



“Lo nuevo en EM: A dónde ir desde aquí”

Presented by Fernando Cuascut, MD, MPH

Moderator:

Hello and welcome to the Multiple Sclerosis Association of America educational webinar, “What's New in MS: Where to go from here,” part of the educational series entitled Living Strong with Multiple Sclerosis. On behalf of MSAA, we greatly appreciate the opportunity to connect with you. As you may know, the MSAA is a national nonprofit organization based in the United States, dedicated to improving people's lives with multiple sclerosis and their care community. Some of our free services include patient education programming, a national helpline, cooling equipment and products, funding for MRIs, an online community, and a solid library of publications. Visit our website at MyMSAA.org for more information about our programs and services, recent educational webinars and videos, and much more. And as a kind reminder, we invite everyone viewing this program to complete the MSAA Patient Education survey form below.

This information will help us evaluate the quality, impact, and usefulness of educational programs, as well as to provide support for future education funding. What's new in MS: Where to go from here, which is part of our Living Strong with Multiple Sclerosis educational program, is provided by MSAA and our partner Impact Education. This webinar series is made possible by generous financial support for education from Bristol Myers Squibb, Genentech, and Johnson & Johnson. Sponsors of the virtual exhibition, including Biogen, Genentech, and Sanofi Janssen, provide additional support for this series. Details can be found in our new virtual showroom by visiting the link below. Before we begin, we have some important points. The information that will be shared today is for educational purposes only and is not a substitute for professional medical advice.

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It is an honor and a pleasure to introduce our speaker today, Dr. Fernando Cuascut. Dr. Cuascut is an assistant professor of neurology at Baylor College of Medicine, as well as director of the Multiple Sclerosis Clinic, and head of neurology at Harris Health in Houston, Texas. Dr. Cuascut attended the University of Puerto Rico Río Piedras in San Juan, where he earned his Doctor of Medicine, MD, and Master of Public Health, MPH.

He completed his residency at SUNY Downstate Medical Center in Brooklyn, New York and his fellowship at Baylor College of Medicine. Welcome, Dr. Cuascut.

Dr. Cuascut:

Many thanks. Thanks for your introduction. Well, my name is Dr. Fernando Cuascut. I'm a multiple sclerosis specialist working at Baylor School of Medicine. Today, we will be talking about navigating new feelings when faced with a new diagnosis. First, I would like to talk a little about emotional health, and it's important to highlight that actions or emotions can be different. One represents a new diagnosis of multiple sclerosis.

For example, if you're talking... Some people may feel angry, sad, stressed, anxious, depressed or in pain. And this is a result of where the doctor establishes the importance of understanding that all these feelings are normal and that many patients may feel the same as you. It's important to understand that often it's very difficult to accept a new diagnosis and these symptoms should be faced and accepted as they come. Here, one can understand a little more of what's going on with the diagnosis.

For example, some patients may feel sad when they talk to their doctor about their diagnosis, and it must be understood that sadness is a feeling. For example, that they can make us understand that this is important to us, that health is hidden and sadness is something that has treatments. It depends on how deep the case is. Again, acknowledging such feelings as they come is the first step in understanding and accepting the process of a new diagnosis.

Depression, anxiety, and stress are common feelings. And people with multiple sclerosis, or their family members, can feel any of these symptoms, sometimes all of them.

It takes a while to accept the diagnosis and understand how one must adjust and adapt to the whole process that one is facing. The good news about all of this is that there are treatments, and feelings can improve over time. What can help these symptoms? Once faced with a multiple sclerosis diagnosis, there are different resources, as well as pharmaceutical treatments or drugs.

There are also different ways to manage and understand your symptoms, such as discussing support groups with your neurologist, as well as family counseling groups that include those important people in your life to understand the process and make appropriate decisions. There's also support from loved ones, as well as patient mindfulness or self-care.

Here in this slide are some of the processes that can be done, activities for a patient to cope with anger and be able to deal with their feelings and manage their emotional health. Patients who like to have hobbies, and they should take time for themselves to be able to understand what the symptoms are, the root of those symptoms, and having time to deal with that and reflect on it.

For example, some patients who would like to disconnect a little from what's happening and take on their emotional health by doing different activities. For example, yoga, patients who like to be with their pets and feel that this is something therapeutic. Also connecting with your loved ones through different platforms, for example, video calls or visiting their home. It's also important for patients who like to write down feelings to try to find solutions through these and other hobbies, such as patients who like to do puzzles or any hobby that the patient feels connects with themselves and helps understand the whole process of what's going on. Once the patient understands and accepts their feelings and begins to take the steps to accept the diagnosis, they need to build a health care team that can help manage the symptoms and the

illness. For example, we're talking about a family doctor. I always tell my patients that once you establish your care management with your doctor or neurologist, it is important to understand that the neurologist is aware of your neurological problems, which are related to multiple sclerosis. But you also need to follow up with a GP, who can handle other medical components that are not necessarily neurological.

There's also the neurologist, as I had said specifically, well, a neurologist specializing in multiple sclerosis. There are other specialists too that you may be considering depending on your symptoms. For example, a urologist, an ophthalmologist, or a neuropsychologist. If memory problems occur, for example, other nursing professionals would also be important to you. Some nurses would help manage or advise on feelings, medical assistants or nurse practitioners, for example.

Also other professional doctors that you should be considering, for example, are physical therapists or physiatrists, who are health professionals. They'll be handling rehabilitation, for example, occupational therapy. A social worker is often needed if social problems have to be addressed or considered. Mental health professionals, as we've said, and how we started the conference. And a dietitian and also a pharmacist particularly who would be dispensing the patient's medications. And everything, as you can see, is a medical team that is very directly involved in making you feel better. When you begin to understand and accept the process and begin to create your medical team, one or two questions that you'd have to ask yourself is what characteristics would a great doctor have to help you feel better. The most common response would be for the doctor to listen to your needs. Apart from the fact that they care, that they show they care, about what you're saying, that you don't feel rushed during your visit. Therefore, you can present or express everything you feel, and that they answer your questions. Those are common responses that patients come up with when they feel like they're trying to describe who would make a great doctor.

Also that you understand what the doctor is telling you. It's important that the doctor understands... You understand that the doctor is a professional and that the doctor also has to be able to explain to you at his level what the reasons are, or also to discuss how to manage your illness at a level that you can understand. When looking for a new doctor, it's important to consider certain criteria, for example recommendations.

You're listening to a recommendation from a patient who has already established their medical care with a neurologist. It would be something you could reconsider. You can also do your research on the Internet or by booking with other resources to try to establish your medical care. A specialist neurologist. Also, have the doctor take your insurance. It's important to understand that insurers or health insurance are not accepted in all places and it's important to know that before you make your visit.

The communication that you feel or express with the doctor is important considering that distance is something very, very important. There are also times when specialist doctors, neurologists in sclerosis are a bit scarce, and you have to understand that there are times when the distance can be very far and that, therefore, computing is something important to consider. Also that the doctor has basic fundamental knowledge concerning your illness.

There may also be other considerations that you can... it depends on your particular case, but these are some very important points that you have to ask yourself and consider when looking for a new doctor who can manage your condition. When you meet and find a doctor that you feel comfortable with, you should make a list of questions for your interview. These questions

can be asked directly to the doctor and that will help him to understand more about your case and its management.

Some questions you can ask your doctor would be, for example, starting here on the left, if the doctor is part of a group practice. And if so, if there are other doctors you can go to for an appointment. There must be doctors who do work in groups and doctors who work independently. You should then understand what the case would be. The experience level of the doctor treating multiple sclerosis is also very, very important.

If they're a specialist neurologist. Usually, yes well, they already have a little more experience. But if they're a general neurologist, then you have every right to ask what their experience with the illness is. It's also important to ask about the duration of appointments, how long is an average appointment, for example. It's important that you understand how long an appointment will be so you'll know how to better handle the time to express your concerns.

Moving a little further to the right, other things you should consider is whether laboratory services exist. If there are medical or health services. For example, now with the COVID-19 pandemic, some patients may prefer to discuss their affairs via telemedicine. And it's important to know if doctors do provide that service. It's also important to consider if there's a translation service, as language may prevent your GP or specialist from understanding you, being able to recognize your problems, and explain to you how to handle those problems in your language so that you understand fully about your illness.

And finally, knowing if appointment times are flexible. You may lead a very busy life and need to make time to go to the appointment. And if those times are scheduled to make an appointment at different times of the day in order to adapt to your schedule. I want to continue now talking a little about things that you should reflect on after your appointment. Once you establish your medical care, you find a new neurologist that you feel comfortable with.

There are some things you should consider and reflect on after your appointment. For example, if your provider made you feel comfortable. It's important to feel comfortable so that you can express how you feel and that the doctor can hear you out. For example, the next question would be if the doctor listened to you and explained in a way that you can understand your problems.

And that the doctor also asked about your medical history. This is important because depending on what your complete medical history is, you can take different ways of coping with or treating your illness. If you felt rushed and if you were asked if you have any questions. These two texts are reflections that you can make once you complete your visit to understand if you sincerely felt comfortable with that encounter and if you should continue making appointments with the doctor. Other questions to consider after your visit would be whether you feel comfortable discussing your problems and sexual health with your provider.

Some patients may have sexual health problems and it's important that they feel comfortable to discuss this with their neurologist so that the appropriate treatments can be taken. If you consider that your experience from beginning to end was pleasant, or if you felt any discomfort, any discomfort, you should also reflect on that. And also, consider your feelings about the general experience. Was it positive or negative? These are other points that you should reflect on your visit with your GP.

And it's important that when you sit down and make this list, to ask these questions that I'm expressing to you today. But you may also have your own particular questions. Most importantly, you understand that you need to create an experienced, comfortable relationship with your doctor or neurologist. That you feel that you're being listened to and well-informed so that you can make the right decisions about your illness and your health. An important tip to mention is that you find a way to keep track of your medical information that works for you.

Many times you may have different symptoms and you may suddenly forget to show up for your visit. And there must be different resources to try to make one remember those symptoms, or rather show up for the visit. For example, some patients write their symptoms in a diary and thus, when they go to discuss it with their doctor, they have that information ready to review with their doctor.

There are also apps that you can use to try to record your information, and if you forget you can then use that database and show it to your doctor. Counseling... It's important to find the right therapy. These questions about your neurologist that we just mentioned can also apply to your mental health therapist.

It's important to find someone you feel comfortable with, and all of those questions we've asked can apply here too. There are different types of mental health professionals. Counseling can be helpful not only for you but also for your family and your partner. Accepting multiple sclerosis is a complex process that may involve different people who are related to you and it's important to understand that mental health counseling is something that can also be managed.

Other questions you should ask yourself would be, as we've said earlier, if your insurance will cover your services. It's important to understand that not all insurance can cover all services. You could ask your insurer, health insurance, to understand what services they would be paying for and, if necessary, what you would have to be paying out of pocket. So if we keep moving here, if you have experience working with multiple sclerosis patients or people with chronic conditions. Again we're talking about mental health counseling.

As we said, there are different types with different backgrounds. If you're establishing your mental health care with a professional, it's important that the professional understands your medical history. Specifically, that you have multiple sclerosis and how that can affect your emotional health. And you can ask the next question, what does he think about the use of medications for anxiety or depression. Also if the health professional works with caregivers and family members, and if they offer teletherapy, these are other questions that you should be asking your mental health counsellor in order to understand a little more of what's expected of the visits and how they can be managed.

The next step would be preparation. Talk a little about how to prepare for your appointment. You must understand what your provider needs in order to help you. The more information you present to your doctor about how you feel, the better the doctor will be able to help manage your illness. Think of your care as a partnership. The doctor is there for you and the doctor needs to know what your concerns and symptoms are to make a team or to be able to manage them properly.

What are some important points for preparing for an appointment? What are your expectations for appointments? It's very important that you understand that and establish it, take the time to establish that before. What are your symptoms? As I mentioned recently, there are times when

you may forget or you may have many symptoms at different stages or dates. It's important to write down those symptoms so that you can present them to your doctor.

You'll be asked about your family medical history during your appointment. So it's important that you have that information. Medications that you're taking is another very, very, very important thing here to discuss with your doctor. At your appointment, have a list ready of all your medications to present to your doctor. Some drugs could interact with each other and make them harmful or dangerous.

And also make a list of questions that you have, or concerns that you have, to resolve them with your doctor. Now I want to take a little time to present this reflection and it's important to understand when we have an appointment with your doctor. If you write down the questions that you're going to ask the doctor before the appointment, and here the possible answers are if you always do it, sometimes, never, or if you're not sure what to ask your doctor.

It's important that we take the time to try to answer this question, because if you're presenting all the appropriate information to your doctor, the doctor can then be able to make the correct decisions and provide the information that you need. I hope that you've taken a little time to reflect on the matter and that you understand that there is no correct answer. It's for you to further understand how you're presenting yourself for appointments.

It's important that you ask your doctor, or make a list of questions that you have for your doctor, before your appointment. And again, it's important that you do it, because when you arrive for your appointment, you may be discussing information that may not be directly related to solving your problems or your concerns. And if you don't get these questions over to your doctor beforehand, your doctor may not have planned for it or won't take it into account when discussing your particular points, and therefore you may not get the information or solutions you're after. Many times some patients who, for example, wouldn't ask a question directly to their doctor, either because they don't have that confidence yet or because they're just getting to know their doctor... You have the right to write those questions.

Take the paper to your doctor, the neurologist, so that they can act on the matter and try to discuss those points that you have that are important to you in other ways. During your visit, when you have a question, don't wait until the end. Again, that's the point of the appointment, because the doctor is trying to solve your problems and trying to answer those questions. If you suddenly have a new question that you weren't considering or didn't write down, let your doctor know about it as soon as possible since it might be forgotten and the necessary measures are not taken to solve this problem.

Some questions to ask your doctor may include what happens if I have new symptoms or if problems arise between visits. I tell my patients that there are methods of how to communicate with us and if the patient presents a new symptom, that they let us know as soon as possible and not wait until their next appointment. It's important that you ask your doctor that question so that you understand what to do in that particular situation, if you need to make any changes to your diet or exercise routine.

It's important also. It's a question that is totally valid and a question that should be discussed very early on in the diagnosis to make the correct decisions in relation to diet and exercise. Always ask what comes next. It's important to understand that multiple sclerosis can be somewhat unpredictable in terms of how it can develop, since each patient can be totally different in relation to their symptoms and their relapses.

But the specialist doctor or neurologist can always make you understand what to expect of your disease so that you can feel more in control over your medical management. Now I would like to talk a little bit about the importance of care and compliance with your illness. The importance of care and therapeutic compliance. I always tell my patients that it's very important, once one establishes the diagnosis, to discuss medications, the options for treatment. There are different ways to treat multiple sclerosis.

For example, here I'm presenting what would be disease modifying treatments, or as they say, DMTs. And these are drugs that do treat your disease, multiple sclerosis, and the focus is on trying to decrease relapses, but these drugs don't treat your symptoms and so they bring us to the next point here. There are drugs or medications that are used to treat symptoms.

Those medications aren't going to treat your illness, but that is a very, very, very important point to discern in order to understand the purpose of taking medication for your illness. There are also lifestyle options that we will be discussing shortly. Here, as I had recently told you in this illustration, I want to make you understand that on the left side DMTs are, as I had said, the drugs to treat the disease.

What these drugs try to do is alter immune activity to prevent future damage to the nervous system and thus prevent relapses. These medications aren't necessarily going to treat your symptoms, but they are very, very, very important in order to prevent an activity and reduce disease progression, which is the purpose of these medications. Now, on the right side we can see that there are a couple of drugs or therapies to manage those symptoms that you may present.

And here I put a list of some. For example, bladder dysfunction, depression, insomnia, walking difficulties, etc. These are some symptoms that can occur as a result of a diagnosis and there are medications that can make these symptoms better and can impact your quality of life, since you can feel better about your symptoms and can control your symptoms. Here you should know that it's important to discuss with your doctor all the symptoms that affect your well-being in order to provide an integrated or comprehensive treatment.

What are the goals of medical intervention? Well, the most important thing is to control the symptoms. You can improve your quality of life. It's also important to understand that this medical intervention can be handled outside of the hospital and in order to prevent you from having to be in a hospital for its handling. We also try to prevent relapses. Therefore, the prevention of the disease. Maintaining independence in your activities of daily living is one of the very important goals to start a treatment and also to improve your quality of life.

These are all very, very, very important points to consider when trying to establish the best medical intervention for you. Another very, very important point that I let my patients know, for example, is lifestyle choices. You must be more proactive about your illness. Once the diagnosis is established, the necessary resources are considered, you go to your appointment, you ask your doctor the necessary questions, you begin a treatment. Another very, very important point that lies a bit more up to you would be what your lifestyle choices are. And here, for example, I'm talking about exercising, eating a more balanced diet, having better nutrition. A very important point that we talked about earlier, how is your mental health? If your mental health is stable or if you feel you have a lot of anxiety problems that need to be addressed. That you present a balance between your life and your work.

Multiple sclerosis unfortunately can happen to anyone, and this does not mean that their life is going to stop. If you are to believe that there are ways to create that balance in your life, including your diagnosis of illness with your work, it is important to create that balance. Many patients also turn to spirituality and this helps them to have a better lifestyle and feel better about themselves.

Cognitive health is also very important to consider, what you're doing to maintain that cognitive reserve. If you, for example, read or do mental exercises, that you can keep it actively considering your cognitive health. And finally, what medications are you taking. Also if they are other options that you can control according to your lifestyle. All of these are very important points, as they can impact your quality of life and your illness. Shared decision-making is an important component of personalized care. I always tell my patients that I want them to feel comfortable and understand their illness as well as possible and that the patient is a team between their medical provider and the patient to make all the shared decisions, that at the end of the day, the patient is the one who is going to be making his decisions as a result of... consulting his doctor who is the specialist in the matter.

For example, the care team may present or manage the guidelines necessary to be able to manage your illness. It's also important that you ask about the experience of your care in relation to your illness, that you use scientific evidence to make decisions and prove to you the appropriate information and also what are the goals of that care team. On the other side, we have patients who have to consider what their lifestyle is, what their values or morals are in order to make adequate decisions regarding their disease, what their preferences are and what their resources are.

All these factors are very important to integrate to make shared decisions. Now I could give you a little moment here to leave it open to all of you. If you have any questions for me.

Moderator:

1. My doctor knows what's best for me, so I'm not sure why I should ask questions during my visit. I don't want to give the impression that I'm challenging them. What are your views on this?

Dr. Cuascut:

Thank you very much for this question. Yes, it's very... This is an excellent question. Many times I feel that some patients may present this concern and the most important thing I want you to understand that management, as I was talking about, is an integrated decision and it's a team effort. The doctor, if he is the specialist in providing the appropriate information as the information is presented to him, you should not feel that you are challenging your doctor in any way, since the doctor needs to know all your concerns and understand what your questions are in order to that the doctor can then make the right decisions and provide the right information to you.

The doctor does understand, we understand that the doctor does have that knowledge on the subject, in the matter of multiple sclerosis. But for the doctor to help you, you have to provide the doctor with all information or all your concerns so that then it can be managed and an integrated and appropriate management can be made to your particular case.

Moderator:

2. You mentioned that denial could be something a person faces after being diagnosed with MS. I have MS and it seems like my family may be in denial of my diagnosis. I have accepted it and

accepted my diagnosis, but how can I communicate with my family about MS if they don't fully believe that I have MS?

Dr. Cuascut:

As I had told you at the beginning of the presentation, after a new diagnosis of multiple sclerosis, a number of problems or feelings can arise from that point. And it's a process that happens very, very independently in each human being, in each person. What it implies is that a patient can present any of these symptoms that we have mentioned, anger, sadness, anxiety, and it's a process that the patient will be carrying out until accepting their diagnosis.

But it's also a process that happens independently in their relatives or loved ones. It's a process that, despite the fact that you've already accepted it, for your family members the process is not necessarily the same. What I recommend is that one understand that it's a process that takes time and that each person takes it in different ways, firstly. And secondly, that you can, for example, make your family understand that you've accepted your diagnosis and that you understand that they are still processing it. One of the things that I always try to let my patients know is that you also have the option of bringing your family member to one of the appointments so they can also discuss their concerns or their particular questions with the neurologist. This way they can understand that they're part of your care and that, at the end of the day, you feel it's very important for your loved ones to understand your illness and its process.

But understand that it takes time for each person to come to terms with a personal diagnosis or a diagnosis to a loved one. And that's exactly what I try to make patients understand.

Moderator:

3. What's one thing you wish your newly diagnosed MS patients knew?

Dr. Cuascut:

One of the most important things that I would like each patient to understand is that they are not alone. The new diagnosis of multiple sclerosis can be presented with many symptoms, as we have discussed. Most of the time, patients feel sad and it gives them a lot of anxiety. And part of it is because of the uncertainty of what's happening and they're facing. It's a sudden change of events, it's something that was not expected.

And many times patients can feel isolated and therefore feel worse and affect their mental health. What I want all of you to understand today is that even though a new diagnosis of multiple sclerosis can be very difficult to cope with, you are not alone. You'll be part of a team that will care for and appropriately treat all your symptoms.

So don't feel alone. Understand that it's difficult, but that a healthy balance can be reached. Thanks for all your questions. It was a pleasure to be with you today and to discuss this topic. To close our presentation today, I would like to thank you again for being here and sharing your time with me. The important points to discuss today is that you may experience a series of feelings as a result of a new diagnosis and that you understand that these feelings are totally normal.

Don't feel that you have to go against your feelings, but rather accept them as they come and those feelings will make you... If you can understand what the reason and motive for your feelings are, you can understand or better manage your situation, particularly with the new diagnosis. Many times some patients feel angry. And anger can sometimes help us understand

what our limits are. Other patients may feel sad after a diagnosis, and sadness makes us understand that it is important to us and that is why we feel sad.

Sometimes even fear also makes us understand what we should focus on to try to solve problems. Again, many or most patients may present one or multiple symptoms, and it's important that you understand that each symptom that you present, accept it as it comes. Understand that there is treatment, that you are not alone, that there are many resources for patients like you that you can manage and treat.

It's a long-term illness that can be managed and treated, and we can erase those stigmas that have been presented to us. For example, on social media, there are times when a new diagnosis of multiple sclerosis is presented, it can be understood as if that meant ending up in a wheelchair. That is not true. We don't think that way. With proper treatment, you can have a full life, you can follow your quality of life to the fullest. These are very important points.

And finally, understand that your management is an integrated component between you and your medical team, that it's not just your medical team making decisions for you. It's better and important to integrate those two components of your health. It's necessary to also include your family members or loved ones in your management together with your medical team. That would be an important integral component in order to deliver better care to you.

And with that I leave you today. It was a pleasure to be here with you. Many thanks.

Moderator:

Thank you for joining us in this webinar. MSAA would like to thank our funding partners Bristol Myers Squibb, Genetech, and Johnson & Johnson for supporting this series. We'd also like to thank Dr. Cuascut for taking time out of his busy schedule to provide us with this critically important information, and to Impact Education, LLC for their partnership in presenting this program. To learn more about our online educational programs, visit the MSAA event calendar for upcoming webinars. And a friendly reminder. We invite all reviewers of this program to complete the MSAA Patient Education Survey form found at the link below. This information will help us evaluate the quality, impact, and usefulness of educational programs, as well as to provide support for future education funding. On behalf of MSAA, thank you for participating.