

# *Living Well With* **MIGRAINE DISEASE & HEADACHES**

**What your doctor doesn't tell you...  
That You Need to Know**

**Are you suffering from:**

- Pulsing, pounding, or throbbing head pain?
- Pain on one side of your head?
- Nausea or vomiting?
- Sensitivity to light and sound?
- Head pain when you move or bend over?

**You could be suffering from severe  
headaches or Migraine disease.**

**TERI ROBERT**

About.com Guide to Headaches and Migraine Disease



# LIVING WELL WITH Migraine Disease and Headaches

What Your Doctor

Doesn't Tell You . . .

That You Need to Know

**TERI ROBERT**



*With affection, admiration, and hope,  
I dedicate this book to all of you who live with  
Migraine disease and headaches  
and to those of you who are reading this book  
because you care about someone else who does.  
Keep learning, hoping, loving, and laughing.  
Those are what will get us all through life in one piece.*

*Never forget:  
You are not alone.  
There is hope.*

*This book is also lovingly dedicated to those  
who have lost their lives to Migraine disease, including*

*Sarah Crawford  
Janice  
and Abi Smith,*

*whose last request of me was to “keep educating people.”*

## TOO SHORT

almost 22-years-old  
almost, not quite  
she visited a few times  
then was gone  
she needed  
but gave more than she asked  
then she was gone  
she loved and laughed and cried  
but then she was gone  
was it with a whisper  
or with a shout that she left?

*In memory of Abi, from Teri Robert*

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# CONTENTS

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<b>Acknowledgments</b>	vii
<b>Foreword</b>	xi
<b>Introduction</b>	xv
<b>Part I: Headache and Migraine Disease Basics</b>	
1: What Are Headaches and Migraine Disease?	3
2: The Importance of Proper Diagnosis	14
3: Education: Essential to Our Health and Well-Being	23
4: The Most Common Headache: Tension Headaches	31
5: Migraine Disease: Migraines Are Not “Just Bad Headaches”	37
6: Cluster Headaches	65
7: Rebound, aka Medication Overuse Headaches	71
8: Other Headache Disorders	80
<b>Part II: Your Health Care Team and Treatment Regimen</b>	
9: Your Role on Your Health Care Team	95
10: Choosing the Right Doctor	103
11: Trigger Identification and Management	109
12: Preventive Therapies	122
13: Abortive Therapies	134
14: Emergency Care and Pain Management	142
15: Complementary Therapies	152

**Part III: Support and Empowerment**

<b>16:</b> Support: As Important as Good Medical Care	163
<b>17:</b> When Those Close to You Don't Understand	168
<b>18:</b> Building Your Support System	184
<b>19:</b> Empowerment over Headaches and Migraines	189
<b>20:</b> Advocacy Issues: Knowing and Claiming Your Rights	196

**Part IV: What Does It All Mean?**

<b>21:</b> If Your Situation Seems Hopeless	215
<b>22:</b> Summary and Review	220
<b>23:</b> My Personal Approach to My Headaches and Migraines	223
<b>24:</b> Frequently Asked Questions	231

**APPENDIXES**

<b>Appendix A:</b> Glossary	241
<b>Appendix B:</b> Supplemental Materials Available Online for Free Reference and/or Download	261
<b>Appendix C:</b> Resources	263
<b>Appendix D:</b> Recommended Reading	273
<b>Appendix E:</b> Referenced Experts	279
<b>Appendix F:</b> References	285

<b>Index</b>	290
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# ACKNOWLEDGMENTS

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I also owe a great debt to my forum and chat hosts for my About.com site. They have managed the forums and chat room as well as I could have managed them myself, freeing me to write. They have also become my friends and part of my extended family. My forum members, too, are family. They love it when I'm there to

talk with them but understand when I'm not. Not only do I offer them support, but they offer me support. As you read this book, you'll find a piece of advice that I had to include or never be allowed back in my forums because they love it so much. To all of you, I give my thanks and love.

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I feel as if I've just delivered an Academy Awards acceptance speech and as if I need to add a disclaimer here. I'm bound to have inadvertently left someone out of my thanks. Please know that I didn't mean to, and I do thank you!



# FOREWORD

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*by Fred Sheftell, M.D.*

First, I need to say how honored I am that Teri Robert has asked me to write the foreword for her important contribution to the field of headache and Migraine disease. There are many experts who would have been delighted to write the foreword, and I am truly proud that she asked me to do so.

Anyone who has been touched by headache or Migraine, be they sufferer, family, provider, employer, or friend, owes Teri Robert a debt of gratitude for her years of effort and advocacy on behalf of headache and Migraine sufferers and now her book. Reading through the pages, one can clearly see that this has been a labor of love and will serve as an invaluable resource for so many of us who work with and on behalf of headache and Migraine disease sufferers.

For twenty-five years I have heard the pain and anguish from so many whose lives have been devastated by headache disorders, Migraine disease and cluster headache in particular. Heaping insult onto injury are the stories of sufferers whose complaints have been minimized, doubted, and even dismissed! I have tried in my own small way to turn this around through my work with patients, teaching providers, as chairman of the World Headache Alliance for the past ten years, and as past president of the American Council for Headache Education. The National Headache Foundation has made monumental contributions to patient and physician education alike

and honored Teri Robert last year at its annual fund-raiser for her work on behalf of sufferers.

Eighty percent of the patients referred to our center have chronic daily headache, and 80 percent are overusing a variety of over-the-counter (OTC) medications and prescription medications, mostly barbiturate-containing products (Fiorinal, Fioricet both with and without codeine, Esgic, and the like) and opiates (Vicodin, Lortab, Percocet, Percodan, and others). The problem of overuse (expertly described by Teri) is not confined to prescription medications. As one example, I can think of a man I saw in his late forties who prior to seeing us had been using eight ibuprofen tablets (Advil) per day for two years initially for episodic headache, which became daily over time. He began to notice black tarry stools and subsequently almost died secondary to developing three gastric ulcers that bled to the point where he went into hypovolemic shock, had virtually no blood pressure in the emergency room, and required three pints of blood. He was lucky—he lived. The story of Kellie as related by Teri and Kellie’s mother did not have such an ending. This seventeen-year-old girl with her entire life in front of her died as a result of taking “just Tylenol” in quantities sufficient to cause acute liver and kidney failure! These stories are but a few of the tragedies that can occur with “just headache.” (By the way, ever seen side effects and warnings on TV commercials for OTC products, the way you do for prescription products? I haven’t.)

Teri’s chosen “mission” has brought stories and questions from all over the globe to her Internet sites [www.HelpForHeadaches.com](http://www.HelpForHeadaches.com) and [www.headaches.about.com](http://www.headaches.about.com), a true oasis for those in need. Not only can you get information and expert advice from Teri and her cadre of expert providers, but you can actually feel her smile and get an Internet hug! If you’ve never been to the sites, you will surely become a regular visitor after reading her book.

Teri begins by sharing her own story, which should be all too fa-

miliar to many of you with chronic headache or Migraine in terms of the pain itself, the impact on her life and on those who love her, the years of being doubted, and her search for help. She never gave up and tells her readers not to, either. Fortunately for so many of us, she turned her struggle in a positive direction by providing a road map of the pitfalls to be encountered on this road and by giving us accurate directions to find the right help and treatment for her fellow pilgrims. One of the many wonderful aspects of this book is her use of personal stories of sufferers who like herself have been willing to share their experience with us. The experience of my good friend Michael John Coleman as a child is another example. Michael John is another who on the basis of his experiences and struggles created an invaluable resource (MAGNUM), the National Migraine Association, for those who struggle with Migraine disease. These personal vignettes precede a discussion of what we need to know about a particular type of headache disorder, treatment, or empowerment technique, including getting around the many obstacles and detours thrown at us by “the system.” That system includes “damaged” care (oh, excuse me, I meant “managed” care), limits or denials on treatments you require (by the way, my patients have never received letters from an HMO warning them that they may be overusing butalbital compounds or opiates, but as soon as they exceed nine triptan tablets per month . . . ), emergency room interventions, hospitalization, getting your records, disability, and so forth.

The book is divided into five parts, with subchapters in each comprehensively covering the necessary topics from disease basics, treatment approaches and alternatives, support and empowerment, how to put it together, and finally appendixes providing the reader with easy-to-locate terms, resources, and references.

The most important nonpharmacological intervention is education. I'll never forget my patient who told me that when she questioned her previous doctor about the side effects of a particular

medication and told him, “The *PDR* [*Physicians’ Desk Reference*] says—” he slammed his hand on the table and said, “I hate when patients read the *PDR*!” I agree with my colleague Bill Young with respect to self-education. I’ve always disagreed with the statement that an educated patient is a dangerous patient, and like Dr. Young, I prefer patients who take an active role in their own treatment and enter a partnership-type relationship. The evidence suggests that those who come looking for the “magic bullet” and want something done to them to make it go away have an “external” locus of control, where someone or something outside of themselves will make it better, as opposed to those who have an “internal” locus of control, where they come in with the attitude “How can we work together to help my headaches?” This is a book for those who want to take that active role. All the tools, information, and resources you’ll need are found in this wonderful book.

Just as Migraine is not “just a headache,” this is not “just another headache book.” It is a book of hope. If you are a sufferer, this book is a must; if you are touched by a sufferer, giving this book would be as good a gift as you will ever find.

Thank you, Teri Robert, for this book. And thanks to all of you who have struggled with us.

—Dr. Fred Sheftell, Director and Founder,  
New England Center for Headache,  
Stamford, Connecticut

# INTRODUCTION

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## **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 to cry. 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 rubbing my back gently 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 baby-sat 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 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 1970s 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 was 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 Mi-

graineur. 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 take 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 twenties, my Migraines gradually became more frequent and more severe. My family doctor sent me to an ENT (ear, 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 twenty 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 of 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, "Okay. 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 anytime 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 twenty-eight, 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 it 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 thirties, my Migraines were wreaking havoc with my life. I was newly married, with two newly acquired teenage 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 ninety-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