

**ANDREA ARZT**

**'Understanding the Emotional Aspects of Multiple Sclerosis'  
Mental Health Symposium June 18<sup>th</sup> 2016**

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[2016/06/18 09:55] LV (lorivonne.lustre): Hello everyone.

Today's presentation is being transcribed so those without audio or who require text only can participate in real time.

A little explanation about this service.

Voice-to-text transcriptionists provide a translation of the key ideas discussed, NOT a word for word transcription.

Voice-to-text services provide an in-the-moment snapshot of ideas and concepts, so that those who are unable to hear or to understand the audio program are able to participate in real-time.

You will see the transcription in Nearby Chat.

Transcription is provided by Virtual Ability, Inc.

The transcriptionists are:

LoriVonne Lustre

Carolyn Carillon

The following initials in the transcription record will identify the speakers:

AA = Andrea Arzt

Andrea will be using a speakeasy.

<transcription begins>

[2016/06/18 10:00] FidgetsWidgets Resident: Hello and welcome to the Virtual Ability Mental Health Symposium.

The title of this session is "Understanding the Emotional Aspects of Multiple Sclerosis."

My name is Fidget, and I am an SL resident of the Virtual Ability environs and participant in the SL Ethnographia Island project.

It gives me great pleasure to introduce to you Andrea Arzt.

Andrea is Associate Vice President of Clinical Programs and Direct Services for the New York City-Southern New York Chapter of the National MS Society (US).

She has worked for over 25 years with individuals with chronic illness and disabilities and their families.

Her special interest has been in working with people living with neurological diseases and injuries, with a focus for the past 13 years on Multiple Sclerosis.

In her current position at the National MS Society, she works closely with health care professionals who treat people with MS, and with MS researchers. She provides trainings on MS and psychosocial and emotional issues for professionals and as well as for people living with MS, and she develops programs for families and caregivers.

Please hold your questions until Andrea is done presenting, and join me now with a warm VAI welcome to Andrea Arzt as she comes to the podium!

[2016/06/18 10:02] LV (lorivonne.lustre): CC will be providing the transcript for Andrea Arzt

[2016/06/18 10:03] Carolyn Carillon: AA: thank you all

I want to thank the organizers of today's exciting conference for inviting me to present these important issues as they affect people living with Multiple Sclerosis. It is an honor to be here.

Here are the key goals of my presentation today.

I want to give a quick overview of Multiple Sclerosis (MS) so those of you who are new to understanding this disease have a basic background regarding the medical aspects to put the rest of the presentation in context.

I want you to understand the psychosocial aspects of living with MS – a key component of understanding the emotional aspects of this chronic illness.

I want you to learn the emotional changes and mood related symptoms that can be associated with MS

We'll talk about treatment of emotional symptoms in view of the total wellness picture

What are barriers to treatment?

What are the continuing questions?

The best way I can think of to help you understand MS – is to show you what MS looks like by sharing the wide variety of faces of people living with MS:

Let's have a look at a few of these people.

Julia—a 35 year old white married mother of 3 who is exhausted all the time and can't drive because of vision problems and numbness in her feet

Jackson—a 25 year old African-American man who stopped working because he can't control his bladder or remember what he read in the morning paper

Maria—a 10 year old Hispanic girl who falls down a lot and whose parents just told her she has MS

Loretta—a 47 year old white single woman who moved into a nursing home because she can no longer care for herself

Here are some more faces:

Sam—a 45 year old divorced white man who has looked and felt fine since he was diagnosed seven years ago

Karen—a 24 year old single white woman who is severely depressed and worried about losing her job because of her diagnosis of MS

Sandra—a 30 year old single mother of two who experiences severe burning pain in her legs and feet

Richard—who was found on autopsy at age 76 to have MS but never knew it

Jeannette—whose tremors are so severe that she cannot feed herself

So what does this tell you about MS? That it is very different in each person – and that those of you who know someone with MS, may not have the total picture of everyone with MS.

One of the hallmarks of MS is the variety of symptoms and the different ways it can manifest itself in different people.

So, what is MS?

MS is an unpredictable, often disabling disease of the central nervous system. MS interrupts the flow of information from the brain to the body and can make moving difficult.

MS is an auto-immune disorder, which means the immune system incorrectly attacks the person's own healthy tissue.

In MS, the immune system attacks myelin, a substance that surrounds and insulates nerve fibers. Myelin is essential for nerves to conduct electricity and carry out their function.

When myelin is destroyed or damaged, the nerves lose their ability to transmit electrical impulses to and from the brain effectively.

You can think about our nervous system as an electrical wire

The wire is on the inside and the insulation is the outside

If the insulation is damaged, the electricity doesn't work properly

All those things happen when someone has MS

The progress, severity and specific symptoms of MS in any one person cannot yet be predicted, they can range from fatigue, numbness and tingling to blindness and paralysis.

However, advances in research and treatment are moving us closer to a world free of MS.

What are some facts to know?

Diagnosis can happen at any age, but mostly between 20-50. Although commonly thought of as “an adult disease” it is estimated that 8,000 - 10,000 children are living with MS.

It is not fatal or contagious

It's more common in temperate zones

It occurs more commonly in Caucasians  
but others are not immune

Women tend to be diagnosed 2 to 3 times more often  
as with other autoimmune disorders

There may be connections to hormones

Women do better with their MS during pregnancy

What are some myths about MS?

MS is not fatal, not contagious, not directly inherited (although there may be a genetic predisposition), it is not always severely disabling.

Being diagnosed with MS is not a reason to stop:

Living and enjoying life.

Moving!

Or building a family---there is a very small risk of having a child with MS. 3-5% vs. 97% chance of not having child with MS

What causes MS?

MS is believed to have a genetic factor, environmental factor, and an autoimmune factor.

When a person who is genetically susceptible encounters the environmental trigger, the autoimmune response is initiated. It is the autoimmune response that causes damage in the central nervous system.

Studies indicated that genetic factors make certain individuals more susceptible than others, but there is no evidence that MS is directly inherited. No single gene is responsible for the disease.

The average person in the United States has about one chance in 750 of developing MS. But relatives of people with MS, such as children, siblings or non-identical twins, have a higher chance—ranging from one in 100 to one in 40.

The identical twin of someone with MS, who shares all the same genes, has a one in three chance of developing the disease. The identical twin of a person with MS would always get MS if genes were the only factor involved.

How is MS diagnosed?

There is no single test that can determine if a person has MS. It is a clinical diagnosis based on gathering of medical history and looking for symptoms and signs in a neurological exam.

The current criteria for the diagnosis of MS require evidence of plaques that occurred in different places in the Central Nervous System at different points in time.

This is why it can sometimes take months or even years to confirm the diagnosis. Until the second attack has occurred, the current criteria for the diagnosis of MS have not been met.

What you might see on an MRI. The spots, which show yellow because of a gadolinium enhancement – shows plaques or scars in areas typical for MS.

There are four known types of MS:

Clinically isolated syndrome:

CIS is a first episode of neurologic symptoms caused by inflammation and demyelination in the central nervous system. It is characteristic of MS but does not yet meet the criteria for a diagnosis of MS.

When CIS is accompanied by brain lesions on MRI that are similar to those seen in MS, the person has a high likelihood of a second attack and a diagnosis of MS.

When no brain lesions are present, the likelihood is much lower.

#### Relapsing-remitting MS:

People with this type of MS experience clearly defined attacks (also called relapses or exacerbations).

These are episodes of acute worsening followed by partial or complete recovery periods (remissions) that are free of disease progression.

RRMS can be further characterized as Active (with lesion activity and/or relapses) or Not Active AND Worsening (increased disability resulting from symptoms that do not completely disappear following a relapse) or Not Worsening.

Frequency: Most common form of MS at time of initial diagnosis.

Approximately 85%.

#### Primary-Progressive:

People with this type of MS experience a slow but nearly continuous worsening of their disease from the onset of symptoms, with no distinct relapses or remissions.

However, there are variations in rates of progression over time, occasional plateaus, and temporary minor improvements.

PPMS can be further characterized as Active (with MRI activity and/or relapses) or Not Active AND Progressing (showing a confirmed increase in disability over a given period of time) or Not Progressing.

Approximately 15% of people are diagnosed with PPMS.

#### Secondary-Progressive:

People with this type of MS experience an initial period of relapsing-remitting MS, followed by a steadily worsening disease course with or without occasional flare-ups, minor recoveries (remissions), or plateaus.

The majority of people with relapsing-remitting MS will eventually transition to SPMS, although early and ongoing treatment with a disease-modifying therapy has been shown to delay SPMS in many people.

These charts give a pictorial view of how a person's MS might look over time. The first chart showing a relapsing remitting course, show clearly defined attacks of new or increasing symptoms – with periods in between of partial or complete recovery.

Most people with relapsing remitting MS will eventually – possibly over 10 or 20 years, perhaps longer-- transition to a secondary progressive course in which there is a progressive worsening of neurologic function or in other words increased disability. Sometimes relapses continue. Sometimes with no more actual relapses.

Primary progressive MS is characterized by worsening neurologic function and disability from the onset of symptoms, sometimes with a few relapses, sometimes with no exacerbations.

This cartoon drawing shows the steps involved in the damage to myelin and axons.

1. The yellow segments represent the myelin coating.
2. One area of myelin has been damaged.
3. The immune attack then becomes directed towards the axon or nerve itself.
4. The axon is severed. This leads to permanent disability.

Myelin has some ability to repair itself, and the potential of myelin repair is an area of intensive research at this time.

Once the axons are damaged, however, at this point we do not know how to repair them.

Because axonal damage can occur even in the earliest stages of the disease, early treatment with a disease modifying medication should be considered by anyone with a confirmed diagnosis of MS.

Axonal damage occurs earlier in the disease than ever suspected (this is why the Society suggests people start on DMDs as early as possible after diagnosis).

What are the symptoms?

Symptoms range from numbness or tingling in the limbs to paralysis or loss of vision. The progress, severity and specific symptoms of MS in any one person cannot be predicted;

therefore, a person with MS never knows when attacks will occur, how long they will last or how severe they will be.

Symptoms include:

Fatigue, vision problems, stiffness, spasticity, bladder/bowel dysfunction, sexual problems, sensory problems such as numbness, tingling, pain, emotional changes, depression, walking difficulties, cognitive changes, speech/swallowing difficulties, tremors.

Symptoms of MS are unpredictable, varying from person to person and from time to time in the same individual.

Patients with multiple sclerosis can go into remission, experiencing none of the typical symptoms of multiple sclerosis, and function normally for long periods of time. Other patients continually experience symptoms in varying degrees.

Those symptoms marked in orange here – are the most common symptoms: Fatigue, Emotional changes (depression, mood swings) and Cognitive difficulties – mostly memory programs, slowed information processing.

One very important hallmark of MS is its unpredictability.

Approximately one third of people living with MS will have a very mild course. Approximately one third will have a moderate course. And approximately one third of people living with MS will become more disabled.

It is often not possible to predict which third any one individual will be in.

However, it is important to remember that the majority of people with MS do not become severely disabled.

Most will remain able to walk, although they may need an assistive device—such as a cane or walker—to do so. Which does not mean that those

people will not be dealing with other symptoms which can strongly affect their life functioning.

How is MS treated?

Although there is still no cure for MS, effective strategies are available to modify the disease course, treat exacerbations (also called attacks, relapses, or flare-ups), manage symptoms, improve function and safety, and provide emotional support.

Each person's journey with MS is different therefore treatment plans will be best identified in an ongoing collaboration with a knowledgeable physician and other members of the treatment team.

The Medical Advisory Board of the National MS Society recommends early treatment!

Even if symptoms are mild in the beginning

There are now 13 disease modifying agents that can reduce disease activity and disease progression for many individuals with relapsing forms of MS, including those with secondary progressive disease who continue to have relapses.

That's a change from when I first came into the field.

It can be confusing having so many choices

but it means there are more options for each individual

The healthcare provider will work with each person with MS to determine which of these medications might be best for that individual.

Why is MS such a challenging disease?

It is a chronic disease with no known cure or completely effective treatments.

It is not fatal, which is a good thing.

But it does mean that people will be living with it and its symptoms, and its progression whether fast or slow – for a very long time.

It is variable and unpredictable—with no clear roadmap of what is going to happen to you in any particular day or over time, or what treatments will or will not be helpful.

MS involves ongoing change and loss. I'll talk more about that in a few moments.

It confronts people with complex choices for which the right and wrong options aren't clearly marked.

Which medication should I take?

Will I be able to walk easily down the line?

If not, should I stay in my 3 story house or move to a more accessible location?

Is the career I have chosen going to be the right one for me in 10 years?

Should I have a child? Will I be able to care for him/her? Will he/she have MS?

There are no right or wrong answers.

It is very expensive!

The average cost per person with MS per year—including both direct and indirect costs—is close to \$70,000, with close to \$40,000 being directly

related to healthcare. With an estimated 400,000 people with MS in the U.S., that comes to \$28 billion.

(Original cost data are from a study by Whetten-Goldstein (1998). All costs were adjusted by the NMSS through the 2nd quarter of 2004 using data from the U.S. Bureau of Labor Statistics.)

It's expensive and I feel that's one of the reasons it's so stressful.

That's why it's important to find cures and to help people be productive.

The adjustment to include disease-modifying drugs assumes that 60% of the MS population of 400,000 are taking these drugs and that the cost of these drugs averages \$23,000 per year.

It is very expensive to live with MS – a huge cause of stress for those families living with it – and by the way for our country overall.

What are the most common feelings among people living with MS?

Grief is a prominent part of life with MS. It will ebb and flow over the course of the illness as people face changes in functional abilities. This healthy grieving needs to be distinguished from clinical depression, which is also quite common in MS.

Anxiety is a response to unpredictability, loss of control feelings of vulnerability, difficult decisions and choices.

For many, the diagnosis of MS is the first significant challenge to their feeling of control and invulnerability. People with MS cannot predict how they are going to feel or function from morning to afternoon, let alone from one week or month to the next.

And when basic functions like thinking, bladder and bowel control become less predictable, people become very anxious.

Anger in response to loss of control and unpredictability is normal. Anger can be directed at the healthcare system, family members, or God – the goal is to help someone channel it effectively.

The goal is to help someone channel their anger in a helpful way.

Put that anger into its place.

Guilt is common among people with MS– feelings relating to not meeting their own expectations of themselves or the expectations of others. Both persons with MS and family members have to deal with this “guilt of expectations.”

Important – is to know that these feelings likely won't come just once and then are gone. These reactions will ebb and flow with the ups and downs of the disease course.

A helpful analogy for people are the jigsaw puzzles made out of photographs. If you can imagine the puzzle as a self-image that has been slowly pieced together over a lifetime, the diagnosis of a chronic disease represents a new oddly-shaped piece that somehow needs to be fit into the puzzle.

Some people “go to pieces” with the news of MS – as if they had thrown their puzzle into the air;

others refuse to acknowledge the MS and try to avoid adding this new piece to their self-image for as long as possible;  
and still others engage in a gradual process of education and adaptation that allows them to acknowledge the MS as a new part of themselves.

Each time the person experiences a significant change or loss in his/her ability to do things, a role they cherished that they might no longer be able to do, or do in the same way, the picture puzzle needs to accommodate that as well.

Who am I with this new addition in the picture of me?

Every time that MS changes the things a person is able to do, or changes the way he or she has to do them, grieving is the first—and necessary—response.

You have to mourn the loss of that function (no longer can walk) or role (if you can no longer work, or drive your children back and forth to school) or view of yourself (if your career which now has to change, was who you thought you were?)

Letting go of the past is the first step toward managing the present and planning for the future. Just like the loss of a good friend or partner, mourning that loss and finding a new life, and eventually a new love or loves is a process.

And it's a process that someone with MS may have to do again and again.

One client with whom I work says with each change, she is always having to discover her “new normal” and go on from there.

She has to put that puzzle back together.

It's a process ... and not an easy one.

Learning to live with MS – adjusting to its ebbs and flows and lack of control and continual losses, is only a part of the emotional aspects one needs to understand with MS.

If you remember the long list of MS symptoms several slides back, you'll recall that depression and mood swings were listed specifically. Emotional issues in MS are not just reactive.

What do we know about depression in MS?

We know that depression differs from normal grieving, the grieving or mourning that we talked about earlier, which is reactive and generally transient.

When sadness, hopelessness, helplessness, lack of motivation, irritability, negativity or inability to take pleasure in anything – all symptoms of depression last for 6 months or longer, we are no longer talking about grief – but rather depression.

We know that people with MS are at a greater risk of depression than the general population as well as greater risk than people with other chronic diseases.

Research has shown that there are immune system changes and physical changes in the brain that are seen in people with MS who are depressed, that are not seen in people with MS who are not depressed.

So it is clear that depression is a neurological part of the MS symptom picture, not just a reaction to being ill.

And it is a common symptom. 50-60 % of people with MS will experience a major depressive episode at some point over the course of the disease. At risk points such as at diagnosis, relapses, major transitions – but also at any time.

Suicide is 7.5x more common in MS than in the general population.

What is the greatest risk factor for suicide in MS? Depression! So prompt recognition and treatment of depression are critical.

In one 2002 study, depression together with alcohol abuse and social isolation accounted for an 85% predictive accuracy for suicidal intent (Feinstein, 2002). Despite knowing the prevalence of depression in people living with MS, it is grossly undertreated.

In one study, Anthony Feinstein, a psychiatrist at the University of Toronto, conducted at an MS clinic found that:

31.4% of the patients who had an episode of major depression at some point in their lifetime had received no treatment.

66% of patients with current major depression had not received medication.

In another 2006 study, Mohr found that over half of the depressed MS patients in a neurological clinic were not receiving antidepressants, and of those on treatment for depression, a quarter were receiving sub therapeutic doses.

Now, one reason depression in MS may be undertreated is that its symptoms can be confused with other symptoms of MS.

Fatigue, impaired attention and concentration, motor slowing, feelings of worthlessness and guilt, impaired sleep can all be part of the MS picture and symptoms in their own right, making it difficult to distinguish clinical depression.

It is important that people with MS work with their neurologist and other clinicians to take the time to tease out the differences. Patients need to be able to be clear when they are experiencing symptoms.

Anti-depressants can be very effective in treating depression – however it can take time to find the right medication and the right dose. That takes careful monitoring and knowledgeable clinicians.

Information about the high prevalence of depression in MS and its relationship to the disease process itself is very helpful for patients and their families.

Many are more comfortable acknowledging their depression and getting help for it when they understand its relationship to MS and it is normalized.

One of the most effective combinations of treatment of depression some research has shown appears to be a combination of antidepressant medication, psychotherapy and aerobic exercise tailored to the abilities of the individual.

People need to understand that it's not their fault.

Talking about depression is not about being a complainer.

You have to talk about it to get it addressed.

One of the most effective combinations of treatment of depression some research has shown appears to be a combination of antidepressant medication, psychotherapy and aerobic exercise tailored to the abilities of the individual.

But people need to be able to talk about their depression to get treated.

People who are depressed carry an additional, painful burden that compounds the difficulty of living with MS.

They cannot participate actively in their own care – and therefore are frequently not treated appropriately for any aspects of the disease they live with.

People who are depressed cannot plan or problem solve effectively, therefore are not managing their MS or their lives in the best way they can.

Studies have shown that depression is associated with fatigue that worsened over time, with greater pain accumulation and with increased cognitive difficulties.

And importantly, people who are depressed are difficult to live with. Therefore depression becomes an additional burden on the entire family.

The irony of this is that depression is one of the most treatable symptoms of MS. Of course, only if people recognize it and deal with it.

There are other emotional changes that are also associated with MS.

Moodiness/irritability: Particularly emotional withdrawal and/or anger that seem sudden and out of proportion to the situation—are extremely common in MS, and may be neurologic as well as reactive.

People with MS and family members will often describe the moodiness/irritability as frustrating and difficult to live with.

Children in particular find the moods very hard to understand, in large part because they are easy targets. Low doses of Depakote® (divalproic sodium) can be very helpful for these kinds of swings or outbursts.

The hallmark of pathological laughing and/or crying (pseudobulbar affect) is that emotional expression is unrelated to any underlying emotion. The person may laugh at a funeral or cry at a comedy.

PA is definitely neurologically based and responds well to amitriptyline. A medication called Nuedexta (dextromethorphan + quinidine) was approved by the FDA in 2010 to treat PBA in MS and other neurologic conditions.

Euphoria—an inappropriately cheerful affect in the face of dire problems generally occurs only in individuals with significant cognitive impairment. Pseudobulbar affect and euphoria can be extremely confusing, frustrating, and embarrassing for family members. Fortunately they are much rarer in MS than depression and mood swings.

What are some of the barriers to treatment?

In June 2015, the National MS Society convened a group that included people with MS and support partners, healthcare professionals in the fields of neurology and mental health, researchers and Society staff

to address depression and other mental health issues in MS. Participants identified three areas of priority focus for reducing the impact of mental health issues, particularly depression in MS.

Increased need for education and awareness so to reduce the stigma of mental health issues and promote early and ongoing conversations about depression between people with MS and their healthcare professionals and family members.

Help people with MS and healthcare professionals recognize and accept depression as a common symptom of MS.

Provide support partners with education and support they need to recognize and deal with these symptoms in their loved ones.

Increase access to appropriate and affordable treatment options.

Identify points in the disease course when depression screening and treatment are most effective.

Identify the most effective treatment options to meet individual needs.

Explore ways to increase the workforce of mental health professionals who are knowledgeable about MS and willing to provide treatment.

Advocate with third party payers for greater access to effective treatment and adequate coverage for mental health services. Better partnerships and collaborations.

Partner with treatment, policy and research experts in mood disorders and other medical conditions to capitalize on their expertise and combine efforts to better understand the causes and effects of depression in MS as well as optimal treatment modalities.

At the same meeting, the participants identified a large number of questions about depression in MS for which we do not yet have adequate answers: What are the causes of depression in MS? (relationship to genetics, inflammatory processes, immune regulation, neurodegeneration, microbiome, etc.,)

What are the risk factors for depression in MS?

What are the best screening measures for depression in MS?

How can we determine which treatments work best for which individuals?

How can we best prevent MS-related suicide?

How can we provide access to mental health care for underserved populations?

What are the current barriers to accessing mental health services among people with MS?

We're talking about physical accessibility, knowledge of practitioners etc

People with MS want to learn how to manage mood changes that are part of MS and develop strategies to achieve emotional wellness.

From the time of diagnosis, people with MS use a variety of self-management strategies to maintain or enhance their emotional well-being in the face of MS-related challenges.

Thus far, the research in MS suggests that:

Exercise – (aerobic and resistance training) may help reduce depressive symptoms and being physically active may help people feel less depressed over time.

Telephone-delivered physical activity counseling (including motivational strategies, goal-setting, action planning) – may reduce the severity of depression in people who become more active.

Mindfulness and meditation, as well as yoga, Tai chi, acupuncture and massage, among others – may be effective in reducing mild to moderate depressive symptoms, anxiety and stress.

St. John's Wort – is probably effective for treating mild to moderate depression. Because St. John's Wort interacts with many prescription medications, it is important to talk with one's healthcare professional before starting it.

Adaptive coping and solution-focused coping – help to enhance adaptation and adjustment in people with MS.

Stress management strategies of various types –may help to reduce stress.

While none of these strategies have been shown to work for everyone with MS, it is likely that any person with MS can find a strategy that would be beneficial.

It is important for people with MS and their healthcare providers to have ongoing conversations about lifestyle interventions that can promote emotional wellbeing,

while also being alert to significant mood changes that may require standard medical approaches such as medications and psychotherapy.

In order for people to engage successfully in wellness or self-care strategies of any kind, attention must be paid to major mood disturbances – including depression and anxiety – that may get in their way.

They must recognize when they need to move beyond self-management strategies and seek professional intervention.

The MS Society has started to work closely with Mental Health America.

They offer an online self-screening tool which anyone can complete

You can do it, print it out, and take it to your care provider to help you start a conversation about what you need to feel better.

The url is [www.mentalhealthamerica.net](http://www.mentalhealthamerica.net)

Living our best lives is something that we all want to achieve– whether we are living with a chronic illness, or not. We used to believe that the way to manage life with MS was to manage symptoms.

But we have come to believe that this is not enough to help someone feel “well.” Wellness is personal, multidimensional and holistic.

Wellness involves not only the emotional aspects, but also physical, social, intellectual, occupational and spiritual dimensions, with each existing along a continuum. Achieving wellness does not occur quickly or with a single behavior.

Rather, it is a lifelong journey that involves taking action and making lifestyle choices with the goal of attaining optimal well-being.

The journey towards optimal well-being is unique for each individual – and attainable for everyone within the context of his or her priorities and abilities. This includes each individual acknowledging their emotional and psychological needs and challenges and then working to find ways to reduce their impact.

Here's one child's view of his mother's MS. We'd like to change that view. (picture of a person & their nervous system)

In Summary:

There are many emotional aspects of multiple sclerosis – coming from both reactive and neurologic causes.

Depression in particular is a common symptom found in more than 50% of people living with MS. It is different than normal grieving.

Depression is very treatable with self management techniques and when necessary with professional intervention.

Treatment can only occur if the barriers to treatment can be reduced.

More research is needed to better understand the causes, effects and optimal treatments for each individual.

For more information please visit

[www.nationalmssociety.org](http://www.nationalmssociety.org)

[www.msconnection.org](http://www.msconnection.org)

Or call: 1-800-344-4867

Internationally – contact the MS International Federation:

<http://www.msif.org/>

Thank you & I hope this information was useful to you.

[2016/06/18 10:59] Gentle Heron: The notecard of MS resources is in the poster in front of the podium.

Thank you for your excellent presentation, Ms. Arzt. Perhaps our MS peer support groups in SL can invite you to come back and present again.

[2016/06/18 10:59] Carolyn Carillon: QUESTION: Andrea, will Virtual Ability be posting your slides, or will you make them available on SlideShare?

[2016/06/18 11:00] Carolyn Carillon: AA: I believe that Virtual Ability is going to post my slides

[2016/06/18 11:00] iSkye Silverweb nods, yes

[2016/06/18 11:00] Carolyn Carillon: AA: but I'm also happy to make them available on Slideshare

[2016/06/18 11:00] Gentle Heron: QUESTION: Thank you for your excellent presentation, Ms. Arzt. I am an older woman with MS, diagnosed in middle age. I am still a little surprised to see kids being diagnosed. Is there a better prognosis in terms of less progression for those who are diagnosed as children than for us older folks who were not diagnosed until much later in life?

[2016/06/18 11:01] Carolyn Carillon: AA: That's actually a good question

I think it varies  
just as much as it does for adults  
since we are finding it earlier in children  
and we're able to get them on disease modifying agents earlier  
for some there's a better prognosis  
and progression will be slowed  
but that varies  
but it's not as effective as we'd like it to be  
what's useful research-wise  
is that the triggers probably occur in childhood  
even though the disease isn't diagnosed until adulthood  
there's a long time between when the disease was triggered and when the  
disease is diagnosed  
as we understand more about the triggers in children  
that will help us understand more about MS in general  
and help us figure out better treatment

[2016/06/18 11:03] Gentle Heron: QUESTION: In my days, you had kids before you found out you had MS. Might diagnosing kids nowadays cause them to decide early that they will not have kids? Might that stop MS?

[2016/06/18 11:03] Carolyn Carillon: AA: i don't know because it does seem to be so genetically complicated there's a debate over how much of the disease is genetic even if people with MS chose not to have children there would still be people in the general population who'd be diagnosed without a family history there's an increase in autoimmune-related disease anyway as we understand more that will help us learn more and help treat MS

rather than people deciding not to have children

[2016/06/18 11:04] Amy Waverider: I have MS and I choose to not have children partially because of the MS diagnosis and life situations.

[2016/06/18 11:05] Ruby Vandyke: QUESTION: is it an environmental factor that causes a cluster of MS cases in the same town or area?

[2016/06/18 11:05] Carolyn Carillon: AA: that's a good question possibly

the problem is that it's very hard when you look at clusters to understand why it's occurred because the trigger may have occurred in childhood and people move it's hard when you look at the statistics to make the case that something's going on in a particular area there are lots of studies to look at the pieces but it's not so simple just to look at a particular area

[2016/06/18 11:06] Ruby Vandyke: oh okay, yes, it's radiation exposure. thanks!

[2016/06/18 11:06] Gentle Heron: Radiation?

[2016/06/18 11:08] Ruby Vandyke: yes, look at Hanford Nuclear Reservation in Washington state and the MS cluster found around that area.

[2016/06/18 11:07] Carolyn Carillon: AA: one of the things they've been looking at in terms of area and less in people who live near the equator what's the difference about northern areas that's amount of sun & sunshine vitamin D exposure there are a lot of studies at this point looking at that connection is that it's found more in people who live in colder climates

[2016/06/18 11:07] Amy Waverider: QUESTION: Has that happened a lot where an area has outbreaks in MS? Or has it happened at all where somebody had to say umm whats going on here?

[2016/06/18 11:08] Carolyn Carillon: AA: there are some areas ... not as many as you think... where you find out that people in a particular area who have MS when you look closer those people live in that area but didn't live there in childhood so it's hard to identify particular causes by area there's a study that looked at a particular increase in an island area that hadn't had a lot of incidences of MS they looked at a particular parasite that might have been a trigger there are some people who say that there's not enough statistics to say that's the cause and others say there are there's one thing to say there's an association but to actually look more closely and find a causal relationship is much harder

[2016/06/18 11:10] Amy Waverider: QUESTION: I know you said chemicals environment may be a trigger in MS. I have some people who are afraid of me because of the unknown cause. Can you clarify if someone can catch it from another person?

[2016/06/18 11:10] Carolyn Carillon: AA: It's definitely not contagious there's no known case where someone caught MS from another person when we talk about environmental causes we're probably talking about something that's already in the environment but if you don't have a genetic disposition it may not affect you for example, they're looking at Epstein-Barr disease some people go on to develop MS some don't but there's no evidence that you can pass it on in any contagion kind of way

[2016/06/18 11:12] Gentle Heron: As we wrap up this session I'll remind our audience that there is a poster presentation about "Depression and MS" over on Healthinfo Island (along with other mental health displays and exhibits). Thank you again to Ms. Arzt for an excellent informative presentation.

[2016/06/18 11:12] Fidget (fidgetswidgets): Andrea! Thank you so much for sharing your invaluable insights and information with us. You rocked it!

[2016/06/18 11:12] LV (lorivonne.lustre): <<transcription ends>>