A Guide to Understanding What Multiple Sclerosis Is

by ABIGAIL BUDD

What Is MS? A Guide to Understanding MS

For those of us with multiple sclerosis (MS), we quickly become experts in all aspects of the disease. Once the numbness and confusion of diagnosis pass, you'll find us on google or other trusted MS websites, looking up symptoms, treatments, and research progress and trying to make sense of our new reality.

It can be easy to forget that those around us don't necessarily have an encyclopedic knowledge of MS and often can't tell it apart from other conditions.

I remember being at a party shortly after my diagnosis and someone I barely knew came up to me with a sympathetic smile on his face and said, "my dad's got MND (ALS) so I know what you're going through."

I was also confused the other day when my colleague started talking about Michael J. Fox and how brave he is. I played along for a while but eventually had to point out that he, in fact, has Parkinson's disease.

Most MSers have also experienced a well-meaning friend telling them all about their brother, auntie, cousin or postman's wife who has MS and can't even feed themselves or get to the bathroom without help.

All this is well-meaning but highlights the fact that most people have no idea what MS is, how it's different for everyone and how the prognosis doesn't have to be disastrous.

In this article, I'd like to pretend I'm talking to one of these people and telling them all about it. I'll imagine they've asked what MS actually is and I'll sit them down and start talking.

What Is Multiple Sclerosis?

MS is an auto-immune disease where the body is attacking itself. It's a neurological condition, so it affects your nerves. It makes your immune system faulty, so instead of protecting you by fighting off infection, it attacks your nerves instead.

It's a condition that affects your brain and spinal cord. There's a coating around your nerves called myelin, and in MS this coating is damaged which causes a variety of symptoms, depending on where the damage is.

I like to imagine a flex on an electrical appliance. The plastic coating is the myelin, and the wires underneath are protected by this plastic. If it's damaged, the appliance won't work properly.

It's always amazing to me that something so small causes such havoc! That's all that's wrong with me! Some bits of myelin are damaged, causing the signals to my brain to be disrupted, and this causes all hell to break loose! Ten years ago, I'd never even heard of myelin, yet it was conspiring beneath my skin to ruin my life.

Are There Different Types of MS?

Yes, there are four different types of MS:

- **Relapsing and remitting MS (RRMS)** – This is the most common form of MS, and about 85 percent of people are initially diagnosed with this. People with RRMS have flare-ups of symptoms called relapses which can last a few weeks but can then get better completely. Over time and if you have a particularly nasty relapse, then residual damage can occur which causes disability.
- **Secondary progressive MS (SPMS)** – In SPMS symptoms worsen over time or without the regular relapses and remissions. Most people with RRMS will develop SPMS over time. I am in the process of being diagnosed with this as I don't have obvious relapses and scan show no new disease activity.
- **Primary progressive MS (PPMS)** – Only around 10 percent of people with MS have this form of the disease. It's characterized by a steady worsening of symptoms from the beginning with no relapses or periods of remission.
- **Progressive relapsing MS (PRMS)** – This is rare as only 5 percent of people with MS have this. It's characterized by steadily worsening symptoms from the beginning with acute relapses with no remission and recovery,

There's also such a thing as Clinically Isolated Syndrome where you have one major relapse, completely recover and never have any other symptoms. I think I'll choose that type of MS, please!

What Causes MS?

This is a good question, and scientists and medical experts have been arguing about what causes MS for years. From genetics to environmental to lifestyle, here are some potential causes of MS.

Genetic Factors

No single gene causes MS, and over 100 different genes might affect your chances of getting it. It's not directly inherited from parent to child, and there's little chance of you being more likely to get it just because a family member has it.

MS can occur more than once in a family, but it's more likely this won't happen. According to statistics, there's only around a 1.5 percent chance of a child developing MS when their mother has it and 2.7 percent chance if your sibling has it.

This is a relief for parents like me as the guilt of having MS is enough without worrying about passing it on to children.

Next page: What causes MS? How is MS diagnosed? Who is at risk for MS? And what are the symptoms of MS?

What Causes MS?

Environmental Factors

Geographically, people closer to the equator are much less likely to get it, and it's much more common in Scotland, Canada, and Scandinavian countries. This is changing though, and some academics think that the spread of a more western diet might be having an impact on Asian countries as MS is on the rise there. It's also strange that Australia has such a high MS population, seeming to disprove the theory that sunlight could be a factor and hinting at diet being a possible cause.

There is a link between vitamin D deficiency and MS, especially in the womb or early childhood. This could also be linked to living in sunnier places as mentioned above as those with higher exposure to sunlight in the womb and childhood are at a reduced risk of vitamin D deficiency.

Infection such as the Epstein-Barr virus has also been linked to MS but not everyone who's carried the infection gets MS, so it can't be the whole story.

Lifestyle Factors

Smoking is the worst thing you can do as evidence now proves it can increase the progression and some people even think it causes MS. This is because it can have a negative impact on the immune system and cause inflammation. Give up now. No excuses.

Obesity can also increase your chance of getting MS, possibly due to making your immune system overactive and causing inflammation or by vitamin D deficiency caused by obesity.

Although losing weight can be harder for those with MS as exercise isn't always easy, following a diet and eating healthily can have a dramatic effect on weight and well-being. I managed to lose around 50lbs by following one of the MS diets and cutting out foods such as dairy and gluten helped with fatigue.

So, it's not clear from the above what causes MS. It's frustrating not knowing for sure, but I'm encouraged that it's probably not my fault and there are things I can change to improve it.

How Is MS Diagnosed?

It can take several months to diagnose MS because it's different for everyone and there can be many symptoms going on at once. A range of other causes also needs to be explored and ruled out before a diagnosis can be made.

For example, a deficiency in vitamin B can cause mobility problems. Tests found that I was deficient in vitamin B, so I was treated for this before diagnosis to rule it out. Unfortunately, the treatment didn't make any difference, and it was obvious something more sinister was going on.

A neurologist will use a specific criterion called the McDonald criteria to diagnose MS, and further tests follow this.

- **Neurological exam** – The neurologist will ask a lot of questions about your family and medical history to build up a picture of you. A physical examination is then carried out, to identify changes or weaknesses in your eye movements, leg or hand coordination, speech or reflexes, balance and walking. Even if he has a good idea that you have MS, he won't diagnose it till further tests are carried out. This exam was painless, and I was fully clothed, so there was nothing to worry about.
- **Magnetic Resonance Imaging (MRI)** – An MRS scanner is a huge contraption that uses powerful, magnetic fields to create an image of the inside of your brain and spinal cord. You have to lay still while you're wheeled into it and waited around 20-40 minutes while it scans you.

It's extremely loud and claustrophobic, and I was terrified the first time I had a scan, but you soon get used to it, and I've fallen asleep the last couple of times! It's extremely accurate and can pinpoint the location and size of lesions on your brain causing the symptoms. The MRI scan can diagnose MS in 90 percent of people and is also used to detect changes in disease activity, indicting SPMS.

I will never forget the look on the face of the lady who did my initial scan. She obviously saw what was going on and asked if I had an appointment to see my neurologist soon. I cheerfully confirmed that I did and thought nothing of it but, looking back, she must have known.

- **Evoked potentials tests** – This test is painless and involves testing the time it takes your brain to receive messages from your eyes, ears, and skin by having electrodes attached to your skull. The message will be slower in those with MS if the myelin has been damaged. I remember finding this test quite good fun!
- **Lumber puncture** – Also known as a spinal tap, this involves removing spinal fluid, and I found this extremely painful and upsetting! The test is looking for antibodies which aren't found in people who don't have MS.

- **Other tests** – You may also have blood tests, inner ear tests and urine tests to rule out other conditions.

Who Is at Risk for MS?

Usually, people are diagnosed with MS between the ages of 20 and 40, but many of those people identify symptoms in their teens, and it takes years to piece it together to come up with MS. Often, the symptoms don't seem to go together, so it's only by looking back do you link the symptoms up.

Children can also get MS but only around 5-10 percent of people with MS report symptoms under the age of 16.

MS has a more significant impact on women and three times more women are diagnosed with it than men. Researchers are still trying to figure out why and maybe hormones also play a part in its cause.

What Are the Symptoms of MS?

As mentioned above, numerous symptoms can be caused by the damaged myelin sending confused messages to the brain, and no two people will experience MS in the same way.

Some of the most common symptoms are listed below.

- Mobility issues – This includes difficulty walking or standing, and weakness or spasticity in the limbs. Foot drop can also cause a problem with walking.
- Balance problems – Often exacerbated by inactivity.
- MS hands – Weakness and numbness, causing difficulty holding things or doing manual tasks.
- Fatigue – 60-80 percent of people with MS experience crippling fatigue which isn't the same as tiredness.
- Bladder and bowel issues – Needing to go frequently, being unable to empty the bladder fully as well as constipation or incontinence.

Next page: What are the symptoms of MS? How is MS treated? And what does life with MS look like?

What Are the Symptoms of MS?

- Sexual problems – Especially erectile dysfunction in men.
- Pain – Including strange neuropathic sensations.
- Pins and needles and numbness.
- Sight problems – Including optic neuritis.
- Heat sensitivity – Worsening of symptoms in extreme heat or cold.
- Cognitive problems – Memory, concentration and word retrieval.
- Speech difficulties.
- Swallowing problems.

Luckily, we won't suffer all these symptoms all the time, and in those with RRMS, a full recovery can be made after a flare-up or relapse in symptoms.

What MS Treatment Options Are Available?

The best treatment for those with RRMS are disease-modifying drugs or therapies (DMD/DMT's), and it's advised people start on these as soon as possible after diagnosis. These include injections and infusions as well as daily drugs, but sometimes the side effects seem to outweigh any benefits you may feel.

The research suggests, however, that being on DMT's can reduce the number and severity of relapses and can prevent progression, so it's worth trying different kinds till you find one that suits you. It's also worth pointing out that different drugs and therapies are being developed all the time so if one doesn't suit you, speak to your

neurologist and try something else.

Unfortunately, DMT’s are only available when the MRI scan indicates disease activity, and if none is present and it’s decided you have SPMS, there are no treatments available.

Research is going on all the time though, and Stem Cell treatment could be the answer in future.

Beware of “miracle cures” on the internet where paying a fortune to travel to distance places promises dramatic results. There is little conclusive evidence for these treatments, and it’s far better to wait patiently for the real breakthroughs.

There are treatments for symptoms though such as medication for pain and bladder issues as well as physiotherapy and more holistic approaches.

Changes in lifestyle and diet can also ease fatigue and exercise can have a significant impact on mobility issues, but trial and error are necessary till you find what works for you.

I’ve started using CBD oil as there is some evidence that it can ease pain and spasticity. It’s also recommended that people with MS take vitamin D supplements and I’ve met MSers who swear by turmeric or evening primrose oil. As with all these types of treatments, there is little evidence of the benefits, but they won’t do you any harm, so they’re worth a try.

What Does an MS Prognosis Look Like?

Not everyone with MS will end up severely disabled and need a wheelchair. As we have seen, there are numerous symptoms associated with MS, but no two people with MS will be the same, and we won’t experience all the symptoms all the time.

My main symptoms are mobility issues and balance, but cognitively I’m doing well! I can’t walk well but I can read a book, write and I still work part-time in a job I love. I feel I lead as full a life as I can and although I need to rest frequently, and my disabilities make it harder to get out and about, I still make a contribution to life and can feel proud of myself.

Also, I think my attitude and outlook plays a considerable part, and as long as I stay positive things don’t seem so bad. There are worse things to have than MS.

What's Next With MS?

So, as you can see from this entire article, MS can be a complicated and devastating condition with many symptoms.

So now you know all about the condition what do we need you to take away? We MSers don’t want your pity. We don’t want you feeling sorry for us, but we may occasionally need your help, and we always need your understanding.

If we can’t make a social engagement, it’s probably fatigue stopping us rather than being rude. Although many of our symptoms are invisible, that doesn’t mean we’re not having a rubbish day, even if we’re still smiling.