MSAA Podcast - Episode 23:

Rebuilding the Continuum of MS Care

Host: Kimberlee Baugh

With special guests:

Barry Hendin, MD

Tina Brown

Kimberlee Baugh
Hello everyone, and welcome to MSAA's podcast episode, Rebuilding the Continuum of MS Care. My name is Kimberlee Baugh, Manager of Health Education and Equity with MSAA, and today we are diving into a topic that affects anyone impacted by multiple sclerosis. To help us get a better understanding of this complex disease and how it's treated, I will be joined by two experts who will share their insights based on the knowledge shared at the Arizona MS Forum in Phoenix, Arizona - MS specialist Dr. Barry Hendin and MS advocate Tina Brown.

Please know that these conversations are for educational and informational purposes only. This program is made possible through the generous support of Bristol-Myers Squibb, Genentech, and Sanofi.

To begin our discussion, I want to welcome our first guest speaker, Dr. Barry Hendin, MS specialist and also MSAA's Chief Medical Officer. Thank you, Dr. Hendin, for joining us. I'm excited to have this conversation.

Dr. Barry Hendin
Thank you, Kimberly. I'm equally happy to be here with you.

Kimberlee Baugh
Awesome. So let's start with the state of care in Arizona, where you're based. Talk a little bit about some of the challenges you're seeing locally.

Dr. Barry Hendin
It's clear that the challenges we face, patients and providers in Arizona, have nuances that are specific to Arizona, but mostly the problems and challenges that we face are faced nationally. And I would say they begin with a difficulty of diminished resources. We need more clinicians: doctors, nurse practitioners, PAs, nurses. If we don't have sufficient numbers of providers, it usually means that there's something that is more difficult down the line. So, access to care will be more difficult. There will be delays in seeing a provider. If there's a delay in seeing providers,

there'll be a delay in initiating therapy. If there's a delay in initiating therapy, people will get less high quality care and will often seek their therapies elsewhere, emergency rooms, sometimes unfortunately hospitalizations due to relapses.

So the first thing to address is the limitations that we have in resources, and that is exacerbated depending upon circumstances. So It's bad enough in Arizona in general, where it can be up to 30 days to see a neurologist, and for a quarter (1/4) of the patients up to a few months to see a neurologist, much less an MS specialist. But then all of those are even worse if you're in a rural area in Arizona where access to care is that much more difficult. All the more difficult if you are underinsured or uninsured.

Where do you go for your medical care? You may not have a primary provider. There may be cultural impediments. There may be language impediments. We have a very large Hispanic population. Some are monolingual. Most are either English-speaking or bilingual. But if there's a language barrier, if there is a deficit in insurance, if there's reluctance to seek medical care, all those things lead to delays in access, delays in therapy, poorer outcomes. So I would say that is the primary issue that I face. Diminished resources leading to poor outcomes, to consequences.

Kimberlee Baugh
Great. Can you share how the local challenges in the state of Arizona relate to the national landscape of MS care?

Dr. Barry Hendin
I think everything I said about Arizona I could say about the nation. And that is, it's difficult to get in to see a neurologist. It's more difficult to get in to see an MS specialist, with the consequences I talked about. And then I think the resources include decreasing funding of medical care. So we have a decrease in our Medicaid, which is our access program, the funding of our access program. That's a national issue as well. If people are uninsured or underinsured, it leads to poorer care, delayed care, poorer outcomes.

The other is just the complexity of the system. So it is very difficult for people with MS sometimes to know who to see once they see a clinician to navigate what are the appropriate medications, who are the subspecialists they should be seeing, how do they deal with insurance, how do they deal with restrictions in care?

So I think one of the things nationally that we're dealing with is complexity of the system leading to really difficult choices and uninformed choices by many of the people with MS.

Kimberlee Baugh
Thank you for sharing. So something we know all too well in the MS community is the importance of early diagnosis, right? So why is early diagnosis so important and how does it impact both patients and MS clinicians?

Dr. Barry Hendin
One of the things that we know about early diagnosis and early therapy is that it does make a big difference. And we have a lot of data about the evolution of outcomes over time in the United States, and that is the mortality rate before we had disease-modifying therapies was relatively high, a seven-year difference between people with MS and people without MS - a lot of that had to do with no therapies and not just delays in diagnosis.

As we have gotten therapies and as our therapies have gotten more and more effective, mortality has diminished and capabilities have increased, disabilities have decreased. So what we've watched over the course of time with our early use of high efficacy therapies is that people come in with MS and the clinician can say to them, Our goal is to keep you the way you are now. We have therapies that are sufficiently effective that when initiated early, we can really reduce relapses dramatically, reduce progression that is due to those relapses significantly, and really lead to a much higher likelihood of a life that you can live without the old burdens of MS, and that is the physical burdens of MS. It doesn't mean that MS doesn't create any burden because it obviously does.

But some of the progressive disability that we used to see is just not being seen now in most of our patients because of early effective therapies. We know that that's different from late use of therapies or early use of ineffective therapies. And so we really do have a philosophic direction toward early use of high-efficacy therapies. We know it makes a difference, not just for relapse reduction, but for progressive disability.

Kimberlee Baugh

Gotcha. So let's talk solutions, Dr. Hendin. What are a few solutions to some of the common barriers we discussed earlier, like access for folks who live in rural areas? What were some of the things you guys discuss at the forum?

Dr. Barry Hendin

If there is a shortage of MS neurologists, and part of it is education of non-MS neurologists so that they feel more comfortable taking care of the day-to-day issues of people with MS. And part of it is collaboration. So I have to say that I take care of a number of people with MS who are also taken care of by non-MS neurologists.

Some of that is educating people who aren't MS specialists so that they're more comfortable taking care. Some of that is physicians, some of that's nurse practitioners, some of that's PAs, and a lot of that is navigators. And so in my hospital system, I have a nurse navigator. I talk about the complexity of care. That complexity can be significantly reduced by a nurse navigator who explains to patients at length the complexity of the system, the complexities of their medications, and walks them through the systems, including insurance, payments, etc.

I think it would be helpful for those navigators to also exist in systems and from payors. So to the extent that payors have navigators as well, we can reduce a lot of the complexities. MSAA has at least thought about the idea of a passport. Could we have something that we could give a patient in this complex system, a card that talked about who are the MS providers, what are the MS resources, what are the available medications, etc. So I think somehow educating our patients whether or not they're seeing an MS specialist and somehow a passport that provided them navigation could be helpful.

But I think more than or equal to that is something that Tina is going to talk about at greater length hereafter and that is we need to have the stakeholders collaborate with each other. And in that regard, we have initiated a project a few years ago with one of our payors, Blue Cross Blue Shield of Arizona, in which we have a clinician council of MS specialists and Blue Cross Blue Shield, so that a lot of the complexities of what is the right medications? What's the right formulary? What's the right philosophy? How do we deal with overuse of emergency rooms and hospitalizations? How can we provide access early? The physician council collaborated with

Blue Cross Blue Shield and said, "We will be available within the week to see a patient if you have someone who needs to be seen immediately." So that collaboration goes both ways. We can call them, they can call us, and some of those things can be improved just by the human interaction of what previously had been silos.

Kimberlee Baugh
Thank you, Dr. Hendin. Thank you for sharing your expertise. That's a perfect segue for me to introduce our next guest, MS patient advocate Tina Brown. Tina was diagnosed with relapsing-remitting multiple sclerosis in 2010. Since her diagnosis, she has established herself as an advocate, committed to sharing her experiences and insights with individuals impacted by MS. Tina, thank you for joining us.

Tina Brown
Thank you for having me. I'm excited to be here.

Kimberlee Baugh
Awesome. So let's jump right in, Tina. Based on your experience at the forum and your lived experience, are folks interested in working together to solve some of the barriers we've discussed today?

Tina Brown
Well, actually, when I attended the forum, that was pretty much, I'm going to say pretty much in a long time that I've seen that many people in the room all gathered passionately about MS care. So I was very excited to be there. I thought it was awesome.

I personally got to share a little bit of my own MS journey. And what was most emotional for me was I didn't know that my MS doctor at Mayo Clinic would be in attendance and he was there and I hadn't seen him for years. And I personally got to thank him for saving my life. So he was one of those MS doctors that actually took the time to speak to me and let me know what was going on with my MS. So that was really emotional for me. I'm getting emotional now. But anyway, that was emotional for me to be able to personally thank him. Also during the forum, I was able to gain knowledge about the benefits of telehealth. That could have come in very handy for me in the early years. I had no knowledge about that.

I also learned about the MRI program that you have, that also could have come in very handy for me in the beginning as well. So just fabulous, fantastic for me to learn. And that's why I'm here. I'm ready to get back into it and share my journey, my experience to be able to help others that are impacted by MS.

Kimberlee Baugh
Wonderful. So what are some ways patients, clinicians, caregivers, insurers, anyone with a stake in MS care, what are some ways we can collaborate to improve outcomes for anyone living with multiple sclerosis?

Tina Brown
So if I can just share just a little bit of reflecting on my own personal experience, and that was pretty much in the beginning. My biggest barriers were initially, of course, was the fear of the unknown and the unpredictable of the MS nature. I also had anxiety about stigma, discrimination, and then the possibility of me losing my ability to work. So I begin treatment right away. I begin

my therapy right away. And when I began, I actually withdrew. I isolated myself of just pretty much shutting down. And I struggled in silence for three years.

But it wasn't until later after that three years that I realized that education was, education about MS, was vital in me understanding MS and the treatment options that I had. And if I had known the treatment options, that would have made a huge difference in my care. I also learned that some of my mental health challenges were actually caused by the side effects of my medication. That experience taught me how important it is to communicate the needs for my support, both with providers and for my caregivers and to become comfortable, I would say comfortable or educate myself a little more about navigating the healthcare system. So navigating insurance and prior auth were particularly stressful for me, even leading to my first psychosis episode. So I said there has to be a better way for patient-centered care moving forward.

So the most powerful lesson that I've learned is the value of self advocacy. So sharing my story was truly a source of healing for me. So what I would have for clinicians and providers, I would encourage them to focus on just a little bit. I would encourage them to focus on building relationships with the patients through active listening, just getting to know me, how to approach me, how to speak to me, about giving me results or how to take the medication, etc, asking questions. I would also advise about cultural competency training. So I may be African American or they may be Hispanic. Everybody does not communicate the same. So I would totally advise cultural competency training for understanding individual needs and improving health literacy.

And additionally, I would encourage partnering with community health workers. They can be extremely beneficial. Community health workers support follow-up care, connect patients to resources, education, and help with language and cultural barriers and strengthen outreach efforts.

Kimberlee Baugh
Thank you for raising those points, Tina. Dr. Hendin, did you want to touch a little bit on the importance of collaboration?

Dr. Barry Hendin
Tina talked about the forum that we had in November, and what was impressive to her was impressive to me, and that was how many people who cared about MS were in the same room talking about solutions? So we had several payors, including our Medicaid access program, Indiana Health Service, a couple of the private payors, the university, ASU, the Arizona Medical Society, the Maricopa County, which is local, medical society, and people with MS and providers of care for MS, clinicians, nurses, navigators, all gathered really, because we care about MS and we care passionately about finding solutions for those places where there are impediments to best care. So my view is that we too often live in silos in which the clinicians speak to clinicians and payors speak to payors and pharma speaks to pharma, patients speak to patients, but we too seldom are gathered together to seek common solutions. And yet the best solutions really are the collaborations. So what impressed Tina is exactly what impressed me.

Kimberlee Baugh
Great. To wrap us up on our conversation today, what is one key takeaway or final message you both would like to share with our listeners as it relates to the topic of rebuilding the continuum of MS care? Tina, we'll start with you.

Tina Brown
So one key takeaway for me personally in my own experience is what I've learned is sharing is healing. So the more I shared with others that have MS, I learn a little bit more, I help them, they help me. So the more you share for me is healing.

Kimberlee Baugh
That's perfect. Dr. Hendin, any key takeaways for you?

Dr. Barry Hendin
It's a couple things. One is, we have an imperfect system, but we have shown ourselves capable of working on and finding solutions to those problems which we have. And we're talking about those very same things now. I am actually optimistic about our ability to address a lot of the issues that we're speaking about today. Whether that's rural and how to deal with diversity of populations or distances. Maybe it's telehealth, maybe it's education. How do we find solutions by navigation? We're getting there. How do we collaborate better? And that's the one that I hope that we will address increasingly, and that is not to believe that we are in this by ourselves, but rather that the solutions will come from our working together.

And my gratitude to MSAA for providing the resources and the forum and the energy to try to be an active facilitator and collaborator in bringing us together to reduce the places where MS care is not smoothly performed to create a much smoother journey for people with MS.

Kimberlee Baugh
Well, thank you very much, both of you, for sharing your time and your experience with us today. That brings us to the end of today's episode, "Rebuilding the Continuum of MS Care." A big thank you to our two guests, Dr. Barry Hendin and Tina Brown, for sharing their valuable insights and expertise. We hope you found the discussion helpful and informative.

I would also like to take a moment to thank BMS, Genentech, and Sanofi for supporting this program. Also, a huge thank you to Gradwell House Recording for hosting us today and producing today's episode. If you would like to stay connected with MSAA and access more resources, be sure to visit our website at MyMSAA.org, where you can opt in for informative e-mail updates, follow us on social media, and check out additional podcast episodes and videos. You can also text MSAA to 75101 to receive text updates right on your phone.

Thank you for listening and take care.