

Managing
*Multiple
Sclerosis*
Naturally



A SELF-HELP GUIDE
TO LIVING WITH MS

Judy Graham

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Acknowledgments



THIS BOOK COULD NOT HAVE BEEN WRITTEN written without the help of a great many people. Very little in it is original material—I have simply gathered into one place a number of various bits and pieces researched and written by others about the management of MS. To credit all of those people would fill several pages. Many doctors—both M.D. and Ph.D.—have written papers and books of their own, given verbal advice. Others, such as Ashton Embry, Ph.D., offer goldmines of information on their websites, listed in the Resources chapter at the back of the book.

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I also wish to extend my gratitude to the many people with MS who so kindly allowed me to use their stories.^{*1} Nearly all of these first appeared in *New Pathways*, the magazine I edit, which is published by the Multiple Sclerosis Resource Centre. I wish to thank the MSRC and Helen Yates, its chief executive, in particular, for supporting me in writing this book.

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Foreword



A WEEK AFTER MY SON was diagnosed with MS in 1995 a friend gave us a book on managing multiple sclerosis by Judy Graham. Up to that time my wife and I were feeling very helpless and full of despair because it seemed there was nothing to be done about MS except hope it didn't progress too fast. The neurologist who had diagnosed my son had not given us any words of encouragement. The best I could muster was to say to my son, "Don't buy some bricks and jump off the Bowness Bridge yet."

I literally devoured Judy's book, which was clearly written and a wonderful mix of science and practical advice. This was exactly the type of information I was looking for to help guide a course of action to fight our son's MS. Our mood of hopelessness was immediately replaced by one of confidence that MS could be successfully managed.

Ever since that day, Judy Graham has been an icon in our home, and I am most pleased that I have this opportunity to introduce the latest edition of her book on the many ways to fight back against this insidious disease.

Much has changed in the world of multiple sclerosis since 1995, the biggest transformation being the introduction of various drug therapies. Multiple sclerosis is now big business, and drug therapy is essentially the only type of treatment option that is discussed by neurologists and national MS societies. Unfortunately, the drugs have a modest effect at best and only slightly slow progression for most. They also come with a host of semi-toxic side effects.

A person with MS should not rely solely on one of the current drug therapies to ensure they will not progress to severe disabilities. It is fine to use a drug therapy, but it is essential to use additional therapies as well.

In this new edition Judy Graham provides a comprehensive compilation of all the various therapies that have been proposed to help slow MS progression and to relieve symptoms associated with the disease. Notably Judy does not push one therapy over another but objectively describes each one and provides appropriate scientific data and references for many. This is exactly what every person with MS needs in order to make an informed decision as to what therapies exist, which might be worth trying, and which ones might be tried first.

Often experiential accounts are provided with the description of the therapies, and these are always enlightening. I have always believed that if one person with MS has found value in a therapy then there is a chance it may well help another person who tries it. In most cases, one has much to gain and little to lose in trying the various therapies that Judy has chosen to include.

There is no doubt that this book is by far the most comprehensive, objective, and scientifically sound overview of all the options a person with MS has to help keep the MS disease process well controlled.

Judy has done all persons with MS a great service by taking the time and energy to write such

wonderful book. I have no doubt it will help innumerable people lead healthier, much more satisfying lives than if they only listen to what their neurologist has to offer.

Thanks, Judy. Your iconic status remains intact.

ASHTON EMBRY, PH.D.

Ashton Embry, Ph.D., a research scientist for more than forty years, plunged into the scientific literature on MS following his son's diagnosis. Together with his wife and a group of others affected by MS, Embry founded the charity DIRECT-MS to make the information he discovered freely available to all those in need of it. Their website, www.direct-ms.org, provides reliable, science-based information on the role that nutritional factors play in MS. Today, Embry's son, Matt, is in excellent health with no MS symptoms.

Preface to the New Edition



I WAS DIAGNOSED with multiple sclerosis (MS) in 1974 at age twenty-six, and I am writing this in 2010—thirty-six years later and sixty-three years old! During the intervening years I have had a full-time career as a TV producer, radio broadcaster, and print journalist. I also raised a wonderful son, Pasca. For the past ten years, I have been editing a progressive magazine on MS called *New Pathway* published in the United Kingdom by the Multiple Sclerosis Resource Centre.

Back then I didn't think I would last this long, let alone still be walking and working hard. Indeed, thirty-five years is the average life expectancy of someone who has been diagnosed with MS, yet here I am, far from dead.

Perhaps it is a testament to the many things I've been doing—watching my diet, taking nutrition supplements, avoiding foods to which I have intolerance, practicing Pilates, and being treated with many complementary therapies.

In those thirty-six years, an enormous amount has happened in the self-help management of MS, and this book reflects those many changes. In the 1970s, the emphasis in MS healing was very much on fats and oils, and while fats are still important, other things have since emerged in the natural treatment of MS: food sensitivities; the Best Bet Diet (BBD); Dr. Wahls's Brain Nutrient Diet; the importance of vitamin D, antioxidants, and other nutrients; exercise; detox; and also dealing with emotional pain.

In that same period of time, some of the people who inspired me have died, some of the charity groups have morphed into new entities, and new ones have emerged. A new group, informally known as The Best Bet Diet group, sprang up thanks to Ashton Embry, Ph.D., whose son was diagnosed with MS. Embry, a Canadian geologist, did extensive research of the medical literature and came up with scientific data to support a particular treatment for MS. This methodology was used to treat his son Matt, who has been in good health ever since. Embry has written many excellent essays about MS which can be found at www.msrc.co.uk or www.direct-ms.org.

Each MS “guru” who has come along has had firm ideas about how to self-manage MS, and each has disagreed to some extent with the others, emphasizing some unique angle, such as a particular diet, detox, or emotional healing.

However, this book is an ecumenical church and takes a wide overview of all possible solutions. No one has suggested that anything in this book constitutes a cure, but you'll find many suggestions that may help you to improve on several levels. There's no risk of harm, and a great potential for benefit.

This book also provides information about specific exciting products that have been personally tried and tested by people with MS, including me. However, even though we name particular brands and products, there are always other brands and options available, and readers are advised to do their own additional research.

The non-drug approach to MS is still derided by most neurologists, who tend to say, "There's no scientific evidence; don't waste your time and money." However, there is plenty of scientific evidence and you'll find references to this inserted throughout the book. Interestingly, when physicians themselves get MS, they are as likely to turn to the health alternatives described here as to disease-modifying drugs.

I'm also heartened by the increasing number of neurologists who support their MS patients who do well with the techniques described in this book. They offer encouragement by saying, "Whatever you're doing, carry on doing it!"

GETTING BETTER AND NOT WORSE

Total recovery from MS is a lofty aim, and I take my hat off to those who achieve it. Recovery may be the ultimate goal, but many people diagnosed with MS would be quite happy to stabilize the condition and improve their health, rather than have it deteriorate. The intention of this book is to assist anyone with MS in being as healthy and stable as possible.

Recovering from MS, or at least improving and not getting worse, *has* been achieved by many MS sufferers, including such high-profile people as Ann Boroch; Ann Sawyer; Judith Bachrach; Sue Ellen Dickinson; Montel Williams; Gina Kopera, M.H.; Professor George Jelinek; Terry Wahls, M.D.; Dermot O'Connor; and, the now late, Roger MacDougall. There are also countless ordinary people who have gotten better, rather than worse, by following this kind of self-help program. Not all have totally recovered from MS, but they are able to lead productive, useful, "normal" lives.

We can say with confidence that there *are* ways to control, or manage, the disease. There is a huge amount of agreement worldwide on the effectiveness of a holistic approach, and I can personally attest to it. Some of these therapies, then, probably deserve to be called "treatment" for MS.

MY STORY

My first symptoms started when I was about nineteen, or earlier. By the time my MS was diagnosed at the age of twenty-six, I had a range of typical MS symptoms: My feet and legs were often like blocks of ice or felt like cotton wool or Jell-O. I sometimes went numb along my left hand and arm, all the way up my face. At other times both hands tingled and were weak, I had tight banding around my middle, and electric shocks jolted me when I moved my neck. Sometimes my walking was horribly stiff and I had to hold on to walls and furniture to keep my balance when crossing a room.

I remember sometimes coming home from work and collapsing on the sofa, not knowing why I felt so lifeless. After one nightmarish day shooting on location for a TV documentary (I was working as a researcher in BBC Television at the time), I was faced with a flight of stairs that had no handrails, and I knew the only way I could possibly get down them would be on my bottom or on someone's arm.

Thirty-six years later, I still have MS symptoms, but not very badly, and many people who meet me wouldn't even know I have the illness. But I can't wear high-heeled shoes, can't run, and use a mobility scooter for long distances or shopping at the mall. Even so, after thirty-six years, many people with MS would be quite happy to be as mildly disabled as I remain.

So what have I done to help control my MS? Every four months I see a nutritional doctor (Dr. Georges Mouton) who checks me for food sensitivities, measures my body's biochemistry, and prescribes supplements specially formulated for my particular case. I have given up eating eggs, dairy, bananas, and chocolate, and I try to go easy on sugar.

Over the years I have been on (and off) the Best Bet Diet, and always feel better when I'm on it. I have also incorporated some of the elements of Terry Wahls's diet, such as eating more kale, cabbage, and salad greens.

I have been taking evening primrose oil and fish oil capsules every day since 1974, plus a variety of vitamin and mineral supplements (for the full list, see chapter 8). I have also recently started taking the nutrients—both in food and supplements—recommended by Dr. Terry Wahls's Brain Nutrient Diet.

I take a Pilates class once a week and also practice at home, and I'm convinced that sticking to a regular exercise program—and stopping before I get tired—is beneficial in terms of fitness, strength, suppleness, muscle tone, and increased stamina. In the past, I had a course of hyperbaric oxygenation, which gave me a boost of energy. For much of the time since my diagnosis I've been treated by an acupuncturist, who also administers reflexology. I have seen an osteopath and a homeopath, have had deep massage treatments, and currently have shiatsu massage every Friday.

I think there can be no doubt (although some neurologists might disagree) that my high-level functioning can be credited to these various programs and treatments.

PART ONE



Understanding MS



MS Can Be Controlled

IF YOU ARE READING THIS, chances are your life is affected by MS in some way. Maybe you've been told you have MS, or perhaps someone close to you has it. The good news is that MS can be controlled. Far from being all doom and gloom, the future can be joyous and productive.

A natural, drug-free way of self-treating is to use an all-embracing approach covering every aspect of your life and lifestyle—food, exercise, thoughts, and emotions. In brief, it involves:

- Getting tested for food sensitivities and giving up the offending foods
- Dealing with gut problems, such as leaky gut and candida
- Switching to the Best Bet Diet
- Eating a diet high in nutrients for the brain
- Taking many nutritional supplements—vitamins, minerals, trace elements, antioxidants, amino acids, enzymes, and essential fatty acids
- Exercising regularly
- Cleansing your body of environmental toxins
- De-stressing and rebalancing your life, and dealing with emotional and psychological hurts
- Avoiding fatigue, resting as needed, and getting sufficient sleep
- Shifting your thought patterns from negative to positive and making a decision to live life to the fullest
- Having satisfying relationships
- Maintaining your self-esteem

It may also mean receiving some complementary treatments, such as acupuncture, ayurvedic reflexology, shiatsu, or Reiki, all of which have been shown to help MS. You'll find alphabetized information in chapter 13.

THE BEST TIME TO START IS NOW

The earlier you start this program, the better. Studies have shown that the people who benefit most from this self-help regimen are those who have been recently diagnosed. Don't wait until you get worse before you decide to try this program. Use it as an insurance policy to help prevent you from getting worse.

However, all is not lost if your illness has progressed. Some people have reversed their MS symptoms several years after diagnosis, and even in the secondary progressive stage of the disease.

It is not a cure, nor is it recognized as a treatment by the medical establishment (although there are elements in it that have had so much, and such good, scientific research that they deserve to be recognized as treatments for MS). This program can help you manage your illness. It gives you a

opportunity to enjoy life fully—even with MS.

PRESCRIPTION MEDICATION

Most neurologists wonder why anyone would want to go on such a rigorous program as this when there are drugs to treat MS. Part of the answer is that the pharmaceuticals that have been used so far—the “disease-modifying” drugs—can help somewhat in reducing relapses but can’t stop disease progression. Also, some people don’t like having injections or the flu-like side effects of some of these drugs. Also, we don’t really know the long-term effects of these drugs.

The next generation of drugs includes Tysabri, which is used to slow the progression of aggressive MS and is usually only prescribed for severe cases. Some people definitely do benefit from this drug. However, as of November 2009, there had been twenty-four cases of a brain infection called progressive multifocal leukoencephalopathy (PML) and four subsequent deaths linked to Tysabri. Because of this, Tysabri was temporarily withdrawn from the market in 2005, but was reintroduced in July 2006 with stricter safety warnings.

In the pipeline are “immune modulating” drugs, such as alemtuzumab (Campath), which has had dramatically good results in trials, but also carries risks. It has been shown to stop MS in its tracks and is hailed as the most effective treatment yet for early relapsing/remitting MS, reducing attacks by 70 percent, reducing sustained disability by 71 percent, and in many cases restoring lost function. However, any benefits need to be weighed against the associated risks; doctors are hesitant to prescribe this drug except in patients in the early stages of the disease, not yet disabled, who have frequent bad attacks.

During the trials for this drug, three patients contracted a condition called idiopathic thrombocytopenic purpura, in which low blood platelet counts can lead to abnormal bleeding. This was fatal in one case. Also, nearly a quarter of the patients on alemtuzumab suffered from a thyroid autoimmune condition, with a very high prevalence of Graves’ disease. In addition, because alemtuzumab suppresses the immune system by seriously depleting white blood cells called T lymphocytes, vital for fighting infection, patients on this drug have an increased risk of serious bacterial, fungal, and viral infections.

All pharmaceutical drugs have side effects, and you have to weigh whether taking them is worth it—the choice is yours. Some people do both—they take drugs for MS *and* follow this book’s management program. However, one of the benefits of the program outlined in this book is that the treatments do not have unpleasant side effects. Also, unlike many of the drugs for MS, they are intended to do the exact opposite of suppressing the immune system; they are designed to actually boost, or normalize, the immune system.

As to taking certain drugs for specific MS symptoms, such as pain or bladder urgency, that, again, is up to you. Many people with MS favor a natural approach to healing, yet swear by certain drugs for specific individual symptoms.

Personally, I have never taken any disease-modifying or immune suppressant drugs to treat my MS. On the other hand, I do take ibuprofen for pain and HRT for estrogen (see chapter 15, Hormones and MS), and I would not be opposed to taking tolterodine (Detrol or Detrusitol) or Botox injections if my bladder were to worsen.

A DARK CLOUD LIFTS

Many people with MS have successfully managed to control or even recover from MS by using

techniques described in this book. When you see how effective these strategies can be, a great dark cloud lifts from your shoulders as you realize that MS doesn't have to be a life sentence, or a death sentence.

However, care is needed. This is *not* a cure, it is an ongoing, life-long treatment. If you go back to your old diet, lifestyle, and negative thought patterns, MS is likely to come back. The treatments, management programs, may not all have been rigorously tested by scientific method, but there are enough studies to suggest strongly that the progression of MS can be slowed, halted, or even reversed. In addition to the scientific studies, there is also a huge amount of anecdotal evidence.

At the very least, this book suggests healthier ways to live your life.



What Exactly Is MS?

IF YOU KNOW what is happening in MS, it's easier to understand why the self-help management program is relevant.

MS is described as an autoimmune, degenerative disease. The prevailing wisdom is that the body mistakenly attacks part of itself as if it were a foreign body. In MS, the myelin sheath—the insulating layer that protects the nerves—is targeted and attacked by rogue cells in the immune system.

ROGUE T CELLS

In a healthy immune system, white blood cells called lymphocytes are the crack troops that defend the body against attack from foreign invaders. Lymphocytes are made up of three types of cells: T cells, B cells, and NK (natural killer) cells.

Receptors on T cells are normally able to differentiate between antigens—those invaders that cause your body to produce antibodies, such as bacteria or viruses—and your own body. Once an antigen is identified, certain T cells, called helper T cells, trigger the B cells to release those antibodies. These are molecules designed to attach to, and destroy, the chosen target antigen, or foreign body.

In MS, the T cells in the immune system have a hard time distinguishing between a foreign invader and self. The T cells mistake the body's own myelin as foreign and target it in the same way they would target a bacteria or virus.

In response, the deranged T cells set off a cascade of immune events, including the release of more lymphocytes, to rid the body of the perceived threat. These B lymphocytes fire off antibodies, and the destructive process perpetuates through a cascading series of events in which the B and T cells continue to interact, creating numerous different self-antigens.

Once the lymphocytes have launched a response to an antigen, they also release masses of other white blood cells to gather at the injured or infected site. The major players in this destructive process are called leukocytes, in particular, ones called cytokines. When too many are produced, it causes inflammation and damage.

MALFUNCTIONING NK CELLS

In September 2009, scientists at the prestigious Imperial College, University of London, published a paper in which they put forward the hypothesis that MS (among other diseases) is caused by malfunctioning NK cells that turn on the body, attacking healthy cells.

They also identified the master gene—E4bp4—that causes blood stem cells to turn into natural killer cells; and they have succeeded in putting this gene out of action in a mouse model. This breakthrough should help solve the mystery of NK cells in diseases such as MS. Clarifying NK cell role could lead to new ways of treating MS and other similar conditions.

MYELIN

Myelin is an insulating material that wraps many times around nerve fibers to form what looks a bit like a Swiss roll.

The function of myelin is similar to that of insulating material surrounding an electrical cable—allows impulses to travel along the cable. Myelin helps messages to be delivered quickly and smoothly between the brain and various parts of the body.

Myelin Damage and MS

If myelin gets damaged, the nerve signals travel more slowly, get distorted, follow the wrong path, and don't get properly transmitted.

When myelin is attacked, there is inflammation that leaves a scar, or sclerosis (from the Greek word *skleros*, for hard). Several attacks leave multiple scars, or multiple sclerosis, and increasing disability.

The usual course of MS is to get progressively worse. In the later stages of MS both the axons (nerve fibers) and the cells that make myelin (oligodendrocytes) are damaged by the MS disease process, causing progressive disability. Other nerve cells may also be involved.

Myelin Can Regenerate

Whatever the reason or reasons for myelin breaking down, the heartening thing to know is that it can regenerate. Until the mid 1990s it was thought that myelin could not regenerate, but now there has been sufficient research to show that it can. Although myelin is a relatively stable structure, its components break down and—under the right circumstances—are replaced with newly formed components.

This means that some of the damage sustained by the nervous system is, in principle, capable of recovery. It may be that MS plaque sites do not represent permanent damage, but are areas in which damaged tissues are attempting self-repair. The challenge is to know exactly what conditions support that recovery.

Some of the therapies featured in this book, alone or in combination, may provide the conditions that aid myelin regeneration. Researchers have long said that if only they could find out what makes myelin regenerate, they could solve the puzzle of MS, and intensive research continues in this area. (In fact, some of the new generation of drugs for MS aim to regenerate myelin.)

VASCULAR ABNORMALITIES—CHRONIC CEREBROSPINAL VENOUS INSUFFICIENCY

Recently, an Italian vascular surgeon named Paolo Zamboni discovered that every single MS patient he saw had an abnormality in the veins from the brain to the heart. Dr. Zamboni called this defect chronic cerebrospinal venous insufficiency (CCSVI).

CCSVI is a condition in which certain veins in the head and neck become narrowed. This narrowing restricts the normal outflow of blood from the brain, causing alterations in the blood flow within the brain and a reflux of blood back into the brain—something that eventually causes injury to brain tissue and degeneration of neurons.

Blood that refluxes into the brain contains iron and, according to Zamboni, many neurologists consider iron dangerous because it is linked to neurodegeneration, MS progression, and disability. CCSVI was found to be strongly associated with MS, increasing the risk of developing MS by forty-three fold. CCSVI appears to be peculiar to MS and has not been found in other neurodegenerative conditions. At the time of writing, further research into CCSVI and MS was being carried out at the

University of Buffalo, the State University of New York. Principal investigator on the study, Robert Zivadinov, M.D., Ph.D., said: “If we can prove our hypothesis, that cerebrospinal venous insufficiency is the underlying cause of MS, it is going to change the face of how we understand MS.” (See chapter 14, page 208, for further information on this condition.)

IS MS JUST A NEUROLOGICAL DISEASE?

MS is classified as a neurological disease, mainly affecting the nervous system, which is the brain and spinal cord. But it also affects the immune system, the digestive system, and the vascular system.

From an allopathic medical perspective, the elements that comprise MS are ever more complex. However, practitioners of alternative medicine do not see things in the same way at all. Their holistic viewpoint doesn't fragment the body into bits and systems, but considers the whole organism—body and mind—as one entity.

Holistic practitioners see each person as an individual, and are willing to try therapies that haven't been submitted to carefully controlled trials. Rather than applying a particular disease label, each patient's unique needs are addressed.

There is a huge amount of anecdotal evidence that presents a very hopeful picture for treating MS, and it's discouraging to see it dismissed so disparagingly by most orthodox doctors. Medical doctors are quite happy to use anecdotal evidence when it suits them, and there's a good argument to be made for listening to anecdotal evidence in regard to MS.

SIGNS AND SYMPTOMS OF MS

Symptoms may include any or all of the following, and generally are worse during an attack.

- Tingling, prickling, or a sensation of pins and needles anywhere in the body
- Numbness—you can hardly feel a needle stuck in your skin
- Heavy legs, as if wearing thick boots and trudging through mud
- Difficulty walking
- Difficulty using arms and hands
- Weakness in any limb
- Paralysis—you cannot move a limb
- Dragging either foot, or dropped foot, where you have difficulty lifting a foot off the floor
- Overwhelming fatigue
- Poor coordination
- Poor balance
- Loss of sensation or distorted sensation anywhere in the body. Feeling as though the body is made of cotton wool, rubber, or Jell-O
- Electric shock sensations on lowering the head
- Clumsiness—often dropping things
- Double or blurred vision, or temporary blindness in an eye
- Slurred speech
- Urgency to urinate and/or frequency, or hesitancy in passing urine; incontinence
- Fecal incontinence

- Constipation
- A feeling of tight bands around the trunk or lower limbs (the “MS hug”), which can be itchy
- Pain anywhere
- Vertigo—dizziness; the room spins
- Vomiting
- Tremors in the hands and arms
- Spasticity—tight, stiff limbs
- A feeling of extreme cold, like frostbite, in the extremities; or the opposite—burning feet
- Abnormal sensitivity to heat and cold
- Feeling like a wet rag in humid weather
- Abnormal sensitivity to light
- Cognitive impairment, from mild to severe, with short-term memory problems
- Emotional volatility—get upset and cry easily

TYPE OF MS

There are two major types of MS. The most common is relapsing/ remitting, which is characterized by symptoms that flare up (an attack, or relapse), followed by a period of remission during which the person’s condition returns to what it was, or slightly worse than it was, before the attack. Attacks, also known as relapses, can range from mild—you’re able to carry on daily activities without hindrance—to so severe that you must be hospitalized. Attacks can involve just one symptom or several. Scientists are trying to discover what triggers the switch into remission, which some believe may be a critical link in the treatment of MS.

In the second type, progressive MS, there are no clear-cut attacks and the person just gets progressively worse. Within this category are primary progressive—the person has never been subjected to attacks; and secondary progressive—the person first develops relapsing/remitting MS, but after a certain period it becomes progressive. This latter form is the most common course.

Although there are rare cases of a galloping form of the severest type of MS, in which the person degenerates rapidly and dies within a few years, sometimes a person will have just one attack of MS and never have another. Those who don’t get worse are said to have a “benign” course, though it may become less benign some years later. How you are at the end of your first five years is sometimes used as a predictor for what is likely to happen later in the course of the disease.

WHO GETS MS?

MS mostly affects young adults between the ages of twenty and forty, but it is increasingly being diagnosed in children younger than sixteen, and it’s not uncommon for people in their fifties and sixties to get MS. The mean age for a first attack of MS is about thirty. It is almost twice as common in women as in men.

MS is twenty times more common in northern Europe and America than in Africa. The further from the equator, the higher the incidence. It is practically unknown in equatorial countries.

Those who get MS invariably have a genetic predisposition. There also has to be one or more environmental triggers.

Studies show that, in adult MS, the risk of MS is determined by exposure to an environmental factor

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