

READING 1

The Challenges of Multiple Sclerosis Symptoms

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As a person living with multiple sclerosis (MS), you likely have your own unique combination of symptoms. Some of your symptoms may not always be visible to others, including healthcare practitioners. Some of your symptoms may be persistent, something you live with on a daily basis. Others may come and go at unpredictable rates. This experience can be frustrating.

A recent participant in the Take Charge of My MS program (an intervention study from the University of Washington) explained his frustrating MS experience this way:

“I was in grad school when I was diagnosed with MS. That was 20 years ago. I have not used my degree in the way that I initially set forth to use it. I have daily struggles that involve depression, pain and fatigue ...”

“...A typical day for me has its own set of limitations. Some days I have enough energy to do a little more, like go to a reunion with a group of old friends, but then I pay for it the next several days; it’s a fatigue issue. It’s like I hit a wall, I’m at the end of the rope, and it’s all I can do to stay home at this point ...”

“... I also find that my friends just don’t understand, and it’s humiliating trying to explain these problems when they just don’t see it. Some sympathize but empathy and compassion is lacking. I am still working towards these goals I set for myself before I was diagnosed, but I have had to adjust my own expectations for myself. I have to find a way to accept myself. Then I find I have to constantly be educating others about my disease in order to just get them to accept and understand me as I am today. Even if I explain myself to others, it’s no long term solution. It will buy me time. If they don’t accept this, fine, I’m moving on. As Bono says “walk on.”

This perspective is unfortunately common for many people living with MS.

The MS experience can include many symptoms and changes, including but not limited to pain, depressed mood, fatigue, sleep problems, and cognitive problems. Many of these symptoms are invisible to others. MS symptoms do not exist in isolation, they interact. They come and go. It's all very unpredictable and individually different. Let's look at each of these challenges in more depth.

Hidden Symptoms

Some of the symptoms that cause the most discomfort or distress among people living with MS are unseen to the outside observer. The most commonly reported "hidden symptoms" among people with MS include pain, fatigue and depression.

Chronic pain is something most people in the general population do not have to deal with. Pain in MS can take different shapes from muscle cramping or headaches to shooting electrical sensations or joint aches. What makes MS pain unique is that it can seem to come out of nowhere and the sensations can vary in intensity and location. Because pain is an internal experience, it is not readily visible to others.

Fatigue is another symptom experienced quite differently by people with MS. Like pain, MS fatigue can come on suddenly and vary in intensity. It is often reported as a regular part of day to day life with MS, worsening towards the end of the day. Fatigue can be very limiting on a person's ability to participate in activities as fully as they desire, as it drains both the physical and mental energy required to be fully engaged.

Depression and other mood changes occur among people with MS in higher rates than the general population. However, depression is not always recognized by care providers due to overlapping symptoms of depression and fatigue. Depression brings on unhelpful thinking and low mood and can make managing other MS symptoms feel overwhelming. Hidden symptoms can be challenging for people with MS for a variety of reasons. When people with MS mention to others that they are forgetful, for example, some friends or family may say something like

“yes, I am too. Aren’t we all?” Although trying to be helpful, others will often minimize the hidden symptoms or attribute them to normal aging or life, rather than MS. Sometimes others may downplay your experience because they can’t see it. You may become tired of or frustrated by explaining to people about the hidden nature of your MS symptoms. Occasionally, others may even accuse you of exaggerating or being “a complainer”, or worse they label you as “high maintenance”, or “the problem”, especially in work environments. Here is what a person with MS told us:

“I can take information in and process it, but can’t retrieve it when it’s needed. I have a low frustration tolerance. I give myself permission to do things I normally would not do like walk away, write things down, or rely on other people. I forget things if I don’t write them down. I have to lower my frustration level for myself. I do this on my own and people see this as me being lazy.”

Others often question the legitimacy of the experience. They may not modify their expectations of the person with MS because they can’t see the effects of these very real symptoms. This lack of empathy can make people with MS feel like they have to advocate that much more for themselves to be understood.

MS Symptoms Often Overlap

MS symptoms don’t occur in isolation. Many symptoms of MS overlap. A flare-up of one symptom can have an impact on other areas of functioning. For example, pain can make for a difficult night’s sleep which in turn can increase daytime fatigue and lower mood. An example from another person with MS illustrates how fatigue is not simply fatigue:

“Fatigue affected my memory. I lost keys, glasses, credit cards. My neurologist told me my cognitive functioning is at 18%. I can’t make decisions at grocery store. For something particularly challenging, I do it in the morning...”

Your MS symptoms can also interact or overlap with other health conditions you may have. As you know, MS does not spare you from getting other health conditions. For example, you may have to manage high blood pressure, diabetes, allergies, or arthritis. It is important

for people with MS to not only pay attention to their MS but also their health in general, including other conditions. MS symptoms can make other conditions worse, and vice versa. Your fatigue or weakness may make it difficult to get regular exercise, which in turn may place you at risk for gaining weight or having hypertension.

Symptoms left untended can worsen over time and have increasingly negative impacts on many areas of living. For example, when people are depressed they often avoid engaging in activities they used to enjoy. Disengaging in activities and withdrawing from social supports can make a person feel isolated, increasing negative thoughts and depressed mood.

Many people have experienced this vicious cycle of symptoms. It can be difficult to know where to intervene to be able to feel better. The compounding effects of multiple unmanaged symptoms or symptoms persisting without intervention over time can decrease a person's quality of life.

MS Is Often Unpredictable

Another challenge to living with MS is the uncertainty of flare-ups. As one person with MS once said, *“the only thing predictable about my MS is that it is unpredictable!”* For example, your fatigue or pain may not have the same pattern every day. As one person with MS noted:

“...It's stressful when my energy changes. It drops as the day goes on and it takes away from family. My energy is different at different times of day. Not every day is the same, either. I have good days and bad days, and I cannot always predict what kind of day I will have. I do know that fatigue occurs daily and it takes me away from my family.”

Addressing the Challenges

Throughout this study we will discuss the complexity of managing MS depression and/or pain and ways to boost your overall well-being.

READING 2

Self-Management: The Keys to Taking Charge of Your MS

Source: Wazenkewitz, J; McMullen, K; Ehde, D. Self-Management: The Keys to Taking Charge of Your MS. *MS Focus*. Summer 2010: 12(3): 11-13.

As a chronic condition, treatment of multiple sclerosis often includes several healthcare providers involved in the medical decisions and direction of your healthcare planning. This system of professionals providing testing, diagnoses, and treatment options is considered the medical management model of chronic disease management. The medical management model includes all medical-based aspects of your MS, including prescriptions, visits with primary care providers and MS specialists, and rehabilitation.

While medical management is an important piece of maintaining good health when living with this condition, the impacts of MS symptoms are not limited to your twice-a-year visits to your neurologist. You experience the symptoms of MS every day, and, as such, your symptoms require management every day.

Self-management is a philosophy of chronic disease management that acknowledges that living with MS is an ongoing experience. And it has been found to be an empowering strategy to improve health and reduce negative impacts of symptoms for people living with many different types of chronic disease ranging from diabetes and heart disease to HIV. After all, you are ultimately the one in the driver's seat navigating the day-to-day aspects of your care and well-being. You are the expert on how your fatigue feels in the morning versus the late afternoon. You are the expert on where the pain in your legs flares up the most. You are the expert on how your symptoms impact your mood.

This insider's perspective puts you in the best position to make decisions about which medical and non-medical strategies you use to

manage your MS. You are also in the best position to reduce negative impacts that your MS symptoms have that prevent you from living your life the way you want.

Putting Your Knowledge to Work

The question is, how do you translate your expert knowledge of your MS experience into positive life changes? Self-management training programs are currently being conducted through some research universities and health clinics across the country to teach this approach to people living with chronic diseases. This training involves a combination of education and skill-building opportunities to give individuals the tools they need to manage their symptoms. As a result, they can then participate more fully in life activities that are meaningful to them.

Self-management acknowledges that MS symptoms do not only impact your body and physical experience, but also influence the way you think, how you feel, and the actions you decide to take.

For example, pain, fatigue, and other MS symptoms may change the way you grocery shop or how you feel at an all-day music festival in the sun. Your symptoms may impact how you communicate with coworkers or how you feel about your role in your family life. Treating MS solely with medications to simply impact the physiological processes involved falls short of addressing the whole picture.

This is why self-management involves strategies that intervene at multiple levels: mind, body, emotion, and actions. These four domains of experience are intertwined, each impacting one another. Let's look at an example of how these domains of experience play out in a situation.

A Portrait of Self-Management

Lisa is on vacation exploring a seaside town with friends when her leg begins to feel very heavy and starts to drag. This physical experience prompts her to think, "This is going to ruin our whole afternoon. My friends are going to be so annoyed that I am slowing them down."

These thoughts, in turn, bring up a wide variety of emotions in her, making Lisa feel frustrated with her body, overwhelmed and sad that she

has to deal with this right now, and worried about how her friends are going to respond to the situation. She changes the way she acts, withdrawing from the conversation, and stops taking pictures of the scenery. Her depressed mood then makes her leg feel even heavier and the rest of her body tenses in response to the stress of the whole situation.

It's easy to see how a vicious cycle of unhelpful thoughts, actions, and emotions can flare up in the face of physical distress. Self-management skills offer a variety of tools with which to address the problem including: self-monitoring, goal setting, problem solving, positive self-talk, energy management, behavior changes, planning for stress, and relaxation strategies.

There are several ways that Lisa, in the situation above, could utilize self-management tools to improve her situation and lessen the negative impacts that the flare-up in her leg is having on her day. Here is what it might look like if she were to draw on positive self-talk skills:

Lisa is on vacation exploring a seaside town with friends when her leg begins to feel very heavy and start to drag. She initially begins to think, *“This is going to ruin our whole afternoon. My friends are going to be so annoyed that I am slowing them down.”* Anticipating that she may be about to get caught in a negative cycle of thinking that could make the situation worse, Lisa challenges her thoughts and replaces them with: *“Although this is annoying, I don’t need to let my leg ruin my day. My friends will understand that I need to rest for a little while.”*

This new line of thinking prevents her from becoming emotionally overwhelmed and prompts her to communicate with her friends to get her needs met rather than withdrawing from her sightseeing. After resting, she feels better and enjoys the rest of the day with her friends.

Maximizing Your Skills

Self-management training gives individuals the opportunity to learn and practice a variety of skills that can be implemented in many situations. Unlike some chronic disease management models that focus primarily on the problems and negative impacts of disease, the philosophy of self-management comes from a strengths perspective. It acknowledges that

every individual brings to the table unique life experiences, knowledge, and skills in which they already excel. It is by tapping into your strengths and building your capacity to handle challenges in new ways that gives you power to be in control of how MS affects your life.

Self-management encourages you to look at your well-being with a holistic, proactive approach. As an effective self manager, you learn to go beyond a putting-out-the-fire approach of treating MS symptoms and their effects after they cause distress. With skills and practice, you will be able to anticipate common disruptions that symptoms cause in your life and be able to take preventative steps to reduce or eliminate the negative impacts those disruptions might cause. As a result, you will enjoy many benefits.

Research has shown that people who are self-managers have more confidence in their ability to address problems such as pain, fatigue, and depressed mood. They are able to better communicate their needs to get improved support from others and strengthen relationships. There is also evidence that feeling more in control of symptom management improves pain, mood, psychological functioning, and daily functioning.

Getting with the Program

Self-management programs may differ somewhat in the specific skills taught, depending on the disease and symptoms needing to be managed.

Yet all of the programs are about being an informed healthcare consumer who knows about your own condition and treatment options. In addition to the skills listed above, self management programs may also include instruction in decision making, resource utilization, and individualizing skills.

To promote a more active role in the health treatment team, training may also include developing productive relationships with healthcare providers. In MS, skills for managing energy, fatigue, pain, and mood are particularly important, given MS so commonly affects these areas. Whatever the specific skills, the strengths-based, proactive philosophy of self-management is the foundation for intervening in day to- day stressors of chronic disease to improve quality of life.

The following websites offer additional resources and information that may be useful to people with multiple sclerosis (MS), their physicians, and their friends and families:

Multiple Sclerosis (MS) Information

- **National Multiple Sclerosis Society**

The National MS Society addresses the challenges of living with MS through its 50-state network of chapters. The Society funds cutting-edge research, drives change through advocacy, facilitates professional education, and provides programs and services that help people with MS and their families move their lives forward.

(www.nationalmssociety.org)

Greater Northwest Chapter: (www.nationalmssociety.org/Chapters/WAS)

- **Multiple Sclerosis Foundation**

The Multiple Sclerosis Foundation's website offers information on MS, as well as programs and events, publications, access to provider information, and a wide variety of online services and forums.

(<https://msfocus.org/>)

- **International Federation of Multiple Sclerosis Societies**

A comprehensive, international and up to date information resource developed by MS experts worldwide, and available in 15 languages.

(www.msif.org)

- **Multiple Sclerosis Association of America**

The website provides information on MS programs and services, and access to several quarterly publications for people with MS.

(<http://mymsaa.org/>)

Multiple Sclerosis (MS) Information

- **MSRRTC.washington.edu**

Our University of Washington-based Multiple Sclerosis Research and Training Center (MSRRTC) website shares the latest findings and studies on psychosocial research for MS as well as offering an online MS workbook with useful information for people with MS. (msrrtc.washington.edu)

- **Multiple Sclerosis Center of Excellence**

As part of the United States Department of Veteran Affairs, the Center of Excellence provides information on understanding, diagnosing, and treating MS, as well as life issues and health problems associated with MS. (www.va.gov/ms)

- **MS World**

Provides information and support for those living with MS. All volunteers managing the website are diagnosed with MS. (www.msworld.org)

- **Can Do Multiple Sclerosis**

Provides lifestyle empowerment programs for people living with MS. (www.mscando.org)

- **HealingWell.com**

A free social network and community for information, resources and support. (www.healingwell.com/ms)

Depression & Mental Health Information

- **National Suicide Prevention Lifeline**

A free, confidential 24-hour hotline available to anyone in suicidal crisis or emotional distress. Your call will be routed to the nearest crisis center to you.

(1-800-273-TALK (8255); www.suicidepreventionlifeline.org)

- **Hopeline**

A free, confidential 24-hour hotline available for anyone in a suicidal crisis or emotional distress. 24-hour email support and online chat support is also available.

(1-800-442-HOPE (442-4673); www.hopeline.com)

- **MS World**

Provides information and support for those living with MS. All volunteers managing the website are diagnosed with MS. (www.msworld.org)

- **American Psychological Association Psychologist Locator**

The Psychologist Locator makes it easy for you to find practicing psychologists in your local area. (1-800-964-2000; <http://locator.apa.org>)

- **Psychology Today Therapy Directory**

Find a therapist, psychologist, psychiatrist, or counselor.

(<http://therapists.psychologytoday.com>)

- **Drug and Alcohol Abuse Treatment Facility Locator**

Search by state and city to find drug and alcohol abuse treatment programs nearest you. (<http://findtreatment.samhsa.gov/>)

- **Center for Substance Abuse Treatment**

Provides 24/7 referrals to treatment facilities.

(1-800-662-HELP (4357); <http://www.samhsa.gov/treatment/index.aspx>)

Pain Information

- **American Chronic Pain Association**

Facilitates peer support and education for individuals with chronic pain and their families. (1-800-533-3231; <http://www.theacpa.org>)

- **American Pain Society**

Provides resources for individuals coping with pain.
(<http://americanpainsociety.org/education/resources>)

General Disability Information

- **UW Center for Technology & Disability Studies**

The University of Washington's Center for Technology & Disability Studies conducts research projects primarily aimed at increasing access to education, community, and employment for people with disabilities through assistive technology and accessible information systems. (<http://uwctds.washington.edu>)

- **DisabilityInfo.gov**

DisabilityInfo.gov is a comprehensive online resource designed to provide access to disability-related information and government programs, including benefits, civil rights, community life, education, employment, housing, health, technology and transportation. (www.disability.gov)