



PODCAST

Women's Health: Balancing Life and Wellness

Episode 128 – Podcast Transcript

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[(0:18)] Stephanie Buxhoeveden, MSCN, MSN, FNP-BC: Welcome to the Can Do MS Podcast. I'm your host, Stephanie Buxhoeveden. I'm an MS specialist and researcher, but I also have MS, and it's an honor to be here and share my perspective with you. This is episode number one twenty eight. Today we're going to talk about the topic of women's health as it relates to MS. We're excited to welcome our guest, Dr. Suma Shah, who is a neurologist and MS specialist at Duke Health. Suma's research focus has been on women NMS, so we're thrilled to have her join us and share her expertise. Welcome Suma.

[(0:50)] Suma Shah, MD: Thank you. Thank you so much for having me. I'm very excited to be here discussing today's topic, which is very near and dear to my heart.

[(0:58)] Stephanie: That's awesome, so tell me, how is MS different in women compared to men?

[(1:05)] Suma: Well, as we've often discussed, MS disproportionately affects, uh, people within their childbearing years, often between the ages of 20 to 45 years old and in women relative to men, some of that disproportionate status persists. For example, in women, there is an increased gender ratio where there's more recently about a 3 to 1 ratio of women being affected with MS compared to men, which equalizes before puberty and after menopause. There has been some data that's shown that uh, women with MS have more inflammation relative to men who are living with more neurodegeneration, and we see this where men tend to have more progressive disease, where in women that really doesn't happen until the perimenopausal state.

Then finally in women, MS tends to affect them a little bit younger, often in their 20s or 30s where men sometimes present in their early 40s, and there again, women may be living with the disease for longer than men are. There's differences in how symptoms affect women with MS, where men have been historically reported to have more motor problems and less frequently, uh, be affected with optic neuritis. Whereas women have far more, uh, episodes of optic neuritis in-in general, and there has been a report in mice, so I don't know how well this can extrapolate to humans quite yet, but there is some science behind whether vitamin D may have a greater benefit in females.

In the mouse model of MS, the ex-experimental autoimmune encephalitis model, mice, female mice that were given vitamin D supplementation had a protective effect against MS. They didn't develop this EAE model, which is promising.

[(2:57)] Stephanie: That's all so interesting and clearly there's still a lot we need to understand

about why MS is different in men versus women, and even though we don't really understand the underlying mechanisms, there is strong evidence that hormones affect both the onset and the progression of MS through a woman's life, so can you tell us a little bit about how MS changes as we age?

[(3:21)] Suma: There's a lot of history here. There was this early recognition as we started learning more about MS, that women who'd never had children before, had a higher risk of developing MS than women with multiple pregnancies, and so that started this conversation about whether there might be some sort of hormonal influence. We've learned a lot over the years we're-we're still learning and a lot of our current science and studies shed insight into the hormonal influence of MS.

Right now we think that estrogen, which has often been implicated in the effects of MS that are unique to women, may have a biphasic dose effect. What that means is that at low doses, like with a menstrual cycle, estrogen can be immunostimulatory, it can be pro-inflammatory, and this relates to some of the symptoms that women with MS may notice around the time of their menstrual cycles, but at high doses, like in pregnancy, it can be immunosuppressive and protective against MS effects, and so we see a little bit of a different relationship with estrogen specifically, depending on where in the spectrum of a woman's life someone is.

I won't go too much into that. I would recommend that we stay tuned for our upcoming episode on family planning and MS, which goes into this topic in far more detail. As an aside, independent of some of those hormone effects, there are some effects that have been noticed in the perimenopausal and menopausal state, and I often start this conversation with my patients about aging with grace. There is so much changing at the time of menopause, whether it's the menopausal symptoms which are pretty aggravating by themselves in addition to the symptoms of MS that someone may already be living with but becoming more aware of over time, particularly in the face of neurodegeneration, and both of these things, the-the menopause and aging in the setting of MS may have a little bit of an additive effect.

Setting that expectation where this can happen, though we hope it doesn't, but it can, can really help people approach that menopausal state with a little bit better information of knowing what to expect.

[(5:42)] Stephanie: I think that's really important what you pointed out, because this is a lifelong disease, and we frequently talk about pregnancy, and we frequently talk about menopause. Um, but we don't really set women up to prepare for having MS throughout their lifespan, and it's really important to know what's normal and what's not and when you should talk to your doctor, so as you mentioned, women do tend to get diagnosed with MS younger than men often in their 20s or 30s, and that's when a lot of us are finishing school and starting our careers. What concerns do women with MS have when it comes to working, and is there anything that might help them navigate those challenges?

[(6:22)] Suma: Well, I'll give a little bit of background here and it's sort of old data, but it's really the most robust data we have, which is this big survey called the Women in MS working Mother report that came out in 2015 and this survey went out nationally to about twelve hundred and fifty working women with an average age of about 40 who had been diagnosed with MS, and the majority of patients who completed this survey had relapsing remitting MS. What we found from

this study back in 2015 was that there are quite a lot of symptoms, and considerations that women living with MS are contending with.

In the survey, it was reported that 60% of women had to hide their MS symptoms at work. That's a huge number. That's two thirds of women who are living with a disease that's chronic. It's not going anywhere. They didn't ask for it and it's a part of their identity, but they're unable to share that with those that they spent a lot of time around and with friends at work. Many of those, uh, women's survey did report that they're comfortable with sharing their symptoms, but only 39% said that their boss felt interested in helping them manage their symptoms at work. Also in this study, 40% of women who were working and were living with MS said that adjusting their work schedules helped them cope with MS.

What that looked like to these women was that 38% reduced work hours, a third worked a flexible schedule and that allowed them to accommodate for appropriate breaks, let's say, to go to the bathroom or to take a short nap in the middle of the workday to help them recharge and battle and combat some of their symptoms that they're living with, and then finally, about 80% of the respondents said that they were experiencing symptoms of the disease currently, or had in the last month. That's pervasive. That means that for the majority, the large majority of women who are working and have MS, they're contending with fatigue or numbness or tingling or difficulty walking or pain and cognitive slowing.

All of which are symptoms that we know are a big part of living with MS, and for most of the women that had responded, their average age at the time of diagnosis was 32, and so that means that up to a decade of living with these symptoms, not being able to share it or ask for appropriate accommodations, so I share all that as background to say there is a lot that goes into the invisible nature of MS as women show up to work, then come home to care for their families or their selves or their partners, and a lot of that adds to that burden of disease, that may not be outwardly recognized unless we go asking about it and offering ways to navigate it.

That's really where I see the healthcare team's role when meeting someone who's living with MS, who may be a working mother or a working woman. Asking about the symptoms, asking about accommodations, and providing direction on how to go about asking for the appropriate flexibility in work, if that's what's needed, can go a long way to advocating for our patients.

[(9:59)] Stephanie: Absolutely, and I know for myself, I've had a lot of different jobs over the last 10 years since I was diagnosed, and some of the key things for me have been, like you said, flexibility. If I have an extremely cognitive heavy task that requires a lot of attention and focus, I try to get that done first thing in the morning before my fatigue really kicks in. I'm in control. Having a portable air conditioner or heater in my office really makes a huge difference for how long I'm able to last throughout the day, and it's just those little tweaks that you might even not think of in the moment, but just talking it out with your provider and saying, "This is I think what is really keeping me from performing at my best." And spit balling ideas for how to address that is really important.

[(10:47)] Suma: I'm so glad you mentioned that. I... it reminds me of a patient who shared with me that she had a lot of benefit by seeing one of our occupational therapists who provided her with a workstation that she could set up for her work for home role, so that she is mitigating her fatigue as much as possible and in the most ergonomic approach, so I'm glad you shared that to-to at least

get that-that thought rolling for our patients who may be living with this.

[(11:15)] Stephanie: Yes, occupational therapists are such amazing resources and we often forget that one of the best things they can do for MS patients is help them manage fatigue throughout the day, so shout out to OT for sure, so women at home also carry the majority of the physical and the mental load, and that includes with their children, with their spouses and often is in addition to the demands of their career, and I know I certainly worry about whether I would be a good mother, or if maybe I would be putting my health in jeopardy by trying to have it all. What are some common concerns your patients talk to you about?

[(11:56)] Suma: That's a great question, so I'll-I'll start by sharing a story. Um, I met a woman, uh, last fall who came to me about four and a half, 5 years after her diagnosis with MS. She at this time is in her early forties and had already had two children, but always knew that she wanted to grow her family, and she shared with me that she spent so much of her first few years chasing this idea of trying to get everything under control before being able to move forward, and it was a really humbling conversation for my end because it led to an I wish statement, which can be really challenging to say I wish I had known that I could keep working on the things that were fulfilling to me, and not completely putting a pause on my life, while I chased this sense of control.

With that story, I'll step back and say I do think that it's an individualized discussion. There is room for different definitions of having it all, and all of that within the context of living alongside, living with MS, but not necessarily skirting around it while trying to make decisions, and that again, is where a healthcare team member can be a really powerful role to share how others may have navigated sim-similar scenarios, so to answer your question, that's what I often start by asking is, what are your goals? What will be your idea of a fulfilling life in the setting of chronic illness, knowing what it can change and bring, and then how do we work towards that?

To go back to my patient's story, that's what we discussed that day. We spent forty-five minutes talking through what having a third child would look like, because she started that conversation by telling me she knew she'd always wanted that, and she felt that she wasn't being true to herself if she wasn't able to pursue it.

[(14:05)] Stephanie: I think that's a really great story and really highlights the issue so well. I often heard that women would be concerned their child's experience growing up would be negatively impacted by their MS. You know, maybe they might not be able to attend every game or take big trips to Disney because they have other costs, but actually it's the opposite. Children with a parent who has MS often are lovely, compassionate people who are more likely to give back to their communities, because having a parent with a chronic disease has showed them empathy, and I think that's something that's really nice to think about and highlights, but it can definitely be a positive and help you and your family grow together.

I think that story is shifting, where about a decade ago I felt like I heard more from my patients that they were hiding their MS, that they didn't want to share a vulnerability or have their children or family members feel like they were less than, and these days I'm seeing a lot more openness about that diagnostic conversation, a lot more openness about the kinds of symptoms that people are living with, and as you mentioned, on the flip side, I'm hearing stories about children who choose to go into healthcare careers inspired by seeing the challenges that their payers may have faced, or recognizing that the immense motivation it takes to be able to show up and live that life that a

person has imagined.

I do think there's a lot to be said about allowing for functionality and a fulfilling quality of life while acknowledging the challenges of the disease. I've... I will never sit here and not be a realist. Um, I think that I've seen the full spectrum of... I often share, I've got patients who are marathoners and I've got patients who have been severely limited by the challenges of the disease, and in the individual nature, it would be unfair to not make those plans individually for our patients.

[[16:25]] Stephanie: Definitely. What else can women do to take care of themselves and thrive with MS?

[[16:34]] Suma: I think this too comes down to a little bit of tailored planning, so we'll set out with some of those broad strokes, which are the importance of physical wellness and emotional well-being, and my patients probably get tired of me asking, but I'm a big proponent of pursuing both equally, and so at every visit every 6 months, I'll often ask my patients, well, do you feel like you're in a good emotional space? If so, how are you doing that? And if not, have you reached out to the resources that can help with that? Counselors, psychiatrists, a mental healthcare team that can be made up of many different faces and roles, and then physical well-being, which we have a lot less data for, but I often say this again, broad statement of brain health is MS health is health in general.

What that means is what we know about taking care of our bodies, and participating in cardiovascular exercise, in participating in activities that get the blood pumping and the heart beating, are all going to help with aging with grace, as I mentioned earlier, as well as feeling good and mitigating some of that fatigue and that cognitive compromise that can come from MS, and so there does need to be a dedicated attention to all of those things that come into this category of lifestyle measures, things that people living with MS and those around them can do in their control to choose health, and to choose activities that can support them in the long term.

I also think it's an important reminder when these conversations come up that it is not selfish to focus on yourself, and I have seen it where the patients who invested in themselves... I met one patient last Friday who has been walking twenty thousand steps a day ever since she's had something that can count her steps for over a decade, and I do think that that reinforces some of that physical activity, and helps combat some of the neurodegeneration that can occur with MS, and so taking that time and making that investment early on, is only going to pay dividends later, and finally, having an eye towards comorbidities.

This is something that's become a hot topic in the last 5 to 10 years in the MS research space, which is that MS doesn't exist in a silo in our bodies. There are other things that can coexist, high blood pressure, cardiovascular disease, heart disease, migraines, depression, and all of those things in conjunction with living with a chronic inflammatory disease like MS may compound the trouble of each other, and so knowing that, providing that counseling to say, all of this needs treating because our bodies keep track of all of these things and they all may weigh into how we do in the long term.

[[20:01]] Stephanie: Absolutely. There's the old saying in neurology, treat the body right and the mind will follow, and I truly do believe that, and whenever I'm talking to women who have MS, I always try to remind them it's not a get out of jail free card, you can absolutely still get all of these

common things like heart disease, like breast cancer, and even though it's hard enough to keep up with your neurology appointments, MRIs, blood tests, coordinating your medications, you do also have to see your primary care doctor, get your physicals, do all of the cancer preventative screenings just like everybody else does. In fact, it's even more important for you to do them, so never forget that.

[(20:43)] Suma: Absolutely.

[(20:45)] Stephanie: Finally, are there any resources for women with MS that can help them navigate this work, and family life that we all try to balance so delicately?

[(20:55)] Suma: Well, I'll start with the resources I've learned of over the years, but I'd love to hear from you as well, Stephanie. Um, there are quite a few resources that I've seen over the years. A lot of them are often under the umbrella of the National MS Society where there are pages on their website dedicated to sharing the news of a diagnosis, how to speak to a child about a parent living with MS, how to find resources for emotional support, and how to navigate the discussion with an employer regarding asking for accommodations. In fact, for healthcare providers, there's an example letter that's out on the website for the National MS Society that I have used as a template to help advocate for my patients, and write in this symptoms that they may be living with so that they can get the flexibility that they need to keep doing their job well.

All of these tool kits on how to go about some of these sensitive conversations are available online. Different resources from other companies exist, where there are YouTube videos, cartoon based, um, stories that are shared about a child living with a parent or a mother with MS, and I do think over the years those stories have provided a platform where people can turn to for what this looks like for others and how to navigate that resource, uh, how to navigate that discussion for themselves.

[(22:39)] Stephanie: Yeah, absolutely, and I know providers help patients navigate these things all the time, so if you don't know where to start first, talk to your provider, ask what resources they've used or for them to put you in touch with those resources, and the National MS Society's website, like you mentioned, has all of those wonderful things like Keep Smiling, which is the magazine for kids and they even have one for teens that helps you talk to your children about your MS diagnosis. I also have a friend, Julie Sam, who wrote a phenomenal book called Some Days, and it talks about living with a mom who has chronic disease, and some days are worse than others and some days we can do big things and some days we have to stay in and take it easy, and that's on Amazon.

I'm a huge fan of her book and like you mentioned, the tool kits on disclosing your diagnosis to an employer, how if when and things you can do to accommodate just a really nice way of getting started.

[(23:47)] Suma: That sounds like a great resource. I think that shares that there's so much flexibility and demand from the disease that requires a woman living with MS to know when to draw her line and boundaries, and when to show up for her family or work, and these are all tools that we can help build into a person living with MS's Tool Belt to say, "Hey, reach for them if you need it. Stand up for yourself when you can and show up for yourself when you can as well."

[(24:21)] Stephanie: Absolutely, and that might change throughout our lives. In fact it will change

throughout our lives, and so having to constantly readjust and reacclimate, that's just part of the journey, so I'd really like to thank you for being here today, for talking about this really great topic and we look forward to having you back on the show to discuss family planning and not just from a woman's point of view, but we're going to talk about considerations for men as well.

[(24:47)] Suma: Thanks so much for having me. I look forward to coming back.

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[(24:55)] Stephanie: Thank you for tuning into this episode of the Can Do MS podcast. We hope that today's episode helps shed light on the challenges that women with MS face. Please be sure to join us again for another episode with Dr. Suma Shah. She'll be back here to share her knowledge about family planning, so stay tuned for the episode release date. In the meantime, we'd also like to thank Biogen and all our generous sponsors for their support of the 2023 Can Do MS podcast series. Thank you and until next time, be well and have a great day.

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