



## **MS, Spirituality, and Health**

Presented by:

Annette Okai, MD, FAAN

Mitzi Joi Williams, MD, FAAN

Pastor Claval Hunter

Tyler Campbell (*MS community member and patient advocate*)

### **Marie LeGrand:**

Hello and welcome to MSAA's live webinar, MS, Spirituality and Health. This webinar is part of our New Directions series, which is geared towards blacks and African Americans who are living with MS as well as their care partners and families. I would like to take this opportunity to thank you for joining us this evening. I'm Marie LeGrand, Senior Director of Mission Delivery and Health Equity for MSAA and your host for tonight's program.

Now, as you may know, MSC A is a national nonprofit organization dedicated to improving lives today for the entire MS community. Some of our free services include a national helpline, we have equipment and cooling products, MRI funding, an online community, webinars, and many more free programs available to people living with MS nationwide. To speak with one of our specialists, you can reach our Helpline Monday through Friday from 8:30 a.m. until 8 p.m. Eastern Time. And to learn more about MSAA'S programs and services, please do visit our website at [mymsaa.org](http://mymsaa.org) or you can also give us a call.

Now, before we begin our program, I would like to take this opportunity to thank Biogen, Genentech and Sanofi Genzyme for making this program possible through educational funding.

Tonight, we are extremely grateful to have Dr. Annette Okai, Dr. Mitzi Joi Williams, Pastor Claval Hunter, and Tyler Campbell with us who will be presenting on this topic. Together, these speakers will take a deep look into how leaning on spirituality can help you manage your MS and your overall health. The topics that we're going to discuss tonight are listed here on your screen, and we're going to touch on the importance of spirituality and faith in the MS patient journey, how spirituality and faith can be used to drive action and increase resilience, and finally, the role that spirituality and faith has in the life of the MS caregiver.

Please note that this program is for educational and informational purposes only and does not constitute as formal recommendations. Please do speak with your doctor or healthcare provider if you have any questions or concerns. Throughout tonight's program, you will have the opportunity to ask questions by typing them into the chat box. We encourage you to submit

questions throughout the program, and we're going to do our very best to answer your questions during the Q&A portion of tonight's webinar. At the end of the program, we ask that you please complete a brief survey. Your feedback is extremely important and will help us in developing future programming and content. A link to the survey will be included in the chat box.

Without further ado, I would like to introduce our first speaker for this evening, Dr. Annette Okai. Dr. Okai is fellowship trained in MS. She is the Director of Clinical Neuroimmunology and MS Research at North Texas Institute of Neurology and Headache in Plano, Texas, as well as Clinical Associate Professor of Neurology at Texas Tech University's Health Center Science Center. In addition to her clinical practice, she is actively engaged in multiple clinical trials in MS and is published in several neurological journals. She also serves as a member of MSAA's Healthcare Advisory Council and the African American Advisory Board. Dr. Okai, welcome.

**Dr. Annette Okai:**

Thank you so much, Marie. I am so excited this evening to be here today. I want to thank the MSAA for putting on this program. And I think it's especially important because this is the first time I'm speaking on spirituality and faith in relationship to MS. And oftentimes for us as healthcare providers, we deal with patients, and I will say that this topic creeps into the exam room on multiple occasions. But how do we deal with it and how does it relate to patients? So in the next hour and a half, my colleagues and I are going to take you through this journey, and hope that this will be educational and that you are going to take something from it. So, without further ado, let's get started with the first part of the program.

So... here we go. Sorry, I went too fast. So MS... daily life, life as a whole is anything but simple. It is very hectic. We all have lifestyles that we are working, we have to take care of family. But if you have MS, that is something that makes it even more difficult, as opposed to simple. Lots of things get into the way, that includes your emotions, that includes your physical functioning, that includes your spiritual life as well. So because life with MS is not as simple as we want it to be or as it could be, we have to take time to ground ourselves and try to make sense of everything that's going on around us to improve quality of life.

For an MS patient., in addition to life itself, and then MS is also very difficult when we have outsiders that only see certain things. So with our population today, it's difficult because we do not have a whole lot of people that show symptoms early on or now even later on in the disease. Usually when people think about MS, they think about walking difficulties, people using assistive devices. But there are lots of other things that go on with the patient with MS. What people do not see can be very debilitating. So you're looking at symptoms such as numbness, tingling, fatigue is a big one, difficulty swallowing, speech changes, weakness that may not necessarily lead to difficulty with walking, bowel and bladder issues are also very common. So sometimes it gets very frustrating when the outside world looks at MS patients and not knowing if someone disclosed that they have MS and they say, "well, you look so good." Well, it's not all about what appears on the outside. There are lots of things that goes on in the inside that make that patient's life a little bit more difficult. It goes beyond what the outside eye sees. So this program is going to focus on the emotional and spirituality part as opposed to the physical part. So let's talk about some emotions.

OK, MS can have a real impact on emotions. And these are just a few that are listed here. So as a person with MS, they may have a wide range of emotion. First, imagine getting the diagnosis and trying to deal with that diagnosis. And then every step of the MS journey, sometimes these emotions come into play. Depression is very common because as with chronic diseases, that's something that can have a huge impact on the lifestyle and can lead to some depression. Grief

of things that are lost when that diagnosis is given, and over time life doesn't go as planned, and there are things that are lost with it. Anger can also come about, behavioral changes, pseudobulbar affect, and this is where there is inappropriate response to certain situation where you may be laughing, when you should be crying or vice versa. But all of these things can occur throughout the disease and for some people it's a daily struggle to deal with their emotions. And when you are dealing with different emotions throughout the day, life gets more hectic, life gets more hard, and quality of life is impacted.

So how do you deal with all of this? Learning to live with MS is important, and I say learning to live with MS, that does not mean it's a defeatist thing. Okay, that does not mean you are defeated. It means that you have this disease, it has been given to you, there's nothing you can do about it, but you are not going to give in to it. You are going to try to live your life and then live it at the best way possible. And how do you do that? First, you start with the right healthcare team. You need the right doctor, someone who's familiar with the disease, someone who understands the biology, the symptoms and everything that comes with the disease, that can make decisions, that can ease your MS journey over time. Because we know that lots of things can look like MS, we have to make sure that that is not the case, and your symptoms can impact your lifestyle. And also, controlling the disease is important in making quality of life better. So the right doctor is important.

For you as a patient with MS, learning the facts. Learn the facts about the symptoms that occur, the treatments and what you can do and what we do not recommend doing. To incorporate that into your lifestyle as well. A healthy, positive attitude is also needed to keep you grounded. Stay positive. With a chronic disease it's tough to stay positive when there are symptoms that impact your lifestyle, when you are limited from doing things that you did before. But it's important to have a positive attitude despite these setbacks. How do you do that? Some people love to meditate. Having a healthy lifestyle. Exercising is one way to do that, and there are lots of other things that are listed on here that you can do. So health and wellness go hand in hand, and health and wellness complete the comprehensive picture that we want for our MS patient.

You have the ability to choose your own path. This is a disease that has no cure, only treatments. But we have such efficacious treatment at this time that you have to take the opportunity that is given to make these treatments work for you. And you do that in conjunction with your healthcare provider. Okay. So not only treating the disease but treating the symptoms that limit lifestyle is something that has to be taken into consideration as well.

New treatment research. Research is going on every day and over the past 20 years, we have seen that the MS phase explode with treatment, all due to the research that's going on in this phase. So reach out to your healthcare provider and see what's available that's there that can also help you in your MS journey.

The next slide is How do you have optimal care and how it's best achieved with a team. Now, usually on a slide you want to focus on the content of the slide, but when I first saw this slide, the first thing that I focused on was this picture in the middle. And what did this picture say to me? That the patient is the center of everything. You as a patient, you are the center of your MS journey. Who you are surrounded with makes that journey what it is. You start with an MS neurologist, and you start with a primary care doctor. Those are your anchors in your MS journey. Depending on your symptoms, other specialists may come in to play. Physical therapists or other rehabilitation specialists may be needed. Nurses are also important because of the medications that we prescribe for our patients. For your emotional support, there are

support groups, community support organization, advocacy groups. And then for your overall wellness, health and wellness and nutrition specialists.

I tell patients is a 50/50 thing when we're dealing with MS. I as a healthcare provider is there to treat the disease, the biology of the disease, and prescribe treatment for you. You as a patient, your 50% is a healthy lifestyle. Keeping fit, making sure that your nutrition matches what is needed to keep your symptoms at bay. So when you have a good treatment plan in place and you have the health and wellness part, you have a comprehensive approach to your diagnosis. As I said, other specialists may come into play if there are mental health issues such as anxiety, depression, or other types of emotional ability. Don't be afraid to seek out a mental health specialist, a counselor, a psychiatrist, a social worker. All of those are important in the MS journey.

How do you live with the challenges MS? Ok, these emotions that I mentioned in the past slide, we can't avoid them. You are going to experience them. You are allowed to have that. It is your response to these emotions that make things the way they are or make the journey easier. So you have to learn to live with the challenges to the best of your ability. One thing is try to prioritize. You don't want to tackle everything all at once. Then you get overwhelmed, and disorganization occurs and then that leaves nothing accomplished. So you have to focus on one issue and take it one step at a time. This will help in improving quality of life.

How do you cope overall? Here are some steps. It may not be in this same manner for everyone, but something here in this chain can speak to you. So first you have to acknowledge when things are tough, and once you acknowledge it, then you have to take care of yourself. Do not neglect yourself. Once again, you are the center of this journey. If you neglect yourself, then are other things around you start to be neglected. Don't compare yourself to everyone else. Someone may look like they have things under control, and they do not. You do not know what that other person is going through. You are your own control, so whatever you do, do it for yourself, not in comparison to someone else.

For some, it may be beneficial to share a diagnosis with people around you so that they may understand what you're going through. They may not understand why you do not want to socialize, or you are not participating in certain activities, but sharing that diagnosis can help them understand and probably say, Well, okay, while you may not want to do this at this time, we can do it at another time, or just help them to understand that you are not being anti-social or whatever you are declining.

Work with your healthcare team, your doctor or healthcare provider to manage your pain, fatigue, cognitive symptoms. These are the things that impact life, and they are quite manageable if you talk to your provider about it. So you have a team, use your team to cope with MS.

How does spirituality play into your MS journey? So when you receive the diagnosis and throughout the journey, your life has changed. Everyone has an idea of what they want their life to be, but MS throws a wrench into this idea of what it should be. So it's not headed in the direction you imagined. But you cannot change the diagnosis. But you have the ability to come to peace with your disease. And I say, "come to peace", once again, MS patients are fighters and they want to fight the disease. That does not mean that you are not fighting. "At peace with your diagnosis" means you acknowledge it, but you are going to continue to live your life how you want it with MS as a passenger and not the driver of your car. Some people, the way to do

that is through spiritual practices that can help them find that path that they need to go on the journey. And that's what we are going to focus on with the rest of the program.

So how do you find that spiritual path? How can faith and spirituality help you support your MS journey? It can help you by becoming more self-aware. You can discover inner strength and resources that you didn't have. You can find meaning in the challenges that are placed before you. You have greater balance in your life. You can change your feeling of helplessness and powerlessness into feelings of creative strength. You find opportunities for spiritual growth, and you have deeper and more meaningful relationships with others.

So keeping that in mind and when we move on to the next session, just realize that daily life with MS is not easy. It is full of challenges and includes many symptoms that often some people do not notice. But each person has to live with these challenges and it's best not to try to tackle everything at once, you have to prioritize what is important to you. Healthcare professionals can help you meet some of these challenges and goals, and sometimes spirituality is what helps other people find their path and remain grounded. Reconciling spirituality with treatment, that is something that most MS patients struggle with at some point in time and when they are faced with faith and treatment choices. But hopefully as we go through all of this, you as the MS patient may come to some realization that there are benefits to this. And with that, I will turn it over to Pastor Claval Hunter who will talk about spiritual care in MS.

**Marie LeGrand:**

Thank you so very much, Dr. Okai, for the excellent presentation. You gave us all some great advice on coping with MS. So, thank you so much once again. Next, I would like to introduce Pastor Claval Hunter. Pastor Hunter is currently serving as the lead pastor of Berean Seventh Day Adventist Church in South Bend, Indiana, and the Voice of Hope Seventh Day Adventist Church in Michigan City. Pastor Hunter also holds the distinct honor of being inducted into the prominent Morehouse College, Martin Luther King Jr. International Board of Preachers in Atlanta, Georgia for his recognized community and social justice contributions. Welcome, Pastor Hunter.

**Pastor Claval Hunter:**

Thank you. Thank you. Greetings. It's truly an honor, is truly an honor to participate in this MS webinar. I want to begin this presentation with a quote from an Austrian neurologist and psychiatrist who survived the Nazi Holocaust. After his experience in Nazi concentration camps, he penned these words. He says that "individuals are not destroyed by suffering; they are destroyed by suffering without meaning." That's Viktor Frankl.

For those dealing with MS, as Dr. Okai mentioned, perhaps you are facing the premise that your life may not be headed in the direction you envision. However, I want you to know that you are not alone, that your life is not over. Your life does have meaning. You can find meaning in your life. And despite the pain, you can still live a purpose-driven life. You see, although you cannot change your MS diagnosis, I need to reiterate the point that you do have the ability to come to peace with your chronic disease.

I love this Bible text, John 14:27: Jesus says to his followers, "I am leaving you with a gift - peace of mind and heart! And the peace I give isn't fragile like the peace the world gives. So don't be troubled or afraid." And one of my favorite Bible texts, Jeremiah 29, verse 11, the one who is omniscient and who knows everything, he says, "I alone know the plans I have for you, plans to bring you prosperity and not disaster, plans to bring about the future you hope for."

Today we are talking about spirituality and religion and medicine. And for many people, for many people, religion and spirituality form the basis of meaning and purpose in life. And when you look at illness and disease, they can profoundly disturb the balance each of us seeks and leads to disillusionment, stress, depression, low self-esteem and uncertainty. And throughout history, religion and spirituality and practice of medicine have been intertwined. And sometimes they complement each other and sometimes they go against each other. However, when you look at this, the doctor bandages the wound and God heals it.

And so I want us to look at how, discover how religion and spirituality are integral. And when you look at religion, it comes from the Latin word "religare", which means to bind together. It's like that glue that is holding something tight and it's holding it together. And so a religion organizes the spiritual experiences of a group of people into a system of beliefs and practices. So as a Christian, in my religious group we believe that we are not here by chance, but we are created by an intelligent being who is the true God of Heaven and earth. The chair that we sit on today is not there by chance, somebody created there, somebody put it there for us to sit on. And I believe the reason why we are experiencing wars and sufferings and diseases and pain and even death is because of an enemy by the name of Satan or the devil. And the Bible calls him a thief, there in John chapter 10, where it says that his only purpose is to kill, steal and destroy one's life, destroy one's family, destroy one's health, destroy you emotionally and even spiritually. But here's the good news for us, Jesus says, I have come that we might have life and live life to the fullest, even in this broken world, in a world that is riddled with disease and pain.

And when you also now look at spirituality, spirituality is from the Latin word "spiritualitas", which means breath. And when God took the time to form the first human beings, here on Planet Earth, Adam and Eve, in Genesis 2, verse 7, it says that he breathed into man, the breath of life, the very air that we breathe is life from an intelligent being, God himself. And so when we look at spirituality, it is a broader concept than religion and it is primarily a dynamic personal experiential process. Someone spiritual is on the personal quest for hope, personal quest for purpose and ultimate meaning in life.

And though there are many different ways to define religion and spirituality, the main thing I want you to understand is that religion and spirituality can help, can help you not only know yourself and your place or role in the world, but also authentic spirituality has its origin with God and it is empowered by his Holy Spirit. And I need you to understand that to find meaning in life and in experience, an intimate relationship with God ought to be our first and most important priority. The Bible says to know him is life eternal.

Also, and when you look at religion and spirituality, they provide, they give our life value. And so for me, each day when I wake up, I have this desire to push past life issues, to push past the struggles, to push past the pain. That's what religion and spirituality helps me to do. They also help me to seek, it helps one to seek well-being and inner freedom and inner peace, and that can come only from the one who can give us that peace of mind, that's God himself. Religion and spirituality allows the person to flourish and be resilient when challenges come back. Yes, life is hitting you, but you can bounce back.

Religion and spirituality connect individuals with others and with something beyond us. It provides a sense of belonging. Not only that, it encourages the person to live in the present, mindful awareness. I love the Bible text that talks about, in Matthew 6:34, it says, "Therefore do not worry about tomorrow, for tomorrow will worry about itself. Each day has enough trouble of its own." I know that living in the now, the present, is so difficult because we are always encouraged to think about the future or dwell on the past. Nevertheless, living in the present and

having this type of mindset is the key to staying healthy and happy. It helps you to fight anxiety and cut down on your worrying and it keeps you grounded and connected to the source of your strength. It keeps you connected to yourself, and it keeps you connected to everything around you.

As we move on, let's look at religion and spirituality and see how they are a significant part of American life. Look at this 83% of Americans believe in a god or higher power. 75% of Americans say religion or spirituality is very important in their lives. Wow. 90%, and this is it, 90% of Americans with medical conditions rely, they depend, on their spiritual/religious beliefs to cope. Doctor Okai talked about coping. Here's another thing that can help us cope. Faith in God is another way to help one cope with this chronic disease.

What is faith? What is faith? The Bible says it. Here's this version, the message translation that says "The fundamental fact of existence is that this trust in God, this faith, is the firm foundation under everything that makes life worth living. It's our handle on what we can't see." And so faith, faith for me is not some good luck charm that gets me whatever I want. No. Faith is simply just believing, hoping, trusting in God. Faith for me is the very foundation of my life. And it should be the very foundation of our lives. Faith sustains us in the perplexing questions of life. Some are saying, Will I never experience better health? Will my life ever be made whole? What I love about faith is that it does not know defeat. It does not understand the word impossible. It is filled with courage.

And so spiritual people may utilize their beliefs in coping with illness, pain and life stressors. Some studies indicate that spiritual people tend to have a more positive outlook and a better quality of life. And this is our creator's hope for us. It says here in 3 John, verse 2, "Beloved, My dear friends, I pray that you may prosper in every way, and that your body, this physical body, may keep well, even as I know your soul keeps well and prosperous." One study showed that spiritual well-being was related to the ability to enjoy life, even in the midst of symptoms, including pain. That's God's will for our lives, not for us to be broken down and experiencing pain. He is not the God of suffering. The enemy has brought suffering to the human race. That enemy is Satan himself.

Now, some people living with MS find spiritual practices can help them find relief from their symptoms and accept their path with gratitude. So what is spiritual practice? What is spiritual practice? Here are a few things. What is spiritual practice? Well, it's something you do that reminds you about what really matters. Number two, it is an activity that brings peace and ease. For me, prayer is one activity that brings peace and ease to my life. Prayer can take many forms, it can be part of organized religious services, informal groups, or it can be done alone. Some people recite traditional texts, others speak in their own words or use a journal to write down their prayers. You can pray even if you don't consider yourself a faith community member or believe in a higher power. Prayer can be beneficial for several reasons. It can help you to cultivate feelings of gratitude and compassion. It can lower anxiety and release control to a higher power or external force. Some research also shows that prayer can help people better manage chronic pain.

Other activities include, but are not limited to, spending time in nature. Spending time in nature can boost your mood and help you connect to the outside world. What about gardening? Yes. Gardening allows you to be able to move about and breathe that fresh air. And it also can put you in a space where a spiritual activity called meditation that can calm your heart and relax your muscles. And so, there are other things, some things that helps you feel a sense of connection. These are all spiritual, spiritual practices. And if you are, those who are here,

maybe in the chat, what spiritual practices have you found beneficial? You can just share that in the chat even right now.

As we move on, know that there are limitless ways to cultivate spirituality in your life. The goal is to find what works for you. And I saw someone posted "volunteering", yes, it is essential that you not only take care... "prayer", yes... take care of yourself physically, but spiritually as well. Yes, "yoga" is another way, good, "reading scriptures", yes, I see it. Good, good, good. Those are great, helpful things. And so, it's important that we take care of ourselves not only physically, but spiritually as well.

So, what is spiritual care? So, to understand, spiritual care attends to a person's spiritual or religious needs as he or she copes with illness, loss, grief or pain. It can help the person heal emotionally as well as physically. It can help you rebuild relationships and regain a sense of spiritual well-being. I want to present to you, here are some sources of spiritual care. You perhaps know this - Chaplains and clergy can help, family and friends, great supporters, community resources, and scriptures readily available Bible texts or religious texts or artifacts. Physicians, yes, they are important, don't neglect consulting with your doctors and healthcare providers. And churches or chapels or quiet rooms, meditation rooms. And there are a whole lot more sources of spiritual care.

Also, when you look at this, I have to address, there are concerns and negative experiences when it comes to religion and spirituality. You know, having a disease like MS, perhaps, have caused many to doubt a divine power. As a matter of fact, it has caused some to struggle with the divine, some get angry at God and begin to, perhaps, blame God for this sickness, this pain. Here, keep on putting it in the chat, I see it. Also, some feel like God has abandoned them and they feel like God is punishing them. Some also view the illness as a moral or spiritual failure, and some are having to experience, daily, all the rejection, the stigma, and discrimination that comes with having such a debilitating disease as MS.

And the question many are asking, Does God care? If God is so loving, why am I experiencing these sufferings? Why am I experiencing the daily pain and going through being traumatized? Why am I going through all of this? Well, once again, remember, God is not the author of human suffering. He's a God who gives life, but the enemy, Satan himself, wants to destroy your life. And he wants to destroy your future and he wants to bring pain and suffering to our life. And I want to remind you today and encourage somebody to believe that as you go through this disease and as days become hectic and sometimes you feel like, man, my life is not in order and it's burdensome. I want you to remember this, that God cares.

And here's a few texts I want to leave you with - Jeremiah 31, verse 3 says "Yes, I have loved you with an everlasting love; therefore, with loving kindness have I drawn you and continued my faithfulness to you." And he says these words to someone today, "Fear not. There's nothing to fear, for I am with you. Do not look around you in terror and be dismayed, for I am your God." He says, "I will strengthen and harden you to difficulties, yes, I will help you; yes, I will hold you up and retain you with my victorious right hand of rightness and justice." I love this text, Isaiah 54 verse 17, "But no weapon", I can say no disease, no pain, no suffering, "that is formed against you shall prosper." It will not succeed. And here is the promise that we have. Will life ever get better? Will I ever experience the healing one day? Will I ever be made whole? Here's the promise, perhaps it may not have happened for you on this side of the earth, but God says, when he comes, he says, I "...will wipe away every tear from your eyes; and death shall be no more, neither shall there be anguish, sorrow or mourning, nor grief nor pain any more, for the old conditions and the former order of things have passed away."

So how do I overcome the barriers of spiritual growth? Well, it's a day to day process, and we encourage you and we challenge you to look closely and reflect on your thoughts and feelings, beliefs and motivations. Periodically, yes, you've got to take the time to examine your experience. What is going on today? How's my body feeling? And look at the decisions that you're making, the relationships you have, and the things you engage in, provide useful insights into your priorities. You know, some people will grow more quickly, while others progress at a slower pace. And as Dr. Okai mentioned, don't compare yourself with anybody. You are unique. You are an overcomer. You will get through a day, amen, just ask God each and every day to pull you through the struggle, pull you through the pain, pull you through the trauma, pull you through whatever you are feeling inside. Even when others do not understand what is happening in your body, don't not compare yourself.

And so, as we move on, let's just summarize what we have discussed thus far. Remember, religion and spirituality often form the basis of meaning and purpose in life, and throughout history, religion and spirituality and the practice of medicine have been intertwined. Spiritual practice includes activities that provide a sense of connection, peace and ease and meaning. Spiritual care can help a person heal emotionally as well as physically. And building spiritual growth is a day to day process.

#### **Marie LeGrand:**

Thank you so much, Pastor Hunter, for the excellent presentation. We truly appreciate your expertise as well as your guidance on spiritual care. Next, I would like to introduce Dr. Mitzi Joi Williams. Dr. Williams is a neurologist and MS specialist in Atlanta, Georgia, and has a strong interest in understanding and furthering research in MS in ethnic minority populations. She continues to educate patients and colleagues about self-advocacy and the importance of shared decision making between patients and their healthcare team. She also serves as the co-chairperson of MSAA's African-American Advisory Board. Welcome, Dr. Williams.

#### **Dr. Mitzi Joi Williams:**

Thank you so much, Marie, and thank you to MSAA for hosting this amazing program, an amazing forum to talk about something that, you know, is very much a part of the exam room, very much a part of our lives. But I think we don't express it explicitly enough in forums like this. And so, I'm really appreciative of the opportunity to be a part of this amazing program with my fellow panelists.

So Dr. Okai started us out talking a bit about the science, and Dr. Hunter kind of brought us on to the church and just gave us some amazing, inspirational words and also explained some of the difficulties or areas of tension that people have with spirituality, especially if they have a chronic condition that affects their health. So I'm going to kind of bring both of those together before we go on to Tyler, who's going to tell us about his personal journey.

So we'll talk a little bit about spiritual care, and we'll talk some about some of the science that we have. We don't have enough science. We certainly have lots of personal experience, but we do have some science that really suggests what we intuitively know that our spiritual health affects our physical health. All right. So this is an interesting quote by Stephen King, not the horror film writer, but Stephen King, the Ph.D., and it says that "Unmet spiritual needs have been associated with greater emotional distress, more pain and poor quality of life. Patients with

struggles often have poor daily, physical, functioning, more depression and anxiety, higher costs of medical care, poor satisfaction with care, and increased mortality."

And I want to paint a picture for you. I think one of the things that has really solidified my understanding, or I would say my recognition, of the connection between mind, body, and spirit, was the very first neurology patient that I ever saw as a student. And it was a young woman who was in her thirties and had experienced some emotional trauma and unfortunately had attempted suicide, but fortunately did have a failed attempt. And so when this young woman came in to see me, she could not walk, and she was in a wheelchair. And so as a medical student, I really didn't know how to do a neurologic exam very well. But certainly, there were some things that she had significant difficulty with. And so I go out and I present, you know, to the doctor who I'm working with, and we go back in and see this young woman and come to find out once the doctor starts talking to her and once he starts examining her and having her mimic certain movements, she can indeed walk.

And so essentially because of that spiritual brokenness and because of the issues that she had faced, it had literally affected her physical body to the point where she was immobile for a whole year. And I bring up that because it's an extreme example. Right? But many times in life we have more milder examples of where our spiritual health and our mental health may not be doing very well, and it absolutely affects our physical health. And so I think it's very important for us to be aware of that, whether we have MS or whether you have any chronic condition or just as we're moving through life.

So when we bring this kind of back to MS, we think about how the different treatments that we have for MS have really made a difference. Right? So, you know, if we look at things kind of from a 50 foot view, MS is a disease we've known about since the 1800s. There were no medications approved until the 1990s, you know, so there was a long period of time where there wasn't a lot of hope because there was really not very much that we can do as physicians and as scientists to help people who were suffering with multiple sclerosis. And so in 1969, the average survival of someone with MS was roughly 17 years. And now in 2017, which was not too long ago, it's over 40 years. And the life span of people with MS is very full, for many of my patients in their seventies and eighties. And so now that we've got some treatments and we're not so concerned about the mortality of the disease, you know, there's now a shift and a focus on quality of life. So it's not just enough for us to say we're treating the MS to this extent, but we want to decrease suffering. We want to see how we can improve a person's quality of life on a daily basis. So it's important to have a good quality of life and not just a long quantity of life. And one of the things that's been found in, you know, studies is that many people with MS consider their spiritual well-being equally as important as their physical well-being. So these things are very closely connected, but also very important to people living with chronic conditions.

So one of the things to kind of bring back to is, again, although we've made many advances in terms of how we treat MS, there still is a lot of uncertainty. So when people are diagnosed, there's a fear about the future. What's going to happen to me? Am I going to be able to use this education that I just spent ten years obtaining? How will I be able to take care of my family? And those are real concerns. But faith and spirituality and having that connection to a source, you know, can really help provide resilience. To be able to deal with these things as well as help people to feel empowered. One of the difficulties with a MS diagnosis is that people often feel helpless. So I think empowerment is extremely important to living a life, living well and living a great life with multiple sclerosis.

So I like this picture because it has two pieces of a puzzle, right? So faith and health are part of the same puzzle. And so we think about our spiritual health, as we said, it definitely affects our physical health. And so it is very important in helping us to manage chronic and debilitating symptoms, especially from diseases like MS. There are studies that suggest that spiritual care has been linked to improved health outcomes. So when you're taking care yourself spiritually, you know, and it makes sense that you're probably a little bit more likely to also be taking care of yourself physically, that there's increased quality of life, that there's resilience against symptoms like depression and anxiety, which we can see very commonly in people who have multiple sclerosis. And also we talk... Pastor Hunter talked about that peace of mind, that spiritual strength and peace of mind can also come when people share their story or give their testimony, and everybody can give that in different venues and in different ways. But you never know how sharing your story can really not just help you, but also help someone else.

As healthcare practitioners, you know, we have to catch up to the times and we have to catch up with what's going on. I definitely talk about spiritual matters with many of my patients. I do personally pray with my patients in some cases depending on the situation. But it's important for us as, you know, physicians, as nurses, as other healthcare practitioners, to make sure that we acknowledge someone's religious preferences, their beliefs and their spiritual practices. And this also is part of the treatment plan. So we look at the whole person, not just at the disease, not just at the disease modifying therapy. But we have to look at how to treat and how to help the whole person live their best life with multiple sclerosis.

Research also suggests that faith or spirituality can be associated with better outcomes for a couple of or multiple different areas. People tend to live longer when they have regular spiritual practices. Whether they go to a church on a regular basis or listen to, you know, religious sermons, etc., on a regular basis. People can also cope with symptoms such as pain and also deal with that uncertainty about the future. Quality of life can be improved and also can help people rebound or recover from illness more effectively if they have some type of spiritual commitment or spiritual practice on a regular basis.

Also, spiritual practices, having faith and having that connection can actually affect how long you live. So this was a study that looked at adults and it looked at mortality. And what they suggested was that at a 28 year follow up, there was a 23% reduction in mortality for those who attended some type of religious service at least once a week. And then this other part of the study looked at an 18 year follow up at 75,000 people, women in particular, and found that if they attended type of service once a week, they were 33% less likely to die than those who were not attending. So it does indeed affect our health as well as our longevity.

Other studies, you know, discuss how faith and spirituality can affect symptoms like pain, as well as things like depression. And so this study looked at the correlation between spirituality and spiritual well-being versus depression and pain. And what they found was an association that was a negative association, meaning if you had better spiritual well-being, you had less depression and less pain.

And also, faith is associated with higher quality of life, positive attitudes and behaviors. So this was a study looking at people who regarded themselves as religious or spiritual, who had MS, so this was specific to MS, and it found that a higher percentage of people led a healthy lifestyle that had a more positive perception of illness, as well as a more positive outlook on life.

And also looking at recovery, this one was not specific to MS, but this was looking at patients who had had strokes in the left hand side with the graph found that patients who had a stroke in

this instance felt that their spirituality and their religion contributed to their recovery. And even in the way that they thought about that was that they felt like there was a greater power who was in control of their situation or that there was a higher power, there's a helper, for their situation.

And I think this one is extremely interesting because, again, the way that we interact and our spiritual well-being and our connection to Christ or God or a higher power affects not only us but affects those who are around us. And I think that this is an excellent example because, you know, oftentimes when we talk about MS, we focus on the person who has MS and they are at the center of our treatment plans and all the things that we do. But oftentimes those who are care partners may not be as well recognized or may be forgotten or left by the wayside. And they often deal with symptoms of depression or other things related to caring or watching someone that they love go through this difficulty and go through some of the changes that people go through with MS. And this particular study looked at care partners and looked at the effect on care partners for those people living with, you know, a condition that had reports of spirituality or said they had high spiritual well-being.

So what they found was that the care partners, even those who had high levels of depression, seemed to have a better quality of life if the person that they are caring for had a higher level of spirituality or a closer connection or a very good spiritual well-being, and also the people with high levels of spirituality had a little bit of resilience even when they had someone around them who had that depression. So even though the care partner had depression, people were able to combat the effects on themselves with higher levels of spirituality in connection.

Now, Pastor Hunter addressed many of these, but we also have to look at the converse, right? So there are many, many positives to our spiritual health, to having faith in God, having a connection to our source. But there are also some potential negatives. Some of those can include people may avoid traditional treatments and traditional medicine altogether. You know, I always... I've never looked at faith and medicine as mutually exclusive. There are definitely things that can work together to enhance someone's quality of life. But certainly in some instances, people may feel that taking treatments, and I've had this happen in clinic, demonstrated a lack of faith. Or I've also had people who may not have gone to the doctor for symptoms because they may have been praying that they would go away and, unfortunately, that allowed the symptoms to get worse and potentially for diseases to progress.

Also, some people may avoid certain preventive health measures, such as visits to the doctor for prenatal care, etc. or they may on the opposite side have unrealistic expectations. Even with our disease modifying therapies and how far we've come with treatment of MS, we don't yet have a cure and we don't yet have things that fix what's already affected, so to speak. And so sometimes that level of spirituality can cause people to have unrealistic expectations, which can lead to disappointment and then alienation from the medical system, or alienation for other people from other people around them who don't necessarily share the same beliefs.

And these are some other examples of spiritual concerns. I'm not going to read all of these because Pastor Hunter did cover some of these. But I think it's important to address, you know, one of the first things that I tell people when they are diagnosed with multiple sclerosis is that there is nothing that you did to cause this to happen. Sometimes people feel that there is guilt or shame, like there was something that they did to make themselves have multiple sclerosis, whether it's something dietary, whether it's something spiritual. Other people may get angry at God or angry at those around them because of what happened. And then some people may even lose their faith, unfortunately. So I think that these are things that we have to make sure that we're talking about, make sure that we are addressing to the best of our ability with our faith

leaders who are helping us with counselors, especially in the beginning of diagnosis and also with our healthcare team.

So in summary, we know that spiritual health is very important. We know that there is a strong mind, body, spirit connection and all of those things are intertwined and help us to live an excellent life or a great life or can cause us to have some additional suffering in addition to other things that we may have going on with chronic illnesses. We know that there's evidence, right, that there's scientific evidence that taking care of yourself spiritually can absolutely affect your health outcomes, that it cannot only help you to cope with illness, but also to live a longer life and have a better quality of life. Because, again, it's so important not just to have quantity, right? But we want to have quality of life. And I think is very important. And I always stress that you can live well with MS. You may not have all of the function that you had in the past, but you can live well.

I think also, in summary, some of the other important points here are that the elevated level of spirituality or spiritual well-being, taking care of yourself spiritually, can influence not only you, but can also affect your partners and those around you who have difficulty seeing you suffer in certain ways. And then also, we have to be aware, of course, of some of the negative aspects. But I think this last point is extremely important, especially for us as part of the healthcare team to recognize that spiritual well-being is very important. And to many people with MS is equally as important as physical well-being. Okay. Thank you so much.

**Marie LeGrand:**

Thank you so much, Dr. Williams. There was a lot of great points as to how spiritual health is important for coping with the burdens of MS, so thank you so much for your guidance on that once again. Finally, I would like to introduce Tyler Campbell. Tyler was diagnosed with MS during his junior year at San Diego State University. He now travels the country as a professional speaker, delivering empowering messages of self-worth. Tyler also serves as a member of MSAA's African-American Advisory Board. Welcome, Tyler.

**Tyler Campbell:**

Oh, my gosh. Hello everybody, this has been fantastic. I've enjoyed every single bit of this. I've had my pen handy. I've been taking notes just like everybody else in the audience. So, thank you so very much, Marie. Thank you to all the panelists, all the great job that you have done. And so now I'm going to be able to pick up what it is that you all have been putting down this entire time. And I'm just going to give you my heart, if that's okay with everybody else. I just want to give you guys my heart and just share my journey with everybody else. And the topic for me is, listen, I may have MS, but MS does not have me. And that's my focal point. And that's the creed, that's the slogan that I live by, even to this day.

As Marie hinted, I was diagnosed when I was 21 years old at San Diego State University while there on a football scholarship, and MS hit me like a thief in the night. After playing a football game, I woke up the next morning, fell out of bed, could not feel my arms, my legs, my equilibrium was totally shot without any warning. There was no lead up. This is me, this is what came into my life literally a couple of weeks after my 21st birthday. And upon hearing all the information and those of us who are MS patients, we know what it's like to get all of this dialog, all of this information, all this terminology and just feeling so completely overwhelmed. I had so much fear, so much level of uncertainty and so much concern over what the next part of my journey in life was going to look like, figuring out all these things.

And I had no friends or family present. I'm from the state of Texas. Shout out to all my Texans out there. I'm from the great state of Texas. I was in California for school, so I had no friends, no family members, no teammates, no team doctors accompanied me on the road to my diagnosis at a neurologist office. I barely even knew what a neurologist was. So I'm picking up all the pieces of my broken puzzle, literally piece by piece, little by little, trying to figure out my life.

And when I read these pamphlets, so when I looked up on the computer, everybody, I didn't know any better. I went to Doctor Google, to all the doctors present, Dr. Mitzi, Dr. Okai, I'm sorry I did it, I went to. Dr. Google. I know I wasn't supposed to at that time, but you know, that's what I did. And when I read, oh, I didn't see any faces that looked like mine. A lot of the stories that I found about MS, they weren't positive stories. They weren't stories that made me feel like I wasn't going to lose my football scholarship and get sent back home. There weren't stories that told me that I was going to be able to continue my education and get my business management degree. So a level of anxiety and depression were the ensuing things that came over my spirit and over my soul.

And I prayed continually for the Lord to show me, show me some form of positivity. Show me something that will allow me to believe that what you are giving me, that I can cling to and have the hope that I can make it through. And literally, after praying my prayer, after leaning on that faith that I've been instructed to lean on in my childhood, in the way that I grew up in my upbringing. The following day I went back to the computer, and I found the story of a gentleman by the name of Montel Williams. Montel Williams looked like me. I never seen a face that looked like mine that was living with multiple sclerosis. I saw him. I recognized him. How could I not? I'm a child of the... I grew up, I was born in the eighties, a child of the nineties. You know Montel Williams, he come on before Jerry Springer. And I found that man and I saw that journey, and the first thing that I saw about him, how he spoke out about his MS, was I saw a smile. I hadn't smiled in a very, very long time since my diagnosis of MS. I saw him smile. His smile gave me hope, it gave me peace.

And it referred me to look back over the thing that showed me that I'm not alone. You see, I prayed. I had the faith. I clung to my religion. My faith as a Christian. And I was shown to me. And when I got that information, I dove into the book of Proverbs, and I recognized that being all the way out in California, I'm not as alone as I think because my heavenly father is sitting high and he's looking low, and he's taking care of me. And I read that book of Proverbs every day, and I went through a regimen that I put before myself, and it was wake up and it was read your Bible then it was read your devotional. Then it was go through the day and as you make it through the course of the day, you end your day in prayer, revert back to your Bible and you lay your head at rest. I had a regimen as to how I gained peace and recognized that I wasn't alone. And that's what... I'm sorry, that's what led me to my next slide here.

And let me see, I'm trying to get to this next slide for you guys. Oh, there we go. False truths multiply when wise men and women with MS become silent. False truths multiply when wise men and wise women with MS become silent. We need stories. And I recognize that I didn't want somebody else to be in my position ever again. I didn't want somebody to be newly diagnosed and never find a story that they could cling to that would give them hope, that would give them everything, that would give them peace, that would give them a moment of saying, "Yes I can and why not me?" Like I found with Montel and I was blessed to find that. But the Lord says, you got to speak that over not just your life, you got to keep that... you can't keep that to yourself. You got to begin the journey of what it takes to be able to share that message with somebody else.

Yeah, my grandma used to always say, she used to say, Tyler, you got to leave things better than the way that you found them. Hello. So it was my job to leave this MS world a lot better than the way that it was received. And so it gave me something to cling to, and then it led to a level of grace. I was never alone. My Heavenly Father was keeping me. And as I look back over my life and what I was supposed to do with this MS thing, you see, he had given me principles all along the way, and he had given me things all along the way to let me know that I was built for this. Yeah, yeah, yeah, yeah.

I was wired for this. I had always been on the leadership council of any sport that I had ever played on. Yeah, I had always been someone to speak up to other brothers and sisters, my other brothers on the team and talk about generational curses and use my tongue and use my mouth for the betterment of somebody else. So now that MS has come into my life, I was chosen for it, kind of involuntarily. And trust me, I ain't saying that I wanted this disease. This is one of the worst things that I wouldn't wish on my worst enemy. But now that I have it, I got to use what he equipped with me. I read a book called "The Purpose Driven Life" when I was 16 years old by Rick Warren. So I recognized that I was here for a reason on this earth, that I have a calling and that I have a purpose to fulfill. So with this MS, we still, I will still fulfill a purpose and a calling to leave it better than the way that I found it, and to make sure that no more false truths multiply because I will live a life in silence.

And I was saying, you know my thing, man, I might not be the most tech savvy, if you can hit me with the next slide, because I'm feeling it right now. There we go. Yeah, we teamwork here at MSAA. So that leads me to my next point. Be less concerned about how others see us and more focused on how we see ourselves. Yeah, yeah, yeah. When I was able to lay down the embarrassment of being in a wheelchair, suffering from relapsing and remitting from time to time when I dealt with my relapses, from having drop-foot, from being a person on campus that people would literally stare at trying to figure out what's wrong with you when you're dragging your foot through campus and you're limping and you have a steroid ball out the side of your pocket and you have to take your final exams with your left hand. I had to recognize that people aren't necessarily staring at me to ridicule me. They're staring at me because I hadn't yet accepted my platform yet. Yeah. Yeah, they needed that education. And those are the things that I started to leave out of college with as I would transition the rest of my life. And I had to start getting comfortable with MS and be less concerned about how people view me and more concerned about how I viewed myself.

It led me down a path of selfishness. Hmm, write that down. It led me down a path of selfishness to lead me to selflessness, and in religion, in our faith, and in what I come from as a believer, it is often taught that you are supposed to not be selfish. But when this disease, I want to grant you permission as somebody living with MS, or you know someone who has MS, give them permission to know that it is okay, my goodness, to be selfish and take care of yourself first. Hello. Yeah, yeah, you deserve that. And so when I had to backtrack and erase all the guilt of what I felt as a man of faith, that it was not okay to take care of myself first, that I am supposed to take care of others, that I supposed to be selfless. But then I recognized that I have to be selfish first so I can get to that level of selflessness and not put my cup into overflowing.

Yeah, that's I was doing. I felt like I was ripping and running with this MS and nothing was coming back into my cup because I wasn't refilling it for myself. I had to take the time to learn to be selfish, and to say that it is okay with the man in the mirror. Tyler You can be selfish and as you're selfish, watch this Tyler, you then open up your heart to live a life of selflessness to help other people. And it all starts with being less concerned about how other people view yourself with MS, how they view your cane, how they view your wheelchair, how they view your pain,

how they view your hurt, how they view the tragedies that you've experienced and you be focused on how you view your doggone self.

Yeah, those are the things that helped me, and Allison, we're going to get to principal number three because I feel it, I'm excited. Here we go! Let this marinate on your cerebrum. That is the front cortex of your brain. Dr. Mitzi and Dr. Okai know what I'm talking about, that thing that controls your cognitive. Right? That thing that controls your mindset. Let this marinate on that. "The storms in our life are not meant to always destroy us, sometimes they are meant to create a new path." A lot of times I'll say sometimes you have to find a new approach to the dreams that you have. MS doesn't derail them, and, if anything, I'm want to speak hope, life and prosperity over you today because our Heavenly Father spoke it over me. You are all the more unique. You are all the more beautiful. My fellows, you are all the more handsome. You are all the more amazing because you live with MS when most people would cripple and crumble if they had to step and walk a step or a mile in your shoes. That storm came into your life not necessarily, of MS, to destroy you, it became prevalent for you to create a new path for yourself.

So it doesn't mean your dreams have to die. It just means you have to approach them in a totally different way and accept the small wins that you experience within your life. Hey, I walked to the mailbox today. Hey, I fixed my own cereal. Hey, I walked through the doorway, and praise him, I didn't hit the side of the wall when I was walking through. Yeah Yeah, all of those things. Because that's your message, that is your testimony. That is what you share with others. And we need your stories so that you can rescue those other newly diagnosed individuals or those people who are searching. Those people don't have the same support system that you do. They need your story. We need your advocacy. We need your perspective. And those are the things that will shine brighter than any light on this earth in the life of somebody who lives with MS or a caretaker who has it. Never let somebody step to your face to tell you that you don't matter with MS or that you aren't important or that you don't have perspective and that you don't have a purpose.

But our Heavenly Father is watching over you. A lot of the things that I have, my goodness, a lot of the things that I have, 15 weeks on the Amazon best-selling list, having the number one talk radio show on a Saturday for a sports radio station, and I don't talk nothing about sports, but I tell everybody how blessed I am and who's in control of my life. I take credit for none of those things. The storm of MS did not come to derail me, it came to create a new path that started from that young 21 year old boy who saw a gap in seeing that people with MS, their positive stories weren't being shown. That's my work. That's my mission. That's my purpose. I'm going to be selfish first so that I can be selfless for other people.

All right. So false truths have the tendency to multiply when wise men and wise women become silent with MS. Principle number two, be less concerned about how others see you and more concerned, my brothers and my sisters, about how you view yourself. And it will open your heart up to be able to do exceeding and abundant things in your life, as our Heavenly Father promised. And principle number three, that storm of MS, I'm here to tell you, I want to take that off your back today, the storms in your life of MS did not come and it wasn't meant to destroy you, it came to carve out and create a new path. I love you all. I respect you all. Man, let's go, ladies and gentlemen, so we can grow. Take it away, Marie.

**Marie LeGrand:**

Thank you so much, Tyler, it's always a joy just hearing you speak. And I truly appreciate, and I'm sure all of our viewers appreciate, you giving us a glimpse into your MS journey and for sharing your three principles of encouragement with us and for also being so inspirational. So,

thank you so much. I would now like to bring in all of our speakers tonight for a brief fireside chat. And they're going to provide us with a more in-depth look into healthy grieving, dealing with challenges and changes, connecting with your true self, building spirituality into your life, and maintaining balance. So let's go ahead and get started. So we'll start with you, Dr. Williams, and of course, Dr. Okai, Pastor Hunter, and Tyler. I would also love your input as well. So how can spirituality and faith help a person with MS recognize and accept the physical and emotional impact of the disease?

**Dr. Mitzi Joi Williams:**

Yeah, you know, so when we think about coping mechanisms, we talked a lot today about how faith is a coping mechanism. And so how do we deal with any kind of difficulty, right? We lean on those things that help us to grab hold of parts of the world that are unseen and things that we don't understand. Right? And so, faith is definitely a way that people can connect and try to understand what's going on in the world around them. I think that, you know, it's something that we don't talk about enough, especially in the exam room when people are dealing with a diagnosis of MS. But I think that when we talk about developing your tribe and developing your sense of support, you know, the church and faith are a huge part of that. Right? So many people, you know, lean to their spiritual leaders, etc. But it is definitely an effective way for people to begin to grasp things that they don't understand and to deal with the diagnosis of multiple sclerosis and accept it.

**Marie LeGrand:**

Doctor Okai?

**Dr. Annette Okai:**

So when I think about faith, spirituality and MS, it's for me what I think of, I draw on my own personal experience. So MS is just a journey, a part of life journey. And we all have parts of our journey that are difficult. And when you have faith and you trust God, you have that inner peace to deal with whatever is being placed in front of you. And that's how I would like patients to think about faith in their MS journey.

Once again, I will like to point out that having faith in accepting the diagnosis doesn't mean you are accepting defeat. We have just heard Tyler. We heard from Pastor Hunter and from Dr. Williams how all of these things come together is what you do with those emotions. So it's having that inner peace to deal with whatever is thrown in your path because you know that God is there to carry you through. God is there to carry you through this. And periods of hard times does not mean that he has abandoned you. You are going to come out stronger. So you have to use those tools and resources that Dr. Williams mentioned that faith provides to you to get through those times. And that's what patients with MS, I will encourage them to do.

**Marie LeGrand:**

Thank you. Thank you.

**Dr. Annette Okai:**

And I'm not the pastor in the room, by the way.

**Dr. Mitzi Joi Williams:**

Listen, I'm ready to pass the offering basket. I mean...

**Pastor Claval Hunter:**

I know, man.

**Tyler Campbell:**

But listen, to your credit, Dr. Okai, you had to wait the longest to get back to the microphone. So, you got a lot to give right now. That's what people got to recognize. That's powerful. Powerful.

**Pastor Claval Hunter:**

I know.

**Marie LeGrand:**

Did anyone else want to add anything to this?

**Pastor Claval Hunter:**

Yeah, I'll add. You know, grief is a natural reaction to loss. And when we look at healthy grieving, prayer can help us to grieve in a healthy way. Having trust, complete confidence in God during life challenges is another way to help us to grieve healthy. So healthy grieving is the first step toward healing. The grieving process sets the stage for goal setting, creative problem solving and personal growth.

As I was preparing for this presentation, I had one of my members living with MS share with me that she has found that her spiritual and faith both provide a foundation and stability to her life with MS. She's leading an MS support group for women who are all African-American women in various stages of MS, from being in a wheelchair and those walking independent. And then this particular group that she is running, she said that they can laugh, they can pray, and they support one another through a foundation of faith and various stages of grief.

She says that when it comes to grief, she says that grief starts with the initial diagnosis of MS. Grieving, our way of life, recognizing that we have no idea how one's life will unfold with this disease. And she says, we grieve every stage that we have to go through. We grieve when we realize we no longer can walk, we no longer have control over our body. We grieve when we have to go from a cane to a wheelchair. We grieve when we realize we have no more help in our lives to live a full life. And she says it's an ongoing thing. And so grieving is an ongoing part of our existence and those dealing with MS, but she says because of her foundation and faith and spirituality, she recognized that God loves her and he continues to be with her. And regardless of what she faces or what they face, she knows that he is always there to provide that ongoing love and support. So faith is that firm foundation.

**Marie LeGrand:**

Thank you. Thank you, Pastor Hunter.

**Dr. Mitzi Joi Williams:**

And can I say one more thing, Marie? You know, grieving, that grief process is so important. But I also think that it's important that at some point we do have to refocus on where we are now. And what is our purpose in this moment or in this season. Because it may be very different from our purpose in the last season. And so one of the things that I tell my patients all the time, especially as we're going through transitions with MS, and I say if you're still here, God still has a purpose for you. And so now we need to focus on what is that purpose right now. So, no, you may not be able to do the things that you used to be able to do. And yes, we grieve that, it's a

real thing, it's a real loss. But now we're right here. So what direction do we need to move in right here?

You know, and I'm always so inspired by Tyler's story because Tyler does so much amazing public speaking. I'm sure that probably was nowhere near his mind when he was playing football, you know what I mean? But look at the amazing inspiration, how that redirection has been such a blessing to so many people. And so, you know, I say if you're here, you have a purpose. What is that purpose? And let's focus on how we can fulfill the purpose for you in this season of your life.

**Marie LeGrand:**

Well, now, that was really interesting, and I'm glad you all brought up some of those points, because it leads me to my next question. So we'll start with you, Tyler. Based on your personal experience, how can spirituality and help... spirituality and faith help a person with MS prioritize their daily life?

**Tyler Campbell:**

Yeah, I think one of the first things is it gave me a regimen. Right? It helped me, it gave me a level of accountability and fulfilled a level of loneliness. Like I literally... you go through so much with this disease and no day looks the same. You don't go through MS judging what happened yesterday, because, man, we all know you wake up the next day is going to be something totally, totally different.

And so, the remembrance of who I serve, who's always been there, that had to come to the forefront of my mind. And when I did those things, I just reverted back to a lot of the things I had been doing, that when MS diagnosis came, I kind of forgot to... I'm going to be honest, for a while I forgot to pray. There was so much other emotion, like we talk about, you know, I know the Lord, I know my Bible. I'd forgotten about the book of Proverbs. I had forgotten to pray. I had forgotten to have prayer in the morning. I'd forgotten to have it in the evening. You get wrapped up in school, you get wrapped up in a relationship. And what you lack that you forget who's been there the entire doggone time.

And so, for me, it was reverting back to what has always been there and for the individual who's listening in because I grew up a certain way, I had that to cling to. Right. It was easy for me to pull, you know, the good book off the shelf and get back to that. Because I had known that, it had been taught to me before. But I recognize that there are people on here who are searching for answers who don't have that. And if you don't have that, please remember what it was that I started with, Marie, and it was the thought that anybody can get down on their knees and you can pray. You can start there and just saying that you are in search of an answer, that you are looking for something to cling to. And watch this, you give yourself, grace to know, and patience to know, that those things happen over time, and you don't have to beat yourself up if you don't have that for yourself right now. The fact that you're aware and that you're searching means that those answers will be revealed to you because you're looking for them. And you guys take it away and chime in from your professional standpoint. But those are the things that helped me with my regimen. I had to revert back.

**Marie LeGrand:**

Thank you, Tyler. Did anyone else want to jump in before we go to the next question?

**Pastor Claval Hunter:**

He did such a great job answering it.

**Dr. Mitzi Joi Williams:**

He said it all.

**Dr. Annette Okai:**

Tyler, I think you said it all.

**Tyler Campbell:**

No problem, go to the next one. I know there's plenty of questions for all the panelists. Go right ahead. Move on.

**Marie LeGrand:**

All right. All right. Okay. So, Doctor. Okai, can spirituality and faith help a person with MS learn to recognize and trust their own motives, emotions, and ideas?

**Dr. Annette Okai:**

Certainly can. But we have to look at it both ways. Right? If you have strong faith and your spirituality is where you need to be keeping you grounded, it can give you that, in a sense, of what your motives are, understanding what you have inside, understanding how you go about achieving what life has set out in your path. Sometimes though, as I said, there's always two ways that it can go. Spirituality, or what we believe our spirituality and faith to be, can also give us a different picture. And I say give us a different picture, sometimes people can overinterpret things or the interpretation can be wrong or may not be what it was meant to be. And during those times, I think, is when we need to look at others and take insight from others around us, that's when we need our spiritual support group, people who we can go and talk things over and say, look, this is what I think this means, this is what God has in store for me or this is what I read in this scripture and this is what I'm interpreting it. What do you think about it? Is this the right way to go? So it's important that we recognize that we can move way further using the tools, our spiritual tools that we have with our faith guiding us. But we also have to take a stop at points in time and make sure that we are on the right path, and we are continuing in the right manner that we should be.

**Marie LeGrand:**

Thank you. Thank you for sharing, Doctor. Okai. So, Pastor Hunter, how can a person find and maintain one's spiritual self?

**Pastor Claval Hunter:**

Well, I love, you know, Tyler's story, going back to where he started. You know, he says, I have MS, but MS does not have me. Man, that's incredible faith. I call it crazy faith, crazy faith, man. Just looking foolish in the eyes of unbelievers. So my brother, you have that unrealistic faith. You're not allowing this disease to cause you to lose sight of who you really are or want to be. God is like that global positioning system, he knows how to reroute our lives. And the Bible talks about it there in Genesis, when you look at what the enemy meant for evil, God can turn it around for our good to save many. And so, though people are faced with such challenges and even this disease, it's their faith that can help them to rise above it. And remember this text, in him we live, move, and have our identity; we have our being.

And so, I am who God says I am. I am an overcomer. This sickness is not going to control my day, it's not going to control my attitude, on my outlook on life. Like David says, when my heart

is overwhelmed, lead me to the rock that is higher than I. And he says that this God that I serve, he never sleeps, he never slumbers. And that's why when this sickness tried to knock me down and caused me to say "woe is me" and caused me to complain about my problems, my faith, it pushes me, it empowers me to look up from whence coming. My help, my help come from the Lord.

**Marie LeGrand:**

Thank you. Thank you so much for sharing, Pastor Hunter, and I saw Tyler in the background. But and... I hate that, again, you know, we're running out of time, but I did want to touch just a little bit on one thing, I wanted to pivot slightly. So, Dr. Williams, you did talk a little bit about spirituality and treatment and how that plays a role in the choices that an individual makes. So can religion and spiritual belief impact decisions regarding treatment? And in the same token, and I wanted you and also Dr. Okai to touch on that slightly, we also know the importance in shared decision making between patients and their healthcare teams. So how can healthcare providers support a person's religious and spiritual belief?

**Dr. Mitzi Joi Williams:**

Right. So I think first thing, again, faith and medicine are not mutually exclusive. Right? Taking a medicine is not an admission or lack of faith. Right? God created everything. God created science. He created the people who discovered the medicine. He created all it. Right? And so I think that that's the first thing that's really important to acknowledge.

I think that in shared decision making, again, people pray about all kinds of decisions. So why would you not pray about which treatment you should take? My job as a provider is to explain the options that are available. And then what I often do is I give people time to let it marinate on their cerebrum, as Tyler would say. Right? So I give them time to let that marinate. Right? So, it used to be when we had a treatment decision, we would come, I would lay everything out and say, okay, tell me what you want to do right now. Right? But these things take time. So you take time, talk with your family, pray about it. What do you feel peaceful about? Because at the end of the day, my goal is I want to sleep at night, and I want you to sleep at night. Okay.

So how do we come to that conclusion? And oftentimes, prayer will help people when they're having concerns about which condition. So I think that it's important to recognize that we incorporate that. You know, if we're going to pray about what car to buy, you should pray about what medication you're going to take, or if you're going to pray about what hairstyle to get, I mean, this is important enough for you to pray about.

So I think that looking at it in that vein is something that's normal and a part of the decision-making process makes it easier and not pressuring people to do something with a snap decision and giving them time to really kind of think about it and be at peace with it. Not only will help make a better decision but will help people to follow through with that treatment plan because you feel at peace about it versus you feeling like somebody pressured you to do it. So I think that plays a significant role and can be an extremely important tool in helping us to come to decisions together.

**Marie LeGrand:**

All right, Doctor Okai, quickly. Did you have anything you wanted to add? I wish we could go on and on, but we have time limit.

**Dr. Annette Okai:**

Yeah. So once again, medicine is not a betrayal of your faith. That's the first thing I agree that patients should have time to think about the medication, and I give them time and I say, ask whatever questions you want, come back at another time. It's important. But one thing I like to point out is that when you look at faith, spirituality, and religion, interpretation can be different. So for that person who is interpreting that, you know, I have faith that God is going to cure me of this disease or is going to help me with this disease and I don't need medication, I try to respect them, it's not my place to say that is not what this scripture meant. I do encourage them to go and talk to their spiritual advisor. You know, I have people I need to go and speak to my pastor. I have people to say, well, I'm not doing anything past a certain date in this one because my astrologist told me that's when I'm going to make this decision or I cannot take this medication because this compound has something that is against my religion. I've had the whole gamut of it, but I have to respect their religion. I have to respect the faith and spirituality and work with them in terms of managing their disease and how I can get them to the place that we are in agreement of what's best for them in terms of disease modifying therapy or not. So there are lots of ways that religion, spirituality, and faith can come into the exam rooms, but we have to be able to meet our patients where they are, work with it to come up with the best solution for them.

**Marie LeGrand:**

Wonderful, wonderful.

**Dr. Mitzi Joi Williams:**

And can I say this? I just tell people, listen, when we get that MRI and it's normal and God healed that MS, listen, I will run ten laps around the church with you. But until then, let's do what we know to do. Right? And then if that happens, you know, I unfortunately have not seen that happen in my career. But, you know, I believe one day I may, you know, but until that happens, let's do what we know to do and take the steps that are right before us and then we can always pivot and change our plan if the situation changes. Right? So, you know, we can always change, but let's do the things we know to do now and then we can, you know, adjust if we need to.

**Marie LeGrand:**

Wonderful. Wonderful. Again, I wish we had more time. You know, it goes by so quickly when we're having such a fun and phenomenal discussion, especially from such a wonderful group of experts and speakers such as yourselves. So, I guess we can pretty much end on this. So thank you all so much. Thank you again, Dr. Okai, Dr. Williams, Pastor Hunter, and Tyler, for your amazing and insightful presentations, you've provided our viewers with more information on a topic that can be challenging for some. So thank you once again. This concludes...

**Dr. Annette Okai:**

Can I just say I would like to thank the MSAA for starting this conversation. This is the first one I've had, and I'm so blessed that we were able to have it and have this panel. So, thank you for taking the initiative. And this is something that we can provide to patients living with MS. Thank you so much.

**Marie LeGrand:**

Oh, well, thank you. Thank you. My pleasure. Thank you all so very much. So, thank you again. This concludes the webcast and tonight's webinar was recorded and it will be made available on our website at [mysaa.org](http://mysaa.org). Please visit MSAA's calendar of events for our upcoming webinars and on behalf of MSAA, we would like to thank you all for joining us this evening. We would also like to, again, thank our expert panelists, Dr. Okai, Dr. Williams, Pastor Hunter, and Tyler for the

great presentations. We would also like to thank Biogen, Genentech, and Sanofi Genzyme for making this program possible through educational funding. And we would like to thank our partners at Impact Education in delivering this program. And again, thank you all for joining us this evening. Please consider completing the brief survey which will appear on your screen momentarily and know that we are thinking of entire MS community and hope that you and your families continue to stay safe. Thank you all and have a good night.