



Talking to My Loved Ones about My MS

Presented by:
Víctor M. Rivera, MD, FAAN

Yahaira Rivera:

Hello, good evening! Thank you for joining us. On behalf of the Multiple Sclerosis Association of America, welcome to our seminar “Talking to My Loved Ones About My Multiple Sclerosis” which will be presented by multiple sclerosis neurologist Dr. Victor Rivera. My name is Yahaira Rivera and I am the Director of Mission and Program Development for the Multiple Sclerosis Association of America, and I will be the moderator for this program.

This seminar is part of our series “Together Finding Resilience Living with Multiple Sclerosis.” This series is dedicated to our Hispanic and Latino community living with multiple sclerosis. This program is made possible through the generosity of our sponsors Biogen, Genentech and Sanofi Genzyme.

Before starting our talk, in case any of you are joining us for the first time, I would like to give you information about who we are and the services we offer. The Multiple Sclerosis Association of America is a national nonprofit organization dedicated to improving the quality of life of the multiple sclerosis community through vital support services.

Our services include a nationwide toll-free telephone line that provides services in English and Spanish Monday through Friday from 8:30 a.m. to 8:00 p.m., Eastern time. We also have an equipment distribution program with products designed to improve safety, mobility, and also to help with heat sensitivity. For this program you can fill out an application and if you qualify you will be granted this aid. We also have a Magnetic Resonance Access Program, or MRI, as we know it in English, to which you also can apply, and if you qualify, you are granted assistance for the cost of this exam. We also offer many educational programs. We have publications and digital resources to keep you informed and also to help you make decisions and monitor the progress of your multiple sclerosis. These programs and services are available to people living with multiple sclerosis in the United States. Many of our resources are free and are also available in Spanish. For more information about our programs and services, I invite you to visit our website, as you see on the screen, at mysaa.org. Or you can call us, send us an email, or follow us on social networks.

Now I'd like to share some reminders with you. During the program, you will have the opportunity to share your comments and ask questions using the Q&A icon or button, which

means “questions and answers.” You can also send us comments using the chat. We will do our best to answer your questions at the end of the presentation. I also ask you to help us complete a short survey that will appear on your screen and will also be available in the chat. Your comments and suggestions are important to us and always help us improve and plan future programs. Lastly, I want to let you know that this show is being recorded and will be available in our digital library in the coming weeks, so you can watch it again and share it with loved ones.

Now, a reminder to let you know that this program is for informational and educational purposes only and does not constitute or replace recommendations previously provided. If you have concerns, questions or concerns that are specific to your diagnosis and treatment, we recommend that you contact your doctor or healthcare provider.

And now, without further ado, I want to introduce you to our guest tonight. Honoring us with his presence, we are joined by Dr. Victor Rivera, distinguished professor emeritus of neurology at Baylor College of Medicine and founding medical director of the Maxine Mesinger Multiple Sclerosis Clinic in Houston, TX. Dr. Rivera obtained his Bachelor of Science from the University Center of Mexico City and his Doctorate in Medicine from the National Autonomous University of Mexico. He completed his internship at Manchester Memorial Hospital in Connecticut and neurology residencies at Wayne State University in Detroit and Baylor College of Medicine in Houston. Dr. Rivera is a member of several professional organizations. He has always been active in research in the field of multiple sclerosis and is part of LACTRIMS and the MSAA Hispanic and Latino Advisory Board. Welcome Dr. Rivera. It is a pleasure to have you with us. We pass the mic to you.

Dr. Victor Rivera:

Thank you very much for such a generous introduction. For me it is a pleasure to be able to contribute by being with you. I personally, and on behalf of our beloved audience, appreciate MSAA's efforts to provide information, education and support to all of our patients. I believe that these situations are very important because in this way we can maintain our communication not only with our families, but also with our friends and often with our co-workers, because even though multiple sclerosis is no longer a rare disease, unfortunately it is very common, but it still has many questions, it has many aspects that are mysterious, and I think that those kinds of conversations, like the one we are going to have tonight, can be useful in many ways.

So, the question we often discuss with our patients is what causes multiple sclerosis? Why does a person get sick with multiple sclerosis? And in fact, what we know now is very advanced, because just about 30, 40 years ago we had much less knowledge than we have now. And from what is known, from what we know, multiple sclerosis is a neurological disease that results when several factors come together in a person. The words for a person to develop multiple sclerosis, this group of factors come together like a perfect storm in this person. All that has been identified to date is that the individual, the person who has multiple sclerosis, is born with a genetic message of propensity that they will have multiple sclerosis as long as certain circumstances are met during the course of their early life. We know then that multiple sclerosis is not a so-called hereditary disease. When I say a tendency or a genetic message it is because many times that message reaches the person, but from previous generations, very previous, many times, and it is known from which part of the family or who had multiple sclerosis than generations before. It rarely occurs as a family manifestation. But it is rare, rare and not the case in general.

During the first years of life, a lack of vitamin D, either due to lack of sun exposure or because many people with multiple sclerosis are actually deficient in vitamin D. This is a situation that

has been considered a risk factor, vitamin D in deficient or insufficient quantities. And this can be known simply with a blood study. It is very easy to obtain and is almost part of the routine initial screening for multiple sclerosis.

Well, we now know that exposure to certain types of viruses, particularly mononucleosis, which is Epstein Barr, and in some places in the world, for example, in Mexico, there are many very interesting studies in which it has been found that the virus of chickenpox is the one that predominates as an antecedent or as a complement to the mechanism of multiple sclerosis. Not even lack of vitamin D, nor exposure to a viral infection, are causes of multiple sclerosis. These are factors that come together in this very complex situation that is the mechanism of development of the disease. And there are still many, many factors missing that have not yet been identified. Childhood obesity, unfortunately, is very common among our Latin American groups and therefore it is a situation that has to be controlled, that has to be viewed with some caution because it has been found that childhood obesity, or being overweight, in a young adult is also considered a risk factor for it to develop the disease. And finally, environmental pollution that exists more than anything in urban places with high industrial development, here I would include smoking. Smoking is definitely a very, very important and very common risk factor in multiple sclerosis. And again, these are risk factors.

So, we are talking with my patient or my patients and we have this kind of conversation, let's say what are the factors, the possible causes that contribute to the development of multiple sclerosis. Not necessarily that there is a single factor that causes multiple sclerosis, not one. So, some situations in which we insist is that our patient knows what multiple sclerosis is not. So what is not multiple sclerosis, it is not a hereditary disease as we mentioned, although familial cases are rare, less than 5% of cases of multiple sclerosis in general have a first-degree relative, but it is 5%, it is very low. It is not a fatal disease. That is, the disease can last many years, as long as the life of a "normal" person, but it is not a disease that will kill the person, as unfortunately happens with other diseases, for example, amyotrophic lateral sclerosis, or ALS, which is totally different from multiple sclerosis. And in these cases, unfortunately the disease in a process of a few years becomes a fatal process. This is not what happens with multiple sclerosis. It is not an infectious or contagious disease, and it is not necessarily a progressive disease. That is to say, the fact that the patient is diagnosed with multiple sclerosis does not mean that person will necessarily have some mental alteration or paralysis in the future. That was possibly the forecast decades ago. But now, fortunately, we have many means that avoid this situation and it is a completely treatable disease, with therapies that modify the course of the disease. So our patients discuss all of this with us and they transmit this information that can be very useful to the people around them.

So, we consider that multiple sclerosis, among many other things, is an autoimmune disease. What we can say is that part of the complex mechanism of the disease is that the person produces cells and chemicals that affect their own central nervous system. There are many autoimmune diseases, for example lupus, for example rheumatism, etc., etc. There are many autoimmune diseases. Multiple sclerosis is considered an autoimmune disease in part of its mechanism, not all, but in part of its mechanism. So, the production of these abnormal cells and according to the chemicals that mistakenly attack the person's central nervous system, will affect the myelin, which is what covers the covering of the nerves within the central nervous system. The central nervous system is the brain, the brain stem. Here I would include the cerebellum and the spinal cord.

It is interesting that we have thousands of pathways that transmit information from the brain and down segments of the person. The brain stem, then the spinal cord, and these pathways are the

ones that have a very important function in movement, coordination, balance, etc., and they are also covered by myelin and are descending pathways (they go down). But there are also thousands of pathways that go up because they take information from the peripheral nerves about sensation, perception of heat, pain, etc., and that information is transmitted through the pathways upwards, they ascend to the brain where it is integrated and becomes conscious.

But we are going to try to explain what the auto-immune mechanism consists of. Imagine for a moment that this is a vein, it is a cerebral vessel and this is a virus that penetrates the body, that attacks the body. The viruses that I already mentioned, the Epstein Barr that causes multiple sclerosis, etc. When the virus enters the person's system, leukocytes or lymphocytes, which are white cells that are designed to defend, to protect the body from infections. T lymphocytes, "Thomas", produce chemical substances to attack and stop the virus, the infectious process. And the lymphocytes or B cells produce antibodies, antibodies against the virus. Other cells that we have that are circulating such as platelets do not play a role here. That is mostly for coagulation, red cells or erythrocytes, or those that carry oxygen and do not have a specific role in the case of autoimmunity. And other very large cells that are called macrophages, with an "M," macrophages means a large cell that eats, and in fact these macrophages ingest the viruses when this virus penetrates and causes all that kind of immune reaction that is normal. This normally happens under any circumstance in exposure to an infection, exposure to a virus.

However, in multiple sclerosis there is an error. Instead of effectively attacking the virus, the infection, those cells escape from the vessel, from the vein, and enter the central nervous system, that is to say, the brain. And the T cells, which produce those chemicals, and the B cells, which produce antibodies, and the macrophages, which engulf fragments, instead of remaining in circulation to attack the virus, mistakenly, erroneously, they leave the brain, they will attack the myelin and they will attack the cells, the nerve cells or neurons. Eventually, unfortunately, during this process, this can produce demyelination, which is the involvement of the myelin, demyelination and eventually it can produce complete damage to the system, the human neurons and cells die and the other segments in life and the nerves that are inside those protected by the machine that are the axons, which are like electrical cables, which are the ones that transmit messages..

There are some areas of the brain and spinal cord that have been correlated with some of the symptoms. For example, cognitive problems with memory and concentration are located in certain parts of the brain. People who do not have emotional inhibition, different types too, these centers are located in the brain. The optic nerve. These are all structures that are commonly affected in multiple sclerosis. As we see in the back, the cerebellum and the brain stem have a very specific function regarding coordination and balance. In many people, injuries to the cerebellum and brain stem can manifest as tremors. When other sections or other areas of the brainstem are affected, double vision, dizziness, vertigo may occur, language is affected, eye movement is affected. And when we move towards damage or injuries to the spinal cord, sensory symptoms of sensation, pain, problems determining the person's sense of position occur, the sense of position is lost. This also affects balance and bladder dysfunction, bowel dysfunction, sexual dysfunction, etc.

So to give you an example of the optic nerves, when the optic nerve is attacked by multiple sclerosis it produces inflammation of the optic nerve, which is called optic neuritis. It's a very common episode as the first attack of the disease and is characterized by the affected eye, it is painful, it hurts, it hurts and produces blurred vision and difficulty distinguishing colors. The good news is that once you feel that optic neuritis is not suitable, treatment can usually be given with steroids and generally the problem is improved in cases of multiple sclerosis.

So, my patient says well, how do I explain that sometimes or all the time I have problems with my legs, that I don't move them well, a feeling of heaviness in my legs. Well, this suggests that there are lesions in the spinal cord, and as we will see later, it is possible to make this diagnosis properly with appropriate studies such as magnetic resonance imaging. My patient also says, Well, what happens when people have numbness, itching, a feeling like ants are on their legs, burning? I say, Well, in those cases it is also very likely that there are lesions in the spinal cord.

I have to confess an interesting situation, because what is called the multiple sclerosis hug, which in English is called the "MS hug," but in fact it means the hug of multiple sclerosis. A patient of mine told me, I have this hug of multiple sclerosis thing like twice a week and it is a very, very uncomfortable thing, a very annoying thing. And I told him sometimes that I don't fully understand, in fact, the hug. Yes, it is a hug that makes me feel as if they were oppressing me, squeezing my chest or stomach tremendously. And I really didn't understand exactly what that patient of mine was trying to explain to me, because I also learn from my patients, and then the next time she came she brought me this photo in which that tiger is giving that person a hug. And then I understood perfectly what she was trying to tell me. When this happens it means that there are also lesions in the spinal cord, so this situation must be taken into account, mainly in the people in whom this hug is frequently repeated.

We mentioned the cerebellum and this slide shows many cells, neurons with many connections, which are the nerves that connect with the cells and send the message to the spinal cord and from there they go to the peripheral nerves. But in multiple sclerosis the problem is in the spinal cord, brain and cerebellum, the stem, not in the nerves, what is happening is that it is affecting the central system. So everything that goes to the periphery is also affected, including problems with balance, routine things, movements that would be very easy for anyone to do almost automatically, such as putting on shoes while standing. For a person who has cerebellar stem involvement, it becomes a very difficult situation to handle. And it also manifests itself with tremors, loss of balance, incoordination, all of these are symptoms that suggest that there are injuries or there is a certain revision of the cerebellum that may increase.

Cognitive problems are unfortunately very common, almost half of people with multiple sclerosis have some manifestation of cognitive problems. For example, affected memory, easy forgetting, problems memorizing, problems retaining information, difficulty learning, difficulty making decisions, what is called executive dysfunction, that is what it is called in psychology. Difficulties doing several tasks at the same time, what in English is called "multitasking," several areas of tasks, are experienced by many people with multiple sclerosis. Due to this problem of cognitive dysfunction it is quite a difficult situation to carry out the difficulties of concentrating. Cognitive dysfunction is mainly associated with fatigue, which is one of the most common manifestations of multiple sclerosis. Fatigue. So, when cognitive dysfunction is combined with fatigue, it becomes the most common cause of disability to work for the person with multiple sclerosis. Interestingly, more than motor problems, because a person who has difficulty walking and requires the use of a cane or other assistance to walk, a walker, etc., is not the most common cause of work problems or disability to work, but rather it is cognitive dysfunction associated with fatigue.

I always find the example of the iceberg very useful to try to explain and my patient understands perfectly what the visible part of the iceberg is, which is above the surface of the water, and the invisible part of the iceberg, which is what cannot be seen, and that it is sunk in the water. So, within what is visible are the neurological manifestations, for example, lack of balance, difficulty walking, etc., when a relapse or attack develops, you realize it, you see exactly that there is a

new neurological situation. The increase in disability and cognitive problems is very obvious when the person already has very noticeable absences or memory problems. I say this is visible. And finally the lesions that are detected in magnetic resonance imaging.

What is invisible is fatigue, because until now, no matter how much you tell the person with multiple sclerosis, to their husband or wife, their family, their friends or their boss, that they have tremendous fatigue and that they feel very tired or exhausted, it is difficult to understand because it is not seen, there is no way to measure fatigue, or when there are cognitive problems that are not very obvious, and when there is pain, which is also a subjective situation that the person reports, but that others don't see. And of course, when there are MRI lesions that are silent, that have not been determined, or because they have not been diagnosed previously.

But let's have the conversation about how many people there are in the world. I say I want to know, my patients tell me, if this is a situation that happened to me or are there other people. Of course it does, unfortunately. There are more than 2.5 million people in the world. It is estimated that every hour of every day a new case of multiple sclerosis is diagnosed in the world. It is increasing notably among Latin Americans and is the second most common cause of neurological disability in young adults. Case number one would be trauma due to accidents, due to falls, but it is the number two most common cause of neurological disability in young adults.

In the United States it is estimated that there are 1 million people with multiple sclerosis, and that is called prevalence, which is the number of patients or people with the disease per 100,000 people. It is very high here in the United States. It is estimated that there are between 150 and 200 cases per 100,000 inhabitants in general. It can vary from place to place, from one area of the United States to another. But if you think about this, if you have a population, a town, a city of 100,000 people, almost 200 of those people are going to have multiple sclerosis. So it is a disease that has become very common. It affects women more than men in the United States. It is 2 to 3 women for one man. In certain Latin American countries it is much more prevalent in women, for example, up to four women to one man in certain places in Latin America.

Symptoms develop between 18 and 45 years of age. Children can be affected. There is a variety of pediatric multiple sclerosis. All the races, but more in white people of European origin, and racial mixtures, Latin American Mestizos, all Latin Americans are de facto Mestizos and people of African or African descent, Afro-Americans as they are identified in the United States. Most people are diagnosed between the ages of 20 and 40 and after 50 the disease is rare.

When we see this curve, it is easy to understand and I will explain it to you right now. It is age zero, birth, ten years of age, 20, 30, 40, etc. Very good. The first definite attack of multiple sclerosis, that is, when the person is already manifesting a problem that is multiple sclerosis with something, optic neuritis, etc., generally occurs in the twenties, late twenties or early thirties. However, now we know that for a period of almost 10 or 20 years before this definitive or defined problem shows itself, the person already has certain symptoms that we call premonitory, or one like a problem are names that are used for that, but they are not specific. Before they have the disease already defined, many patients may have anxiety and depression problems. Studies have even been done in Canada, for example, in which studies have shown that patients tend to have more medical consultations than, say, the population in general, and then they debut, develop with the first symptom of multiple sclerosis. There are more than 25,000 children with multiple sclerosis in the United States, meaning people under 18 years of age. And the clinical debut, the appearance of symptoms after 50 years of age, is rare.

This study was done by Dr. Liliana Amezcua in Los Angeles, a person that I admire and esteem very much, a true leader, who has done many Latin American studies on multiple sclerosis. And she studied Mexicans or Mexican Americans in Los Angeles, who were born in the United States, and Mexican immigrants who came to the United States after the age of 15, were born in Mexico. So what she found was a very interesting situation. Mexican Americans born in the United States had a much earlier onset of symptoms than immigrant Mexicans. In the case of Mexican Americans born in Los Angeles, it began on average at 28.5 years of age, while for immigrants it was 34.2 years. And also the degree of disability was much higher, 28% in emigrants compared to 18% in those born in Los Angeles around 40 years of age. A discussion I've had with my great colleague Dr. Amezcua, what I personally believe is that there are many sociological and political factors that affect this situation.

Magnetic resonance imaging continues to be the most important instrument to make a rapid diagnosis, to monitor the course of the disease well, to determine if the person is responding to treatment, etc., etc. And in this case it is a cut called lateral or sagittal, and the person is looking forward and we see all these spots that are demyelinating plaques of multiple sclerosis. And in other cuts, for example, this is a horizontal cut, that is, the upper part of the front, in the back, left side, right side. We also see the arrangement and size of the plates demyelinating. It is very important how intravenous contrast media is administered. If the disease is active, acutely inflamed, inflammatory, then the lesions reinforce, capture the contrast medium and manifest in a very, very noticeable way.

Some people require a lumbar puncture to detect abnormal proteins in the cerebrospinal fluid, and these are called oligoclonal bands. Then, in a conversation with the patient, we explain why lumbar puncture is done. It's not necessary. I mean, it is a situation of clinical precision between the patient and their doctor. In many cases it is important to do so if the situation is not very clear, but it is not 100% mandatory or necessary in all cases. And these oligoclonal or polyoclonal bands can be seen in both blood serum and spinal fluid. Normally the bands are not seen or do not exist, but in cases of multiple sclerosis, almost 90% of the cases, these bands appear in fluid, but do not appear in a blood sample.

Before we were commenting on spinal cord injuries, that is a good example. This is the person looking to the left, this is the part of the face, this is the spine. And here we see the spinal cord and we immediately see a very clear lesion in this area, and when contrast medium is added, it brightens a little more. It is important to keep in mind, and we have also discussed this, that multiple sclerosis is a tremendously symptomatic disease, that is, there are many symptoms.

There is a book that is a classic, well-known, written by two people I knew very well, years ago. And in their symptoms chapter I counted the number of symptoms that have been reported in multiple sclerosis and I marveled, I was amazed because there were more than 80, including fatigue, pain, double vision, cognitive dysfunction, plasticity, tremor, vertigo, etc. So, there are more than 80, which to me indicates that multiple sclerosis is the most symptomatic disease that can affect a human person. But you also have to be careful because it is very symptomatic and fortunately not all patients have all 80, but they can have one, they can have two or three, but that is normal. But they can produce a situation of disability and significant discomfort. But those are symptoms and we must have an important notion of not confusing symptoms. It is important not to confuse symptoms with a relapse or an attack, because in that case a new symptom appears that did not exist and then it has to consistently last more than 24 hours for it to be considered a relapse, an attack or an exacerbation, relapse, etc. All these terms mean the same thing, but the patient must not have a fever or have an infection because then it does not count.

We already know the clinical types, we only discuss it with the patient, the first suspicious event is also still called clinically isolated syndrome. This indicates a high probability of having the disease, the relapse-remission form, which is almost 80% of cases, characterized by periods of relapse and then a period of stability or improvement called remission. And half of those patients who start with this relapsing-remitted form, half of them without treatment after a few years, are going to become more secondary progressive, which is what we try to avoid. And the other form called progressive primary, which never has a remission period, is up to 15%. So the neurologist has to be very, very careful to make a perfect distinction between the type of multiple sclerosis that is being dealt with.

This gives us a window of opportunity at the beginning of the problem, because if treatment is started immediately after diagnosis, the possibility of long-term disability is reduced tremendously with prompt, timely, early treatment. Delayed treatment also works, but not as good as early treatment. And finally, if treatment is not given, then the natural course of the disease follows, which consists of the accumulation of disability as time passes. We divide the treatments into management of attacks, relapses, etc. The exacerbation is usually treated with steroids administered alone or orally. Management of symptoms, use of medications to control symptoms. There are treatments for almost all types of manifestations, physical therapy, rehabilitation. And of course super important is the management of the disease itself or ongoing modifying treatments.

Then, my patient tells me, "My loved ones and I are more prepared to fight multiple sclerosis the more information and education we have about the different aspects of the disease." So I ask him, do you keep all that information to yourself? And he says to me: "No, no, I always share my experiences and what I learn about the disease with my loved ones. We are all part of a united front, we never give up." Thank you very much for your attention.

Yahaira Rivera:

Thank you Dr. Rivera for that informative presentation and for supporting the content and information with visuals and graphics. That helps a lot with understanding, and as you just said, it is very important that all people living with multiple sclerosis inform themselves, because the more they know about the disease, the more they can understand it and the better they can communicate with their loved ones.

Now we have a few minutes for questions and answers. You spoke, Dr. Rivera, about the symptoms of multiple sclerosis, many of the symptoms, some can be seen and others are what we call invisible symptoms. We got some questions about that. How can I make my family understand that I am not complaining, that I am not acting, as we say in some countries? But I have, for example, fatigue, which I have symptoms that are not necessarily seen. I may look physically fine, but I'm feeling them. So, they ask for advice on how to make loved ones understand about these invisible symptoms.

Dr. Victor Rivera:

Very good, because it is really part of the conversation with our people that the more knowledge there is, and I have had a very interesting situation where the husband does not want to understand that his wife has serious fatigue, and that is due to the illness. So what we do in this case is also talk to the husband, explain that fatigue is definitely part of the disease, and the example of the iceberg is interesting because it is the invisible part of the disease. It is rare for a person with multiple sclerosis to use one of these symptoms just to get attention. So you have to take all those situations seriously, but, again, education throughout the person's environment.

Yahaira Rivera:

Thanks for that advice. Another question is about... a patient asks us, "how should I help myself, so as not to feel useless when I can no longer do things the way I did before?"

Dr. Victor Rivera:

But sometimes that is very important. One way to do this is if there is a physical limitation of some kind, have a good conversation with your doctor, with your neurologist. I know that everything is fast and many times it is difficult, but you have to try to have a good conversation and express this limitation that is affecting the person, because there can be many situations, there may be programs that the person can do themselves at home, certain exercises, certain disciplines, or even if the situation warrants it, designing a physical therapy program. There are certain techniques used to conserve energy, for example to improve balance. Then, all of that can be used and in that way the person can become more functional and also feel like they are contributing to their own program, to their illness.

Yahaira Rivera:

Thank you, Dr. Rivera. Another question is about relapses, when a patient has a relapse, a crisis, how to guide, what things to say and what things not to say so that their family members understand.

Dr. Victor Rivera:

Well, let's remember that the disease is very symptomatic and many times even doctors themselves can confuse symptoms with a relapse, which is not convenient. A real relapse requires the presence of the development of a new symptom, something that did not exist before. I already had numbness in my right arm and now the appearance of numbness in my left arm and it lasted almost all day. That is already a new symptom. So it has to be a new symptom, it is principle number one and number two that it be persistent, if it comes and goes, it is a symptom. And it happened that they spoke to me at 2 in the morning and my patient told me "Look, I think I have a relapse" And I say, what happened? "Well, I have numbness in my arm." Oh no, did you have numbness in your left arm? He says "yes and nothing more, it's gone." Then remember that for it to be a real relapse it has to be a new symptom that did not exist before and that it has to be persistent. If that happens, the person has to be treated because they require treatment for relapse.

Yahaira Rivera:

Thank you, Dr. Rivera. Another thing we received, another topic that is related to the topic tonight is the family, especially the Hispanic and Latino family, there are always many activities, many parties, holidays as we say in English, birthdays, and so, what advice would you give to the family members of a person with multiple sclerosis or what things should they take into account so that the person living with multiple sclerosis feels valued and respected and also understood? Because the dynamics are going to change and maybe they won't be able to attend as many events anymore. Or if you can go to the event, it would be less time. Any advice related to this topic?

Dr. Victor Rivera:

Yeah. No, no. It is a very important observation. Again, everything is part of education, the environment, the surroundings, the people who are... There are very understanding people and

there are people who are not, but not because they are not understanding, simply because they do not know or do not understand, you do not have the information about what is happening to that person. The person with multiple sclerosis should not isolate themselves, that is a tremendous mistake. So the family has to facilitate this constant integration into the environment with its people, even if it is limited, but at least it is part of all the elements that exist.

Yahaira Rivera:

Thanks for that great advice. We just received a question tonight and they asked us if you have any advice, speaking of fatigue, if you have any advice or a strategy so that people living with multiple sclerosis can alleviate a little of that chronic fatigue that they feel?

Dr. Victor Rivera:

Well, it is a question that is tremendously common between doctor and patient, with people with multiple sclerosis, as I mentioned, almost 80% have some type of fatigue. Some more, others less. But what is important is that the person who has fatigue manages himself physically in some way. And there are many strategies. For example, when you have to go out to the supermarket or do an activity outside the house, it should be done during the hours, at times of the day when there is no extreme fatigue, the person has to take this break and has to do their own work, an energy management program. That helps a lot and it also has to be studied properly for itself. What is contributing to the fatigue? Many times the person comes and tells me I have tremendous fatigue, almost like a dream during the course of the day, because it happens that that person sleeps poorly due to some other circumstance and then a person who does not rest, who does not have adequate sleep, the next day it will manifest itself with drowsiness and fatigue, but it is not necessarily associated with multiple sclerosis, so all these circumstances must be studied. There are people with spasticity in which the muscles are very, very rigid, very stiff, let's say. This situation wastes a lot of energy and tires the person. So, in those cases, if there is a treatment for spasticity, there are also physical therapy maneuvers that can help, not wearing very tight clothes. In short, a series of techniques that can be used. So each person has to develop their own individualized program, but I always, always consider that they must integrate with the people who live with that person and of course integrate their neurologist, their doctor, because even if another conversation has to be had, I say, an individualized program has to be made to improve this situation.

Yahaira Rivera:

Of course. Good advice. And our last question before finishing our program, do you recommend that a patient with multiple sclerosis take a friend or their husband, or their partner, or a family member to their medical appointments?

Dr. Victor Rivera:

Yes, I say yes. If the person feels calmer having another person to understand what is being discussed, it is quite reasonable and quite justifiable. Not a minor, because that's not legal in certain places, it's not legal to begin with, but let's say someone you trust, whether it's your own family, your partner, your friend, that's very common and it's very justifiable. And you have to talk to that person, they have every right to advocate for the patient, contribute to the conversation and ask questions.

Yahaira Rivera:

Thank you Dr. Rivera, our time is up, we have reached the end of our program, but first I want to thank Dr. Rivera on behalf of the Multiple Sclerosis Association of America for always supporting our programs for the Hispanic family. We thank you for your time and for sharing

your wise advice that I know will help the participants who were present to talk better about multiple sclerosis, to explain it, to explain its symptoms so that there is more understanding, respect and compassion among the family.

We thank our audience, thank you very much for participating! We hope you enjoyed the learning and advice that Dr. Rivera shared. Don't forget to complete the survey that will appear on the screen and which we will also put in the chat, so you can access it. I invite you to visit our website for more information about our services, programs and events. I remind you that this program was recorded, so it will be available soon on our website and you can watch it again and share it with your loved ones. Thank you all very much, blessings, and have a nice night. Until next time, ye bye.