You Don’t Look Sick!

SECOND EDITION

Living Well with Invisible Chronic Illness

Joy H. Selak • Steven S. Overman, MD

“I’ve learned that having a chronic illness is not a prison sentence. … It does not mean that I am useless and no longer have any gifts to share, but it may mean that I must develop some new ones.”

—Joy H. Selak
Praise for the First Edition

You Don’t LOOK Sick! is a poignant and easy-to-read journey of a person afflicted with a chronic illness, her struggle to come to terms with her disease, and her acceptance of and adaptation to it. Joy Selak takes this journey with her physician who adds to the book valuable reflection and a medical perspective. This book combines the difficult lessons learned with humor and with more grace than I could imagine mustering. This text will be very helpful to many of my patients going on the same journey.

Bob Crittenden, MD, MPH
Chief of Family Medicine
Harborview Medical Center
Seattle, Washington

This book is a masterful, insightful, and useful account of the patient’s and physician’s perspective, in their own words and frames of mind, on recognizing, confronting and dealing with chronic illness. This multifaceted perspective is one with which not only patients with chronic illnesses of any nature, but also their health care providers and family members, will certainly identify, and from which all will benefit. Chronic illnesses are greatly underrecognized and undertreated, and books such as this contribute to educating a broad audience in a meaningful and practical way.

Roberto Patarca-Montero, MD, PhD, HCLD
Author of Concise Encyclopedia of Chronic Fatigue Syndrome

If you live with a chronic condition and know others who are challenged by such a condition, this is an easy-to-understand, practical and compassionate book that shows a patient and physician partnership in healing. Many conditions cannot be cured, but all suffering can find meaning when the mind is taken seriously, the body finds balance and the spirit integrates the experience in a movement toward wholeness. Joy Selak, with the help of her physician, comes to terms with a life that is radically challenged by that process.

Hannah O’Donoghue, CCVI, RN, MS
Holistic Nurse Practitioner
Seton Cove Spirituality Center
Austin, Texas
Readers Praise You Don’t LOOK Sick!

Thank you, thank you, thank you. I came across your book quite by accident in an online catalogue because the title grabbed me. Even as I clicked “place hold” I thought, here we go again, another pile of blah, blah, preaching... take this, do that, and you’ll be cured, that will inevitably leave me feeling frustrated and depressed for being the only one who can’t cure myself. I brightened when I saw that it was light enough to hold, propped on pillows, while I lie on the heating pad... I read excerpts from the beginning to (my husband) Willy and we looked at each other, stunned. It was like reading about our lives. I have been there and he has watched, helplessly, feeling my pain.

— Deborah Hall, London, Ontario, Canada

I ordered your book and read it in 24 hours. Thank you. It is the first of many steps I hope to be making in learning how to live well despite my chronic illness. Your book has given me some new insights and much validation. I wanted you to know.

— Sarah F. Brownell, Laredo, TX

I can’t tell you how wonderful it was to read your book. I have felt everything you discussed, every feeling you were so wonderfully able to put words to. I have struggled with putting it all into words that represent my life with Sjogren’s syndrome. Thank you for sharing so much with me. You have changed my life.

— Deborah Gowrie, Old Saybrook, CT

I want to thank you for taking the time, stepping out of your box and sharing your gift in your book—You Don’t LOOK Sick!

— Deb M-S

You came to speak, at one of our meetings, and I remember your talk very well, and learned a lot from it. I have your book and learned a lot from that, too.

— Kari Cain, Austin, TX

I love your book and I am passing it around like a plate of mashed potatoes to everyone that knows me. It’s SO helpful and explains SO much!! Next on my list, my pain management doc. She can be a real pill but is willing to listen. I hope she will read it!!

— Tracy Rupp, Atlanta, GA

On our drive home from the conference, I read your book and can relate to your experience on so many levels. The book made me laugh, cry, and mostly nod in agreement. I really feel I was meant to read this book.

— Alyssia Ventura

Thank you for writing your book. Since being diagnosed with Interstitial Cystitis and Fibromyalgia I have read everything on the subject of chronic illness that I could get my hands on. Your book is by far the most informative, enjoyable and uplifting book I have read.

— Jenny Greiner, San Juan Capistrano, CA
You Don’t LOOK Sick!
Living Well with Invisible Chronic Illness

Second Edition

Joy H. Selak
and
Steven S. Overman, MD

demosHEALTH
New York

Published Demos Health
For Dan, again and always.

&

For Holly, who nurtures mind, body, and spirit.

We have been motivated by the feedback we have received from many chronically ill patients in Dr. Overman’s offices, at conferences, and in our daily lives. We also appreciate those readers we do not know, but who found us by letter or email and took the time to tell us their stories.

Our thanks to our agent Stephany Evans at FinePrint Literary Management and Noreen Henson at Demos Health Publishing for taking on this second edition. It has been empowering to work with such consummate professionals. Our guest contributor, Bob Crittenden, MD, is valuable for his friendship, his efforts to bring about national health care reform, and his continued efforts to help those who live with chronic illness find their own path to living well.

Others who gave valuable advice and insight for this edition are: Alice Acheson, Susan Asplund, Claudia Cerenzie, Randolph “Huey” Houston, Mavourneen McGinty, Leslie Savage, Lisa Sterling, Lynne Tredennick, and Don Uslan.
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Preface to the Second Edition

You Don’t LOOK Sick! Living Well with Invisible Chronic Illness was published by The Haworth Press in 2005 and we have been gratified by its success. It was a finalist for USABookNews Best Health Book that year, coming in second to Supersize Me. It was also runner-up for the Independent Publishers Book Awards, or IPPY, as the Best Health Book of the Year. You Don’t LOOK Sick! became our publisher’s bestseller and soon we began receiving invitations to speak at physician and patient meetings and conferences across the United States and even abroad. These in-person engagements have given us the opportunity to share our hopeful message—that it is possible to live well, even if you can’t get well—to thousands who might benefit.

We have learned from our audiences and the many kind readers who took the time to send us letters. You have asked questions, shared your own stories of the challenges of invisible chronic illness, and let us know how our book helped you move forward. We also learned that our book could be better. For this edition, Joy felt she could reorganize and add to her stories so they fit the phases more accurately, and she wanted to clarify the positive opportunities that occur in even the most frustrating experiences with illness. Dr. Overman wanted to offer
readers specific travel tips for each phase of the journey in order to deepen understanding and offer helpful tools to progress through the phases.

Most importantly we decided that we needed to include a fourth phase of the chronic illness experience: Grief and Acceptance. We had shared with readers how we learned to navigate three phases, Getting Sick, Being Sick, and Living Well, but this necessary additional passage, which includes grief at the loss of function, followed by acceptance that the illness is not going to go away, usually occurs first sometime near the end of the Being Sick phase and is likely to recur repeatedly throughout the illness journey. This time of transition allows patients to make peace with their new reality and affords the foundation and the freedom to build a new and meaningful life.

In 2007, our publisher was bought by a large British house and, soon after, the U.S. offices were closed and all operations moved to the U.K. Pricing and shipping issues with our new publisher made the continued sales success of our book in the United States impossible. We are grateful to FinePrint Literary Management and Demos Health Publishing for taking us on and believe this improved second edition will be of value to both new and returning readers.

We originally chose our stories from a collection of Joy’s true life experiences that we felt were common to many with invisible illness. From a stack of ideas written on dozens of index cards, we settled on the twelve we felt best represented our three phases. For this second edition, there are still twelve stories, divided among the four phases. Some are new stories, some extensively edited, and all supported by the enhanced comments by Dr. Overman, based on the years of experience he has working with patients as they move through the phases of chronic illness.

Finally, we believe we have more avenues to help patients and health care workers cope with chronic illness successfully. We are collecting stories and strategies from patients, physicians, other practitioners, and researchers to help readers access the many, many ways they can weave a web of wellness in their lives. We look forward to offering returning readers other voices,
Preface to the Second Edition

wisdom, and experience beyond our own and activities that can support success.

Please let us hear from you and perhaps join you in person at your next meeting or conference to continue the conversation about *You Don’t LOOK Sick! Living Well with Invisible Chronic Illness*.

Joy H. Selak and Dr. Steven S. Overman

Joy may be reached at joy@joywrites.com and Dr. Overman at DocOverman@gmail.com.

More information about the book can be found at:

www.chronicinvisibleillness.com and www.joywrites.com
Dr. Overman and I have some real life stories and a few simple principles we want to share with you in the coming pages. Our book isn’t long, or hard to understand, and we wrote it this way on purpose. We know many of you are tired and hurting, and may be frustrated and angry that illness has robbed you of the person you once were. If your illness is invisible, you may have found it hard to find the right doctor, and you may receive little support, even suspicion, about your symptoms from friends and family. We identify and sympathize with all of this and believe you will find parts of your own life in our stories. We hope you will laugh some and maybe cry a little but, most of all, we hope you will be encouraged that the future can be better for you, even if you can’t make your illness go away.

Dr. Overman and I know that our voices are specific to our own experiences and we have had many advantages, both personal and professional. However, our combined years of experience and our trial by fire as patient and physician have taught us to appreciate the diversity of the human experience that we believe will allow our book to have meaning for those with different demographics. We believe we all share similarities that are much greater than our differences—we all will die and experience loss and most of us will live long enough to have a chronic illness.
The many ways we can find solace by helping each other is at the core of our stories.

Dr. Overman and I believe help is available for your body, mind, and spirit. We believe humor is a great way to cope with what ails you. We believe you are still a citizen of your community and have positive contributions to make, even if that might seem impossible right now. Most importantly, we believe there are phases to living with chronic illness and each phase has its own set of challenges, opportunities, and lessons. By helping to guide you through these phases we believe you will discover that your future, even with a chronic illness, does not have to be dismal, rather you can build a future that is peaceful and rich with meaning.

You will find many stories in the pages to come, written by both Dr. Overman and myself. This is because we believe the important things in life are most vividly expressed in stories and stories are a great teacher, much better than a lot of advice and rules for you to follow. We hope that by sharing our stories about living with and treating chronic illness, you might benefit from our experiences and find in these pages a roadmap that will help you on your own journey.

The story of my own strange symptoms first began in the 1980s when I was in my late 30s. Like many chronic illnesses, mine began with vague, but steadily worsening, symptoms of pain, fatigue, sleeplessness, and memory loss. As time went on, I experienced allergies and asthma, bowel and bladder disorders, and skin irritations. The pain, which began in my pelvis, became worse and generalized. It seemed as if my body was at war with itself and my environment.

I reported these symptoms to various doctors over seven years before I received my first diagnosis. It took another three years of searching before I assembled a team of doctors, led by rheumatologist Dr. Steve Overman, with whom I could communicate and build trust. Slowly, and with my doctors’ help, I gained the tools to manage my symptoms, accepted that my illness was chronic, and made peace with the quiet lifestyle that illness demands. I was shattered with grief at the loss of the person I once was, but in time I built a new life and no longer felt regret at the turn my life had taken. Without realizing it at the time,
I had passed through what Dr. Overman and I came to call the Four Phases of Invisible Chronic Illness. They are:

- Getting Sick
- Being Sick
- Grief and Acceptance
- Living Well

My first seven years of searching for answers is what we call the difficult Getting Sick phase. As I learned to understand and better manage my symptoms and gain control over the health care I received, I passed through the Being Sick phase. Over and over again, I experienced the third phase Grief at the loss of the person I used to be, followed by Acceptance of the person I had become. This grief was deepest when I confronted the reality that my illness was not going to go away. Eventually, as I made peace with my new circumstances, I found the path to Living Well and began to enjoy my new life—a life that contained long-term illness.

**DR. OVERMAN**

Joy and I had already spent some time talking about Joy’s three stages of illness when I heard Patricia Fennell, MSW, LCSW-R, speak about her own research on chronic illness. It gave credence to Joy’s experience that Fennell also divided chronic illness into phases. In 1993, she began publishing data on the Fennell Four Phase Model, comprised of Crisis, Stabilization, Resolution, and Integration.™ The Four Phase Model is discussed extensively in her books and articles, including *Managing Chronic Illness Using the Four-Phase Approach*, *The Chronic Illness Workbook* (2001, 2012), and the *Handbook of Chronic Fatigue Syndrome and Fatiguing Illnesses* (2003) [1].

In the first edition of our book we divided Joy’s illness into three stages (Getting Sick, Being Sick, and Living Well). Joy wrote extensively throughout about her grief at the loss of function and her work identity and how she had to come to terms with this loss to begin to build a new life. After publication, we continued
to work with these ideas in Joy’s life and in my practice. We came to see that although grief can recur over and over throughout the illness journey, it is a necessary phase that must be navigated in order to begin to live well with illness. So in this edition, we add *Grief and Acceptance* as a defined third of four phases and have grouped our stories accordingly.

Joy’s experience can be described to reflect Fennell’s Four Phase Model. Fennell’s first phase, *Crisis*, includes the anger, fear, and loss, which Joy experienced while getting sick. In Fennell’s second phase, *Stabilization*, Joy tells stories of being sick and putting into action a plan for managing her illness and her life. Joy’s grief and acceptance of illness as a part of her life is Fennell’s third phase, *Resolution*. Finally, Joy began living well as she found value, meaning, and purpose in her new life during her fourth phase, Fennell’s *Integration* phase.

In working with my patients, I have observed that learning to live well with illness is not like reaching a destination. They frequently experience repeated episodes of fear, anger, and loss. It is a difficult challenge to accept that no matter how well they manage their illness, their symptoms are now part of their lives and their identity. Even if patients make positive lifestyle changes, and medical advances and new treatments result in regained good health, the experience of chronic illness will still have been life altering. Joy’s journey demonstrates how even an experience as devastating as illness can be used by each of us to learn, grow, and become a different, and better, person.

**JOY**

Coming to terms with my new reality was similar to accepting the death of a loved one. The life I had was gone and I had to bury it, grieve, and go on. Sometimes, on a bad day, I remember my old self, and how my life used to be, and I grow sad. Most of the time, however, I love my life the way it is now, good days and bad. Very early in my illness, my husband and I moved to a small island in the Pacific Northwest, and illness afforded me time to be still and truly see the wondrous beauty of this unique place. Later we moved to my home state of Texas, and I felt the
deep emotional connection I had as a child to this land and its hospitable people. Through my struggles, I’ve learned to live more in the present moment and appreciate any small blessings that may come along each day. Illness made me a better person. I am not so quick to judge people and their actions, now that I know what it feels like to be judged unfairly. Illness has also given me the time to pursue quiet interests that were once stored away in the attic of my life, waiting for a rainy day. I am no longer sorry that the long, rainy day came for me.

Like millions of people who become chronically ill in their prime, but do not die prematurely, I have also had to face the fact that I am likely to live more than half my life ill. It only makes practical sense for me to use this precious time to fashion a fulfilling life, one that includes my illness.

**DR. OVERMAN**

There have been significant changes in the national conversation around health care since we published the first edition of *You Don’t LOOK Sick*. Congress passed the Affordable Health Care Act in 2010, but the debate goes on. We have all heard chronic illness care addressed during this debate, usually in terms of how much it costs to treat and care for chronically ill patients. The debate rarely considers the patient perspective, nor does it focus on how poorly we, as a nation, meet patient needs. I feel that our nation needs to hear stories like Joy’s, and yours, about the realities of living with chronic illness.

Let me offer some basic definitions about chronic illness so that we have a shared understanding of the terms. By general definition, a chronic condition lasts more than three months and most have the following general characteristics in common:

- The illness is treatable, but the cure is unknown.
- The causes are often unknown or poorly understood.
- Related symptoms are persistent and recurring.
- Remissions are possible, but unpredictable, and often temporary.
Don’t let this definition cause you to lose hope; we are making progress. Although many chronic illnesses have no known cause, others now have a partial answer such as the insulin deficiency in diabetes. We are learning more every day about genetic and environmental factors that can cause chronic disease. For example, certain genes, such as the HLA DQ2 or DQ8, are almost always present in persons with celiac disease. While we have long known that smoking is a risk factor in cancer, we now know it also increases the risk of rheumatoid arthritis.

By contrast, an acute illness has a quick or serious onset of symptoms and a more clearly defined prognosis. A person with an acute illness generally gets sick and, in short order, is either cured or dies. With successful treatment, some acute illnesses can develop into chronic illnesses. For example, with advances in treatment, many forms of cancer and human immunodeficiency virus (HIV)-related illnesses that were once terminal have now evolved into manageable chronic illnesses. Understanding how an acute illness affects the immune, metabolic, nervous, and transport systems is also critical to understanding why so many different chronic illnesses have symptoms in common, such as pain, fatigue, sleep disorders, changes in weight, poor function, susceptibility to infection, dietary sensitivities, and emotional irritability.

**JOY**

During the seven long years I spent searching for answers before I received my first diagnosis, my physicians sometimes got inconclusive results on their medical tests and consequently were either dismissive of my symptoms or minimized them. It was up to me to keep looking. Even after I was diagnosed with a bladder disease, interstitial cystitis, and began to receive treatment, I knew the search was not over as there was more going on with me than just this illness. When I found my way to Dr. Overman, I learned I also had an autoimmune disease: undifferentiated connective tissue disease. This meant my immune system was out of balance and attacking me instead of helping me to heal. The label *undifferentiated* meant I had symptoms common to many autoimmune disorders, but did not test as classic for any particular one. 

**XX**

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Other doctors added the diagnosis of fibromyalgia, a disorder of amplified, widespread pain. Putting a name to what was wrong not only gave me resolution and the opportunity for effective treatment, but allowed me to put aside the deep fear that I was going to die from my ailments.

Later, the national press began to report on women becoming ill from silicone breast implants. I had implants and decided to have surgery to remove them. If there was any chance they might be making me ill, I wanted to take action. During the surgery, my doctor found one of the implants had ruptured and the silicone gel had leaked into my body. Now, I had a whole new and poorly understood complication to add to my mix of symptoms and the possible causes.

A few years after that, I began to have pain along the upper jaw line on the right side of my face. Once again, I spent three years searching for the cause, with the pain continually worsening. I underwent many dental procedures and even sinus surgery before I finally learned I had a neurological disorder called trigeminal neuralgia, also a chronic condition. It could be treated with medication, but I was offered no hope for a cure at that time. I was thrust once again into the phase of Being Sick as I worked with my doctor to find the best treatment and altered my lifestyle to manage my symptoms. I also experienced another phase of Grief and Acceptance.

At first this new diagnosis, which seemed so unrelated to the others, really took me to my knees and seemed to be more than I could bear. Did I really have to endure another painful chronic condition? It was tempting to descend into self-pity, but I was more experienced at working my way through these feelings and able to move through this phase with more skill and ease.

I am grateful this journey gets easier with time, but it is still hard to understand why just identifying what was wrong with me took so many years. From speaking to other patients around the country, I know that my story is not unusual.

DR. OVERMAN

Arthritis, musculoskeletal pain, and neuromuscular and autoimmune disorders represent the most common causes of disability.
due to illness in the United States today. These include illnesses such as rheumatoid arthritis, osteoarthritis, Sjögren’s syndrome, lupus, Crohn’s disease, degenerative disc disease, fibromyalgia, chronic fatigue syndrome, celiac disease, multiple sclerosis, Hashimoto’s thyroiditis, spondylitis, and even chronic low back pain. Although each condition has its own unique features, they also have similar symptoms that can be disabling to patients, such as muscle and joint pain, nerve pain, chronic fatigue, sleep disturbance, short-term memory loss, skin sensitivity, bowel or bladder abnormalities, allergies, and sometimes organ involvement. Tens of millions of people have these illnesses and each year they spend billions of dollars seeking effective treatment. It should not take Joy, or anyone else, multiple years to get a diagnosis. I understand the frustration.

My specialty, rheumatology, is focused on the diagnosis and treatment of complex, chronic illnesses like the ones I have described above, but the primary focus of modern Western medicine has been to identify acute illnesses and treat them with acute interventions, such as surgery or antibiotics. Although Western doctors can take justifiable pride in our advanced abilities to offer the high-tech quick fix, our system has yet to catch up with other countries in meeting the needs of persons with chronic conditions, a group whose numbers are growing as our life span increases. The focus of our medical education, research investment, and insurance compensation also fail to meet the increasing needs of the chronically ill. Too many physicians lack the skill, and sometimes the interest, to offer diagnosis and ongoing care for the chronically ill, especially those with chronic pain syndromes.

Chronic illness care requires a lot of time—time to listen to the story, assess the physiology of the conditions, evaluate the risks and benefits of various medications, and help patients understand the expected phases of their illness. Because all this is so time consuming, it frequently leads our overworked and poorly equipped primary care physicians to treat symptoms only, without diagnosing and addressing the underlying medical, environmental, or lifestyle causes of the illness. In other words, they find themselves unable to care for the whole person. Unfortunately, our insurance system pays highly for procedures like surgery, laboratory tests, and diagnostic radiology, but much less
for the time spent in communication with patients. The arbitrary way these payment priorities are set has resulted in fewer physicians entering chronic illness care specialties. Patients in need find they are often limited to only fifteen-minute visits with their physician.

An understanding of the label *syndrome* will further illustrate the difficulty in making a clear diagnosis. A syndrome is simply a poorly understood illness. It is often initially defined for research purposes and given a name because sufficient laboratory, clinical, or symptom criteria are present. A syndrome may have more than one cause and symptoms that are not unique to it. The label *syndrome* does not mean the illness is not real, but rather that the medical community still does not understand it well enough to call it a disease.

For example, Joy’s fibromyalgia is a chronic pain syndrome and was until recently diagnosed by a patient reporting pain that occurs with pressure on eleven out of eighteen specific points around the body. Now, in an effort to better understand the illness, there are recommendations to drop the examination findings of tenderness from the diagnosis of fibromyalgia, and instead use only symptom criteria. This is partially because tenderness at these points can frequently be attributed to other causes, such as tennis elbow or neck strain. We also know now that fibromyalgia patients usually have a variety of symptoms beyond those of musculoskeletal pain and tenderness. For example, as was true in Joy’s case, patients often report nonrestorative sleep, irritable bowel symptoms, bladder urgency, cognitive problems, anxiety, and fatigue. Fibromyalgia is now thought to be a syndrome of nervous system amplification. This means the nervous system is more sensitive to all stimuli and therefore magnifies the reporting to your brain. Light touch may feel like pain and normal bodily sensations may be uncomfortable.

Many women with fibromyalgia are also diagnosed with chronic fatigue syndrome, or CFS. But can you have two syndromes, or more, at once? The answer is yes, but CFS has different diagnosis requirements than fibromyalgia. CFS is a diagnosis of exclusion, meaning that other causes of fatigue must be ruled out. Fibromyalgia can be inclusive. For example, if you have rheumatoid arthritis or lupus, and you also have the tenderness
of a sensitized nervous system, you can meet the criteria for fibromyalgia.

I usually tell new patients that getting the diagnosis of fibromyalgia is like being told that those dark spots on your body are bruises. Immediately you would ask the question most important to you—what is causing the bruises? With fibromyalgia, the diagnosis is only the beginning of the search for answers. Next we must ask, is your illness caused or triggered by inflammatory illness, sleep disorder, stress, metabolic problems, or neck injury? While the medical literature does not clarify these distinctions, I tell my patients that it takes problems in at least two of these domains to disrupt the balance of the nervous system to a degree that leads to the widespread body sensitivity called fibromyalgia.

Chronic fatigue syndrome is different. CFS has specific diagnostic criteria a patient must have:

- Clinically evaluated, unexplained, persistent, or relapsing fatigue that is of new or definite onset.
- Not the result of ongoing exertion.
- Not alleviated by rest.
- Results in substantial reduction in previous levels of occupational, educational, social, or personal activities.

In addition, patients need to have four or more of the following symptoms that persist or recur during six or more consecutive months of illness and that do not predate the fatigue: self-reported impairment in short-term memory or concentration, sore throat, tender cervical or axillary nodes, muscle pain, multi-joint pain without redness or swelling, headaches of a new pattern or severity, sleep that is not refreshing, or post-exertion malaise lasting longer than 24 hours. Note that the word unexplained means other causes have been ruled out, with the exception of fibromyalgia, since it occurs so frequently with CFS. So if you are beginning to think this whole process of figuring out what is wrong, what caused it, and what to do about it is extremely complicated, you can imagine how a primary care physician feels when asked to assess and effectively treat a patient reporting these symptoms.
Fatigue is one of the most common symptoms reported to primary care physicians, occurring in a quarter of the individuals who enter their offices, and it is more commonly reported by women than by men. Epidemiology researchers make the CFS syndrome definition restrictive so as to exclude common, known causes of fatigue. This strategy maximizes the chances that research studies will detect significant associations with a specific cause or group of factors that lead to CFS. Though this clinical case definition is well established, its strict use may not always be appropriate in the evaluation of a specific patient. For me, these strict criteria are useful as a constant reminder that there are many diseases or other syndromes that may present like CFS or just fatigue in general. Since there is no known treatment for persons with classic CFS, I rarely put the label CFS on my problem list for a patient. Instead, I usually list the various symptoms that are present so that I am constantly looking for patterns that might lead to other diagnoses that are known to be treatable. Yes, this is complicated and it is why rheumatology is both an exciting and challenging specialty, and why I have gray hair!

Even though we don’t fully understand how or why, I believe all of Joy’s diagnoses are likely related to one another, much like the elephant that was really one beast, even though each of the blind examiners could only identify the separate parts.

JOY

It wouldn’t make much difference if the blind men could see all of me, since so few of my symptoms are visible. Since I don’t look sick, I don’t get much acknowledgment for being sick either. Often people are downright skeptical about the reality of my illnesses, and say so. I wasn’t able to find many books to prepare me for the real world of living with illnesses like mine. Most of the books in the health section promised to explain “Everything You Ever Wanted to Know” about one specific disease. I have more than one illness, with symptoms that overlap, so this perspective was of limited help. I found other books that offered the “Seven Easy Steps to the Cure.” I thought these books implied
that if the promised cure didn’t happen for me, it was somehow my own fault. If my well-trained doctors could not offer me a cure for my illnesses, the last thing I needed to do was blame myself for failing to do so.

I decided I should write the book I could not find, but wanted to read. It wouldn’t overwhelm the reader with technical information or promise an easy fix, but it would make them feel recognized. Readers would know they weren’t alone in feeling scared and angry. They would feel empowered to fight for their rights and needs. I could offer hope that finding peace and personal growth can be a part of the long-term illness experience. If I could share my stories about the physical and emotional phases I went through in dealing with the impact of multiple chronic illnesses, and how I traveled through these phases, maybe I could help others get started on their way.

I asked Dr. Overman if he would write the book with me. It took me a long time to find Dr. Overman, and I thought by demonstrating how we work together, readers would be encouraged to keep looking until they found the right doctor for them. He could add his professional insight and wisdom and share other patients’ stories, so readers would get more than just my experience. Between the two of us, perhaps the book could become a useful road map to guide others on a journey to a better life with illness.

**DR. OVERMAN**

When Joy first asked me to write a book with her, I casually said, "Sure," assuming the idea would pass. Obviously, I didn’t know Joy very well yet, but I was curious and began to talk to my patients about these ideas. I asked, "What would be your best advice to help someone live well with a chronic illness?"

One patient, Sharon, gave my question some thought, and then wrote this insightful response: “To live well, you need to understand that in a fast-paced, success-oriented society you are still valuable, even though you may be bedridden, unemployed, or suffering from chronic pain. The way to do this is to retain a positive self-image and a sense of usefulness. This is difficult to do, but essential.”
The next time Joy asked me to co-author her book, I realized she was serious and I was hooked. I responded with a sincere and enthusiastic, “Yes!”

JOY

Working with Dr. Overman as my physician, teacher, co-author, and friend has really helped me cope with my illness in a positive way. I’ve had other advantages, too. I have a large and supportive family and my children were grown and on their own before I became seriously ill. I had a professional career that gave me confidence in dealing with other professionals, like physicians. Through my employer, I had excellent medical and disability insurance. I went on long-term disability in 1994 and my contract enabled me to continue to receive an income that made me feel safe.

I had worked in finance and knew something about corporations and the importance of corporate earnings, so when I had to deal with insurance companies and their denied claims, impersonal treatment, and logjams of paperwork, it made me mad but I realized it wasn’t really about me. They were merely applying what they call risk management. After I became sick, they were spending more money to cover my claims than they were receiving in premiums. Though I had been a profitable client for these companies for many years, this current imbalance was a threat to their bottom line and to shareholder value. One result of having a for-profit, and often publicly traded, health insurance system in America is that corporations may be motivated to make decisions that benefit business goals more than public health care needs. This fact puts patient needs further down the pipeline than they should be. For example, people like me who work for large corporations often enjoy better insurance packages because large corporations can negotiate more favorable insurance rates than a small employer or the self-employed. Those of us who are seriously ill collectively bear the consequences resulting from this discrimination and conflict of interest, and it is our job to fight for all patients’ rights and needs.
The security I am fortunate enough to enjoy in my life gave me the time and freedom to take on the big task of writing this book. Those of you who read it might not be as secure, and therefore have an even more difficult journey than mine. Please know that I sympathize with you and will continue to do all I can to advocate for you and improve the system to better serve the needs of those with chronic illness.

DR. OVERMAN

Unfortunately, what Joy experienced with her insurers is too often the norm, and our health care system continues to provide inadequate care for the millions of people with chronic conditions. However, even as positive change occurs, learning to live well with an invisible chronic illness will remain a challenging, personal journey. To help you meet the challenge, we share three of Joy’s stories we believe are common to many in each phase of the illness. These are followed by my own stories, professional insights, and tips to support your successful progress through this phase. At the end of the book we offer online resources and names of patient support organizations, as well as discussion questions, to promote your deepening knowledge.

Each of you will have your own unique journey to take, teenagers to octogenarians, men as well as women, singly or with a partner, and the life experiences that allow you to grow and come to terms with illness will surely be different than ours. It is our hope that as you read our stories, you will be prompted to consider the ways your own experiences might offer opportunities to better understand your chronic illness. We hope our book helps you find your way from Getting Sick to Being Sick and to navigate your Grief and find Acceptance in your new life. Joy and I both wish you well in your journey all the way to Living Well.
Phase I

Getting Sick
Snake in the Mist

The Seattle porch where I sit this fall night is wet and shrouded in a chilling fog. I can’t see two feet in front of me. I try to push aside the curtain of mist to peer through it, but my hand moves as if through water, the moisture quickly backfilling the slight cavity I have made. I am afraid of this dense dark, and I am dismayed that I am powerless to penetrate it even slightly. I fear there may be something out there I can’t see, like a snake in the mist, poised and waiting to strike me.

The truth is I am just afraid. I have come to Seattle for a medical test, one of a series of medical tests that only seem to raise questions without offering answers. Before this one today, there have been many other days of many other tests, resulting in no more than guesses and stabs at naming all that is wrong with me. I believe I have done the best I can to help find the answers. I have gone to dozens of doctors, read volumes of research, and sought the advice of alternative health care practitioners. Yet I am still so lost, so confused, and so frightened. I am still so very, very ill.

After the test today, I am tired and hurting. I will stay tonight in Seattle with dear friends. They, sensing my despair, gave me dinner and hugs and wished me well, and then wisely left me alone with my thoughts, here on their dank porch.

I reflect that it has been seven years since I first sensed that something was wrong with me and began reporting symptoms
to my doctors. It has been over a year since I began a determined search to finally find out just what it is and what to do about it. I wonder if I have moved from the spot where I first began. I need someone to lead me, a good doctor in whom I can place my trust. Should that be so hard to find? Yes, my experience tells me, yes, it is just as hard to find a partner in illness as it is to find a partner in life.

That is not to say I haven’t been able to find any good doctors, I have. But I don’t have that one special doctor. I have had a hysterectomy at the recommendation of a respected gynecologist. I think he did a good job, but his surgery did not make me well. I went to see a neurologist who, gratefully, has ruled out that I have multiple sclerosis, which might have explained my clumsiness, my inability to think straight, and my fatigue. He has referred me to a rheumatologist who is treating women made sick from silicone breast implants. Perhaps this doctor will find my symptoms familiar and will have some experience in how to treat them. So far, none of my efforts, or these doctors’ efforts, have improved my health, or even clearly explained what is making me so sick.

Today’s tests were an attempt to identify the cause of sudden, acute episodes of pelvic pain I have had since the hysterectomy. The first time it happened the pain was so severe, and escalated so intensely, my local island doctor had me flown to the nearest hospital, fearing kidney stones or appendicitis, but it was neither. Then it happened again, and again. Today’s ultrasound was inconclusive, but the technician said my left ovary is a little enlarged. When I asked what could cause that swelling, she said, among other possibilities, ovarian cancer. She did not think it was cancer, but in my fearsome state that was all I really heard her say—cancer. Ovarian cancer. A killer cancer.

Now, sitting on this porch in the dark and the wet, I still hear her words ringing in my ears, clanging around in my head, and I know this is the source of my fear—that I will die. I-am-afraid-I-am-going-to-die. I am afraid I am going to die before I even find out what is killing me.

Again, I reach out my hand to try to part the mist, and again I cannot penetrate it. I cannot see a thing out there, but I fear that what I can’t see is coming right at me. The death sentence. The snake in the mist.
After waiting in the lobby for forty minutes, I am now sitting in a child-sized chair in the office of a bow-tied and bespectacled urologist. He is sitting in a grown-up chair behind his grown-up desk, ignoring me while reviewing my file. This is only our third meeting, but I doubt that I will back for a fourth. I adhere to a “Three Strikes” policy and once I’ve called the third strike on a doctor, I move on. At our first meeting, this doctor kept me waiting forty-five minutes, and another thirty-five minutes for the second, so I’ve already called Strike One. I was offered no apology for this, even though common courtesy would dictate that my time is as valuable as his. Besides, if he can’t even manage his own schedule, how good can he be at managing my illness?

He has given me my first actual diagnosis, though, which is a relief. He says I have a chronic bladder disease with a wicked-sounding name—interstitial cystitis. He has prescribed for me the medication most commonly used in its treatment, which I am mortified to learn is the same medication given to young children who wet the bed. He has also offered his opinion that there is clearly something else going on with me, yet to be diagnosed, as my set of symptoms are not “classic” for interstitial cystitis. Today I am here to discuss my progress.
“Since I started on the medication, I’ve been having a rapid, irregular heartbeat,” I tell him.
“All the time?” He pops the top off his old-fashioned fountain pen.
“No, mostly in the morning, and mostly at rest.”
“That’s an unusual side effect.”
“It’s listed on the package literature, I checked,” I say, feeling I have to justify my report.
“Well,” he peers at me suspiciously over his glasses, “none of my other patients has ever reported that side effect.”

Strike Two! It’s not my job to be like his other patients.
I move the meeting along to my next concern. “I had a surgery once and they found a big adhesion right on my bladder. Do you think that could have been a factor in causing this disease?”

“Absolutely not,” he answers smugly. “The outside of the bladder is entirely separate from the inside of the bladder. No relationship.” He relaxes in his chair, back in control.
“I guess that means you’re not a big fan of holistic medicine then, where everything is pretty much assumed to be related to everything else.”
He snorts.
“Okay, let me ask you this—you know this big controversy over the safety of silicone breast implants?”
A second snort answers that question.
“I have implants and I’ve read that a lot of the sick silicone women also have bladder dysfunction.”
“Well, I know all about that lawsuit against breast implants, young lady, and I can tell you it’s about one thing, and one thing only—lawyers making money. There’s no science to it. It’s a big bunch of hooey. Besides,” he attests, “I have hundreds of male patients with silicone penile implants and none of them are sick.”
“Really? How do you know?”
“How do I know what?”
“How do you know that silicone didn’t make any of your male implant patients sick?”
“What do you mean, how do I know?”
“Well, who are they, a bunch of old guys?”
“Mature.”
“Okay, mature. Do any of them ever report debilitating fatigue or memory loss?”
“Certainly.”
“How about joint and muscle pain?”
“Of course.”
“Why do you say, of course?”
“Because they’re old.”
“Mature,” I remind him. “Anyway, aren’t those the same symptoms the lawsuit claims the women are reporting?”
“I suppose so. I never thought about it.”
“So, if you did think about it, isn’t it possible your male implant patients could also be having a reaction to silicone? I mean, have you given them tests or anything? How do you know for sure?”
“Because…” he pauses, lowers his chin, takes a bead on me over the tops of his glasses, and repeats, “Because, young lady, I’m the doctor. That’s how I know.”
STEE-RIKE THU-REE! I am out of here!
I struggle out of my little chair, hoist my big-girl briefcase onto my shoulder, and thrust out my hand to him. In the most polite voice I can muster I say, “Thank you for your time today. I think I will take a break from that medication for a little while. You know, give my heart rate a chance to calm down.”
He shrugs, offers me a limp handshake and I leave.
I will not be back. It’s not that this urologist is a bad person, or necessarily even a bad doctor. To be fair, I did confront him on an issue that was not in his area of expertise. Still, he talked down to me as if I were a child, a lesser person. I need to find a doctor who will treat me like a grown up, thinking person, not act like a scolding parent. I want a doctor who can become my health care partner, and I don’t think this man would ever be willing to do that. In order for the partnership I envision to work, there are certain things we would both need to commit to do:

- We must treat each other with courtesy.
- We must see each other as unique.
- We must be as honest and informed as we possibly can.
- We must be willing to work together to build trust.
I am willing to do this, and I don’t think that it is too much to ask of my doctor. This relationship is too important to settle for less, so I’ll just have to keep on looking. I know there is a doctor out there somewhere, just right for me.
The good news is I have two great doctors and three actual, treatable diagnoses now: interstitial cystitis, mixed connective tissue disease, and fibromyalgia. The not so good news is I feel like a lab rat. I’ve been pricked and poked and prodded and photographed more times in the last year than in all my previous years put together. After my first urologist struck out, I started asking around for a referral, a doctor who really knew something about interstitial cystitis. Often I can get the best referrals from practicing nurses, but this time it came from a physician I met at a garden party. He told me I could find a leading female doctor in this field at the University of Washington Medical School in Seattle. I called for an appointment the very next day and found my perfect fit. She is eager, interested, and has lots of patients with a diagnosis of interstitial cystitis.

I also started asking around for the name of a physician treating women who have become ill from silicone breast implants. I don’t know if this is what is wrong with me, but there is so much press about it that cite symptoms similar to mine I’ve become suspicious. Recently when I saw my neurologist, I asked him if he could give me a referral.

“There are only two docs in town treating these women that I know of,” he said. “They are rheumatologists and both are at Minor and James.”
I wouldn’t have thought to look for a rheumatologist, I thought they were doctors for old people, but on this advice I called for an appointment.

Dr. Overman actually took my call personally. “I’m on call this weekend,” he said. “I have to be in the office anyway, so why don’t you come on in?”

I was sold before I even met him, and once I did he diagnosed and began treating me for mixed connective tissue disease, an autoimmune disorder. MCTD is the label used when a patient exhibits individual symptoms that may be common to several diseases, but taken together are classic for none. He said that many of the women with silicone breast implants who have become ill have this diagnosis. I have the dry mouth and eyes of Sjögren’s syndrome, the aching joints of arthritis, the deep fatigue of lupus, but lab tests are inconclusive and don’t confirm any of these. He also says I meet the diagnostic criteria for fibromyalgia, yet another mystery disease. Dr. Overman, like my new urologist, believes what I report and is determined to find answers that will improve my function and quality of life, even if he can’t offer me a cure. After my long search for just one good doctor, I feel like I have landed in Dr. Nirvana.

Overcome with gratitude, I am determined to be the best patient I can be. I want to be the patient they are glad to see come through the door each month. To this end, I come prepared for each visit with my trusty yellow legal pad. On it I have written my list of current medications, new, changing, or continuing symptoms, my three questions for the meeting, and room at the bottom to take notes. I know my doctors are always pressed for time, so I choose these three questions carefully.

One day in a meeting, I sit beside Dr. Overman. My chair is the same size as his, like we are both grown-ups. I have my yellow legal pad in my lap and I am reading to him from my list. He is busy taking notes for his ever-expanding file on me. After a few minutes, he leans closer to me, peers at my pad, and says, “Is this our meeting?”

“Yes,” I answer proudly.

“Then why don’t you give it to me?” He takes the pad from my lap and begins to read for himself with interest.
I’m not sure whether to feel robbed or proud, but I adapt. I make a Dr. Visit template for my computer and save it in my own ever-expanding file. For each meeting, I fill out the template and bring two copies with me, one for him to use and keep, and one for me. Both of my new doctors are referring me to other practitioners, so I’ve also prepared a complete medical history that I take to each new doctor. Now, when the nurse hands me the detailed new patient form to fill out, I can just write, “See Attached.” These time-saving devices have greatly helped me to improve my attitude about becoming a career lab rat.

I recently visited an immunologist from Bastyr College of Naturopathic Medicine who drew a blood sample to test me for over 350 food sensitivities and allergies. He says if we can identify the substances that cause my immune system to overreact and avoid them, it might allow my condition to calm down. He seems a little disappointed to find I am sensitive to absolutely nothing. He was hoping he could at least get me to stop drinking coffee. The acupuncturist I am seeing tells me these sensitivities may not indicate an allergy so much as a system out of balance. Certain highly reactive foods, like wheat and milk products, are more likely to signal this imbalance than others, but when the system is brought into proper balance these intolerances may disappear. Somehow both of these views, conflicting on the surface, make sense to me now. I’m learning that issues around illness and health that I once thought of as a straight line—get sick, take medicine, get well—now look more like a sphere. Explore, Understand, Adapt.

My medical insurer has suddenly got me on their radar. I think they have put a big red sticker on my file that indicates Too Many Claims, Not Enough Premiums. The result is an increase in challenged and denied claims, most recently for chiropractic care. This is serious because my chiropractor is the only practitioner in my small island town who can offer me real relief from a flare of widespread pain. Here’s the way I experience it: First, I have a spasm of pelvic pain, originating in my poor, beleaguered bladder. The pain spreads outward and into the nerves that exit my bladder, traveling along this neural highway until it enters my sacrum. I feel as if something reaches out and gives
my sacrum a yank, which alerts my spine and the pain travels straight up, vertebra by vertebra, until it reaches my neck. Then the pain control knob in my brain starts to move the dial higher until my entire central nervous system becomes involved and pain fans out to my whole body, into every one of my limbs and penetrates all my tissues. Ultimately, it hurts to press my finger against my skin.

The remedy is to go see the chiropractor. He sets the now swollen sacrum back in place, adjusts my pelvis, does some acupressure on my spine, and the process begins to reverse itself. The pain control knob in the brain turns the volume back down, the neck and spine relax, and my whole body begins to ease as the pain subdues like a receding tide. I feel like I can exhale again.

The letter from the medical insurer denying coverage for this life altering treatment states that it is not “medically necessary.” I call them up and ask what the heck that means. I am told that because the chiropractor has been unable to cure me in a reasonable amount of time, his treatment is not medically necessary. This statement is being made to a woman diagnosed with three chronic conditions that no one has been able to cure in any way whatsoever. I decide to appeal. In order to do this, my chiropractor is required to send in his records, called his S.O.A.P. notes, which stands for Subjective Objective Assessment Plan. This sounds like an oxymoron to me, but so be it.

While I wait for the ruling, I continue to make my monthly trips to the mainland to see my ever-growing stable of health care providers. My urologist has referred me to a physical therapist whose specialty is treating pelvic pain or myalgia. She uses biofeedback to help her patients become aware of their involuntary pelvic floor muscles and to learn to intentionally relax them when they spasm. As I come to understand that the brain can communicate with and influence a part of the body whose function is described as involuntary, another of my assumptions about the linear relationship between the mind and body is scuttled. I will not describe exactly how the physical therapist works with me as the “yuck” factor is too great, but let me just say a probe is involved. The learning curve is both steep and embarrassing, but the practice helps. Now when I feel pelvic
pain coming on, I can get still, locate those muscles in my mind and will them to relax. This is a small miracle to me.

Urology offers endless opportunity for embarrassment. First of all, it's embarrassing to tell people I have a bladder disease—it's embarrassing to even say the word bladder in a social situation. I find I am reluctant to tell people I am sick because they will ask what I have and I don't want to say it out loud. This is a socially isolating position, made worse by the fibromyalgia diagnosis. A lot of people don't believe fibromyalgia is real, plus it's called a syndrome, which makes it sound like a mental illness. I don't like to tell people I have that either. Usually, I just say I have undifferentiated connective tissue disease, which no one has ever heard of and is unpronounceable, therefore more credible. I guess the silver lining in all this is that I have three diagnoses to choose from and at least one of them has some social benefits.

The University of Washington is a teaching hospital and because of this, my urologist often asks if medical students can observe the procedures she does with me. Since I am committed to be her very best patient, I always agree. Recently I found myself sitting in a metal chair so rigged up with wires it looked like a torture machine from a science fiction movie. A roomful of doctors, technicians, and medical students crowd into the exam room while the machine fills my bladder, then empties it, fills, then empties again. We are testing bladder capacity and we learn that, unlike many patients with interstitial cystitis, I have plenty of it.

No one is really paying any attention to me, as they are glued to the screen charting the results of the test, but as the machine pumps my bladder beyond full, I am taken back to those terrible childhood memories of having to pee so badly I had to sit with my legs crossed. The adults in my life, after spending months teaching me to pee in a toilet and asking me every ten minutes if I had to go, suddenly reversed their course. Whether in a car, store, restaurant, or classroom, when I told an adult that I had to pee, instead of rushing me to the bathroom as they once had, they would now say, “Can't you wait a while longer?” Much of my childhood was spent desperately waiting for adults to allow me to pee.
Now I sit on the torture chair in this crowded room, squirming with increasing discomfort until, suddenly, the awful memory is replaced by the realization of an even more horrible childhood fear. I feel myself actually peeing in the middle of a room full of strangers. For an entire afternoon, these dual horrors are repeated over, and over, and over, without my having any ability to control them. My urologist is so pleased at my bladder capacity. Good for her. I’m thinking I may not volunteer anymore.

When I return home, I open the mail to find my insurance claim appeal for chiropractic care has been denied. Further, the insurer now declares that my chiropractor’s S.O.A.P. notes, the ironic subjective/objective ones, are incomplete. I find this odd since four of the employees in the office where I work see this same chiropractor and the notes have never been deemed inadequate to justify their treatment, nor have any of them ever had a claim denied. It seems the doctor is being held to a different standard only in my case. I decide to appeal again. This time, they want him to provide three years of records on my treatment, in spite of the fact that the claims for these three previous years are not in question. It feels like busy work to me. I think it is the increasing volume of my claims that is being resisted, not just this one. He’s just taking the hit. I am lucky he is supportive of me and willing to take up staff time to collect these data.

All these pills, procedures, and paperwork wear me out. Fatigue is an overwhelming struggle, especially since I have to travel to the mainland for care. I find I cannot make the trip in a day, nor can my husband drive me because he must cover my clients in the office where we both work. After I travel an hour and a half on the ferry bound for the mainland, I must drive for another hour and a half to Seattle, with several requisite stops to pee along the way. I have identified the cleanest bathrooms in gas station and fast food restaurants in western Washington. I could write a User’s Guide to the Best Bathrooms. Once I make it to Seattle, I see a doctor or two in the afternoon, then collapse overnight in a hotel, get up early, and see another one or two in the morning before driving home. I have learned to keep a pillow and comforter in the back seat of my car so I can lie down and rest while I wait in the ferry line for the boat to arrive. I’m often awakened by the sound of the cars behind me honking for
me to board. I struggle out of the back, dive into the front seat, drive onto the ferry, return to the back seat, and fall asleep again. Repeat, repeat, repeat.

The second appeal is denied. The insurer writes:

After review of the medical documentation submitted, the professional consultant reports to the plan that care is considered chronic/supportive care. There is not objective documentation submitted that verifies the medical necessity of continuing services. The duration of care is not reasonable and customary for the diagnosis on file.

This reads like a form letter, or a few form letters pieced together. I don’t think they are responding to my unique case at all. Besides, all my doctors are offering me chronic/supportive care; most of them just do it with prescription drugs rather than a chiropractic adjustment. I’ve been to dozens of doctors in the last few years, and filed many dozens of prescription drug claims, but never once has my insurance company questioned the medical necessity of a pill, or required the prescription to be accompanied by objective documentation. I’d speculate a for-profit, corporate health care system sees more opportunity for growing profits in big pharma than among chiropractors.

The insurer allows a final chance to appeal. For this third round, all treating physicians are required to send letters recommending that I continue therapy with the chiropractor. Clever tactic, as they know MDs aren’t always entirely supportive of chiropractic care, some even see it as quackery. But mine are willing. They know I am doing many things to help improve my symptoms and this is relief I can get without leaving the island. They trust me when I report that it helps. My urologist, rheumatologist, physical therapist, and chiropractor all provide me with a letter plus their diagnosis and treatment notes for the past three years. All state that this treatment relieves my symptoms and improves my function and quality of life. They acknowledge that with a chronic condition, they can do no more for me themselves. Dr. Overman, as my principal physician, requests that the insurer contact him personally if they intend to deny this claim again. He tells me that when you ask someone way out in insurance land
to take the time to talk to a doctor in the real world, they usually just pay the claim. The time it takes to make the call is not worth the money. Ah, that human touch.

Dr. Overman and I continue our efforts at unraveling the complicated mystery of what ails me. My illnesses are poorly understood, which makes treatment a murky stew of possibilities. He tells me the big challenge in treating a case like mine is determining the driver of my chronic pain. Is it inflammation, low serotonin in the brain, the central nervous system? He says treatment itself will teach us. If we choose the right medication, I will get better. If not, I won’t. I realize this is contrary to conventional wisdom. I thought that based on the diagnosis, a doctor should be able to choose the right medicine and, bull’s-eye, problem solved. But when illnesses are defined with descriptive words like “chronic,” “hard to diagnose,” “difficult to treat,” and “poorly understood” as mine are, this protocol is reversed. Further, Dr. Overman tells me, it’s not just one medication that we seek; rather, we will likely end up with several medications in a subtle variety of doses and add to that any alternative therapies that might help. He says that even when we do find a combination that works, we must continue to monitor my response because it is likely to change over time. The protocol will need to be adjusted as I get better, new symptoms arise, or my tolerance for the medication changes. In order to be an effective partner, I must learn to pay close attention to my symptoms so I can report them accurately. I have to learn a new language to describe what I am feeling and experiencing so that it is clear to him, and then he can help me. This same process is going on with all my prescribing physicians; I find the demands endless and exhausting.

At the end of the year, to try to bring order to this confusion and overlap, I decide to provide my physicians with an Annual Report. I need to do this for myself to sort it all out, so I reason that they might find it helpful, too. I write a brief history of the year, including all the treatments I’ve tried and the outcomes I’ve experienced. I outline the symptoms at year end and the medications I am currently taking. I list the names and specialties of my treating physicians and their contact information, and I send a copy of the report to each one of them. They like it, I get a gold star. If there was a Patient of the Year award, I might have
a shot. Now when I go to an appointment, I often find my doctor at the desk reviewing my Annual Report in preparation for our meeting.

My medical insurer does not contact Dr. Overman about my appeal as requested and, again, the claim is denied. I am told there are no more appeals allowed; the case is closed. I review my contract with the insurer. It says I am entitled to up to 20 chiropractic visits annually. They denied coverage of my treatment in September, after only 15 visits. I decide to contact my employer. My company signed a contract with this insurer on behalf of all their employees and is paying a lot for the service. I want to see if the way I am being treated meets their expectations. The insurer may be in the business of collecting premiums and denying claims, but I bet my employer is in the business of getting their money’s worth. I send the entire file to Human Resources including a cover letter that tracks the appeal process. I write that all I want is coverage for the 20 visits annually outlined in my contract and I would expect to pay out of pocket after that. If this denial of claim does not match the expectations my employer had when they hired this insurer, I ask that they intervene on my behalf.

A month and a half later, I receive a check for $665.60 in the mail, reimbursement for the 9 months of denied claims that I’ve submitted during this process. This time the cover letter has only this brief statement:

*Remark code 22: We have reconsidered these charges because of additional information we received.*

I bet they got some additional information! I guess it’s true what they say—it’s the squeaky wheel that gets the grease and $665 is a lot of grease. I send a thank you note to the head of my employer’s Human Resources Department.

This journey through pills, procedures, and paperwork is teaching me something. I had thought of illness as something that happened to me, like an attack from an unseen enemy—that snake in the mist. My work with my physicians is teaching me that this illness is me. Not all of me, but a big part of me. I’m learning that what I must think of as *me* includes the
mind, the body, and the spirit all together and this union is a lot more complicated and interdependent than I realized. I am reminded of all my years studying ballet and how I was taught to perform through injury and pain, to use my mind to deny the body. Although this denial is at the core of the grueling discipline of classical ballet, I realize now I must unlearn that skill. Instead, I need to listen to my body and respect my limitations. I need to live within them. I’m just at the beginning of where this experience might take me, but I am learning and I am changing. I am no longer just getting sick; I am learning how to be sick—the best I can.
Most patients come to see a rheumatologist only after seeing many other doctors. They have had many tests. They are often tired, scared, frustrated, and in pain. Their trust in physicians is low and their hope that they will find answers diminished. They know stress makes them feel worse, but since they don’t understand what is wrong and why they got sick in the first place, they are confused and understandably stressed. Does this sound like you now? To help, I need to start by listening to your story. Your story is the most important data for making proper diagnoses. If I learn from your story that you are in the Getting Sick phase, I might ask, “Do you feel stuck?”

If your answer is yes, I offer this analogy. Let’s say you’ve been driving down the road in your car enjoying the scenery, when suddenly you hit a bump, swerve, go off the road, and find yourself stuck in a muddy ditch. You push on the accelerator, but instead of the car moving forward, your tires spin. You try again, pushing harder on the accelerator, but the tires whirl and your car digs down even deeper. You don’t understand why you can’t get out of the ditch; you are doing what has worked for you in the past. Then you hear an awful new whine. This noise worries you, but you are not aware that pushing on the accelerator is causing it.
The tires spinning, the wheels digging deeper, and the whining noise as the engine begins to overheat are all mounting warning signs. You might hear these sounds, but maybe you aren’t really listening to them. Listening is a deeper effort and involves trying to understand meanings and looking for patterns or explanations. Why aren’t you listening? Perhaps it is because these sounds are brand new to you. Perhaps you are distracted by frustration, or worried about being late. Maybe the only thing you can hear is that voice in your head saying that whatever is going on is all your own fault.

Many new patients come to me after their car has been stuck in the ditch for so long that they feel exhausted and defeated. They fear the worst. They’ve tried and tried to find answers and get well, with no success. Some have endured months of treatment for the wrong diagnosis. Maybe friends, family, co-workers, or other health care providers have suggested they weren’t trying hard enough, their symptoms were all in their head, or they were just depressed. This overwhelming pile up—a lack of experience with illness, worry, frustration, and blame can understandably prevent patients from recognizing they are spinning their wheels and digging themselves deeper and deeper into the ditch.

By the time they get to me, patients often feel defensive and resist any suggestion of mine that anything they are doing might be making their illness worse. I try to reassure them that managing their illness is not only about trying hard. It’s about how illness, like that stuck car, is affected by how we deal with it. If patients are unable to communicate effectively with their physician, family, friends, and other providers, the team that might be able to assist them can also become stuck ankle deep in mud, some pushing, others pulling, and everyone out of synch.

There is a complex relationship between the events that cause an illness and factors that perpetuate, or aggravate, it. Returning to the stuck car analogy, there may be pre-existing factors different from those that forced a person into the ditch that will make getting out more difficult. These may be things no one noticed, like thin treads on the tires or a near-empty gas tank. Maybe the oil was low and needed to be changed, or the engine needed a tune up. All these factors, in addition to the event that sent the car
off the road in the first place, may be contributing to a patient’s difficulty in getting unstuck and back on the road again.

So how might I help you? I am not a tow truck, after all. First, I can throw sand under the tires by diagnosing and treating problems. I can call for help by coordinating an integrated care program and communicating with your family, friends, and other clinicians on your behalf. Perhaps we need to add oil, its absence having caused the engine to overheat, similar to how low brain serotonin levels may lead to inflammation, anxiety, or depression. I can teach you how to listen to what your car is telling you through mind and body awareness, and relaxation and movement therapy.

I must help you take one more essential step. You must learn to drive differently. A chronic illness requires that you accelerate slowly, feel for traction, and ease off the gas pedal if your tires start to spin. You must realize that proper maintenance and repairs take a finely tuned team. Maybe you’ve reached the point where you feel you have tried everything and now you want it all to be up to me. Just figure it out and fix it! Sorry, I cannot drive for you or pull you out of the ditch all by myself. I am willing to be your team captain, but I cannot do for you what you must learn to do for yourself, and I am only one committed member of the team you need to put in place.

This first phase, Getting Sick, is about crisis—the crisis of not knowing what is happening to you, not having a doctor you can trust, not being able to find a diagnosis [1]. People are unique; they may have defined injuries or triggering events, or they have been on a slow slide into sickness, but what they all have in common at this stage is fear. What they are missing is hope. Creating hope is my job, so here are some Travel Tips that might help you, like Joy, find that hope and move out of the frightening crisis phase of Getting Sick.

**FREE YOURSELF FROM THE PRISON OF FEAR**

In this first phase, Getting Sick, Joy goes through many emotional stages and must work out her own strategies to move
through them. In “Snake in the Mist,” Joy describes the fear of the unknown, the fear of never getting better, and the fear of death. Joy is not a lightweight. She has fought and won several skirmishes with physicians. She has learned to cope in her personal and professional life, but illness has taken its toll.

Adrenaline is the fuel for the fight and serotonin the buffer of stress, but Joy has been fighting so long trying to deal with chronic pain, fatigue, doctors, and tests, her adrenaline and serotonin are low. Without these fuels, an even greater fatigue develops and Joy feels paralyzed. Some might describe Joy’s state as clinical depression, but she is really experiencing the deeply rooted fears of the dark, the unknown, and of death that most of us retain from childhood. She writes, “I’m afraid of this dense dark, and I’m dismayed that I am powerless to penetrate it even slightly. I fear that there is something out there that I can’t see, like a snake in the mist, coiled and waiting to strike at me. The truth is, I am just afraid.”

What are your greatest fears? Is it that you can’t find a doctor who will listen to you and acknowledge your suffering? Or that a curable illness is being missed? Do you fear the challenge of personal change that is required to cope and to give your body a chance to heal? Are you afraid of telling your friends that you are sick or trying to convince your family that your illness is real? Are all these fears connected to still deeper ones—the fear of death, or the fear of dependency, or the fear of suffering? Dr. Rachel Naomi Remen, author of Kitchen Table Wisdom [2], is frequently quoted, “Healing may not be so much about getting better, as about letting go of everything that isn’t you—all of the expectations, all of the beliefs—and becoming who you are.”

On the night Joy sat out on that damp, misty porch, she had just spent the evening with friends who hugged her and said the right things, but she was still alone and she needed to be. Joy needed time with herself to come to grips with her fears.

After time of reflection, Joy found that her deepest fear was, “I-am-afraid-I-am-going-to-die.” Is this your deepest fear? Ernest Becker wrote a 1974 Pulitzer Prize winning book, The Denial of Death, which helps us understand that the fear of death drives many of the ways we behave as individuals and societies [3]. There is a silver lining, however. Coming through this crisis and learning to deal with your fear of death are critical to your ability
Dr. Overman on Getting Sick: The Stuck Car

DECEIVE ON YOUR STRIKE ZONE AND CALL A STRIKE WHEN YOU NEED TO

In “Three Strikes,” Joy is looking for a physician. She is similar to many chronically ill patients I have seen, very sensitive about being believed or being told her symptoms aren’t real. It is understandably easier for doctors to deal with illnesses they can monitor with measurable laboratory tests. When presented with a patient complaining of vague symptoms that are difficult to accurately diagnose or treat, some doctors react by becoming skeptical. This skepticism says more about the doctor than the reality of the patient’s symptoms. It is easy for a physician and a patient to misunderstand each other, but it is primarily the responsibility of the physician to be the listener and to acknowledge the patient’s reporting and suffering. Unfortunately, there are abundant stories like Joy’s about practitioners who aren’t respectful listeners. If this happens to you, or if you find yourself dealing with this kind of physician, practitioner, or health care provider, let Joy’s title “Three Strikes” be a reminder of three important things she does.

First, she acknowledges communication is not a perfect science and gives the doctor three chances. Second, by calling the strikes she makes it clear that she is in charge. Third, Joy decides on her own strike zone of minimally acceptable behavior, starting with calling her first strike on the doctor’s chronic tardiness.

Once her batter strikes out, Joy demonstrates a willingness to move on. Looking for another physician can be risky. Patients can be perceived as doctor shopping because they didn’t hear what they wanted to hear. Changing doctors can also be costly in terms of co-pays, repeat testing, time and energy, but Joy knows what is important to her and is willing to keep looking until she
finds her match. She believes she has the right to choose a health care provider she can work with and trust. So do we all.

**TO GET THE HELP YOU NEED, UNDERSTAND THAT YOUR MIND AND BODY ARE CONNECTED**

Many patients come see me for the first time when they have had pain symptoms for many months, and are understandably discouraged, perhaps even in despair. I might start a visit like this by saying, “There are very few patients who come to see me who are not candidates for a trial of Prozac.” You undoubtedly know that Prozac is an antidepressant and you may immediately feel confused and upset. Why would I say this? Do I think you are depressed? Not necessarily. Do I think your symptoms are psychological or emotional? No. So why?

Many individuals with difficult to diagnose illnesses are made to think the problem is in their heads or that they are making up symptoms to get attention. While I almost never see someone that I think is malingering, or making up symptoms, it is critical for you to understand how the mind and body do affect each other. I try to create an opportunity to discuss this without putting a person on the defensive. While my responsibility is to diagnose and treat medical conditions, I know true healing will depend on your ability to help your body to stabilize, balance, and restore. Beginning this conversation before I know you well allows me to speak in generalities, not specifically about you. You get the opportunity to understand how I think and to discuss concerns and biases you might have in a nonjudgmental way. I want to help you understand the chemical and coping aspects related to healing, and I hope this will lay the foundation for a trusting relationship with me.

I start by discussing serotonin, the natural brain chemical that is increased by Prozac and other drugs called selective serotonin reuptake inhibitors. Serotonin helps buffer all types of stress to our bodies, and it also modulates many other body and brain chemicals and immune system functions. I can summarize a vast amount of research in this area with the simple statement, “The mind and the body ARE connected.” We know
that frustration, anger, sleep disturbance, and reduced exercise or sunlight may reduce serotonin levels, but there are no blood tests to easily measure these effects. Sometimes only a treatment trial can tell me if your condition could be improved by boosting serotonin levels. Therefore, I may suggest you try one of these medications without diagnosing you as depressed, to see if you experience reduced symptoms or an improvement in your sense of well-being.

About thirty years after Prozac came into the market, an article was published in a leading arthritis journal that described its anti-inflammatory properties in humans and mouse models with rheumatoid arthritis. This remarkable finding further adds to the wide number of balancing affects outside the brain that serotonins and medicines like Prozac play throughout the body.

Often persons with new illnesses are more anxious about what they don’t know than what they do know. Even after getting a diagnosis for their illness, individuals frequently don’t know what actually caused it or what the future may hold. They describe their frustration at being unable to plan for tomorrow, or next week, or next month. They worry that they will let their families or employers down if they commit to do something, only to have their symptoms flare up so they are unable to meet that commitment. Will they be able to continue school and graduate? Are they going to lose their jobs? Will this illness become chronic?

Conversely, some people start to feel guilty when they have a good day and have not committed to an activity they could have performed on that day. As an illness does become chronic, feeling good can be as emotionally difficult as feeling bad. Whether to do more or to do less is a question that carries risks in both directions.

Individuals deal with the stress of illness in many different ways, but many will go through a time when they feel depressed and be overcome by a feeling of hopelessness or a loss interest in doing things. Other symptoms of depression are poor sleep, fatigue, and difficulty concentrating. In these cases, it can be hard to sort out the symptoms of illness versus the depression due to illness. Some patients create a mental barrier that allows them to deny or resist paying attention to their illness. The cost of this effort can become so overwhelming that they feel numb
and fail to acknowledge they are ill at all. Psychologists describe this type of coping as internalization or denial. If hopelessness or denial leads you to a dangerous disinterest in living, then it is an important and positive next step to get professional assistance to help regain control and to find a way out of your despair. If your physician refers you to a psychologist and psychiatrist, it does not mean your illness is not real, but it may mean your illness is overwhelming and you need some help in coping with it. Studies have shown that the combination of medications to treat your symptoms and professional help in coping are more effective when combined than either one is alone.

During the Getting Sick phase you might also have problems in the social domains of illness—at work, with family members, and with insurance companies. It is appropriate to ask the members of your health care team to advocate for you and help educate others. Bring your family to appointments so they can understand what is going on. Some family members become overly protective, while others try too hard to solve your problems and sometimes become angry when they can’t. Counselors or physicians can assist your loved ones in understanding where and how they can be most helpful. A disability counselor can help you understand your rights under the Americans with Disabilities Act of 1990 and work with your employer to prevent misunderstandings. As the saying goes, an ounce of prevention is worth a pound of cure, so it is important for you to get any help you need as soon as problems surface to ensure communication remains open and clear with family members and employers.

SEEK A DIAGNOSIS AND BEGIN TREATMENT

I have heard a number of patients interpret the term chronic illness to mean, “There’s nothing to be done, so I will just have to learn to live with it on my own.” This is only half true; when an illness becomes chronic, it does require learning to live with it, however it does not and should not mean living with it alone. Further, chronic doesn’t mean there is no effective treatment because most of the time much can be done to ease symptoms
and help the body improve balance. For example, rheumatoid arthritis is a chronic illness with many therapies, both old and new, that can bring considerable improvement to most patients and even arrest joint destruction and prevent work disability.

In order to help you during the Getting Sick phase, we must first try to figure out your medical diagnosis and begin a treatment plan. This can be a complex process. We just talked about symptoms caused by an understandable depression. Other symptoms can be caused by an imbalance of the immune or metabolic systems rather than by the underlying disease. So, instead of discussing all the possible diagnoses and the ways doctors think about symptoms, I want to illustrate how we can work together to improve your health and help you cope.

First, you must tell me your story. In medical school we are taught that 90% of making a diagnosis comes from the history, which is what we call your story. You may get tired of telling yours over and over, but it is the most important time of our work together. From your descriptions, a review of past tests and an awareness of prior physician’s opinions, I look for connections and a common picture. It’s like trying to put a puzzle together when there may be some pieces missing from the box. For example, not everyone develops a full-blown condition. Having a partial form of a condition may mean its symptoms are milder, but it is even more frustrating since it’s harder to diagnose. Each part of your story provides a unique piece of information. As we work together, I may have to do a lot of rearranging of the puzzle pieces because the clues I find may not be specific for one disease. Many diseases and syndromes have symptoms in common, so we frequently must look closely for other clues that might lead us to a diagnosis. I am interested in your family history, the factors that aggravate or alleviate your symptoms, and even what you think might be going on. It is my job to look for patterns that could be explained by one diagnosis, and other patterns that might indicate multiple conditions that have colluded together to create an unrecognizable clinical syndrome. I even want to go back to when you were a child to see if you have had prior traumas or infections, which might have triggered a chronic process, or to see if you had an undiagnosed illness that might relate to your current problems.
Once I have your history, I will order tests. Many patients who know they are ill become frustrated when test results come back normal. We expect modern medicine to be able to identify or measure all abnormalities, but the reality is that it can’t. For example, we can’t yet measure whether your brain or other tissues have enough serotonin. Other factors like cytokines, the communication chemicals between immune cells, can be measured by researchers but are not routinely available for practicing physicians. Due to the fact that your illness may wax and wane, abnormalities can appear and disappear, so on any given day test results that previously showed abnormalities may return to normal.

I order more tests as I add pieces to the puzzle. These puzzle pieces include results from the first round of tests, your response to initial treatments, and your own new insights about associations between activities and symptoms. All of these factors influence the picture I see and prompt the second and third round of diagnostic tests I will order. Many common conditions present themselves in unusual ways, and conversely, some rare conditions masquerade as common. For example, celiac sprue is a condition where the immune system reacts against gluten, a protein in wheat. The classic set of symptoms for celiac disease include diarrhea. However, I have seen individuals with sprue whose major symptoms are fatigue or aching joints, or they present with asymptomatic osteoporosis. These patients won’t complain first of diarrhea. In order to solve the mystery of their illness, I have to consider the less common complications of celiac illness before I would think to order celiac tests. This process takes time and care on the part of the patient and the physician, constantly relooking at the whole picture to see if a new pattern is revealing itself.

Sometimes patients respond to one of my therapy suggestions by saying, “I’ve tried that before and it didn’t work.” They have lost faith not only in a treatment, but also in the doctor who first ordered it. Sometimes patients provide a long list of remedies they have tried, and are unwilling to try again. These repeated failures have left them feeling stalled, frustrated, and hopeless. However, just because a therapy did not work once, doesn’t mean that it should go on a black list of treatments never
to be tried again. When it joins other therapies as part of a new effort, at a different time, and with a new team, the results may be more successful. It is like making vegetable soup. There are as many different ways to make the soup as there are cooks and ingredients.

BUILD A SUPPORTIVE HEALTH CARE TEAM AND BECOME A TEAM PLAYER

A trusted physician doesn’t have to meet all your needs, but he or she can be the leader to help you build your team and advocate for you. Other doctors or therapists will give you medicines, provide hands-on care, offer injections, or suggest surgery, but they all need to understand and integrate into one overall treatment plan led by your principal physician.

There are two things you have the right to expect and demand from every practitioner who treats you:

1. Open and detailed discussions with you, answering all your questions and helping you feel heard and in control.
2. Consistent communication with your principal physician and active integration of his or her recommendations into your comprehensive care plan.

This is what integrated care means—many clinicians and professionals working together to help you develop one roadmap for care. This roadmap should be updated continuously as you move through the phases and cover all four domains of life that your illness impacts. The four domains are:

- physical or medical
- emotional or psychological
- family or social
- spiritual or existential

As your principal physician, or team leader, this four-part perspective helps me think about the types of treatments and support I need to offer, what your other providers are offering,
and in what areas you might need to improve your skill and confidence.

Another way I look at integrating care among your many providers is to divide your therapies into three parts: Those done TO YOU; the self-care and therapies that involve YOU FOR YOU; and the strategies that involve YOU AND OTHERS. For each pill, procedure, or hands-on therapy prescribed by your practitioners, the TO YOU, I suggest that you identify and write down a parallel YOU FOR YOU self-care activity that you will engage in to complement it. And then, for each phase of your care, consider how you can modify your relationship with others so they can better help you. These are the YOU AND OTHERS conversations with loved ones, friends, or work associates that can be stressful, but are necessary.

Remember the Stuck Car story and my comment that you may need to learn to drive differently? This means that you must consider and discuss with others how your conventional wisdom may not be working anymore. Do you need to learn how to experience and understand your body differently? What behaviors do you need to change and how can this help you? This responsibility on your part speaks to the reality that your doctor can’t do everything, and that you need to be an active member of the team, too. During the next phase of Being Sick, you will learn that you are not only on the team, but need to be at the center, like the hub of a wheel with many spokes of support.