. This doctor, too, was very patronizing, simply patting me on the shoulder and telling me I'd just have to "put up with" the pain the Midrin didn't relieve.

When I was in my early 30's, my Migraines were wreaking havoc with my life. I was newly married with two newly acquired teen-aged sons and had gone back to college full-time. Unfortunately, I was also having severe Migraines, sometimes two or three times a week. I couldn't care for my family, go to class, or even function for days at a time. Yet another local neurologist was a total waste of time and money, so our family doctor referred me to a neurologist a 90-minute drive away. My first thought when I met this doctor was that he had to be someone's grandfather. It was more than his age. He looked gentle and kind, and he really looked at me when we talked. More importantly, it seemed that he was actually

listening to me! Then came some of the most precious words I had ever heard, "If you're willing to be patient and work with me, you don't have to live like this." That statement actually brought tears to my eyes. For the first time, this doctor explained to me that there were medications that, when taken on a daily basis, could actually help prevent my Migraines! Nobody had ever told me that before. Thus, he was the first doctor to tell me about Migraine preventives and prescribe one for me. After almost a year of periodic appointments and medication adjustments, the medication was keeping my Migraines pretty much tamed. It seemed miraculous, but I was only having about six or eight Migraines a year!

This blissful state of existence lasted for several years. Although this doctor had helped me gain control of my Migraines, he hadn't taught me anything about them, even that Migraine is a disease. Thus, I was still very ignorant of even the basics, and thought this wonderful reduction in my attacks would last forever. Well, forever turned out to be several years, but that was hardly forever. By the time I was in my early 40's, the frequency of my Migraines was increasing again. Unfortunately, my grandfatherly neurologist had retired. I'd already been to and fired every neurologist in my home town, so my primary care doctor referred me to another neurologist a 90-minute drive away. She was also supposed to be a Migraine specialist.

This neurologist's office and way of doing things was different from any I'd ever seen before. I lasted through two appointments with this one. Both times, I saw a nurse practitioner first. Then a doctor breezed in for less than five minutes, and wouldn't even let me get an uninterrupted sentence out of my mouth, let alone answer any questions. A new preventive medication was prescribed at the first appointment. At the second, I was told to continue it, with no changes, even though I was making no progress.

My Migraines didn't get better. They got worse. I called the neurologist's office about a month later, and was told to just keep taking my medication and keep my appointment. There was another problem, too. The preventive medication was causing serious side effects. Getting desperate, I called the neurologist's office a month before my appointment was scheduled. Again, they told me to keep taking the medication and keep my appointment. This was the beginning of the end of my being a door mat. I told the receptionist to cancel my appointment and prepare a copy of my records for me to pick up. She replied that she couldn't give me my records, but would be glad to forward them to another doctor. I informed her that she not only could give me a copy of my records, but was required by law to do so and told her what day I'd be there to pick them up. The day I picked up my records, the neurologist came out of her office to ask what the problem was. I looked her square in the eye, and said, "You are. You're incompetent, and you are SO fired." While she was struggling to pick her chin up off the floor, I left.

At this point, you may wonder what happened to make such a change in my attitude. I'll tell you. I'd started educating myself. It had become obvious to me that there wasn't a doctor within 100 miles of my home who was going to help me, so I was going to have to find a way to help myself.

Where I live, you don't find much medical information in the libraries, so I hit the Internet. About.com is a network of nearly 500 topic sites. Each individual site is written and managed by a "Guide" with expertise in and a passion for their topic. The About.com Diabetes site had already been very helpful to me because the Guide who ran it had already done the research for me. I could go there, read her articles, find links to other sites with good information, and get support from other people in similar situations with their

diabetes. Given that experience, I decided to see if About.com had a site for Migraines, but was disappointed to see that they didn't. It didn't take me long to discover that the Internet has vast amounts of information about headaches and Migraine. Unfortunately, not all of it is accurate, and it can be difficult to figure out what's accurate and what's not. By chance (or maybe not), I went back to the About.com health sites to look around and saw a "Be a Guide" link. There, I discovered that About.com was looking for someone to build a site on their network about headaches and Migraine. It struck me that I couldn't be the only person having so much trouble, so I applied for the position, and I got it. As I researched to write for the site, I was shocked at how much there was to know about Migraines that nobody had ever told me, including the fact that there were actually doctors who specialized in treating headaches and Migraine. I started the forums for the site, and started meeting other Migraineurs. A couple of them told me about the Jefferson Headache Center in Philadelphia. They were patients there and had gotten much better since beginning their treatment at "the Jefferson."

Having just fired the last neurologist, I made an appointment with my primary doctor. I needed his help to taper off the preventive medication I was on. While I was there, I talked to him about a referral to the Jefferson. Yes, Philadelphia is an eight-hour drive away, and I had discovered other specialists closer to home, but I'd been fighting this situation so long that I wanted to go to the Jefferson because I'd talked to people who were being successfully treated there. My doctor agreed and called them for an appointment for me. We were shocked to find that the first available appointment was nine months away! He agreed to prescribe triptans and help me until that appointment.

Finally, the day of my appointment arrived. I'd been told that the appointment would take between five and six hours. A health history and a short psychological evaluation forms had been sent to me to complete in advance and bring with me. When I arrived, I was impressed by the atmosphere of the reception area and waiting room. There were no overhead fluorescent lights in the waiting room. The lighting was subtle, but bright enough to read and complete forms. The room was quiet, and there were signs posted asking people not to wear fragrance to their appointments. (Fragrances are Migraine triggers for many people.) The receptionist took my insurance information and gave me a lengthy psychological survey to complete. Shortly, a nurse asked me to accompany her. She went over my medical history and family medical history in detail, entering the information into a computer as we went. She also asked a multitude of questions about my Migraines and symptoms and got the standard information of height, weight, blood pressure, etc. She then showed me to a place where I could finish the forms I'd been given and wait to see the psychiatrist. I'll admit to you, as I did to the doctors that day, that I had a chip on my shoulder about seeing a psychiatrist. I think the poor man had been warned that I wasn't answering any of his questions until he answered mine. I suspect he'd met such resistance before as he was very kind about it, and not a bit patronizing. I actually had one question: Since Migraine is a neurological disease, just why did I have to see a psychiatrist as part of my treatment? He told me it was a fair question, and that the answer had two parts:

1. Since there is a link between Migraine disease and clinical depression, part of the psychiatrist's job is to assess patients to see if they're also experiencing clinical depression. If they are, he needs to see that they're being treated and that the treatment is appropriate and working. He may have suggestions for changes. If the patient has untreated depression, he needs to make treatment suggestions.
2. Since any chronic illness requires good coping skills and strategies, it's also his job to assess each patient's coping skills and strategies to see if they're adequate or if they need assistance in developing and/or improving them.

Ahhhhhhhh. That was a perfectly acceptable explanation. It made a great deal of sense in fact. Treat the whole patient, the whole disease, not just the symptoms. He told me that the short evaluation form I'd brought back with me had already been reviewed and showed no problems. He'd have the longer one reviewed, and let me know if he saw any reason for another appointment, but doubted that would be the case. At the end of our session, he told me that he didn't see a reason for him to treat me, but that he would be available for me if I ever wanted to see him.

The last part of that first appointment was to see my new neurologist, who specializes in treating headaches and Migraine. Dr. William Young had reviewed the information the nurse had entered into the computer and the psychiatrist's evaluation. I had taken fairly recent MRI films with me, so he put them on the film viewer. He conducted a neurological examination, He checked reflexes, tested strength on both sides of my body, looked at my eyes, listened to the arteries in my neck with his stethoscope, performed various checks for balance and coordination, and more. Then, he showed me that my MRI films showed no problems. They displayed good, clear blood vessels, which he explained he looks for when he's considering prescribing triptan medications such as Imitrex, Zomig, etc. We then discussed both my family and personal Migraine history and my general health, and we reviewed my Migraine diary.

Then, it was time to discuss a treatment plan. He said that he'd prefer to change some of the medications I was already taking for other conditions before adding medications. Since blood pressure medications and antidepressants are often effective Migraine preventives, that's where we started. He changed the medications I was taking for those conditions and explained that it would take some time to know if they were going to work. He also prescribed both a triptan medication to actually stop a Migraine in progress and a pain medication so I wouldn't use either of them more than two days a week. Since I was having Migraines four or five days a week, he instructed me to take the triptan two days a week and the pain medication two other days a week, if necessary. That was to avoid rebound headaches, which can be caused by taking medications too often.

At my next appointment, there was no progress to report. Since neither the preventives prescribed by other doctors nor the preventives Dr. Young had prescribed were working, he suggested that we should rule out a physical condition that could cause headaches and trigger Migraines. Since it could only be diagnosed by doing a spinal tap, we scheduled it, and it showed that I do indeed have that condition.

The spinal tap and resulting treatment turned out to be a major turning point for me. By simply taking a medication twice a day, that condition can be controlled. Right away, approximately 50% of my Migraines were gone – the 50% for which I hadn't been able to identify triggers and that had been accompanied by tinnitus. Three months later, my Migraine diary showed a marked improvement, but there was room for more. I kept returning every three months, and we'd fine tune my regimen a bit more. After a couple of years of working with Dr. Young, with the medications adjusted and dietary supplements added to my regimen, I was getting pain-free periods of up to 45 days between Migraines. Then, to add insult to injury, I developed chronic daily tension headaches. Dr. Young wasn't too surprised. I'd had shoulder surgery, and my movement was significantly impaired. The glaucoma I'd had for several years had progressed to the point of requiring last-resort surgery. The bottom line was that, if the surgery didn't work, I'd be blind in a couple of years. We added a medication to my preventive regimen to address the daily headaches. Not only did it stop the tension headaches, but it increased my length of time between my Migraines. That's where I am now with my preventive regimen. Knowing my Migraine

triggers helps. They're disrupted or lack of sleep, skipping meals, changes in weather, and crying. As I write this, I haven't had a Migraine for over two months. It took time and patience to get to this point, but Migraine disease is no longer controlling my life; I'm controlling it. The last time I thanked Dr. Young, he reminded me that we did it as a team.

My treatment for when I do get a Migraine isn't as simple as it used to be. Imitrex was wonderful. With it, I seldom lost more than two hours to a Migraine, often less. Unfortunately, I was diagnosed with coronary artery disease about a year ago, and that meant the end of my being able to take medications such as Imitrex. Triptans work, at least in part, the action they have to constrict blood vessels (make them smaller). Unfortunately triptans don't totally confine that action to the blood vessels surrounding the brain, so they're not recommended for anyone with heart disease. So, my "miracle" is no longer an option for me. We've tried various "pain pills" and anti-inflammatories, but I'd might as well be swallowing breath mints for all the good they do. I had to make one trip to the emergency room because I had a severe Migraine and no medications that would touch it. When I arrived at the emergency room, the triage nurse checked my blood pressure. It was considerably higher than safe for anyone, let alone a patient whose chart indicates they have coronary artery disease. I've never been treated so quickly as I was that evening. That Migraine attack showed Dr. Young and me that we had a secondary problem. While I might be able to get through the pain since my Migraines are so infrequent, the elevated blood pressure is dangerous. Ultimately, since I have so few Migraines, he wrote a prescription that allows me to do IM (intramuscular) injections of the same medication they used in the emergency room. Having it at home, I inject it into my thigh as soon as the pain begins, and that keeps the pain and my blood pressure from getting out of control. I also have both oral and injectable anti-nausea medication to use as necessary. Handling Migraine attacks in this way is possible only because I have so few of them now.

In addition to my other treatments, I was recently asked to try a new over-the-counter Migraine remedy, GelStat Migraine. It's a gel containing feverfew and ginger, and it's used by squirting it under the tongue, holding it there for 60 seconds, then swallowing it. You repeat it in five minutes. Not for an instant did I think that "stuff" was going to do a thing for my Migraines. I fully anticipated that it was going to taste absolutely horrid and be a total waste of time, but I agreed to try it. I figured I'd try it, then tell them it was worthless, and be done with it. The first time I tried it, I had the very beginning of head pain that I'm still not sure if it was Migraine or a tension headache. Whatever it was, it stopped. "OK, that was just a fluke," I thought. The second time I took it, it did nothing. The third time, I took it at the beginning of a Migraine aura, two doses as described. After 30 minutes, still feeling a Migraine in early stages, I took two more doses. The Migraine never did progress any further. GelStat Migraine doesn't work for me every time. On the other hand, given how limited my treatment options are, I'm grateful that it works part of the time.

Throughout the years that I've struggled with Migraine disease, there have been times when the emotions I experience during a Migraine attack would bring me to my knees, ready to surrender. The strength of the emotions is pretty much proportional to the severity of the Migraine attack. Although I've never felt suicidal, there have been times, especially when I was alone, when I pretty much wanted to die. The only times I've ever experienced panic attacks have been during my worst Migraine attacks. I've now learned that there's a physical explanation for this, and we'll take a look at it in this book.

My family has been absolutely stellar through all of this. My husband has driven me to and from Philadelphia and sat in the hotel room waiting while I went for my appointments. He sat in the waiting room while I had the spinal tap. When I have a Migraine, he'll quietly ask

if I need anything, but for the most part, leaves me alone because he knows that's what I want. Our sons are grown with families of their own. I had a Migraine at a time when one of them was visiting with his children. The girls were probably about three- and five-years-old at the time. It's hard to ask young children to be quiet, so I retreated to the recliner in my home office. Periodically, I'd see two little heads peek around the corner to look at "Granny." Then they'd quietly tiptoe away.

Friends? Well, let's say that illness can show you the difference between friends and acquaintances. An acquaintance is there for you when all is well and you're fun to be with. Friends are always there. My experience is probably much like that of most people with headaches and Migraine disease. I have lots of acquaintances and a few good friends. The people who participate in the forums on my web sites often thank me for my support. Believe me, it works both ways. I count on those forums and the people there for support, too. We're all in this together. Overall, with the family and friends I have, I am blessed.

From Living Well With Migraine Disease and Headaches... What Your Doctor Doesn't Tell You That You Need To Know.

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