

MSAA Podcast: Young Adults Living with MS Episode 11

Host: Yahaira Rivera
With special guest: Nuriel Moghavem, MD

Yahaira Rivera:

Hello, everyone. Welcome, and thank you for listening into MSAA's podcast: "Young Adults Living with Multiple Sclerosis." I'm Yahaira Rivera, Director of Mission Delivery and Program Development for MSAA, and your host for today's program. Please note that this program is for educational and informational purposes only and does not constitute any formal recommendations. Please speak with your doctor or healthcare provider if you have any questions or concerns.

Today's program is part of MSAA's 2023 MS Awareness Month campaign on "Life with MS: Different Stages of the Journey," spotlighting the topic of young adults and MS, which is very important to learn to lead your best life with multiple sclerosis as a young adult. I am honored to welcome our guest speaker, Dr. Nuriel Moghavem, who will be sharing with us his insights and tips for young adults living with multiple sclerosis and for those newly diagnosed.

Dr. Moghavem is a neurologist and MS fellow at Keck School of Medicine at USC in Los Angeles, California, where he was born and raised. He completed his medical school and residency at Stanford University School of Medicine. He has experience in health policy, healthcare outcomes research, healthcare quality, and social media and medical ethics. His clinical interest focuses on neuroimmunology and multiple sclerosis and his research and advocacy efforts both concentrate on improving access to care and lowering drug costs. Dr. Moghavem, thank you so much for being here with us and sharing your expertise.

Dr. Nuriel Moghavem:

Thank you, Yahaira, and thank you to MSAA for having me. I'm really looking forward to chatting.

Yahaira Rivera:

Wonderful. Thank you for being here. So, we know that young adulthood is fundamentally a period of maturation, decision making, lots of changes, independence, and major life events. And this is usually the time when we are choosing our career pathways and joining the workforce, traveling, and perhaps even having a family and thinking about parenting. But we

also know that this is the age range when multiple sclerosis is more likely to strike. MS is the leading cause of disability in young adults. With that said, let's talk about the diagnosis. How is MS diagnosed and what happens when someone is diagnosed or is actually living already with multiple sclerosis as a young adult?

Dr. Nuriel Moghavem:

Yeah, I think it's an excellent question. You know, the piece you touched on there is important. You know, we know that MS is most likely to be diagnosed in someone's twenties or thirties for the most part, and in some ways that makes it even more challenging because that's such an important period in our lives, at least in modern society, in terms of figuring out or planning for the rest of our course. So not only is the diagnosis really difficult because of the time it comes in our lives, but also, I kind of just want to validate anyone out there who's been through the process of being diagnosed or maybe is through it now, it's an incredibly... it can be a very frustrating process itself to get diagnosed. And then we'll talk a little about what happens after.

But, you know, I think the first part that's very difficult is to even figure out whether you should be thinking about getting yourself attention for MS. You know, the symptoms that are prescribed to MS, they can be very, very different between different people. They can sometimes be very non-obvious. They can sometimes be quite subtle. They can especially be non-obvious to people around you. A lot of times the symptoms are only things that you would notice, whether it's a feeling of numbness or whether it's a feeling of pain or vision loss, you know, these are things where it's really going to be dependent on you and there's no highly, highly specific symptom for MS, there's no specific thing, like, yeah, if it hurts in this one spot in your knee that's MS, like that, we don't have that.

And so, it can be very difficult sometimes to even know whether or not you should consider it. And then I think on top of that, you know, when you try to get medical attention, other people might not take it seriously, too. So, we know, based on research, who are the people that are most likely to be dismissed medically? And they do tend to be younger people. They tend to be women. They tend to be people of color. And so, if when we're talking about the people most likely to have MS, who are generally young women, and we're understanding more and more that communities of color have high risk of MS, you're also potentially dealing with, even if you know you think you might be on the radar for having MS, you might have to struggle to get attention.

So, I think this is one of the first pieces of frustration is even getting there. But then the process of, let's say, you do get to a doctor, and they do suspect MS, getting to a diagnosis itself can sometimes be a little bit tough. Again, we don't have that specific test for MS; we don't have a blood test where it tells you up and down whether you have MS. So, what we have is a series of, you know, we take your history and we really try to learn your story. We do some MRIs, we might do a spinal tap, but all of these things are meant to sort of increase the probability that we have the right diagnosis. And, you know, I think to be in this process, you know, I've never been diagnosed with MS, I can't imagine how frustrating and scary it must be because it takes a really long time. But I think, you know, something that's really important is this is a really critical period when we're working on getting diagnosis because there's a few ways it could go wrong.

You know, for one, let's say you do have MS, but the process of getting there to diagnosis is wrong and you end up getting diagnosis not having MS. Well, obviously, that has very clear dangers. So, you want to make sure you get it right and do it the right way. There's actually another challenge, too, which is what if you don't have MS but get misdiagnosed with it. And I think that also happens. You know, I see patients not infrequently who are maybe 40 or 50 who

have been living with MS, their understanding is that they've had MS for 20 or 30 years, and that's meant medications and time at the doctors and great expense, life changes. And they switch doctors for whatever reason, they come to us, and we're looking at their MRIs and listening to their story, and, boy, it doesn't sound like MS, it sounds like something else. And that conversation is really hard because this person maybe took medications unnecessarily for a long time. Their identity formed around it. It becomes a hard challenge.

So, the process of diagnosis can take weeks or months and that can be really scary. But it is an important thing to get right because then once you do get MS, you know, once you're diagnosed, we have to then talk about, okay, well, what's going to be the next steps for you? And I think particularly when people are at this period of their lives where they're planning, they're thinking ahead, they're having big dreams. Sometimes a diagnosis of MS can feel like you have to stop dreaming or like you have to stop planning. And, you know, nothing could be further from the truth today. And I think that that's one of the really big things early on, if you're a young person and it's possible you might have MS, maybe you've just been diagnosed, is it's going to take some adjustment. You know, things are going to be different for you. But I think, and we're going to come back to this, I think, later in this conversation, but you don't need to change your dreams. We're lucky in this era to have a lot of treatments that work and a lot of better scientific understanding.

But, you know, I think the number one step is to say, "okay, this is real, we have to confront this." Because there are certainly people who it's such a scary idea that they might not come back to a doctor for a few years until they really need it. And so really accepting that it's real and it's in your power to actually control this disease is really, really important early on. My two big tips early on are, one, is keep dreaming and the other one is to bring in an ally or a friend or a family member, you know, have somebody that you're going to trust in this journey and bring them with you to doctor's appointments, especially early on, because you might be a little overwhelmed by everything, you might have a little bit of trouble hearing what people are saying when you've been hit with shocking news, and that's normal. And so to have a family member or friend with you who knows you well and can be there to think good questions can be really valuable early on.

So anyway, it was a good question. You know, what do you do when you're first diagnosed? How do you get there? What's the process and what comes first? But, you know, I think in summary, it's going to be a little bit frustrating to get to diagnosis for most people. You know, try your best to have patience with it if you can. Continue to advocate for yourself if there are delays that are unnecessary. But everyone's goal is to get to the right diagnosis. And then once you are, to recognize that, Great, now you're in the driver's seat and you get to sort of control how the rest of your life goes.

Yahaira Rivera:

Thank you for your input and important information. Research has shown that MS is sometimes described in stages. A young adult may naturally advance for one MS type to another, which leads us to our next topic. Knowing the stages can help with understanding and managing MS. What are the stages or types of MS progression and why is it important for us to know this?

Dr. Nuriel Moghavem:

So, you know, we typically put MS into a few different types of disease types. So, you know, you can think about these on the spectrum of the development of the disease of MS. And so really kind of starting at the beginning would be something called RIS, which is radiologically isolated syndrome. And these are people who actually, if you have RIS, you have typically no symptoms,

no symptoms attributed to MS, you don't have any numbness, weakness, balance problems, bladder problems, nothing. The only reason you're even in this conversation is because typically you've had a brain scan for some other reason. You know, whether you had a head injury from skiing, or you have migraines, and got a head scan.

But that MRI looked all the world like the MRI of somebody who has MS. And we've known about people who have what we call RIS, these scans that look like MS with no symptoms for pretty much as long as we've had MRIs for MS. And what's interesting about this category of individuals is many live their entire lives totally normally with no symptoms of MS, and they never develop anything clinically. They just have MRIs that look like it.

And so, if you have RIS, you're in a difficult position, it can be quite frustrating and scary because some percentages of these people do end up developing the symptoms of MS, and these are typically people who are diagnosed with RIS at a younger age or have spinal cord lesions or have spinal fluid that shows inflammation. So that's sort of what we might think of as one of the first earliest stages. You know, almost like we're picking it up before it's manifested.

The next category is what we call CIS, clinically isolated syndrome. And this one, I think, is most useful to understand as it relates to multiple sclerosis. So, the M in multiple sclerosis is critical. It's multiple. This is a process where you've had multiple attacks, it's chronic, you're going to have, potentially, inflammation, you know, for the rest of your life. But CIS is for people who have had an attack but it's not clear that this is going to be a chronic process. It's just a single solitary attack. And this happens for some folks. They have a single episode of Optic Neuritis, or they have a single episode of a spinal cord attack that looks and smells and feels like MS, but they have no other signs of inflammation. They don't have any evidence on their MRIs of any prior attacks they've never had experience of a prior attack.

And again, if you follow people who have CIS for 15 years, some percentage of them never develop MS; they have the one-time attack and never again. And so, what we try to do is try to predict, okay, who's more likely to develop MS or have a second attack in this group, because if you have CIS, your goal is to prevent this from ever developing a second attack, from developing MS. And so, you know, in a conversation with your provider, with your MS doc, you can talk about being on treatments if you have CIS, especially if you have some of the risk factors for developing MS later, which again, there's a number of lesions on your scan, whether your spinal fluid looks like it has inflammation, or your age.

But this is, both RIS and MS, you can almost think of, as some people call it, like pre-MS. You know, I don't love that because it's probably almost in the same family. But in some ways, you haven't yet shown that this is a chronic disease, and so maybe you don't need to be on these kind of heavy duty MS treatments. But then you have the category of MS, and in MS I think there's three main types to discuss. So, one is the most common type that most people are in and that most young people especially will be in, which is relapsing-remitting MS. And in relapsing-remitting MS, you have these attacks, these are the relapses, and then you have some improvement. That's the remitting part. And especially when you're young, you might get back to 100% of your baseline, like it never happened, or 90% or 80%.

But typically these attacks, which get better over the course of weeks usually, and they you know, the era before treatments, they might happen twice a year, once a year. And then between that, nothing. This is what's typical of what we call the relapsing-remitting phase of disease. And most medications for MS that come out are specifically focused on this, on

relapses. Medications we have these days are really good at stopping relapses. And so, you can often get on a medication early in your life to cut your relapses to zero, which is great news.

The next type of MS, then to think about, that naturally flows out of people who have relapsing-remitting MS is called secondary-progressive MS. So, it's secondary because it comes after the relapsing phase. And this might be people who previously had relapsing disease but are maybe in their forties or fifties. And what they're noticing now is that things are... there's no relapses anymore, or if they happen, they're rare, but things are just sort of getting slowly harder every year, it's a little bit harder to walk. The balance is a little bit worse every year. The strength in your right arm is a little bit worse every year. And so, this is what we call relapse independent progression, meaning things are just a little bit harder, there's still some neurodegeneration happening. And again, in secondary-progressive MS, it's after the relapsing phase, and if you're in the relapsing phase, we think around 50% of people develop secondary-progressive MS. 50% of people have the relapsing phase, the relapses will stop and then actually things sort of just stay stable. So, you may still have residual effects of your old attacks, but you don't develop worse disability over time.

The last group is what we call primary-progressive MS. These are folks who they develop MS without any relapses ever. All they have is that slow worsening over time, a little bit worse, a little bit worse every year. You know, the treatments we have for MS, like I mentioned, are really good for the relapsing parts of the disease. There are medications for progressive MS, including secondary-progressive MS, but they don't work quite as well as the relapsing ones, and this is a major area for future research, is how can we get better at treating the progressive phase of the disease. And again, all of this is a framework and one of the things we're understanding over time is there might even be some progressive progression very slowly during the relapsing part of the disease early on and it just doesn't become obvious until later.

So we're still understanding more and more about MS, but really the key in understanding progression stages where you are is, you know, are you somebody who has RIS, which is quite special and maybe you don't have any symptoms and you just got to monitor it over time. CIS, you've had one attack and you're really having to make some decisions with your provider about whether or not to start treatment because you're likely to have more; maybe you have MS and you haven't had your second attack yet. Or are you in MS clearly, this is a chronic process that has multiple periods, and if so, what point of the disease process are you in? Are you relapsing? Are you progressing? And that's key because then that tells you what medications might make more sense for you.

Yahaira Rivera:

Thank you Dr. Moghavem for providing us with a reliable, easy to digest explanation. We know that multiple sclerosis is a complex concept to understand, and you made it easy for all of us. And that's, now, a perfect segue way, is our next discussion about treatments. How is MS treated, and how can someone choose the best treatment for them?

Dr. Nuriel Moghavem:

Yeah, so sometimes I tell my patients that when we live in 2023, it's great news, but it's not great news. Meaning it's great news because, compared to the '80s or the '90s, I mean, we have more than 20 treatments for MS and you have tremendous choice as an individual in terms of what treatment you want to be on, the side effect profile, how it's administered and when. We'll talk about that in a second. But it's bad news because we're not ten years into the future from now, where we'll have even more choices. We might be closer to a cure. And so in

some respects, we're working with what we got. None of the treatments we have are perfect, but what we have is actually pretty, pretty good.

So, I think there's a few keys as you think about your treatment decisions. And one of them is knowing you're not committing to taking for life because ten years from now, who knows what we'll have. But I think it really requires you to sort of sit down with yourself and figure out what your priorities are or what you need at this point in your life, which I'll tell you, in my twenties, I didn't really know what my priorities were. So, this is obviously challenging the younger you are. But, you know, I think a few things are good to think about. So, one is what works within your lifestyle in terms of taking your medication. So, the key to all of these MS medications is they work only as well as you take them.

So, the medications come in generally three forms infusion-based therapy; you go to an infusion center, or they come to your home, they stick an I.V. in once a month, once every six months, depending on what you pick. And then after that, you don't have to think about your treatment for the rest of the month or the rest of the year, you know. So that's one option.

There's another option that are pills, and there's daily pill or twice daily pill options. Some people are great with pills. They remember to take them every day or twice a day, and they never forget. I will tell you, let's say I needed to do that, I would have trouble remembering. If you know, honestly, deep in your heart, you'd have trouble remembering, you know, you can pick a different option, but it's good to just know truly about yourself what works best. And some people find the pill option great because you don't need to take a day off of childcare or a day off of work or a day off of whatever to go get your infusion or whatever. So sometimes the oral medications are great from a lifestyle perspective too because you don't need to take a day off if you live somewhere quite rural, you don't need to travel to get your infusions or other treatment. So, you know, knowing these things about your lifestyle are important.

And then the last category, injection-based therapies, and these include some of the older medications that are daily or a few times a week, or newer medications which are just once a month self-injections. So, some people love this as well because it's totally in their control. They can do the self-injection. They don't have to go somewhere. Some people hate needles and they do not want to under any circumstances give themself an injection. And that's totally fine because, again, we live in 2023. If you want to give yourself an injection, you've plenty of other options. So, I think for one, knowing what's the most likely thing that you will commit to is really key.

And another part of that, by the way, too, is some treatments for MS, if you stop taking them, it can actually result in what we call rebound attacks, where you have an attack after you stop the medication that can be quite severe. So, this is true of medications like Natalizumab, which is Tysabri, or the anti-modulator class, which includes things like Siponimod, which is Mayzent, or Fingolimod, which is Gilenya. So, in those cases in particular, you want to make sure that there's nothing that would interrupt your treatment. So that's piece one, is your lifestyle and what's going to work for you.

The second part, I think, particularly for people who are planning on potentially wanting to give birth in the next, even, 0 to 5 years is to think about family planning. There are some medications for MS, which you should absolutely not take if you're going to get pregnant. There are some medications that have been proven safe in pregnancy, and then there's some medications where you can come up with a pregnancy strategy. So, for instance, if you're on a B-cell depletion agent, so something like rituximab, ocrelizumab, which is Ocrevus, or

ofatumumab, which is Kesimpta, those medications can actually be given in such a way that you get the treatment, aim for conception a few months later and then actually have a safe pregnancy.

So, planning ahead and thinking, you know, "if I want to potentially get pregnant in three years, maybe I start now on a treatment that's safe in pregnancy." So, thinking a little bit ahead about family planning is important. If you're younger and you're like, you know, you're not going to have kids for another ten years, you might be able to make your decision for medications without doing family planning considerations, because you can always switch later. So that's one piece I think is particularly important early on too, because once, if you know you want to get pregnant in the next few years, it actually really limits what we would pick. So I think that fits into that question about life plans and lifestyle, etc.

And then probably the last thing to consider is what's your risk tolerance? This is another question that comes down to like truly knowing yourself. But, you know, how willing are you going to be to take on some side effects? You know, this comes back to the thing about 2023 is not the best time. Ten years from now will be better because right now the medications we have available to treat MS, for the most part, the highest efficacy medications, meaning the ones that work the best for stopping attacks, are also the ones with the most side effects. The ones that have the least side effects are typically the ones that are of somewhat lower efficacy.

And so, it's not a perfectly linear relationship, but mostly, so the most highly effective medications that we know cut relapses by 90%. They tend to have the highest side effects of infections or other kinds of side effects, whereas medications that might cut relapses by 50% have no really significant side effects. They can be the injection-based therapies where you have some irritation at the injection site or you might have some flu-like symptoms where you take Tylenol for it, which are more mild side effects, not that they're not uncomfortable. But understanding, you know, if you're like, "Hey, you know what, I'm willing to take on the risk of a UTI or pneumonia" or, you know, some higher... some medications, for instance, have a slightly higher risk of cancer even.

Am I willing to take on that risk, which can be small, to prevent MS related disability in the future? Some people, we have a great conversation about all the options, and they just want the medication that gives them no side effects. They're willing to incur the risk that MS will add somewhat to their disability, but they just don't want to have any medication related side effects. And that's a personal choice. And some people are on the other side where they're willing to take on a very high risk of side effects to avoid having MS related changes. So understanding for yourself what the tradeoff is in your life, I think is also really important there. And so know yourself, know what your priorities are, what medication you're likely to take, what side effects are you willing to deal with, and then a little bit of a side conversation for those who are thinking about having kids in the next several years is what's going to make sense in terms of pregnancy planning.

Yahaira Rivera:

Thank you for that. It definitely is a very personal choice in having those conversations with their provider and sharing their personal goals and their lifestyles will definitely help to choose what works best for them. Right? And what about the prognosis? Could you tell us more about the prognosis? And can you live a full life with multiple sclerosis?

Dr. Nuriel Moghavem:

Yeah. So, can you live a full life? Yes. I think that's deeply, deeply, deeply something I believe and something that I know that most of my patients agree with is you can live a full life. You know, I think the question we sometimes get is, "okay, well, how about my life expectancy? How long can I live with MS?" And this is such a great question because, you know, if you look historically, the life expectancy for people who live with MS was between five and ten years shorter than the general population, meaning the general population's life expectancy is somewhere in the low 80s and people living with MS, life expectancy was in the mid-70s. However, that's based on people who are in their 70s living with MS, meaning these were people who were diagnosed in the 1950s. These were people who lived the first 20, 30, 40 years of their lives without treatments, because we didn't develop treatments for MS until the '90s, and really until the 2000s. And so what we're actually seeing in the data as more and more research is done is that that life expectancy gap, that 5 to 10 years, is narrowing very quickly.

If you, when you got diagnosed with MS, had this moment of this image in your mind of somebody who lives MS, you know, that image invariably was... not invariably, for the most part, people who did grow up in the 1950s and '60s and who are still living with MS today do often have very high levels of disability because they were untreated for so much of that process. And the image might be someone who's having trouble walking or not able to take care of themselves when they're older. I think for people who are young and are newly diagnosed today, I think something that's so important to keep in mind is we don't even know yet how good people are going to look when they turn 60 or 70 who are diagnosed today. And I would not be surprised if that life expectancy gap closes. I would not be surprised if we understand that by starting treatments really early for people, we actually prevent a lot of the long-term disability.

You know, again, we don't have cures, we can't take the disease away. People will still have symptoms as they get older. We're going to talk about lifestyle changes you can do to try to improve your wellbeing long term. But I think a key piece here is life expectancy. Man, I wouldn't think about it. I think in all likelihood the life expectancy is likely to be quite similar to the general population. And really the question about living a full life, we can talk about this philosophically, but it's really about where do you draw your happiness and meaning from? You know, if you are able to fill your life with meaningful work and relationships, that's really going to be the key to living a full life. And there is absolutely no reason MS can hold you from that. And so, you know, yeah, it's going to be a reality of your life. You're going to see doctors more than you would probably like to. You're going to have to be on medicines more than you would like to. You will probably have side effects that you otherwise wouldn't have to have. It's not that this is no burden, but your potential to live a full, happy, and meaningful life is still very, very much there. And so, you know, to that point about living through your life standard, what do you have to think about?

Let's say you're 20 or 30 getting diagnosed. What does life look like at 50 or 60? You know, a few things there. One, there is a medication for MS that is totally free, that treats your fatigue, your depression, anxiety, osteoporosis, strength, walking, and its exercise and staying active. And I know how annoying it is when doctors tell you to just stay active. And this is totally one of those "do as I say, not as I do" things, because I need to be more active, too. So I know, you know, how hard it is for me to get motivated to get into a good routine of exercise, you know, especially when you have, you know, bad MS related fatigue or depression that keeps you, you know, gives you trouble with motivation to even get out there., But I will tell you early on, if you are not somebody who's active, even if you're fit, if you're not someone who is active, develop an activity routine for yourself, because that's going to be the thing that's going to pay off dividends when not only in your younger life, again, because it does so much good benefit for fatigue and depression, anxiety, but when you're 50, 60, 70, the people I see that are doing

really well at that age are people who have been active through their lives, whether it's yoga, dance, running, you know, whatever it is, cycling.

You know, I have a patient, we have a patient in our clinic who is, I believe, he's in his either late 50s or early 60s, and it's not like he doesn't have symptoms, one of his legs is pretty weak, but he biked across the country, he biked from California to Massachusetts. And not that everyone can do that. I can't do that. But that's the kind of thing I'm talking about, is like, you know, for folks who develop a pattern and a routine of activity, they are able to do more, you know, as their life goes on. So, you know, treat yourself well early in your life, develop those habits and routines, because those will pay off.

You know, things that we also know for the long term are important. And this is that stuff you hear all the time. We know how bad smoking tobacco is for MS. It will worsen your brain lesions. It will lead to more disability over time. If you are smoking, this is another reason to really, really try your hardest to stop smoking because it does make MS and inflammation worse. Other things we know that make MS worse, high blood pressure, hypertension, diabetes. So, all that stuff you've been hearing your whole life about chronic diseases and your heart health, It's actually true for MS and your brain health too. So, if you have other conditions, especially cardiovascular issues, make sure you have a good relationship with your primary care doctor and you're treating those, because they're important not just for your heart, but also for your brain and your MS.

And likewise, anxiety and stress, sometimes harder to control than high blood pressure. Again, exercise is really key. But other things like meditative practices, there's a really great study, it was done a few years ago, they took a group of people living with MS and split them into two groups. One group was enrolled in like a stress management, I think was virtual, actual meditation kind of practice, and the other half wasn't. And then they looked at their brain scans several, I think was two years, later, and the group that was randomized to stress intervention actually had fewer brain lesions accumulate over time, which we don't think about how powerful stress can be. But, you know, and maybe, hey, people who had lower levels of stress were more likely to take their medications. Who knows what it was? But we know that management of anxiety not only makes your quality of life better, but it also actually decreases the activity of your MS, is what it seems like. So, developing those routines to diminish stress and anxiety can be really important.

And then just the last one here, as we talk about healthy habits, is diet, which I think is one of the questions we get most commonly is, "okay, great, what should I eat? Taking the pill seems obvious. I put... 99% of everything else I put in my mouth must affect the course of the disease and so there's kind of two sides to this." One is we don't have a clear answer in 2023 on what the MS diet is. We know for heart health what's a good diet. We know for some other stuff, for digestive health, because there's been good quality long term studies on it. For MS, we don't have that data yet because scientifically there haven't been enough high-quality studies on this.

There's actually just an article that was published in one of our big journals in neurology last month that actually pulled together all of the studies that have ever been done on diet and nutrition in MS to see if, "Ok, each individual study didn't get us to a conclusion, but what if you put all of them together and did an analysis?" And what they found was a few things. One, none of the studies is good enough to be reliable. We need bigger studies that are better. And two, even when you pull the data, there's nothing obvious that comes out of it. There was a suggestion that the Mediterranean diet or certain versions of the paleo diet might be better than

the average American diet, but not even enough proof to show that, which I think shows you how much we need more study.

So, my recommendation for my patients is have a thoughtful, good, healthy diet. You know, have a good mix of vegetables and good nutrition, high quality proteins, making sure that you're using the best ingredients you can, really reducing processed foods as much as you can. You know, the things that contribute to a heart healthy diet, we talked about hypertension, whatever, probably contribute to a brain healthy diet, too. And so, you know, stay tuned because I think there's going to be much more research that's going to show us a little bit more about what kind of diets are positive for inflammation. And there's also a lot of information we can probably borrow from, let's say, people who have lupus and other inflammatory diseases. But so far there's no clear answer. So I think just eating a good high quality diet, reducing junk foods and processed foods is probably the best scientific advice I can give these days. But doing a diet that is healthy and that you can maintain long term.

So long story short, if you're young and you're getting diagnosed, really invest in lifetime good practices early, because you have to start building the habits. You know, it's harder to build a new habit into your life when you're 50 or 60. It's really hard. And so when you're 20 or 30, take advantage of that period of your life where you're going through transformations, you're still figuring out your plans to really invest in yourself, good eating, good exercise, taking care of yourself, managing your mood and focusing on developing a meaningful road for your life.

Yahaira Rivera:

Thank you, Dr. Moghavem, for addressing important topics for young adults living with multiple sclerosis. You gave us great tips. And our last question, and you already touched base on this, but just one last time, what is your advice for any young adult who's listening to us today and has been living with MS or recently received a diagnosis of MS?

Dr. Nuriel Moghavem:

Yeah. So, you know, I think the best tips I can give are this: one is this is probably really scary and probably leads you to a lot of uncertainty for the future and yourself. I think my message to you is you're going to be okay. You know, you don't need to change your dreams. You can still have whatever you want out of your life and you're in control of that. So, I think the key to making sure that you still have the ability to achieve what you want to in life, to have the relationships you want to have, maybe have the occupation you want to have, maybe have the family you want to have is really in your control. And that means, you know, really taking the initiative for yourself and advocating sometimes for yourself, because the medical system requires you to advocate a lot for yourself, unfortunately, to make sure you're on the right medications, to make sure you're doing life right. Lifestyle choices.

You know, I think what's going to be key to do those things, you know, one I mentioned is have an ally or cheerleader or a friend or family member, somebody that you can rely on to keep you accountable. I found, you know, that people who have that really do well as long as you need it. And the other part of that is having a care partner. And I think, you know, you mentioned this before, but have an MS specialist, neurologist, that you know and trust and appreciate, and I know that in some parts of the country, it can be really hard to find, but do what you can to find a neurologist specifically, if you can, MS trained, who's up on the current literature, who understands you and your priorities and your dreams, because that's going to make a lot of the difference to as you try to share what your priorities are, to try to achieve them.

And then the other part of that is - I'm somebody who's telling you about it, but I don't live with MS. You know, I don't really know what that's like. So. some of my closest friends, I mean, everyone I see, you know, on a daily basis lives with it. But that doesn't mean that I really know. And so, I think developing communities of other people who live with MS is going to give you an invaluable insight into tips and tricks that your doctor isn't going to be able to give you, perspectives and approaches, and I think, you know, it'll also give you a community when you're having moments of uncertainty. And so, whether that's through the MSAA or whether it's through the National MS Society or whether your local MS center has its own sort of groups, I think joining those can be super, super helpful. You know, I think there are virtual communities as well. Facebook, Reddit. I mean, a lot of these places are virtual communities. Those are mixed. I would tell you, like join those. I think you're going to learn a lot. But also just, you know, remember, there's a whole lot of nonsense on some of those, too, so use your brain, you know, be skeptical of these if something doesn't make total sense. And also then, you know, use your MS doc or your support community to bounce ideas off of as well.

So, again, I think my tips: figure out what you want to do with your life. Chase those dreams. But be in control of your MS. That's going to be the key part. You know, stay healthy, find the cheerleaders in your life, whether it's your doctor, your friends, your family, an MS community, and hopefully all of that allows you to just retain hope and an understanding that you're going to be fine. And you might have relapses, you might have some really bad days, but it's going to give you the skills to be kind to yourself. I think what's hard sometimes for folks, especially if you're really a go, go, go person, is if you have an attack or you have a bad fatigue day or something like that on top of just feeling bad, you then also may feel guilty about feeling bad. And I think if you really develop a life where you have the support structure around you, where you understand you're in control of your MS, it makes it a little bit easier to be kind to yourself on those days and to just sort of know that it's okay to take a break and that it doesn't mean you screwed up or anything. So that's sort of my general message. You know, I think this is a disease we're getting better and better and better at treating and understanding and you're going to be all right.

Yahaira Rivera:

Thank you. That was motivating and inspiring. So, it's important to highlight that with knowledge, healthy habits, finding a support system, feeling empowered to practice self-advocacy and treatment adherence, there is hope for people living with MS, and there is hope for living well with MS. Know that you're not alone and MSAA offers services and support to help you as you navigate this journey.

With this, we conclude our podcast, "Young Adults Living with Multiple Sclerosis." On behalf of MSAA, I would like to thank Dr. Moghavem once again for his valuable knowledge and insights in addressing topics that are so important, meaningful to young adults living with multiple sclerosis. Your advice brought hope and motivation to anyone out there living with MS or caring for someone who is actually living with MS. Also, I would like to thank Gradwell House Recording for hosting us today and producing this program. Please note that this podcast, along with additional information on multiple sclerosis services and resources, can be found at mymsaa.org. Once again, take care and thank you for listening.