

◆ CHAPTER ◆

1

The Empowered Patient

This chapter relates how five individuals struggle with their rheumatoid arthritis.

THE BIRTH OF VENUS

Ever since 1477 when Sandro Botticelli painted her, 16-year old Simonetta Vespucci has mesmerized the crowd that comes to pay homage. She stands on an immense scallop shell. Her amber eyes gaze into the distance. She dreams. Strands of red hair cascade down her back, waft in the wind, and ineffectively shield her voluptuous body. She is Venus, the goddess of love and beauty. Sandro Botticelli painted her as she emerged fully grown from the depths of the blue Mediterranean.

The real-life Simonetta might not have felt as serene as she looks. Doctors have examined the figure's slightly deformed fingers, the sausage-like enlargement of her left index finger, and her swollen ankles and believe that the world's most beautiful woman suffered from rheumatoid arthritis. The young lady died of tuberculosis soon after Botticelli depicted her in this and two other canvasses. All three were painted to celebrate a major Florentine festival.

It took half a millennium before the nature of Simonetta Vespucci's disease was clearly identified. Both *rheumatism* and *arthritis* are old terms. In *The Merry Wives of Windsor*, Shakespeare talks of a "raw, rheumatic day," because even then arthritis and rheumatism were associated with

6 ♦ The Hospital for Special Surgery Rheumatoid Arthritis Handbook

damp weather. During the 16th century, the French physician Guillaume was the first to associate the word *rheumatism* with joint ailments.

For centuries, doctors lumped all disorders involving joint pain together. Thomas Sydenham (1624–1689), one of medicine's great investigators, began sorting out the mix and provided an accurate clinical description of what might have been rheumatoid arthritis. The term *rheumatoid arthritis* was coined by A. B. Garrod, another English physician, in 1858.

Medical X rays, which made their debut in 1895, enabled physicians to actually look at hard structures such as bones and joint tissues and see the damage arthritis wrought in their patients. The belief that rheumatoid arthritis is the consequence of some bacterial infection was prevalent at the beginning of the 20th century. It serendipitously led to the discovery of several useful treatments, most notably gold and drugs used to treat malaria.

In 1940, the rheumatoid factor that is present in most patients suffering from rheumatoid arthritis was simultaneously discovered in Norway and at Columbia Presbyterian Medical Center in New York. By then, physicians were aware of the inflammatory nature of rheumatoid arthritis. In 1940, Bernard Comroe, an American physician, coined the term *rheumatologist* to designate an arthritis specialist.

It is understandable that the great variability of the disease's presentation and course, together with its fortunate, albeit rare, ability to go into remission, made it difficult to recognize its nature. Even today, rheumatologists are uncertain about the course the disease might follow in any particular patient.

Like most chronic disorders, rheumatoid arthritis is ideally suited for self-care. Its management involves a variety of facets. Before embarking on a review of these aspects of care, we shall visit with five patients who, like Botticelli's Venus, lead full, satisfying lives in spite of serious rheumatoid arthritis. Details of their treatment are in later chapters of this book.

MARION I.¹

Marion I. storms up Broadway on her way to lunch. A graduate of Cornell's Hotel School, Marion is now an executive at Delta Airlines. She is in

¹Except for Venus, everybody in this chapter is real and facts are based on interviews. To protect privacy, names and certain characteristics have been changed.

charge of arranging hotel accommodations for the company's ever-expanding, all-inclusive vacation tours. Marion just returned from the West Coast and is about to travel to Europe for a meeting with other top-level executives. "Jet lag does not affect me," she says in an offhanded manner.

Sports—swimming, skiing, hiking—were always important in her family. When time did not permit her to plan activities, Marion jogged regularly. Twelve years ago, she was working as a hotel consultant in Los Angeles. Most mornings, she raced up and down that city's steep hills. One day she injured her knee. She was 26 years old.

"I had torn my meniscus and needed arthroscopic surgery," she recalls. An arthroscope is a small fiber-optic surgical instrument used for diagnosis and minor joint surgery. The procedure usually does not require hospitalization, and patients are up and about within a few days.

After the surgery, Marion recalls, her knee did not heal. "When the physician investigated, he discovered that my sedimentation rate was sky-high."

A few more tests confirmed that Marion had rheumatoid arthritis. She was in pain, especially at night. "I was terribly stiff—so stiff that I could not even lift my blanket. My feet hurt; my fingers and elbows were excruciatingly painful. The doctors ordered splints to prevent my wrists and hands from becoming deformed and prescribed aspirin, Feldene, and other stuff to reduce the inflammation. Nobody had told me that I had to take these drugs with food, so my stomach revolted.

"I discovered that I was feeling better as long as I moved about. So when I got a bit better, I quit my desk job. During the next 6 months, I just traveled. Then my money ran out."

Marion moved to Canada, found a new job, and became a patient of Dr. Smith, a world-renowned rheumatologist. Her doctor decided to try gold shots. Gold, derived from the precious metal, has been used successfully for selected rheumatoid arthritis patients since the 1920s. In approximately one-third of cases, gold appears to cure arthritis. Actually, certain drugs induce a remission, which means that the rheumatoid arthritis is present but its symptoms are dormant.

Marion developed a severe allergic reaction to the specific gold preparation Dr. Smith used. Fortunately, doctor and patient persevered. Another gold preparation worked, and Marion went into remission. This was 10 years ago, and she has been fine ever since. She is still conscientiously taking a gold shot every 5 weeks. From time to time, she and her physician discuss discontinuing the gold, but they never quite dare. "What if the rheumatoid arthritis comes back?" Marion wonders.

8 ♦ The Hospital for Special Surgery Rheumatoid Arthritis Handbook

Even though Marion only had active rheumatoid arthritis for 2 years, her body exhibits its ravages:

“My feet are all crippled,” she says. “I have hammer toes. The tendons in my feet have shifted, and my elbow is very weak.

“I try to protect my body as best I can, and do exercises and sports in moderation. I am extremely careful not to overdo things. I try to ignore my rheumatoid arthritis, and when friends ask whether I am depressed because I have RA, I tell them that compared to other chronic disorders, RA is not that bad.”

“My daughter refuses to be defeated,” Marion’s Chicago-based father says. “We are grateful that the gold worked. Still, it was a terrible shock when we learned that our child was suffering from a chronic, potentially crippling disease. With hindsight I regret that I did not hop onto a plane when she became sick and that she had to handle her acute illness by herself.” He, however, hopes that he will never have to put his “hindsight” to the test.

JANE M.

“I can’t talk today,” Jane M., the editor of the *Rockland News*, says. “I am off skiing—the first time in 2 years.”

Six years earlier, as Jane got out of bed, her feet felt incredibly stiff. She limped downstairs and went to work. A few weeks later, her knees felt stiff. Then it was her hands. By Christmas, she could no longer hold a pencil.

“The pain just flew around my body,” Jane recalled. “I was turning into the Tin Man.”

Jane went to her primary care physician at her small local hospital, who prescribed Voltaren, one of the newer nonsteroidal anti-inflammatory drugs (NSAIDs). She also talked to her father, a board-certified rheumatologist. Both physicians suspected that she suffered from rheumatoid arthritis.

That spring, Jane and a friend were to tour China. “I flew to the West Coast, and when I emerged from the plane after the long and painful ride, my friend was shocked. In spite of the incredible stiffness, I carried on and had a wonderful time.”

When Jane got back home, she had a proper diagnostic workup. She did have rheumatoid arthritis, got a shot of cortisone, and eventually took methotrexate.

“I went into remission. But I don’t trust methotrexate, and after a year I tapered it off. I was well for 2 years, but then my rheumatoid arthritis

came back. Now I am back on methotrexate and I am doing better. I am scared of methotrexate and don't take my full dose of it, but I am increasing it slowly. I expect to be fine."

REVEREND B.

Methotrexate also made a big difference to Reverend B., the retired rector of Grace Church in Brooklyn. Eighteen years ago, when he was 50, he had trouble walking and "felt stiff all over."

The reverend's mother had suffered from rheumatoid arthritis, so he guessed that he, too, had the same disease. A few tests confirmed his self-diagnosis. It did not upset him, since his mother lived to be 87.

Reverend B. had easy access to excellent therapy in New York. He started taking aspirin, followed by Indocin, an older NSAID. Both medications upset his stomach. Then his physician suggested gold injections. After a few rough months, during which he also received corticosteroids and therapeutic exercises, his rheumatoid arthritis subsided.

Reverend B. served his church for 26 years. Three years ago, he retired and moved to his grandfather's old summer place in Vermont. "It is great living here," he said. "I have known this place all my life and it is like coming back home."

To keep in shape, Reverend B. walks a couple of miles each day. He has not quite given up the pulpit. He serves as a guest minister at various congregations throughout New Hampshire. Even though his disease had responded to gold, his New Hampshire rheumatologist switched him to methotrexate. "It is a wonderful pill," Reverend B. says. "Much better than gold. Instead of those endless injections, a weekly pill does the trick."

The rheumatoid arthritis, however, has left its marks. The reverend's fingers are deformed and cannot wield a tennis racquet. He has trouble with small hand movements and recently he underwent hand surgery that improved function.

Still, he is grateful and advises his fellow sufferers to find a good doctor, follow medical advice, and do as much exercise as possible.

SAMANTHA F.

Not everybody with rheumatoid arthritis does as well as Reverend B., Jane M., and Marion I. Samantha is a lawyer, working for a large multinational corporate firm. Her office is in downtown New York. Whenever

10 ♦ The Hospital for Special Surgery Rheumatoid Arthritis Handbook

she can, she takes cabs to work. When her arthritis is extremely bad, she works from home. Samantha is in charge of the firm's shipping contracts, and she works with phones and computers. Her smiling face, sparkling blue eyes, and relaxed expression are a pleasure to behold. Her features also belie the fact that excruciating pain has dominated her for 20 years.

"Nobody believes the amounts of the narcotics oxycodone, Demerol, and morphine that I require when I am in extreme pain," she explains. "As a matter of fact, I have a letter from my doctor which reassures unfamiliar physicians that it is all right to prescribe such large doses," she says.

Illness, no matter how severe, has always been only one part of Samantha's life. She has always worked. She raised her son, Charlie, as a single mother, and now lives on her own.

"I had my first rheumatic flare when I was 30 and was 3 months pregnant," Samantha recalled. "This in itself is unusual. Rheumatoid arthritis usually vanishes during pregnancy. At first, I did not pay much attention to my discomfort. I took my bar exam when I was 5 months pregnant. At the time, my two thumbs were killing me. I simply splinted them to cocktail forks. That relieved the pain. I passed the bar, gave birth, and stayed home until Charlie was 1 year old.

"By then I knew I had some form of rheumatoid or inflammatory arthritis. My husband left, I went back to work, and Charlie and I carried on as best we could."

From the beginning, Samantha took charge of her illness. She is an expert at self-care. Her freezer is full of gel packs, and her kitchen drawers are loaded with various splints. Samantha owns a TENS (transcutaneous electric nerve stimulation) machine. (The instrument delivers low-intensity electric impulses that relieve pain by an unknown mechanism.) She is knowledgeable about antiarthritis drugs. Over the years, she has taken all of them: aspirin—"until I developed an ulcer"—most of the 20-odd nonsteroidal anti-inflammatory drugs as soon as they were approved by the FDA, gold, penicillamine, and, of course, corticosteroids (see Chapters 7, 8, and 9). "You name it, I took it," she says. "Right now, I am trying methotrexate for the fifth time, and perhaps it will work. I have had a very good 2 months."

Samantha is not afraid of becoming addicted to painkillers. "I am very careful about what I take, and when. I hurt too much to experience any kind of high," she reflects.

Samantha's excellent relationship with her rheumatologists demonstrates that good medical care for a complex disease such as rheumatoid arthritis is based on a true partnership between doctor and patient. Dur-

The Empowered Patient ♦ 11

ing the past 20 years, Samantha has had to deal with more than one arthritis specialist. When her all-time favorite physician relocated to the National Institute of Arthritis and Musculoskeletal and Skin Diseases in Bethesda, Maryland, she almost moved to Washington herself.

From the beginning, Samantha's arthritis has been atypical and unremitting. She experiences unusually severe inflammatory flares when a part of her body simply gives out and she cannot even stand up unaided. Once, when Charlie was still an infant, Samantha could not get to him when he woke up in the middle of the night. It was a terrible night for the two of them and Samantha swore that it would never happen again. After that, she made sure that crutches, a walker, and other self-help devices were within reach. Today, she parks her electric scooter next to her bed.

Samantha knows that her disease was hard on Charlie. "I worried about him growing up feeling responsible for me," she says. He now works full-time at a New York brokerage firm. He is 20 and has his own apartment. Samantha hopes that he realizes how important he is to her. "My son makes me smile," Samantha says. "Having to care for him made me get up in the morning."

Ten years ago, Samantha had breast cancer, and a few years ago, she went into kidney failure. "I wish that I could trade in my body," she says. Her body perhaps, but not her spirit. Like many other people with rheumatoid arthritis, her spirit is indomitable.

"It is so easy to become a patient," Samantha explains. "I refuse that role. I am me." Over the years, she has become softer: "The disease has humanized me. It has brought good people into my life, though I do get impatient when they complain about unimportant things in their lives. Nevertheless, I have learned to ask for help when I need it. I have learned to leave things undone. Nobody can help me when the pain is extreme, but I have learned to deal with it.

"When Charlie was small, my mother was distant. Today, when I am in pain, she is a real help. She is 85 years old now and lives in California. It's 3 hours earlier there, so I can call her in the middle of the night and complain. She had to learn to simply listen, not to mother me, not to promise that things will be better, and not feel sorry for me.

"Ten years ago, I started to sing. I discovered the healing power of hymns and black choral music, and I branched out from that. Friends come over and sing with me. I sing when I hurt and when I feel good. I wish that I could join a chorus, but my disease is too unpredictable for that. I also write poetry when I hurt. The first line always reflects my panic, but gradually as I write, the mood of the poem lifts.

12 ♦ The Hospital for Special Surgery Rheumatoid Arthritis Handbook

“When I am in pain, time passes very slowly. I watch a clock and it barely moves. Distances, like a long hallway, look totally overwhelming when I hurt.

“I guess it is the unpredictability of the disease that is hardest to take. I don’t even know what part of my body will be affected next. I find it hardest to deal with in between pain. When the pain is extreme, I know that I will have to wait it out, and when I feel good, I feel good.

“Sometimes I truly wish that I were rich enough not to work. Chronic disease is awfully expensive. I have a decent salary and good insurance. But still, there are taxis and drugs and deductibles and inlays for my shoes and phone bills... There is no end to it. But basically I know that my work is important to me. I go to the office when I feel good and work at home when I don’t.”

SERENA P.

You cannot tell from looking at her that 40-year-old Serena has severe, unremitting rheumatoid arthritis. She is perfectly groomed and greets everyone with a warm smile. She is scared of her disease because she watched her mother suffer from it.

Serena worked as a shoe sales clerk when her feet started giving out. She went to a podiatrist, who said that she had fallen arches. Soon, however, the pain spread to her ankles, knees, hips, and shoulders. She went to the emergency room at her local hospital. An increased sedimentation rate and a positive rheumatoid factor confirmed what Serena already suspected: She had rheumatoid arthritis.

Serena tried every drug developed for arthritis: ibuprofen, Voltaren, naproxen, prednisone, Plaquenil, ketoprofen, minocycline, methotrexate... Some of these drugs helped, some made her sick, and some scared her. “[Methotrexate] helped, but my hair was falling out and I was really getting scared,” she recalled.

Serena’s worst joint is her hip. “It keeps me from sleeping at night. I just can’t seem to get comfortable.” She will have hip surgery, but her muscles are weak from disuse. She needs to strengthen the muscles surrounding her hip as well as her arm muscles so that she can walk on crutches. Currently, she goes to physical therapy twice a week.

Serena is an expert at doing things for herself. Her toilet is equipped with a raised seat, and her shower has a stool. She puts on her stockings with garters attached to elastics and uses a long shoehorn for her shoes; she picks objects off the floor with a scissor-like reacher.

The Empowered Patient ♦ 13

She, too, does not want to be a patient. “The hospital would send an ambulette for me,” Serena explains, “but I prefer taking the subway.” She keeps a spotless home for her brother and has as much fun as she can.

“I love to dance to all kinds of music—fast, rhythmic, slow. I can only dance 30 minutes or so, then I have to rest. I play cards almost every night.

“I have many friends and talk to them about my disease. I tell my fellow sufferers to stay strong, to keep their clinic appointments, and not to listen to quacks.

“Everybody always tells you that they know how to cure your arthritis. I do some of the stuff they recommend, like drinking herb teas or garlic, but I really know better.

“They tell me that I am much too young to have arthritis. I sometimes think so, too, but ever since I was a child, I figured that I would get arthritis. My mother came down with rheumatoid arthritis when she was 23 years old, and my grandma down in Alabama had some kind of arthritis. So I was not surprised when it hit me, too.”

“I wish that I could go back to work,” she told her physical therapist during her twice-weekly sessions. Then she lowered her expectations: “Perhaps it will at least be easier to keep house after they fix my hip,” she sighed. Then she stretched out on the exercise mat and worked hard at strengthening her joints under the watchful eye of the therapist.

THE NEW APPROACH TO ARTHRITIS CARE

Though their arthritis varies in extent and intensity, the patients in this chapter share important characteristics:

- ♦ They are well informed about their disease.
- ♦ They trust their physicians.
- ♦ They are the captain of their medical team.
- ♦ They are in control, which is particularly important when dealing with an unpredictable, painful disease such as rheumatoid arthritis.

Control does not mean that you should go it alone. Effective management always rests on picking able partners. Before helping you to understand what is currently known about rheumatoid arthritis, let us provide you with the following 10 guidelines that will allow you to be a confident, empowered patient who will triumph over your disease:

14 ♦ The Hospital for Special Surgery Rheumatoid Arthritis Handbook

1. Select your physician carefully.
2. Prepare for visits to the doctor's office.
3. Be well informed.
4. Obtain your medical reports.
5. Understand your drug therapy.
6. Understand your health insurance.
7. Maintain your treatment regimen.
8. Fight depression.
9. Keep an open mind.
10. Accept the fact that you are suffering from a chronic disease that requires some lifestyle modifications.

1. Select Your Physician Carefully

This is your most crucial decision, and it has unfortunately become more difficult with the advent of managed care.

It is absolutely essential that you like and trust your physician. Research has proven that patients suffering from rheumatoid arthritis always feel better after they have seen their physician, even if their treatment has not been altered.

Your physician should be associated with a good hospital. Most RA patients require physical therapy. Some may require occupational therapy, surgery, or other services from specialists. Your life will be simpler when these services are available at the hospital with which your physician is associated.

2. Prepare for Visits to the Doctor's Office

Visits to the doctor are stressful. You and your physician are busy people. To efficiently use your time, prepare a list of what you wish to discuss with your doctor (see Chapter 2).

3. Be Well Informed

You must become an informed consumer of medical care. Information about health and disease has exploded during the past decade. The bookstore shelves are bulging with good and bad self-help books. Television bombards arthritis patients with ads for over-the-counter medicines. Med-

ical advice pours from the Internet. Newspapers, magazines, and specific disease-oriented newsletters keep you abreast of the latest developments. (For sources of information, Web sites, etc., see Appendix A) Be critical about this massive amount of information. If in doubt, discuss it with your physician.

Knowledge is important because your physician will insist that you participate in important decisions concerning your treatment. In addition, some aspects of medical care have become confrontational and sometimes even adversarial. Today, patients must sign informed consent forms before undergoing certain procedures such as surgery or taking certain experimental medications.

However, do not let these informed consent forms scare you unnecessarily. By law, every new drug consent form has to list every side effect it may cause; surgical consent forms must list every possible mishap. Taking the most cautious route may not always be the best option. To prevent permanent joint damage, rheumatologists often opt for aggressive treatment early in the course of the disease.

4. Obtain Your Medical Reports

It is helpful to obtain copies of your laboratory tests, X rays, and other information pertaining to your health. At first, the information may seem overwhelming, but it will start to make sense as you become an expert. After a while, you may recognize that your sedimentation rate, which is an indicator of inflammation (see Chapter 5), has dropped after taking a new type of medication. This clear indication of decreased disease activity may help you put up with some discomfort caused by a new treatment.

5. Understand Your Drug Therapy

Drug therapy for rheumatoid arthritis is both essential and complex. Moreover, and fortunately, entirely new drugs for the treatment of rheumatoid arthritis are in an advanced developmental stage, and your drug regimen may change. Drugs, however, are always double-edged swords. Chapter 6 provides information on how to take drugs safely.

6. Understand Your Health Insurance

It almost seems that red tape is overwhelming medical care. Doctors, nurses, and other medical personnel are spending valuable time figuring out patients' insurance coverage. You must know whether your policy

16 ♦ The Hospital for Special Surgery Rheumatoid Arthritis Handbook

covers drugs, physical therapy, massage, acupuncture, counseling, self-help devices, home health care, and so forth.

In the event that you must (or can) switch health insurance plans, opt for one that covers your particular needs.

7. Maintain Your Treatment Regimen

As an empowered patient it behooves you to stick to your treatment plan, which usually encompasses:

- Drugs
- Exercise
- Rest
- Weight maintenance (or control)
- Good nutrition

Discuss any proposed changes with your physician. Inform your health care team of major noncompliance so that the omission can be factored into the evaluation of the treatment plan.

8. Fight Depression

Rheumatoid arthritis can be depressing. It is often accompanied by chronic pain. Its sufferers often have to abandon or limit favorite activities including sports, dancing, long walks, and even career options. Treatment is expensive and time-consuming, as are the lifestyle changes you may have to make.

Fortunately, many people suffering from rheumatoid arthritis are determined. Many of these people refuse to be victims, and none of those we have met in this chapter have been defeated by their disease.

9. Keep an Open Mind

Any patient suffering from rheumatoid arthritis owes a debt of gratitude to Sir John Charnley, M.D., who developed the artificial hip in a small hospital in Brighton, England, during the late 1950s. The first total hip replacement in the United States was performed in New York City during the late 1960s. Today, more than 300,000 hips and knees are replaced annually in the United States.

Initially, your doctors will do their utmost to prevent extensive joint damage. If the disease, nevertheless, manages to destroy one or more joints, you have the option of having it repaired. Total joint replacement surgery and repair of hips, knees, shoulders, elbows, finger joints, and so forth is like an insurance policy. Today, it is the exceptional patient with rheumatoid arthritis who will end up being totally disabled.

10. Accept Rheumatoid Arthritis in Your Life

Coping with RA is difficult. Most of us either become overly concerned or stubbornly fail to make allowances for pain and disability. Neither approach is helpful. Finding a balance between what you can do and what is too much is a difficult but most effective approach.

ONWARD AND UPWARD

You are now ready to tackle *The Hospital for Special Surgery Rheumatoid Arthritis Handbook*. The authors hope that it will help you navigate through old and new available treatments. You will not need all the information presented. As a matter of fact, it is likely that as medical knowledge about rheumatoid arthritis increases, treatment will become less complex. There is even some talk about finding an RA vaccine that will protect those at risk from developing overt disease. Until that red-letter day arrives, we hope that this book will become a trusted friend.