



**Webcast Transcript**  
**Living Your Best Life with MS**  
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**Webcast Moderator:** Kate Milliken

**Panelists:**

**Dr. Dawn M. Ehde**, Professor, Department of Rehabilitation Medicine, University of Washington and Harborview Medical Center

**Dr. Barbara Giesser**, Clinical Director, UCLA MS Program; Professor of Neurology, David Geffen UCLA School of Medicine

**Dr. Ari Green**, Medical Director UCSF MS Center; Distinguished Professor of the Departments of Neurology and Ophthalmology; Director of the UCSF Neurodiagnostics Center

**Dr. Timothy Coetzee**, Chief Advocacy, Services and Research Officer of the National MS Society

**Presentation**

**Kate Milliken:** Hello, and thank you for joining the National MS Society's live webcast, titled Living Your Best Life. I'm Kate Milliken, your moderator, and I have been living with MS since 2006. Living your best life involves physical, emotional, spiritual, and social well-being, that can be achieved even in the presence of a chronic illness or a disability.

For me, it took a few months to look beyond the shock of the initial diagnosis, but once I did, I began to build a more holistic approach to managing my MS, and that has made a huge difference.

In today's webcast, we will explore subjects that are important to you to achieve the life you want. Topics will include ways to better control MS symptoms, including pain management, how to recognize and address cognitive challenges, and how to make exercise work for you. We also want to look at how to determine when a change in therapy may want to be considered, and what the future holds, as researchers pursue leads in restoring function.

Throughout our live webcast, our panelists will address questions received from participants, both in advance of the webcast, and in real time during the webcast itself. Check your webcast screen now for details on submitting questions during the panel discussion.

We will cover as many questions as we can, and if our participants share their names with their questions, I'll include them with my ask, so let's get started. I'm pleased to be joined by four panelists who recognize the importance of living your best life with MS. Let me introduce them.

First we have Dr. Dawn Ehde. Dr. Ehde is a professor for the Department of Rehabilitation Medicine at the University of Washington and Harborview Medical Center. Dr. Ehde's research interests include the management of chronic pain, and improving function of people with MS, through rehabilitation techniques. It's really great to have you here, Dawn.

**Dr. Ehde:** I'm glad to be here myself.

**Kate Milliken:** Thanks. Next we have Dr. Barbara Giesser. Dr. Giesser is the clinical director of the UCLA MS Program, and professor of neurology at the David Geffen UCLA School of Medicine. Dr. Giesser specializes in MS patient care.

Her direction has been essential to establishing UCLA as an MS comprehensive care center. She has designed trials exploring the effects of exercise in MS disease management. Thank you for being with us.

**Dr. Giesser:** Thank you, Kate. I'm delighted to be here.

**Kate Milliken:** Good. In addition we have Dr. Timothy Coetzee. Dr. Coetzee is the chief advocacy services and research officer for the National MS Society, and oversees Mission Delivery efforts. Dr. Coetzee has a society global investment in MS research.

He is responsible for a diverse portfolio of research initiatives, and recently spearheaded an effort to establish a global collaboration, focused on research in progressive MS. It's nice to see you again, Tim.

**Timothy Coetzee:** Great to be with you, Kate.

**Kate Milliken:** Finally we have Dr. Ari Green. Dr. Green is the medical director of the UCSF MS Center and director of the UCSF Neurodiagnostics Center. He is also distinguished professor of the Departments of Neurology and Ophthalmology. Dr. Green's current research addresses how MS affects the visual system and develops methods to track and predict the course of the disease. Thank you for being here, Ari.

**Dr. Green:** Thanks so much, Kate.

**Kate Milliken:** So let's begin, and why don't we start with you, Tim? I'd love to hear from your perspective some of the research initiatives that are happening in the world of MS, and complimentary therapies.

**Dr. Coetzee:** Sure. Absolutely. It's great to be here with you. When we think about research at the Society, we're taking a holistic approach about stopping the disease, restoring what's been lost, and ending the disease forever.

And so when we make investments, we're trying to understand what's causing it, how do we stop this, how do we manage it, how do we bring back some of what's been lost, and as we look at what we need to do, particularly in complimentary and alternative medicine, and wellness and lifestyle, we need to start asking questions.

We're making investments so that we can get the answers people are looking for, so that they can know OK, if I try this strategy, it makes sense, or we can have the information that doctors and people with MS can discuss when they're trying to understand, what should I try?

And so we take a holistic approach, and we're trying to make lots of different investments that you're going to hear about during our panel today.

**Kate Milliken:** Good. And Barbara, people with MS, everyone is individual, but there are certainly some MS symptoms that come up more than others. What are some that you would say are especially difficult for people?

**Dr. Giesser:** Well, Kate, it turns out that the most common symptom of MS is one that you can't always see, and that's fatigue. That can affect up to 90% of persons with

MS, and it can really interfere with an individual's ability to function, and carry out their daily routine.

The other invisible symptoms include cognitive problems, pain, depression, which my colleague, Dr. Ehde, is going to address, spasticity. We know that the symptoms that you can see, such as problems with mobility, or problems with balance and coordination, can be problematic, but sometimes these invisible symptoms are a lot more challenging.

**Kate Milliken:** And with some of the research that Tim kind of alluded to, why don't we start with one kind of complimentary approach and exercise. So from your perspective and experience, what type of research is coming down the pike?

**Dr. Giesser:** This is a very exciting area, and a very hot topic among MS researchers. We know that exercise is good for everybody in terms of cardiovascular fitness and endurance and wellness.

We're now starting to find out that not only do people with MS get those same benefits, but that exercise has been shown in several studies to actually improve some of the symptoms of MS that we just talked about, in particular fatigue and depression and quality of life.

What's more exciting is that we have some pre-clinical data that suggests that exercise might even be effective in treating the disease itself, that it might have anti-inflammatory or neuro-protective properties.

**Kate Milliken:** So this is a little bit of a getaway from the original disease-modifying therapies, and they are not to be forgotten. So Ari, tell me a little bit about the disease-modifying therapies, and when you should stay on them, and when you should change them up.

**Dr. Green:** Sure. So the disease-modifying therapies have been an opportunity for a seminal change in the field in the last 20 years. Twenty years ago, or a little more, we didn't have any therapies available for patients, and now we have a number.

We have to distinguish between those therapies that are symptomatic, that are meant to treat the symptoms, and those therapies that are meant to improve long-term quality of life, and have an effect on modifying the overall progression of the disease.

| Our therapies are intended for that second, really important function. The challenge is we have to pick a therapy that is individualized, that is targeted for an individual patient,

recognizes their lifestyle needs, their other medical needs, and their own preferences. And so it's working together between the physician and the patient that allows us to pick that right therapy.

**Kate Milliken:** When should a person decide that it is a good time to switch from one disease-modifying therapy to another?

**Dr. Green:** Right. Well the crucial element of that is communication. I mean the opportunity that is provided to us with having lots of available therapies means that we can pick intelligently.

The element of communication is critical: how well is the individual medicine being tolerated, what the symptoms are that medicine creating, and how is it helping with overall management of a person's disease.

It's also in thinking about how we monitor the progression of disease. Sometimes the huge challenge with MS is it's not a short battle. This is a long-term fight. We have to win this over 20, and 30, even 40, 50 years. In order to do that, we have to monitor the disease really carefully so that we know when progression is happening. It may not be detectable by even the person experiencing the disease. It's through that method of communication, both on the part of the doctor, monitoring things and communicating that with the patient, and the patient talking about what they're experiencing, we can pick the right therapy, and change when we need to.

**Dr. Giesser:** I'd like to underscore a great point that Ari made, which is we get often asked what's the best disease-modifying therapy? And there isn't one best therapy. The best therapy is the one that, for that individual patient, is most effective for their disease, fits into their lifestyle, is well-tolerated, and represents the best consensus between the patient and their healthcare provider.

**Kate Milliken:** Certainly the modifying therapies is a long-term goal of care, but there's a lot of short-term considerations for people with MS, in terms of symptoms or whatnot, so Dawn, one of the things I think that you know a lot about is pain, and I'd love to hear how you help people alleviate their pain.

**Dr. Ehde:** Well first of all I'd like to mention, Kate, that pain is unfortunately a very common problem among people with MS. About 50% of people with MS will experience chronic pain at some point during their life, with people having all sorts of types of pain problems.

Just like MS is very individualized, so is pain unfortunately. For some people, they may have headaches, for some they have pain in their legs or their arms, some have back pain, and many have multiple sources of pain.

We also know that pain really negatively affects people's lives in terms of their ability to do what they want to do, their ability to handle their other MS symptoms. For example, people with pain often also have depression. They don't always go together, but unfortunately they often co-occur, because pain can have a very negative effect on people's life.

**Kate Milliken:** With what you do, certainly there are, let's say a prescription that may help with pain, but in the light of what Tim was talking about, these holistic methods, is there something that you could talk to about making pain better, over and above taking a particular therapy.

**Dr. Ehde:** Yes, fortunately there are many things that people with pain can do. I think we often think of medications as the first line approach, but fortunately we're learning more and more about different things that can help people. Those include things like rehabilitation. That could be things like exercise, as we've mentioned, or learning how to perform activities in ways that bring less pain, don't trigger as much pain.

Also, there are a lot of behavioral techniques. Those are things such as relaxation training, learning skills for managing the negative effects of pain, mindfulness meditation which is also growing in popularity and has some nice evidence behind it as well. There are really many, many things people can do.

**Dr. Green:** Thinking about pain is really, I think it's crucial that we're having this discussion, because it wasn't that long ago that we were teaching students that MS patients don't have pain, don't experience it and that's partially because we can't measure it as clinicians. It's easy to ignore those things that we're not experiencing directly, and unless the patient and physician have a close enough relationship that they're talking about those things, then they can get overlooked.

The other challenge is that it really gives an opportunity to integrate care, because, I think Dawn put it perfectly, our first approach might not have to be medicinal. Medicine is only part of the things we have in our repertoire in order to help patients to address these problems.

We have to think about how do we figure out -- how do we address the pain, how do we address the fatigue, how do we address depression, and these things oftentimes

come all together, and we have to think about the patient in the whole, and not just as a collection of symptoms.

**Dr. Coetzee:** This is also, where we have to really continue to invest more in terms of research, because we really still don't have a good handle on what causes that pain from a neurological, biological point of view.

This is where we need to get researchers dialed in to what is causing it, so that we can then think about how we integrate all these strategies, so that the doctors can have a conversation about here are the choices, and here's the why it's making a difference, right. Now it can be challenging to say why am I experiencing pain? And it can be hard to answer that question, about how it relates to MS.

**Kate Milliken:** It's really nice, as someone living with MS, to hear a group of neurologists talking the talk of even with the example of pain, addressing it even though it can't be clinically proven per se, or has yet to be.

Because I think this comes up with a big thing that's happening, where people living with MS, or caregivers, are finding other things outside of the conventional forum that they're going in to their neurologists to talk about, whether it be diet, whether it be exercise, whether it be pain.

And I'm curious, and I'll start with you Tim, because I think this is an important point, how a clinical neurologist is handling someone who wants to know about a way of treating their MS that isn't proven. How are you dealing with this?

**Dr. Coetzee:** Right, and so I think one of the things that we see and we hear about is a person goes in to see the doctor, and says I'm taking green tea to help me manage my MS, and it seems to be helping me. We funded some research in that, we've tried to understand what is the benefit, and sometimes we don't have the answers right, yet. So just to let you know, I'm not a physician, so I don't see patients, but as someone who works with the Society, I know that this is a conversation that many people are having, and people with MS can be frustrated when they're having the conversation with their doctor, who feels like I don't really have the best information to be able to say to you it's this way or that way, and --

**Kate Milliken:** Like it will work, it won't work.

**Dr. Coetzee:** Yes, will it or won't it work, and we're scientists, right. So we're trained as scientists and we want to be able to give the best information, give the best answer. It can be frustrating on both sides of the table because the person living with MS isn't

sure and wants to know, and our doctors want to be able to give the best information. So that's from my vantage point. I think Barbara and Ari will also have --

**Kate Milliken:** Yes, Barbara, what's your thought?

**Dr. Giesser:** Well I think this represents a great opportunity for the person with MS and their healthcare provider to be able to partner on this, the reason being that as physicians and scientists we insist on seeing data because we know with a disease such as multiple sclerosis, very often a symptom or even an exacerbation will remit by itself. If you say well, I was taking this particular therapy, and my symptoms got better, unless you have a control, you don't know if it was the therapy that actually made the symptoms go away, or if they would have gotten better on their own.

So that's why we're such sticklers for the gold standard, which is a randomized placebo-controlled trial, or at least an add-on trial. Having said that, I think there's a dual responsibility here.

I think the person who wants to try a non-allopathic, non-conventional therapy, their responsibility is to try to get as much information about it as possible, and I think the healthcare provider's responsibility is to try to keep an open mind about this.

**Kate Milliken:** Ari, you want to answer that?

**Dr. Green:** I think those are beautifully said comments. The key thing to me is we want to deliver on results, and not just deliver on promises. There are a lot of elements out there in complementary medicine that can make big promises, and we have to be able to find ways to make it so that we can test whether or not those things actually work.

It's a big challenge, and it doesn't mean that in the build-up to that that we close our ears and don't listen to what's going on, and what works for individual patients. We have to, our big responsibility is to make sure we get the right answers, and we can give the best information to people, because that's why people spend their time to come and see us.

**Dr. Coetzee:** That's also part of the challenge of being able to come up with that information, is that thinking about say a trial, or the kind of study you would do on a particular intervention.

When one is doing a clinical trial in human beings, you have to make sure that they actually stick to the plan, and that you're able to actually measure the particular benefit.

And with some of the treatments, we have very clear ways to measure it, the number of relapses a person is having.

When you're doing clinical research, tracking on well, I feel better as a result of this, can be sometimes a challenging thing to actually measure, and part of the research we're trying to do is figure out how do we get the tools to answer those questions.

So that when we do a study, you can actually add something on to a treatment, and say OK, I am going to get a clear answer, just so that we can actually have a conversation that is about integrating some of this into care.

**Kate Milliken:** It does seem to me that there has been some sort of shift of philosophy, in which lots of people are coming more and more to you in different ways, of being open-minded, and really addressing the issues, and address the ideas that people have. Were you going to say something else?

**Dr. Coetzee:** Yes, I was going to say just that this comes through partnership, and the only way we figure out how to measure those things is by listening to patients' experiences, and hearing what's going on with them. Then thinking about ways together, collectively, both patients, providers, and advocates, working together. How can we measure that? How can we actually do a study, and have a conversation. Then we can use our experience and patients can use their experience, to come to some answers.

**Kate Milliken:** Speaking of studies, can you talk a little bit about the study that you're doing with translational-approved medications?

**Dr. Coetzee:** Sure. So we were interested in the idea that there are cells in the brain that are already there that have the potential to restore some of the function that's lost in MS. One of the principles -- primary injuries that occurs in MS is that insulation, that the support cell that surrounds nerve cells gets injured and gets lost. Those cells, once they get damaged, for some reason they don't recover.

The amazing thing is the cells that turn into those cells, they're already there. The cells that have the potential to fix the problem are sitting there, and for some reason, they're not getting turned on.

Our goal with our trial, it was to first screen for a large number of drugs, compounds, that have the capacity to create those cells doing what they're supposed to be doing in the first place. Then we have to find a way, so how do we measure that, and then when do we give it, and how do we best deliver it to patients?

That's all part of a current clinical trial program going on in this arena. Our first trial's ongoing right now, and we're trying to measure outcome, so we can see the recovery, the restoration of myelin.

**Kate Milliken:** Barbara and Dawn, I'll throw this one to you, what do you say to patients who feel that they're too fatigued to exercise? What is your response to that?

**Dr. Giesser:** Well, my response usually is that a journey of 1,000 miles begins with a single step, and then I try to show them some of the data that suggests that when people with MS who have fatigue, exercise, the fatigue actually gets better. So again, we're starting to think of exercise as actually a therapy for fatigue. We tell people to find an exercise that they like, and to start gradually.

**Dr. Ehde:** Yes, and I'd just add to that that I think also it's important to let them know they're maybe going to be more tired, or if it's pain that is the issue, they're going to hurt more as a result at first, of doing that activity. But sometimes that pain or increased fatigue can be a sign of something's going to work for them, and so that they can continue to push through that by gradually and very systematically increasing their activity, that their fatigue and/or pain may get better.

**Dr. Green:** One thing to think about with exercise is it's not just good for the body, it's probably good for the brain. I mean there's a remodeling that goes on with every activity you do.

The old saying that we used to believe that the brain doesn't change when we're adults, is wrong. The brain is constantly changing, and exercise is one of the ways that we might be able to remodel things, and improve function.

**Dr. Giesser:** Ari brings up a great topic, we know from studies of people with other brain diseases such as Alzheimer's, that exercise actually improves their cognitive function, and the MS Society is actually funding research looking at exercise to specifically improve cognitive function. We're starting to get the results of those studies and they indicate that yes, exercise may not only make you more fit, it may make your brain more fit as well.

**Dr. Coetzee:** Part of the reason it's so important that we do this, is it comes back to getting healthcare, right. So sometimes when you go and see a doctor, and the doctor says you should do this, or you should do that, get some physical therapy, the healthcare provider -- the insurers will say well, what's the evidence that that really has a benefit?

By funding this kind of research, getting the answers, we can then go and advocate with both the insurers, and government, and Medicare and Medicaid, to say for people with MS, this is really important, and here's why. It can have really a dual benefit of both benefiting people with MS, but also making sure that it's accessible to them.

**Kate Milliken:** You're eliminating all options of sitting on the sofa.

**Dr. Coetzee:** Totally, completely.

**Kate Milliken:** Good job.

(Laughter)

**Kate Milliken:** Dawn, for you, you do a lot of rehabilitation. What symptoms do you find with MS really work well with rehabilitation?

**Dr. Ehde:** Well really the goal of rehabilitation is to help maintain and even improve function, and so for everybody that might be something different, and so there are a lot of symptoms that rehabilitation can address.

Everything from some of the things we've been talking about here, fatigue, pain, depression, also things like when people have difficulties maybe kind of managing their activities of their day-to-day life, things like getting dressed, or preparing meals, or getting around in the community, or in their home.

Rehab really is a team approach, it's very integrated, and so a person who's having rehabilitation for MS might work with a physical therapist, an occupational therapist, a nurse, a psychologist, there's really a whole team approach to trying to look at the person's goals, what do they want to get back to doing, or what do they want to maintain, and how can we help them.

**Kate Milliken:** From a holistic standpoint, one great thing about a lot of holistic therapies, if you will, is that they're free, right, in terms of doing them on your own. So is there anything you both, I'll extend it to both ladies, for cognition and mood problems, what would be some things you'd recommend?

**Dr. Giesser:** Well I'll take the cognition piece, maybe I'll defer the mood piece to Dawn. We don't have a lot of well-established therapies for cognitive function. Again, we're testing the hypothesis that exercise may be good for this.

We certainly encourage people to stay mentally active, so to keep up with reading and puzzles and things that exercise their brain. There are specific cognitive retraining, cognitive rehabilitation programs, which people can access. So this is an area that we're just starting to find out what works.

**Dr. Ehde:** Certainly there are many things that can help people with depression, to manage their mood, to improve their mood. We've already mentioned it a number of times, but exercise.

We recently published a study showing that helping someone set some exercise goals and start exercising can improve depression. It reduced the number of people who had depression in our study. That was something that really could happen in a home setting, it only required a few visits with someone who could kind of coach them on how to do that. There are a lot of resources available, both at the National MS Society's website, and out there for ways that people can try to start exercising, or look at how they're responding to or managing their depression.

There's a number of what we call cognitive behavioral techniques that people can do on their own, just through the use of information and workbooks. But things that help look at how you are coping with your disease, and are there things you could be doing differently that might improve your mood.

**Kate Milliken:** Wow. Ari, one of the things that you study are the eyes, so is there any work that you've been doing that you think could really help improve the lives of people with MS?

**Dr. Green:** Sure. So when we ask patients about what are the symptoms that trouble them the most, fatigue always ends up at the top of the list, mobility ends up on the top of the list, but one of the other things that ends up on the top of the list is visual problems.

So one of the reasons we're interested in vision is because it affects people's lives so much, and increasingly in a way that wouldn't have been appreciated a generation ago. I mean a generation ago, we would have thought someone with visual dysfunction would have to be blind to say they have visual dysfunction.

Today, we recognize that people's work and their professional lives, and even their personal lives require a kind of visual function that wouldn't have been imagined 10, 20, 30 years ago. On top of that, not just the fact that it affects people's vision and degrades the quality of their vision, it's also a window into what's going on in the brain.

It just happens to be the one part of the central nervous system that's not -- that doesn't have bone and skin covering it. A friend of mine, Fiona Costello, likes to say that the back of the eye is the front of the brain. It's a place where we can see things that are not available to us, can't look at them elsewhere, and it also happens to be separated from the rest of the brain. The brain is unbelievably complex, as everybody here can attest to.

But it also is a place where it's simplified enough that we can answer some fundamental questions that can give us insights into what are the steps that we can do to help really start the path down restoration and recovery.

**Dr. Coetzee:** If I could add, I think what excites me about the trial that Ari is doing with Dr. Jonah Chan about the remyelination strategies, is that by focusing on the eye, we may get a technique that allows us to find those therapies that can repair and restore myelin quicker than say the usual conventional MRI. Because you can see it, what, with an OCT, within 20 minutes you can see there is something happening, and while we're still pioneering that technique, I mean imagine if we'd been having this conversation 4, 5 years ago, we wouldn't have even been talking about that.

Now we're actually talking about a trial where we can look at - can you restore what's been lost in the eye -- and then that could be the cue for the next larger trial for what's going on in the brain.

**Dr. Green:** We want these trials to be cheaper, faster, and more efficient. That allows us to figure out what doesn't work quickly, and figure out what works more quickly, and move things ahead.

And that's exactly, in partnering with the Society, it's a tremendous opportunity for us, in order to get to those questions, and get answers to people, because we totally appreciate, all of us who see patients recognize that it is unbelievably frustrating that we haven't solved some of these problems. We've gotten some answers, we've had some successes, but there are more successes ahead of us.

**Kate Milliken:** Well you have to think too, many years ago, was the idea of you've got MS, there's nothing we can do. Then it was, you've got MS and here's maybe a medicine for you. Now there seems to be this kind of aura of being proactive for yourself, I think it's called self-management. So can you kind of define that, and what you're seeing?

**Dr Ehde:** Yes. So what self-management is, it's really an approach to care, and it has to do with the fact that really the person with MS is the expert. They are the expert, and they are the most important person on the healthcare management team.

Self-management really breaks down to something very simple. It's what people do on a day-to-day basis to not only do what they have to do to get through their day, but to have the kind of life that they're living, where they're really living fully with and despite MS.

**Kate Milliken:** Whatever the problem is, that's right.

**Dr. Ehde:** Yes. So self-management really involves looking at what you're already doing well, what things are already going well, and what strengths do you bring to the situation, and then how can you augment that by doing additional things.

So for example, a person that I was working with was already swimming every day because she found it really helped her MS and her pain, but then she and I worked together on how she could maybe try to get out and socialize more with friends.

That was something she wasn't doing as much of, and really missed. It's identifying goals, learning strategies to get to those goals, and having a very holistic approach to care.

**Kate Milliken:** I'm going to ask you a tough question that somebody in this audience is probably saying excuse me, wait, I'm the expert of my own MS? That doesn't seem right. How do you respond to that?

**Dr. Coetzee:** I think that each of us has to become the expert of our experience. I think that this is what we're hearing. I think, the important change, is that there's a partnership, and it says here are the options I have, and then we also all have to have a responsibility to really step in and get it in. But I think the amazing thing that's happening, is that we see the integration of all this. So we're having -- if you live with relapsing-remitting MS, there are options that can be considered.

We still have work to do on progressive MS, so we still have that gap, and we have that frustration. But then we're also moving beyond that. We're saying OK, how do we bring in exercise mindfulness, and yes, you're right. I mean we have to own it, and really step into it, because at the end of the day each individual is going to -- it's in their hands.

**Kate Milliken:** Well I think Barbara brings up a good point, that every case is individual. When you talked about the disease-modifying therapies, it's hard to know what the best thing is for each person. I think the whole idea of being your own advocate also is a sense of empowerment, that may have lasting affect-- something may happen within that action itself.

So instead of saying I'm mad at my neurologist because he's not giving me all that, to actually understand that maybe a neurologist is doing the best they can to give you a tray of options, but that you need to pick it, or you need to get off the sofa, right.

**Dr. Coetzee:** That comes into the point you made earlier, so how do we have this conversation with our physicians? It can be incredibly frustrating, right. So you go in there and you're having these choices and if you're getting shut down, it can be very frustrating. In which case, you would say, well, maybe there are other options you can consider.

I think what's changing also is that physicians and the other health professionals are seeing this and saying OK, what's the conversation we can have with you about what we can control and what are other areas that, to what Dawn points to, let's talk about what's going on in the rest of your life and how can we leverage that?

**Dr. Green:** Patients have to add to the conversation, and in essence they have to guide the conversation. But we don't seek to add the burden of taking care of everything, onto the patients.

That's why the Society exists, to provide access to things that patients can't do or create for themselves, and that's why providers exist so that we can help patients, provide them information to begin the process of guiding them. But they have to --

**Kate Milliken:** But there is a shift there --

**Dr. Green:** -- they set the context.

**Kate Milliken:** -- there's a real shift there. Barbara?

**Dr. Giesser:** I think that one of the key concepts in self-management that Dawn mentioned, is the whole concept of empowerment. A generation or so ago, patients were not empowered. There was the doctor and the patient, and the patient did what the doctor said.

Fortunately, we are moving away from that old-fashioned style, and now we want our patients to be actively engaged in their management process. We want them to be empowered to get information, to ask questions, to challenge us, but ultimately to work with us to find out what's going to be the best strategy for their individual disease.

**Kate Milliken:** Right. So Ari, I'm going to actually now move to some of our viewer questions. I'm going to start with you. So Cheryl has asked, how do you know if your disease-modifying therapy isn't working for you?

**Dr. Green:** Right. That's a great question, and the best way to know is, again, in figuring out how a patient is doing clinically, so how you're doing, how you're feeling. A second and critical component to that is trying to get ahead of the disease, and not waiting for the disease to cause problems that then become very difficult to reverse.

So there's a lot of monitoring that's required there and that requires ongoing visits with the provider, and ongoing conversation and testing, the most important one is probably MRI.

Other testing that's returning in importance include evoked potentials that we can use to actually measure how quickly electrical signals are conducted through the brain and that's a crucial way to measure whether or not myelin is functioning.

Then other tests like tests of visual system and tests of cognition, and all those things give us a broader picture, so that we're not stuck looking at just the narrowest band of things that are easy to measure at the bedside, but we're looking at the whole patient.

**Kate Milliken:** From Melissa, this is for Barbara, what can I do to restore my balance?

**Dr. Giesser:** Usually the imbalance problems can be very troublesome for many people with MS. We would usually refer somebody with balance problems to a physical therapist and they can work on specific exercises to help people get more balance and more coordination.

**Kate Milliken:** Dawn, what is the latest in pain management?

**Dr. Ehde:** Well I think, as Ari mentioned earlier, one of the most exciting things is that we really didn't pay much attention to pain in MS until recently and now we are. I think there's really been a wealth of research going on, looking at really all sorts of different types of treatments, not only medications, but also many of these self-management or behavioral approaches. The Society has been a big proponent of funding research and letting us look at different ways that people can -- or learning more about strategies for managing pain.

**Kate Milliken:** Barbara, another one for you. How do you recognize more of the common cognitive symptoms in MS?

**Dr. Giesser:** Well, usually it's the person with MS who first notices. They may say, I'm having trouble finding a word, I'm having trouble remembering things, I find that I can't do more than one task at a time.

Unfortunately, sometimes it's not the person with MS who notices this, but it's their family or loved ones or caregiver, and they may notice that the person is having difficulties in these areas.

If a person with MS, or their family, thinks that they're having cognitive problems, it's very important that they do bring this up with the neurologist, because there is a diagnostic paradigm for this.

You can do a series of tests called neuro-psychologic testing. The nice thing about neuro-psychologic testing is it not only shows what areas the person may be having difficulty in cognitively, but it shows where their preserved strengths are. And maybe Dawn would like to comment on that more.

**Dr. Ehde:** Yes. So with the neuro-psychological testing, you can really then design strategies for helping the person to work around the difficulties that they're having, what are some things they could work towards in terms of if it's at work or in home, it just really helps guide care in a very individualized way.

**Kate Milliken:** Can either one of you women figure out a way of actually slowing down the cognitive loss?

**Dr. Giesser:** There's a couple of ways to answer that question. There are some suggestions from some clinical trials that the disease-modifying therapies may be able to slow cognitive loss. This is not uniformly accepted but we have some data in those areas.

As I mentioned, there is data from other diseases, such as Alzheimer's, and pre-clinical data in animal models, that suggest that exercise may slow or reverse cognitive loss. There are other treatments that are being explored as well, and then there are other strategies that Dawn can comment on.

**Dr. Ehde:** Yes, there are number of rehabilitation strategies that are currently being studied, looking at not so much maybe slowing down loss, but really when there is any kind of loss, whether it be mild to more severe, what can people do to try to compensate for it, or work around it. There have been a number of studies that are really ongoing right now, that I think show a lot of promise for helping people manage cognitive loss.

**Kate Milliken:** Is it called brain training?

**Dr. Ehde:** Well, that's not the specific one that I'm thinking of, but it's called cognitive rehabilitation and it's really a whole bunch of different ways of how people approach what they do in their day-to-day life in terms of trying to remember and track information, how they essentially exercise or stay active with their brain.

**Dr. Coetzee:** Kate, to add to that, I think that sort of the next frontier on some of the treatments are potential drugs that we call -- that are neuro-protective, which are really the ideas that they preserve -- they prevent nerve cells from dying.

It's quite likely that some of the cognitive challenges are because nerves are being negatively affected and dying. What the research is showing us is if we can come up with these treatments that can perhaps shield the nerves, preventing us from losing them, then that could also be a strategy for maintaining strong cognitive function.

There are number of trials that are being designed today, and some that are already underway. It's still early days around that, but I think what's different and what's exciting, I think, to us as researchers is that that's actually a concept that we're talking about, how do we figure out how to preserve the brain so that we don't lose nerve cells, because that will also ultimately ensure that we don't lose cognitive function.

**Kate Milliken:** Yes. And what about progress in stem cell research?

**Dr. Coetzee:** Stem cell research?

**Kate Milliken:** Yes, right. Hot topic.

**Dr. Coetzee:** It is a hot topic. I think there's a lot of interest in stem cells. I think when we talk about stem cells it's important to really talk about the two big buckets of types of stem cell therapy.

There is what we call hematopoietic stem cell transplantation, or HSCT as it's referred to, where that's really talking about using stem cells to replace cells in the bone marrow, to really reinvigorate and reboot the immune system in people with MS.

The concept there is that by doing that, you can reset everything and essentially go back so that the immune system is no longer attacking the brain. They're having clinical trials done with that. There are also clinical trials ongoing with that.

Some people have reported that this has really helped them a lot. I think it's important to consider if that's an option someone is thinking about, is this strategy right for me? Is it being done in the context of a clinical trial? You know, some individuals think about traveling to have a procedure done, and in that context you want to say, am I going to have the aftercare when I return and do I just --

**Kate Milliken:** There are valid risks.

**Dr. Coetzee:** Valid risks, and there's a support -- do you have the support system around you? So that's one type of stem cell. Then there's the other type of stem cell which is around using stem cells to repair the nervous system and to really stimulate regeneration. And that's not quite as advanced, but there is some ongoing work to suggest that that strategy may also be valuable, potentially, for people with MS.

**Dr. Green:** It's really important that we distinguish between them because the first type shows the most promise for people probably somewhat earlier in the course of the disease. The challenge is that once the injury has occurred, doing things on the immune system may not fix the problem and you may just take all the risks and get none of the benefit, and that's a big challenge.

**Dr. Coetzee:** Exactly.

**Kate Milliken:** Ari, Jean has a question for you and wants to know if there are any medications that can improve her walking if her gait issues are solely impacted by heat and fatigue.

**Dr. Green:** Yes. So, the first important thing that I always talk to patients about, is that heat and fatigue don't cause permanent injury on their own. They just exacerbate underlying problems.

In terms of how to figure out how to treat that, fortunately we do have some therapies that show some early promise in that area that can actually help with how the electrical signal down at the wire, the nerve cell is conducted. Although those don't work uniformly, they don't work for everybody, they're worth trying and they're worth talking about with your provider.

**Dr. Giesser:** In terms of a non-medicine treatment, the very obvious thing is for people whose activity is limited by heat sensitivity, use ways to cool yourself down --

**Dr. Green:** That's a great point.

**Dr. Giesser:** -- so take a cold drink, or put a cold towel on you, or suck on some ice chips, and that's often very effective.

**Dr. Green:** Even wear a cooling vest. So, Elliot Frohman, a friend from Texas, has done some really great work showing you can actually really precisely measure how people are doing when you cool them off, you'll actually see improvement in function. For people that live in hot areas of the country, wearing cooling vests that -- these days they look -- they're almost sleek, they're an opportunity to help.

**Kate Milliken:** Yes. Sleek and slick.

(Laughter)

**Kate Milliken:** Tim, we have a number of questions actually asking about the status of myelin repair research.

**Dr. Coetzee:** Oh, that's a hot area as well, and rebuilding and restoring what's been lost is the idea of remyelination, restoring what's been lost, was really kind of a foreign concept. People thought that may never happen. The reality is that now, it really is happening.

What Ari is pointing to is that we actually have a drug now that's being tested, and it's one of several where you're actually using a therapy that can bring back what's been lost, whether by promoting new myelin or preventing it from being lost, essentially trying to clear out the damage so that new cells can come in and restore what has been lost.

The challenge we have around this is taking the next step, if we have these treatments that have promise, when we do a phase III clinical trial, what is it that we're going to look for that people are improving?

The FDA and the people that approve treatments are going to be looking for some measure that says you got better. The immune therapies, it's always been, can we prevent relapses? And if you think about repair, we're saying OK --

**Kate Milliken:** This person is going to get some ability. Yes.

**Dr. Coetzee:** How are you going to know they're doing better? So in Ari's case, it's potentially, do you continue to see OK, and can you measure that? We're trying to pioneer some work with a lot of researchers working collaboratively, to say when we get to that point of having treatments we want to test in people, what is it that we're going to measure, and what will the FDA and the EMA, the European equivalent of the FDA,

accept? Because there's no point in doing all of this work if they're not going to accept it and approve the treatment.

**Dr. Green:** Right. I mean that's the part of discoveries that is really hard to see from outside, that it's not just having the right medicine. The reasons why we're so successful in MS by comparison with the other neurodegenerative diseases like Alzheimer's and Parkinson's, isn't just because it's an immune-mediated disease, but it's also because we have a test, the MRI, that people can use to --

**Kate Milliken:** Shows results.

**Dr. Green:** Shows results quickly, and then it can predict whether or not in a big trial, that's going to take huge amount of resources and a huge amount of patient time and really risk on the part of patients, it's worth all that.

We can't do that without having those up-front methods. We're working on them, and that's the crucial thing, I think, as a community of researchers that we have to achieve in the next 5 years.

**Dr. Giesser:** Coming back to the point that I think Dawn made about the patient being the center of the healthcare team, one very important new area of outcome measures is what is called patient self-report measures.

The National Institutes of Health is very interested in this. It is encouraging the development and the testing and the validation of these patients' self-report measures. So in addition to very objective things like MRI or OCT, we are interested in the patient experience.

**Dr. Ehde:** There are number of those measures that have been developed specifically for people with MS that show that they are very useful.

**Kate Milliken:** Yes, wow.

**Dr. Coetzee:** I think the other part of it too, is that it allows people with MS to participate in the research in a way that won't necessarily require them going in to see their doctor. It could be on a smartphone --

**Dr. Green:** That's right.

**Dr. Coetzee:** -- and they tap in, there's a test that you can move your fingers, and you can do that every day, and you don't have to go see a doctor, but then that information

gets taken up. Those are the kinds of interface with people, and doctors, and innovation, that I think we're going to see in the coming years.

**Dr. Green:** But this integration of technology, I think, is a huge area of possibility and opportunity, and we just have to figure out how do we leverage that to bring it to the service of patients?

**Kate Milliken:** Yes, it's going to reset the whole way things are done, and almost mandate it, right.

**Dr. Green:** That's right, in a good ways, in great ways. I mean why have it be that you have to go to a research institution over and over again for visits, but you could go less frequently and have lot more testing going on and would measure how people are doing in their day-to-day life, in their natural environment, and not in the artificial setting of a laboratory.

**Dr. Giesser:** That's a great plan.

**Kate Milliken:** Wow. This is for you, Dawn. Donna advises that she's in constant pain, and the medicines that she's trying aren't helping. Do you have any ideas for her?

**Dr. Ehde:** Yes. Boy, that's hard when you're in constant pain and what you've tried so far isn't working. I guess I would suggest that she partner with her healthcare provider. Sometimes I think how pain affects a person can be overlooked in the healthcare setting because there's so many things to deal with MS.

I think for Donna, it might be important to really have a session devoted to talking about her pain, and to talk with her provider about what are maybe some other ways, in addition to medications, that they could work together with her in terms of trying to manage her pain.

So things like rehabilitation, looking at is there some way she could get some help, either with a psychologist, or a nurse, or other healthcare provider who knows about some of these self-management or behavioral techniques? Can she be referred to them?

I'd also encourage her to really go to the National MS Society's website because there's a lot of information about this very thing, in addition to medications, what are some other ways a person can manage it? And there's a lot of information there.

**Kate Milliken:** I know you spoke earlier about some testing being done on meditation being beneficial. Has that been helpful with pain?

**Dr. Ehde:** Yes. Actually, mindfulness meditation, there's at least one study that has shown that it's very useful in managing a number of symptoms, including pain. We currently are conducting a study looking at the use of meditation specifically for pain.

A specific type, called mindfulness meditation, where a person participates in a group setting, and they get 8 sessions of treatment, and then carry it on in their day-to-day lives. There's a lot of treatments like that that really hold promise for people like Donna.

**Dr. Coetzee:** And Kate, one thing I'd add is that in addition to visiting our website for information, there's also opportunities to connect with people with MS. I think both being with your health provider, but also connecting with other people.

For example, we have MSConnection.org that individuals are connecting with other people experiencing what you're experiencing. It's part of the journey, but an important part not to forget and to reach out.

**Kate Milliken:** Yes, the emotional relatability of the experience.

**Dr. Coetzee:** Absolutely, absolutely.

**Kate Milliken:** Right. How many times have you guys heard, “you guys just don't understand”, right. We don't have to go there, I'm sure none of you -- OK.

**Dr. Coetzee:** Never heard it from you, Kate.

**Kate Milliken:** Yes, I know, right. Barbara, we received several exercise questions. So, Jessica asked for motivational tips to overcome that fatigue that we talked about.

**Dr. Giesser:** If you've set your mind, I think your body will follow. I think people have to internalize why this is important, why it's going to help them, and then you just do it and you just start off a little bit at a time.

I think Dawn mentioned swimming. Swimming is one of the best exercises for somebody with MS. It's cardiovascular, you don't heat up, so you don't have the heat factor, and it exercises large muscle groups.

So anybody who has access to any kind of swimming, that's a great way to start. Take your dog for a walk around the block. If you happen to have a treadmill machine, get on it for 3 minutes and add a minute or 2 every day. Start small.

**Kate Milliken:** Right. What if one side of your body is significantly weaker than the other?

**Dr. Giesser:** This is where you'd want to work with a healthcare professional, I think. I should probably have said earlier that any exercise routine ought to be run by your neurologist, and if you can, get the help of a fitness professional, or a trainer, or a physical therapist. Certainly those professionals can help you design a regimen that will help to incorporate all the body parts and make allowances for the weaker side.

**Kate Milliken:** Ari, Rachel wants to know how long you have to have a symptom of MS before you know it's permanent.

**Dr. Green:** Right. So it's not always the same, but on average I'd say if you have a symptom for more than a year, that's probably an indication that it's likely to be permanent. That said, there's opportunities, again, for remodeling that we've spoken about, the opportunities to regain function via activity.

It always surprises me, and I have patients who, at times, have descended down a path towards loss of function and then via some degree of activity and fortitude and perseverance have shown the capacity to make small steps.

The challenge is, as always, you have to set your expectations realistically, but making those small steps is really important because, of course, going in the good direction is always much better than going in the other direction.

**Kate Milliken:** Right. And, Tim, I know you had said that we're not quite there yet with the progressive MS disease-modifying therapy. Is there any date or any ballpark that you could throw out?

**Dr. Coetzee:** So a couple of things to keep in mind. So all of the disease modifying therapies that we have now for relapsing-remitting MS have been tried in progressive MS and just have not been successful, probably because progressive MS is different in some other respects than relapsing MS.

We are now seeing trials of therapies. So, several new therapies are being tested in progressive forms of MS. We've created the Progressive MS Alliance to help us really galvanize the world community to think about what are the strategies for progressive MS and so, that's also underway.

And some of these trials are phase III trials, so if they're successful, then that means that those therapies would move into addressing progressive forms of the disease. The challenge we have is unlike relapsing MS where you can measure relapses relatively quickly, with progressive MS, it's slow and steady and can take a while to see.

This is where we're investing in a collaborative effort to figure out, can we make a more precise tool, precise measures so that you can say okay, this is what's happening and let's see if we can find a disease -- pick up that disease-modifying therapy that can improve the quality of life?

So I'm not going to give you a date, but what am I going to tell you is that, yes, there are treatments and testing, and the global MS community is dialed in to this, because I think we understand the significant need that people with progressive forms of MS are calling for.

**Kate Milliken:** Tim, how does someone get more information about participating in a clinical trial?

**Dr. Coetzee:** That's also a great question. There are a lot of clinical trials happening, and it can be a little confusing to figure out which one's right for me, and where should I go to get the information?

There are two places to visit. First, on the National MS Society's website, we list all of the clinical trials that are currently recruiting in MS. So you can go there and get information and also, get insight in terms of what it is to participate in a trial.

You can also go to [clinicaltrials.gov](http://clinicaltrials.gov). That website lists all of the clinical trials, where they're recruiting, what your criteria are, and to really have a conversation with your family and your health provider, am I a candidate for this?

It's really important that you have that conversation as you do that. Those are the two main sources of information, and I really encourage people to think about those as options.

**Dr. Green:** Patients' enthusiasm and partnership is the crucial glue that makes those clinical trials successful. I think that one of the challenges we face sometimes, is that early on in the course of disease, some people feel like it's a huge psychological burden to live with MS and I think we all appreciate that.

Sometimes, if people don't want to be focused on the fact they have MS every day, and being engaged in a clinical trial might not be something that is attractive at that moment.

But it is a crucial opportunity to help, and even people with early MS could help us solve the problem of progressive MS.

**Kate Milliken:** Right, like everybody wins.

**Dr. Green:** That's right.

**Dr. Coetzee:** Everybody wins.

**Kate Milliken:** So, I'm throwing this one to all of you guys. Do you have any strategy on making loved ones of somebody who is living with MS, understand the limitations that they have? So how can you make loved ones understand the limitations?

**Dr. Ehde:** Yes. Well that certainly can be a challenge, first of all to have other people understand, because so much of what goes on in MS, you can't see, things like pain, depression, you can't always tell a person's in pain or fatigued, and people have to go on your word for it.

I think fortunately there are number of ways to address that, and one is to, really, as I think we mentioned earlier, to reach out for support from others, whether it be through support groups, or other interactions with people with MS.

It can be helpful to hear how they've dealt with that, because that's very common. Many people deal with that issue of people not understanding. It's also nice to talk with someone who does really get it. I think that's an important step.

I think there's also a lot of resources out there for families and caregivers of people who have MS, and perhaps pointing them in the direction of learning more about it themselves, they may be more supportive or better understand.

**Dr. Giesser:** Yes. I'd like to pick up on what Dawn just said. I think the key here is education, as Ari mentioned a few minutes ago, we used to teach medical students and doctors that people with MS didn't have pain.

So if the medical community wasn't aware that somebody with MS is having pain, how could we expect a family or a caregiver to understand that the person with MS has pain? I think we have to educate caregivers and families and loved ones, that if the person with MS isn't doing their housework, it's not because they're lazy, it's because they have fatigue caused by the disease and they're too tired.

If they're not able to fulfill a full day at work, it's because perhaps they're having a cognitive problem. I think education, as with everything, and accessing appropriate resources from the National MS Society will help them be better to cope with this.

**Dr. Coetzee:** It could also be helping them understand the dimensions of the disease. So for example, we talked a lot about heat, right. So I'm thinking that most people don't want to take vacation somewhere that's nice and warm and hot, part of it is educating your family members saying, my nervous system just can't tolerate that anymore.

**Kate Milliken:** Yes, sounds sexy, but not so much.

**Dr. Coetzee:** It sounds awesome to go to the beach, but not so much. I think just having an understanding of what it is that brings meaning in our life, and finding ways to have that meaning, but also doing it in a way that also recognizes that my body isn't quite what is used to be. So, how do we together find meaningful experiences.

**Kate Milliken:** Yes, how to honor it.

**Dr. Green:** We also, I think, have to think of ways to provide support to those people who are caregivers and loved ones of people with MS, because I think we underappreciate how much of a challenge that is.

It's really hard for a patient living with MS to recognize the challenges for their loved ones, because they're living with their own challenges. So it really puts a burden on us, the advocates and the community that support people with MS, to think about how can we create opportunities for people who are supporting people with MS, to talk, to have venues for figuring out what resources are there for them.

**Dr. Coetzee:** Right. I mean in the end, we're all in it together and I think empowering everyone to work together is, I think, a part of what we all share --

**Kate Milliken:** Well -- and I feel like even the philosophy is beginning to be all in it together. It's not one or the other anymore, or I just go to this person and I'm that person. It seems to be much more integrated.

**Dr. Coetzee:** Exactly.

**Kate Milliken:** Before we wrap up, I want ask each one of our panelists, of what you're most excited about, research-wise, that's coming down the pike?

**Dr. Ehde:** Well I am very excited about the idea of using technology to reach more people who are living with MS, to deliver treatment. So whether it's something as simple as the telephone or web-based, there's really a lot of ways we can use technology.

**Dr. Giesser:** I'm excited about the new data that's coming out about lifestyle choices that people can make, that can actually impact their disease. We certainly talked a lot about exercise. Smoking, we now know that smoking is not only a risk factor for MS but it can make disease progression worse. In terms of what can you do for progressive disease, stop smoking.

We're just starting to get into areas of diet and supplementation. There's a whole fascinating area about the bacteria that live in our intestines that may have an influence on the disease. So again, under the rubric of empowerment, and what people can do for themselves, I think the lifestyle data is going to be very interesting.

**Kate Milliken:** Tim?

**Dr. Coetzee:** Yes, for me, it's really the big picture is that when I look at the research we're doing now, and the fact that we're getting better at stopping the disease, but now we're adding this restorative function and this idea of preventing brain -- loss of nerve cells for neuro-protection, that's really the next frontier.

But then you layer in this idea of lifestyle, and diet, and nutrition, and adding the idea of the conversation that perhaps Ari and Barbara will be able to have, and Dawn will be able to have with their patients over the next few years, it's really transformative. It's that integration of care, and integration of research with care, that really excites me.

**Kate Milliken:** Ari?

**Dr. Green:** I am unbelievably excited that we're on the path to figuring out answers about repair and restoration of function for patients with MS. I really think one of the things that will come about is we'll start to see the possibility for integration of the medical therapies that we're using with other approaches.

Also thinking about how do we actually make things better, in part, it's going to be the activity, and how do we actually tailor activity to the medicinal therapy we're working with, that's the brave new world that we're all moving towards and it's going to be exciting in the next decade.

**Kate Milliken:** Awesome, guys. I want to thank our panelists, Doctors Ehde, Giesser, Coetzee and Green, for being here today and sharing their expertise with us. I also want to thank you, our viewers, for joining us.

If your question wasn't answered, please speak directly to your healthcare provider or visit the Society website at [NationalMSSociety.org](http://NationalMSSociety.org). You can also contact the Society's information resource center and speak with one of our MS navigators at 1-800-344-4867.

We plan to ask our panelists to explore some of the most popular questions in greater detail in a follow-up blog as part of our community chats. So for more information, visit [www.msconnection.org](http://www.msconnection.org). Please note that today's webcast will be archived and available for viewing at [NationalMSSociety.org](http://NationalMSSociety.org). Thank you, all, and goodbye from New York.