

MS – the invisible war on emotion

So you have been diagnosed with Multiple Sclerosis. Like every other serious health diagnosis, the news is really hard to take in, especially if you are feeling relatively good.

While some people feel relieved to finally get a name for all their unexplained symptoms and/or years of misdiagnosis, others will start going through the five stages of grief: denial, anger, bargaining, depression and eventually acceptance.

Mourning takes place throughout many big life changes; we mourn the end of a relationship, the end of a happy era, huge lifestyle changes. We also mourn who and how we used to be. Being told you suffer from a condition that has no cure, that is unpredictable, that could put you in a wheelchair, that will change your life as you know it forever and which comes with so many symptoms and side effects triggers a mourning state which could last for very long.

“Often, people will grieve not just after diagnosis, but each time they experience significant changes in functional abilities or life roles”, Rosalind Kalb, Ph.D., vice president of Clinical Care at the National MS Society

Like many other ‘invisible’ conditions, Multiple Sclerosis is sneaky; many of its symptoms are not seen by others and a few more are not even given much attention, although are detrimental to the sufferer. Of those symptoms are the psychological impact MS has on people and also the emotional problems it brings with it.



Unfortunately, it is understandably difficult for others to comprehend how fatigue, pain, itchiness, body aches, trembling and tingling affect you daily let alone mood swings, depression, and emotional ups and downs.

Saying that, you would wish for people in your life who truly care for you and love you to be actively helping, trying to understand and listen more, getting involved in learning and educating themselves – you are right thinking like that.

Crying, laughing and then crying again...

With an MS diagnosis also comes loss; you might lose the ability to do certain sports, to go to work, to think as clearly as before or the loss to control your emotions. Grieving and feelings of sadness could lead to depression which could last for a few days or even turn into clinical depression which lasts for much more and is more unremitting. You might enter an emotional roller-coaster with confusing feelings that will make you more sensitive and prone to bouts of crying or laughing for no particular reason.

Another reason for why that happens is the '[Pseudobulbar affect](#)'! This is a condition often referred to as 'Involuntary Emotional Expression Disorder'. **You could burst into uncontrollable laughter or cry without necessarily feeling the emotions associated with that expression.** It is a truly frustrating situation where for no apparent reason you could start crying or laughing at something not funny at all, without being able to stop.

“These changes are thought to result from lesions in emotional

pathways in the brain. It is important for family members and caregivers to know this, and realize that people with MS may not always be able to control their emotions”, (National Multiple Sclerosis Society).

Stress, Anxiety, and Depression

Studies, which were conducted as early as in the 80's, had already warned of the mental health risks patients with Ms face. In particular, Devins, Gerald M, in 1987, concluded that two factors—functional loss (imposed by the increased physical disability produced by MS) and disease activity (exacerbation and progression of symptoms)—have been identified as contributors to increased emotional distress in MS patients. He called for further investigation into the matter so that patients get all the needed support. In later studies, more scientists also found that **anxiety and depression occur more frequently in multiple sclerosis patients than in the general population.**

'Studies have found that more than 35 percent of people with MS have some type of anxiety disorder, which is higher than the general population. Within this 35 percent, the majority of people have generalized anxiety disorder, though



obsessive-compulsive disorder and panic disorder are also well represented. Women are more likely to have anxiety than men; the same is true for depressed mood.'

It is easy to see how coping with MS can lead to feelings of anxiety and depression. **The daily struggles patients face are exasperating, stressful and frustrating at best. Trying to adjust to a new reality with many disabilities is exhausting**

and scary.

Regardless of these factors, the condition itself can also cause depression “by destroying the protective coating around nerves that help the brain send signals that affect mood”, (WebMD). As if these were not already enough reasons for a person with an MS diagnosis to suffer from depression, some of the disease modification drugs used, such as interferon, can also cause, sometimes severe, cases of depression.

Stress is a possible trigger that could lead to a relapse in MS so it should be managed as much as possible.

Ask your doctor for help if:

- Your sadness is making your life worse, like causing trouble with relationships, work issues, or family disputes – and there isn't a clear solution to these problems.
- You have thoughts about suicide. If that happens, get medical help right away. (WebMD)

Too many things happening at once...please stop!

Very often, things get too much for a person who suffers from MS. There could either be situations where overloaded data from multiple sources is being processed or even just interacting with one person can feel like a sensory strain. Too many external triggers can kick off many internal responses. Maybe the sounds will feel too loud, the scents too strong, the music too annoying or the sun too bright. It might also be people talking at the same time, the supermarket being too crowded or a 3D movie making you feel really sick.



Sensory overload becomes so unbearable that it can force people to quit their job, stop attending places they used to like going to and it can generally disturb normal daily routines. Many situations like the ones described above result

in excessive stress and anxiety. **What makes everything worse is the inability of the people around MS sufferers to empathize with what is going on inside their heads.**

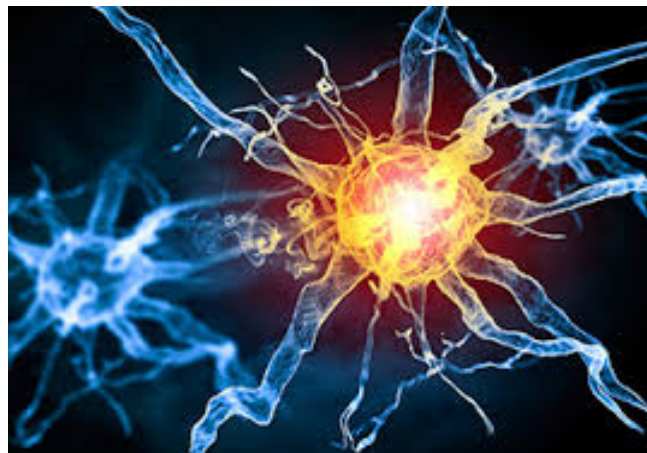
People suffering from Multiple Sclerosis mostly feel alone – lack of understanding or willingness to empathize/support/get informed by family, loved ones and close friends create feelings of loneliness, desperation, and abandonment.

Many people will often tell me that they get most of their emotional and psychological support through Facebook groups rather than from their partners and family.

Feeling angry and frustrated

The problem is that the connection between MS and emotions often goes unrecognized. In moments of great emotional upheaval, there is a need of release and it often comes in the form of anger or frustration. There are times when things can get patients worked up really fast to the point where anger management becomes an issue.

“We believe that the higher levels of withheld anger shown by the study subjects is due to demyelination, loss of the substance in the white matter that insulates the nerve endings and helps people receive and interpret messages from the brain” explains lead



researcher Dr. Ugo Nocentini from the IRCCS S Lucia Foundation in Rome.

In his latest [study](#), he explains that high unexpressed anger in MS patients is linked to nervous system damage and not disease severity which actually means that people in the early stages of diagnosis are also susceptible to it. It is vital for MS sufferers to ask for help and seek support when they feel like they are not in control of their anger and frustration.

Not thinking straight...

I feel like that quite often. Experiencing fatigue is NOT the same as feeling tired and the truth is that 99% of non-MS sufferers will not comprehend the difference. Fatigue is an overwhelming feeling of mental and/or physical exhaustion out of proportion to the task performed. Cognitive symptoms such as difficulties with slowed thinking, poor memory, concentration, and attention span are also quite frequent in sufferers. All these mount up to more of the invisible insane crap that the majority of people will not see, acknowledge or quite grasp.



Living with MS is not great at all. Despite being a totally different experience for every patient depending on the severity of the disease, a plethora of everyday symptoms are struggled with universally the same. The worry and fear

of progression and the uncertainty of the future are also experienced by all.

Emotional and mental problems are often overlooked which potentially makes things ever so much worse. On top of that trying to cope with a condition that for many doesn't have physical manifestations is often met with expressions such as: 'but you don't look sick'.

But although it is all too much to handle at times, this is not a negative and demoralizing post but rather one on awareness which we need to spread around the world so doctors, nurses, family, loved ones, and friends are able to positively contribute to our health plan. **Emotional changes have to be recognized and acknowledged as a serious MS side effect.** Its effects need to be researched more, guidelines should be put in place and medical professionals should receive education on the subject. **Until then, stay positive and hopeful** ☐