The proven international program enabling thousands of people with MS to live active, healthy lives

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ROADMAP TO GOOD HEALTH

Edited by George Jelinek MD Sandra Neate FACEM Michelle O'Donoghue MD MPH 'If you or someone that you love is impacted by MS this book is a must read. The seven-step process for self-management presented in the *Overcoming Multiple Sclerosis Handbook* is a comprehensive and thoughtful approach to living your best life despite having this disease.'

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Dr Aaron Boster, The Boster Center for Multiple Sclerosis, Columbus, Ohio

'This highly recommended book highlights the importance of a holistic approach to MS management, offering a path to achieve the best possible outcome in this potentially devastating condition.' **Professor Richard Nicholas, Imperial College London**

'A deeply insightful account and instructive guide for adopting healthy lifestyle behaviors and thriving while living with MS.' Dr Sarah Mulukutla, Founding Chairperson of the Section on Neurohealth and Integrative Neurology at the American Academy of Neurology, New York

'Written specifically for people who have MS, this inspirational book provides a comprehensive, practicable program for living a full life with this disease.'

Dr Alessandra Solari, Fondazione IRCCS Istituto Neurologico Carlo Besta, Italy

'Overcoming MS is now the essential mainstay of MS management, before or alongside drug therapy, offering the best chance of a full and healthy life for people with MS.'

Dr Peter Silbert, Clinical Professor of Neurology, University of Western Australia Medical School

'A wonderful resource for people living with MS.' Dr Ilana Katz Sand, Associate Professor of Neurology, Icahn School of Medicine at Mount Sinai, New York

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About the Book

A long, healthy, happy life is possible after a diagnosis of multiple sclerosis. Around the world, thousands of people are living active and fulfilling lives on the Overcoming Multiple Sclerosis Program.

The Overcoming Multiple Sclerosis Handbook explains what MS is, and outlines the scientifically credible and evidence-based 7 step self-management program originally devised by Professor George Jelinek. It covers all aspects of living on the program, from first diagnosis to later life, with chapters from medical specialists and other experts on choosing your healthcare team, improving resilience, work, pregnancy and progressive MS. The book taps into the wealth of knowledge and experience in the community of people following the Overcoming Multiple Sclerosis Program, with personal stories from across the world.

If you have recently been diagnosed with MS, if you have been living with MS for years, or if have a family member with MS, the *Overcoming Multiple Sclerosis Handbook* is your best companion. It is also an invaluable resource for doctors treating people with MS.

About the Editors

Professor George Jelinek MBBS, MD developed the OMS 7-Step Recovery Program and founded the Neuroepidemiology Unit at the University of Melbourne. An international leader in research and treatment of multiple sclerosis, he is the author of *Overcoming Multiple Sclerosis*. Dr Sandra Neate MBBS, FACEM is an emergency physician, and Senior Research Fellow and Head of the Neuroepidemiology Unit at the University of Melbourne. Dr Michelle O'Donoghue MD MPH, is Associate Professor of Medicine at Harvard Medical School and a cardiologist at Brigham and Women's Hospital in Boston.

Overcoming Multiple Sclerosis Handbook

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Where can I get the book?

Overcoming Multiple Sclerosis Handbook edited by George Jelinek MD, Sandra Neate FACEM and Michelle O'Donoghue MD MPH is published by Allen & Unwin February 2022 and is available from booksellers around the world here: <u>hyperurl.co/oms</u>

Chapter Sample

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Overview of the OMS Program

Dr Virginia Billson

It feels like I have found a new friend in the OMS Program, allowing me to take control and lead a more healthy and positive life. Bravo!

Clare McKenzie, Burnham-on-Crouch, UK, OMSer

My diagnosis of MS was a mixed blessing in 1996, confirmed as it was by an MRI scan and spinal fluid, blood and visual field tests on my 47th birthday. At least my visual and physical symptoms were not those of a malignant brain tumour, a stroke or any of the other ghastly conditions that I, as a medical specialist pathologist, was aware of and feared. At the same time, so many unexpected and potentially life-changing questions leaped into my rather shocked and addled brain. Were there any successful treatments for MS? Would I be disabled soon? Would I have to cease my dearly loved career? What would become of my active family and social lives?

I developed a bleak outlook after spending two intense months reading a mountain of medical texts and journals. I decided then to pretty much give up researching the topic. I was feeling quite well after a heavy course of prednisone, which, apart from a few slight sensory symptoms, resolved my double vision and leg weakness. I resolved to forget about MS, ignore the reality of my

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diagnosis and get on with my busy life. However, the reality of MS wouldn't be suppressed or ignored. What followed were four years of a wild roller-coaster of attacks, which included weird symptoms, and increasing fatigue and depression, all of which viciously interrupted many aspects of my previously rewarding and rich family, social and professional lives.

And then, at a People with MS Christmas party, I was recommended a book to read that was written by an Australian doctor with MS. It was the very first edition of *Taking Control of Multiple Sclerosis* by Professor George Jelinek. It was a revelation. The book described things I could do for myself to regain control over the disease and improve all aspects of my health and life, which I had felt I was losing a grip on every day. The book outlined a lifestyle program that was based on very convincing scientific evidence and principles that I could buy into, no airy-fairy, hippy-trippy ideas but hard data. And so started my twenty-year adventure slowly incorporating the methods and principles of *Taking Control of Multiple Sclerosis*, which eventually developed into the OMS Program.

What is the OMS Program and where does it fit into our day-to-day lives?

The 21st century is a time of wondrous advances in our daily lives. We can travel to the other side of the world in a day or two (pandemics permitting), we can get into our cars and travel for hundreds of kilometres in a few hours, we can use technology to interact with friends and colleagues around the globe in a matter of minutes, we live longer than our forebears, and medical treatments can cure or alleviate many infectious and other diseases.

It has long been said, initially by Sir Isaac Newton in his laws of motion in 1686, that 'for every action there is an equal and opposite reaction' and along with our incredible advances we unfortunately have had to deal with many negative environmental, social, physical and mental effects.

In the developed world, the fast-paced lives we lead make getting enough exercise and quiet contemplation quite a challenge.

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The busy days seduce us with easily obtained and highly processed fast foods and make us seek 'instant' gratification through sweets and salty snacks. Eating out frequently at cafes and restaurants enables us to overeat too many rich meals to 'get our money's worth'. Excessive alcohol intake, overuse of prescription and illegal drugs and cigarette smoking are also easily indulged in. Increased stress as a result of our high-pressure jobs and rapidly changing environment adds to the burden of illness.

We often neglect our wellbeing and consume too much of the wrong foods, are lax about exercising and disregard the value of quiet pondering or just thinking and appreciating what we have,

not what we could purchase if we earned more money.

As a consequence of these habits that we have so readily incorporated into our daily lives, there has been an epidemic of lifestyle-related health problems, such as type 2 diabetes, cardiovascular disease, some common cancers, respiratory impairment and obesity, to name just a few. We know that these ailments are major risk It is getting harder and harder to stay well in the 21st century, despite, or sometimes because of, all the advances we have made

factors for a host of further disorders, such as sleep disturbances including sleep apnoea, muscle and joint problems and, as shown by recent research, a higher incidence of Alzheimer's disease and other dementias.

Each of the lifestyle diseases mentioned can spiral into further complications requiring medical or even surgical intervention and their often-intrusive side effects. MS, which is increasing in incidence, has been identified as being one such disorder on the long and growing list of lifestyle-related diseases.

The OMS Program is based on sound scientific principles and research and is able to be accessed by anyone with MS. This combination of lifestyle adjustments, when embraced as a whole, has been shown to complement or, in some people, replace the need for medications, and to vastly improve the condition or even

reverse some of the symptoms. Adopting and persisting with the recommended lifestyle changes as part of a healthy approach to the rest of your life certainly requires active engagement with

The OMS Program is based on sound scientific principles and research the philosophy and details of OMS. Incorporating the OMS recommendations into a daily routine requires some research, understanding, trust and belief, and only when it becomes part of daily life can you slowly but surely feel the benefits to MS and general health.

I will give a very brief overview of what the OMS Program is about—more detail on each aspect and other relevant issues will be expanded in the following chapters.

Let's start with diet

Research has consistently shown that the modern Western diet contains large quantities of saturated fats, which come mainly from animal sources, and relatively low quantities of fibre and nutrients, especially the B group vitamins and omega-3 fatty acids. This type of diet promotes the hardening of arteries, with the consequence of an increasing incidence of heart disease and stroke. Saturated fats stimulate inflammation throughout the body and increase the chances of getting various types of cancer, among a host of other diseases.

As described by Dr Beaber in Chapter 1, MS is largely a disorder of an overactive immune system, also known as an autoimmune disorder, which leads to inflammation in the brain and spinal cord that in turn causes the many and varied symptoms with which we are all familiar: loss or blurring of vision, weakness in parts of the muscular system such as your legs, sensations of numbness or tingling, and nerve pain are fairly common. These can to a large extent be improved by the OMS Program, which includes a change in diet that eliminates as much saturated fat as possible. Eating a mainly plant-based and high-fibre range of fresh foods is both nourishing and, using the many cooking resources now

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available, can be delicious. Supplementing the diet with foods rich in omega-3 fatty acids, as found in fish, seafood and flaxseeds and their oils, has been also associated with better outcomes for people with MS. Supplementation with B group vitamins may also be beneficial in some circumstances.

A major change of diet involving restriction or elimination of many of the foods we previously considered normal can be quite daunting and sadly can turn many people off the Program. Some people find that modifying aspects of their dietary regime fairly gradually, and approaching the whole task with curiosity and interest, can make the changes a satisfying objective, especially since they have been proven to have huge benefits. Other people find they are more successful when they actively and rapidly embrace all aspects of modifying their diet.

How we manage the changes depends on each individual's personality and their approach to major life hurdles. It can, however,

be a real adventure to experiment with new ways of preparing our food and research new recipes to produce delicious, satisfying and wholesome meals.

Encouraging your nearest and dearest to join in the food adventure can have fantastic health benefits for you and everyone in the family, as the

dietary recommendations have been shown to reduce many of our Western ailments and potentially reduce the possibility of your genetically related family members from developing MS (see Jack McNulty's views on diet in Chapter 3 and read more detail about family issues in Chapter 9).

Another important aspect of the OMS diet is the avoidance of dairy products. There are two major reasons to avoid the breast milk of other animals such as cows: the fat is largely saturated and therefore unhealthy, and proteins in milk may also cause problems for people with MS or with a predisposition to developing MS. The structure of cow's milk protein is very similar to

Changing to an ultra-healthy diet can be a really enjoyable adventure

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human myelin, the fatty insulating coating of our nerves, which is the target of the inflammatory attack in MS. Consuming dairy products may cause the body to react to this milk protein the effect can then spill over and become part of the damaging autoimmune reaction to our own myelin. Elimination of dairy products is strongly recommended and we are fortunate today that there are many plant-based alternatives that are as nutritionally wholesome as cow's milk and quite delicious too.

On a more positive note, alcohol in moderation does not seem to be harmful for people with MS and a glass of wine with our thoughtfully cooked meal can be enjoyed as a real reward for a job well done.

Sunshine and its vitamin—vitamin D

Epidemiological studies over many decades and in numerous countries have pointed to the fact that low sun exposure can predispose the population to an increase in the incidence of MS. In Chapter 4, Dr Conor Kerley outlines how the sun reacts with chemicals in the skin to produce vitamin D3. This vitamin has many vital roles in the body, including the maintenance of strong bones and muscles and preventing the disabling bone disease called rickets. How vitamin D reacts with the immune system is of crucial importance to those of us with MS. Appropriate vitamin D blood levels can moderate or balance the immune system so that it

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Both sunshine and the vitamin D it produces in the body are helpful for people with MS and their families, but be mindful of getting too much sun exposure reduces a hyperactive immune system without suppressing it.

Sun exposure, and in particular the UVB rays of the sun, has also been shown to act as an immune modulator independent of the vitamin D effects, so direct sunlight is thought to be useful in combination with vitamin D. Of course, we have to be mindful of the harmful effects of too much sun in any sunny environment. Skin cancer is a lethal consequence that we all want

to strenuously avoid. How to get just the right and safe amount is described in detail in Chapter 4.

Get enough of the right sort of exercise

In past decades, exercise was not considered an important part of the management of MS. In many cases it was actively discouraged and people with MS became increasingly weak and disabled. There is now abundant evidence that regular aerobic exercise to build cardiovascular fitness and strength-building exercises are of utmost importance for people living with many chronic diseases, including MS.

Research into the effects of exercise on diabetes, cardiovascular disease, high blood pressure and many cancers has shown clearcut benefits. The research has also shown that regular exercise in people who are living with these conditions results in improvements in many aspects of their quality of life, in particular their mental health. They are happier, have better cognitive abilities such as memory, and often have much improved outcomes for their underlying disease.

Exercise is important in a number of ways. The prospect of losing mobility is one of the most painful fears that people with MS live with every day. Exercise together with the other components of the OMS Program can slow or even reverse a person's physical limitations. Exercise is well known to make people feel better and 'runner's high' is a recognised characteristic that many vigorous exercisers experience. Moderate exercise can also make you feel more optimistic and joyful, which can improve

your mental outlook. In many people exercise can lift a person's mood and decrease the frequency and severity of depression. Dr Stuart White goes into this in a lot more detail in Chapter 5.

Physical exercise can also decrease the incidence of a number of the other Western scourges obesity, diabetes, osteoporosis and cancer. Exercise is beneficial for people with MS in a host of different ways; it is an essential part of the OMS Program

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Fatigue is a very common, disabling and often invisible symptom in people with MS. It can reduce one's enjoyment of daily life and is known to be an influencing factor for many of us deciding to limit or stop paid or voluntary work and curtail social and family activities. Exercise in MS has been shown to alleviate fatigue and increase endurance and this 'side effect' can be extremely powerful.

Exercise can also improve our balance, strength and stability, and in turn reduce the incidence of falls. Even small falls can lead to significant injuries that can severely impact on the ability to manage at home or at work. Exercises building muscular strength can also decrease the development of osteoporosis or 'brittle bones'. Together with general bodily weakness and impaired balance, osteoporosis can lead to bone fragility and fractures. Loss of function and movement is to be strenuously avoided if possible.

And remember the mind-body connection

The mind is a powerful thing. For millennia the impact of the mind on bodily functions and ailments has been increasingly recognised. The mind is known to be responsible for both positive and negative aspects of health, physical as well as mental. External influences like the loss of loved ones or even worldwide disasters, such as pandemics, can lead to severe stress reactions. Even the anticipation of having to sit for an exam, give a speech, perform in front of a crowd or attend an interview can be so stressful as to reduce some of us to the point of tears and even total shutdown. Research has shown that for those living with MS, stress can have profound effects and can trigger an MS attack or relapse.

Many physicians recommend their patients 'de-stress' their lives to assist them in recovering from a range of physical and mental disorders. Unfortunately, advice on how to develop the tools to undertake this often complex task is often lacking. Although psychologists and counsellors skilled in assisting people with chronic diseases can be a valuable aid in helping someone to de-stress, being in control of your own mental strength and

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having the ability to manage your stress levels with the regular practice of meditation or other mindfulness-based strategies can be empowering and can build self-recovery. Internationally renowned mindfulness expert Associate Professor Craig Hassed goes into this in detail in Chapter 6. Don't underestimate the power of the simple techniques he outlines.

I have had many discussions with people with MS over the years in my role as a peer support worker and MS Ambassador, and meditation appears to be one of the OMS strategies that many of us find the most difficult to incorporate into daily life. It is not a natural action to withdraw from often busy lives and actively focus attention elsewhere for a period of time. There are, however, many techniques and online resources available to help people learn to meditate and that can be gradually introduced into day-to-day life. Once I absorbed the large evidence base that describes the profound positive effects that regular meditation can provide, it was much easier to accept some techniques that I could practise regularly and even to enjoy regular meditation. This is a form of therapy with only positive side effects and is one we can implement without a prescription or a pill.

And finally, what part does medication play?

The OMS Program is one that can and does work well together with any prescribed medications from your doctor. Some of the new raft of medicines that have become available to treat mainly the relapsing and remitting forms of MS unfortunately can have many disturbing side effects. Many people with MS have been able to successfully reduce their dependence on medications, under the supervision of their supportive medical practitioner, away from requiring medication to stay well just by strictly adhering to the OMS lifestyle recommendations. Others such as myself choose the 'belt and braces' approach: I have continued with my relatively low-impact medication for over twenty years while following the OMS Program. Still others looking to do whatever it takes to minimise the effects of MS in their lives opt for one of the more recently released potent medications. The OMS approach

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works very well as a complement to other treatments and does not interfere with or complicate them. Dr Jonathan White goes into the issues involved in choosing a disease-modifying therapy in Chapter 7.

Other considerations

Starting a new way of approaching a chronic condition that is going to impact health and daily life can be an initially unsettling prospect, especially for those recently diagnosed and trying to navigate a storm of scary emotions. This book and a couple of other OMS-themed books can set you on a positive road to healing and recovery. Even more powerful is a group retreat or workshop that promotes the lifestyle recommendations discussed above. This may be especially useful early in your travels along this sometimes bumpy highway. The group settings are unfortunately not widely available around the world but researching your own locale to see if one is in reach is strongly encouraged. Two retreats I attended a few years apart were a revelation for me and made the recommendations in the book so much more approachable and understandable. Meeting together with other people with MS who were dealing with the wide range of issues that I was dealing with myself was both reassuring and comforting, and having direct access to the professionals running the course was incredible. Being able to question any and every aspect of the OMS Program was motivating and engaging, so I urge you to do it if you can.

Stop smoking if you are a smoker and avoid a secondhand smoke environment if your household has smokers in it. Extensive research has shown that the contents of tobacco smoke are especially toxic to people with MS and can predispose

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There are many resources available to help people with MS adopt the OMS Program individuals to initially developing MS and its subsequent progression. There are no positive side effects of smoking and it should be strongly discouraged, especially in the household and around genetically related family members.

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Overview of the OMS Program

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Dealing with all aspects of health and management of MS requires a team of both professionals and personal contacts to whom you can easily relate. The team needs to include people who can understand your needs and assist you in being your best self. Some doctors have been quite dismissive of the benefits of the OMS approach. They may not have carefully researched the mountains of evidence that are accumulating on the benefits of the individual components of the Program.

Combining all the aspects of the OMS Program discussed earlier is both powerful and achievable and within your control. So select your team well (Dr Heather King talks about this in detail in Chapter 11) and you may have to educate them too, as I had to. Even some senior professors either hadn't heard of the Program or were quite negative about its potential benefits. I distributed the first book quite widely among my medical colleagues and I think I converted many of them, especially when they took the trouble to absorb all the current scientific data that is accumulating.

It is probably even more important to have a small, easily accessed support group on your team that may be family, friends or people with MS who are peers and who also follow the OMS Program. These people need to be aware of how you are going, able to support you emotionally, and willing to join you on this long adventurous road to being your best self. The internet can be a valuable part of your support but be aware of the various traps and destructive aspects of this source of information. I have accessed a number of sites but have found some to be quite distressing and even dangerous, with dubious (and often expensive) advice sometimes being promoted. Starting with the OMS website (overcomingms.org) is a great way to learn about the wide world of possibilities with this Program and the group of wise and dedicated people who have developed and disseminated it. The website can help with new cooking techniques and tasty recipes, general lifestyle information and inspirational stories of how people with MS manage MS.

Staying motivated and engaged with the OMS philosophy for the long haul is vitally important to sustain commitment to all

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the aspects of the OMS Program. Doing so with a positive, active and conscious mindset will help you to continuously improve yourself, maintain independence and above all enjoy the adventure of transforming your health.

MS is a disorder that is very poorly understood by the community, not to mention many in the medical profession. I was often asked by people who knew my diagnosis when I was first diagnosed if it was contagious. This unnecessary fear could really harm close personal friendships and I had to be very cautious about who I disclosed to. I was and am very open to discussing MS, but it is a complex condition that cannot be easily explained in a few short sentences. It was quite difficult not to start giving a long lecture about what MS is, who gets it and why, especially to casual acquaintances, so I often found it was easier not to bring the subject up if they didn't know me well. Irish lawyer Gregory Hendron gives specific advice about disclosure in Chapter 15.

Clear communication with close family members, particularly blood relatives, remains vital to not only assist you on your MS path but also to educate them about how they can help reduce the likelihood of developing MS themselves. As a positive side effect, overall improvement in their general physical and mental health is a likely consequence.

In summary, the OMS road to recovery is backed by powerful and compelling scientific evidence. The Program also provides a life-changing promise of hope, which is what we crave when coping with the challenges of managing this complex, often frightening and unpredictable condition.

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Ground covered

The OMS Program is a comprehensive suite of lifestyle modifications that, when combined together and integrated into a daily routine, have been shown to reduce the impact of MS. In many people the OMS lifestyle approach can stop or greatly reduce episodes or attacks and reverse some symptoms and adverse effects, although these changes may take some time to fully evolve.

OMS is a sound, scientifically based and researched program, the elements of which have been slowly accepted by a sceptical medical establishment. For many decades the Swank regimen, which has some similar aspects to the OMS Program, has generally not been embraced by neurologists. However, the participants who followed the regimen carefully lived long and healthy lives not limited by their MS. Recent research has verified the value of the primary elements of the Swank program, especially the need to reduce as much saturated fat in the diet as possible. The OMS Program has refined the dietary principles and introduced other changes to further enhance the beneficial effects.

OMS is a self-directed and strongly empowering strategy to improve wellness. Having the tools and knowledge of what we can do for ourselves gives us the hope and the strength to take control of a frightening and often bewildering condition. We can actively work towards and look forward to a better future rather than be burdened by the dismal prospects we faced when first diagnosed.

The OMS Program can not only improve the course of MS but also has the added bonus of counteracting many of the health problems that are a result of our Western lifestyle. The combination of a low-saturated-fat diet, optimal omega-3 and vitamin D levels, exercise, de-stressing and social inclusion can improve mental and physical wellness for anyone, especially those of us dealing with a chronic disease.

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My Story: Phil King

I was diagnosed with MS following a bout of optic neuritis in October 2012. Hot on the heels of the optic neuritis came several, previously unknown symptoms: unusual sensations in both of my legs, as if they were unable to carry me; burning all over my body very similar to acute sunburn; dizzi-



ness, fatigue and deafness; and strange numbness, particularly in my fingers. I felt very scared as I had always been highly fit and active. I didn't want my wife Lizzie or my children Laurence and Lottie to become my caregivers.

I was lucky as I had heard about the book Overcoming Multiple Sclerosis by Professor George Jelinek just before I was diagnosed. I immediately ordered the book and read it cover to cover.

I found the program proposed by the book very compelling and straight to the point. I switched very quickly to a wholefood diet supplemented with seafood; I knew I had to 'dump the junk'. I had always enjoyed seafood so that wasn't a problem. I was so desperate for good health that a diet rich in nutrients didn't seem like an effort.

I had started running for exercise many years ago as an aid to stopping smoking; running had become another addiction for me and one that I wasn't going to relinquish easily. To read that running in sunshine could be beneficial for the production of vitamin D was an added benefit; however, getting lots of sun exposure in England can prove difficult so I also supplement daily with vitamin D3.

I have always been a person who can become easily anxious. In other words, I worry a lot! I downloaded albums by Deepak Chopra and Professor Mark Williams (from Oxford University) onto Spotify and these have helped my mindfulness journey a great deal.

I was determined that all this change would be for life. I wasn't going to let the odd unhealthy snack anywhere near my program, or occasionally skip my meditation—I wanted to remain as healthy as I could possibly be.

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I decided that I didn't want to take any disease-modifying medications. This was my own personal choice. I took the view that if after a year of following the OMS Program I deteriorated further, I would then review my decision.

I have been following the OMS principles for eight years now and I am happy to report that I have not relapsed in all this time. I get occasional 'ghosts of symptoms past' but nothing more than that. I exercise six days a week, either running a 6-mile circuit or doing weight training. I am fitter now than I was before I was diagnosed with MS. The disease doesn't worry me anymore and I feel that my overall outlook is good. I have now become an MS nurse in a bid to help others diagnosed with MS. My good health is all thanks to the OMS Program. I am eternally grateful.

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