



PODCAST

Family Planning Considerations for Men and Women with MS

Episode 139 – Podcast Transcript

[background noise]

[(0:14)] Stephanie Buxhoeveden: 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 139. I am very excited to welcome back our special guest, Dr. Suma Shah, a neurologist and MS specialist from Duke Health. Hopefully, everyone had a chance to tune into our episode on Women's Health, where we talked about different topics that affect women throughout their lifespans. We're excited for her to be here once again to share her expertise with us when it comes to family planning. Welcome, Dr. Shah.

[(0:51)] Dr. Suma Shah: Thank you Stephanie, and thanks so much for inviting me back. As I mentioned last time, this is a topic that I'm so passionate about and I'm so excited to share today's topic with you all.

[(1:01)] Stephanie: So we're going to be talking about family planning. It's a big topic and it goes far and beyond just pregnancy. So let's start with when should men and women with MS talk about their plans for starting or expanding their family in the future?

[(1:16)] Dr. Suma: My catchphrase to answer this question in the last year or two has become early and often. The conversation should come up at the time of diagnosis at the time of follow-up after starting a disease-modifying therapy in between when deciding on a disease-modifying therapy, and then at every visit after that. The current recommendations by some of my colleagues in this space has been to ask at every visit, are you planning on growing your family or becoming pregnant in the next year? And that allows a little bit more scaffolding to take a pause and back up and approach this conversation with care. For men and women living with MS there are a few things to discuss and consider, and the data behind this is exponentially growing and so I, I'll strongly suggest that patients living with MS, be it, men or women, bring up the discussion regarding contraception and planning conception surrounding their diagnosis of MS and specific to whatever disease-modifying therapy they're on with their provider whenever they have a chance.

[(2:26)] Stephanie: Absolutely. I think that's so important and it's okay if plans change, just let us know. So speaking of contraception, is it safe for women with MS? Is there any evidence that it either helps or hurts disease progression or symptoms?

[(2:42)] Dr. Suma: It is safe to use and it's recommended while on the majority of the disease-modifying therapies that are currently approved. There are some unique considerations that are

worth taking into account and have to be approached individually. For example, if someone's on one of the fumarates, like dimethyl fumarate or a diroximel fumarate, they may be having diarrhea, and being on an oral contraceptive agent may render that oral contraceptive ineffective if it's not passing the way that it should. Additionally, if someone has been on teriflunomide and needs to be on an accelerated infusion protocol and have, has to take activated charcoal for expedited elimination, then they too have to take into account that their oral contraceptive agent may not work. But that's about it for most of the disease-modifying therapies and their interactions. Most of the interactions that we do have to consider are the symptomatic treatments such as the anti-seizure medications that many of our patients are on or treatment of central neuropathic pain. And the large majority of these anti-seizure medications can affect the efficacy of oral contraceptives by interacting with liver metabolism. Additionally, another medication that a lot of our patients are on is modafinil, which is commonly prescribed for MS-related fatigue and it has been shown to decrease effectiveness of oral contraceptives. And so knowing all of that, it's important to discuss the entire medication list while on oral contraceptives so that your provider knows where the interaction may occur.

[(4:30)] Stephanie: Very well said. And also there are certain disease-modifying therapies that men should not conceive on. So definitely even for men, talk about considerations for conceiving.

[(4:42)] Dr. Suma: I'm so glad you brought that up. That is an under-recognized area of conversation, but absolutely independent of oral contraceptive agents, there are at least two disease-modifying therapies that I can think of off the top of my head. Teriflunomide and cladribine that have implications to family planning in men. And if these medications are being used, it is important to discuss timing and when it would be appropriate to safely try to conceive.

[(5:12)] Stephanie: Absolutely. And looping their partners into that conversation is really important.

[(5:17)] Dr. Suma: For sure.

[(5:18)] Stephanie: So based on what you've shared with us, it's important for all MS patients to discuss their family plans, whether that involves having children or not. Does having MS affect fertility for those that do want to start a family?

[(5:32)] Dr. Suma: So there's a little bit of conflicting data on this, but I will say it does not seem to be directly affected by MS. And what I mean by that is there are physical and psychosocial factors that may delay pregnancy in patients living with MS, and as a result, people may be running into age-related fertility issues, which has seemed to come up in some of our more recent studies. Additionally, in men living with MS, they have been shown to have lower hormone levels, specifically low testosterone has been associated with a higher risk of developing MS in men and worse disease outcomes. Also, sort of along the same line of thinking, hypogonadism, which is a separate diagnosis, can also affect fertility, and men living with MS have been found to have lower sperm count, sperm motility, and impaired sperm morphology. There is some thought that this linkage may be from a co-existing autoimmune development of this hypogonadism. But with all of that said, if there is, if there is identified challenges with fertility, it is important to refer our male patients to the right resources and specialists to help address that.

[(6:51)] Stephanie: Think that's such an important topic and one that I don't hear often in conversations like these, and I just wanna commend you on really bringing men into this

conversation.

[(7:03)] Dr. Suma: Thank you.

[(7:05)] Stephanie: So what other barriers do people living with MS. Face when trying to have a family?

[(7:13)] Dr. Suma: The most common one that I can think of is sexual dysfunction, which is complex. It affects, in various studies, 40 to 80% of women and 50 to 90% of men and patients often feel embarrassed to bring this up at the visits and providers may not feel certain that there is a lot to offer. So from both directions, there's a limitation in addressing this challenge and being able to come up with a direction forward. It is often secondary to other symptoms like bowel or bladder dysfunction, spasticity, untreated depression, or physical challenges that may have more simpler treatments. With that said, having the relationship with your provider to have that conversation with ease is really the, the first step here. And being open with the strains that may be upon you or your partner when it comes to that sexual dysfunction so that that worst barrier to planning to grow a family can be reduced. I'll add many patients living with MS have significant financial strains and we know that patients living with MS have higher rates of depression, often more in men than women. We could do a better job at recognizing that in our patients, but working together as a team to address it is going to go a long way towards being able to produce some of the barriers to starting a family.

[(8:47)] Stephanie: All very good points. So let's talk a little bit more about pregnancy. It can be confusing to weigh the risks and the benefits when there seems to be so much conflicting data about pregnancy and MS. Why aren't there more clear-cut answers?

[(9:02)] Dr. Suma: That's absolutely the right question to ask. This is a question I've been asking myself since I was a fellow in 2017 and it led me to do some advocacy work with the pregnancy and lactation task force at the NIH. If you Google my name and Greg lacked task force, you'll find a public comment that was published in 2018 as I stood in front of a group of federally appointed researchers to ask them for more resources to answer these questions. And the truth is, our science is limited. Often women that are planning to conceive may become pregnant, are pregnant, or are breastfeeding, are excluded from clinical trials. There's a lot of unknown still because we are relying upon very small studies. These are often retrospective, they're often descriptive, and they're often very, very small and sharing just one person's or one provider's experience. And so you, for any direction you want to go when it comes to family planning and pregnancy, you can find science for it, which leads to a very dilute way of being able to provide care. More recently, these efforts have changed tremendously. And so to answer your question, I'll back up a little bit and address the full spectrum of family planning. We'll start with fertility. Fertility planning in MS has been fraught with these challenges in science. Up until this past month, we did not have any data that was larger than 12 to 20 to maybe even 25 patients with MS who underwent fertility treatments. Earlier this year we had a study published in a major neurology journal that looked at 61 cases of patients undergoing some version of assisted fertility technology.

And as time goes on, I imagine that we'll get more and more such data. This data was particularly notable for sharing that none of the patients who were treated with disease-modifying therapy undergoing fertility treatments relapsed in the three months after fertility treatment. So there has been a little bit of disagreement in the science about whether fertility treatments may worsen MS

or not, and we can say with more certainty in 2023 than we were ever able to before that there seems to be a permissive stance on assistive reproductive technologies and MS. Moving forward to pregnancy planning there's far more data these days than there was even a decade ago on navigating disease-modifying therapies, but it's still not enough. And fast forward to the considerations of breastfeeding. There's even less. So there's some data that it may be protective if exclusive, which is a challenge and there may be some data to show that certain disease-modifying therapies are compatible in breastfeeding. But all of these have to be taken into account with a person, their wishes, and the disease-modifying therapy that they are comfortable with or had been on pre and postpartum. So I know that was a long answer, but there are so many considerations when it comes to family planning that each step of the way really needs to be considered very thoughtfully.

[(12:42)] Stephanie: I think it's very important what you said about clinical trials and excluding pregnant women. And it's very important to me that people understand a clinical trial is designed in a very specific way. You're [?] often looking at a relatively healthy population with limited comorbidities of a very narrow age. Like you said, we usually exclude people who are either pregnant or who are not on birth control. And then these medications are released to the general population, which is a grab bag of everything, right? All ages, all life circumstances, different comorbidities. So it's very normal to continue learning about how any medication affects a whole population of people after it's released. And so a lot of this data that we have on how the DMTs affect pregnancy on breastfeeding, it's called post-marketing data, right? So this is real-time evidence coming from a general population who's now taking a medication and that looks very different than clinical trials. And so that's often why we start hearing about a side effect we didn't see in a clinical trial or we start learning more about what is and is not safe for women who are thinking of getting pregnant. And sometimes it's just not very well explained. So I think it's really important to mention.

[(14:06)] Dr. Suma: Thank you for sharing that. That is very important.

[(14:09)] Stephanie: The pregnancy could be its own podcast episode and I was hoping to get a few key takeaways. You talked about breastfeeding, um, but what else should women know very briefly about pregnancy?

[(14:23)] Dr. Suma: Well, this may sound like a repeat to those of you who listened to our last podcast, but I'll share that women who have not had children were found to have a higher risk of developing MS than those who've had multiple children. And so the takeaway from that is pregnancy can be protective. It does not worsen long-term MS outcomes, and in fact, it could even delay the onset. There are also postpartum considerations outside of breastfeeding. Specifically, we have known since 1993 when the first pregnancy outcomes in MS data came out at large numbers that the relapse rate postpartum is often two to three times higher than the baseline relapse rate for a person living with MS in the in the prepartum state. And over the years, this has been noted to decrease where it used to be that two to three times now that rate has gone up by uh, 50%. And so those numbers are encouraging and may reflect some of our higher efficacy therapies that are doing a better job at being restarted postpartum and keeping the disease under control. Similarly, there has been a push over the last several decades to more mothers with MS choosing to breastfeed. This is reflective of the, the national population also choosing to breastfeed more and that may also provide some protective effect. And then finally, there has been some science that's allowed us as providers to recommend resuming DMTs safely with certain

considerations. The last point I'll make about the postpartum period is that MRIs haven't really been shown to have any specific prognostic value. Meaning what a person's MRI looks like after delivery doesn't really mean anything about what the next few weeks or months may look like. And so we've really gone away from asking that extra financial ask that time ask in this very delicate postpartum state.

And that's often been a little bit freeing for a lot of my patients to hear as well. And for that final consideration in the breastfeeding world, in the lactation world, there are now conversations being had about relative infant doses of medications. How much medication is seen in the breast milk depending on the DMT and part two, how much of that actually gets absorbed by an infant's gut if they were to ingest it through the best, breast milk? And so I often remind patients, depending on the DMT that there are two layers of protection before baby's bloodstream and therefore baby sees any amount of DMT. And knowing the science behind that and knowing what that might look like helps a patient decide whether a DMT is the right choice for them, whether it's compatible with their breastfeeding plans, and what that might look like to them.

[(17:22)] Stephanie: So we've talked a lot about what research has and has not been done, and clearly this is one of the greatest gaps in our understanding of MS. Which is how family planning is affected by different medications and aspects of life. So can you tell us a little bit about the research you're doing? That was terrible.

[(17:43)] Dr. Suma: Absolutely. Yeah, that's okay. [laugh]. Do you wanna restart? I'm, I'm happy to just go from there.

[(17:49)] Stephanie: I feel like, uh, I feel like we can edit that one Krista, and if we, if we need to re-record that question, I can do it, but hopefully she can, she can...

[(17:57)] Krista: I think I can probably grab that. I'll check in if we need to re-record it. [inaudible].

[(18:00)] Stephanie: Okay. All right. Perfect. [laughs].

[(18:04)] Dr. Suma: I'd be happy to share. This is a world that I've been not just passionate about in the clinical care space, but I do want to learn more about how we can contribute to the science so that we can have these conversations with a little bit more evidence base. Most recently, we have looked at a survey that has done at intake for all of our women living with MS, and the survey asks many things regarding pregnancy planning, family planning, and how that might be affected by living with a diagnosis of MS. What was most interesting about that and what we shared at CMSC this year is that there are still quite a few... sorry. There is still quite a lot of room for improvement in how we approach family planning conversations. For example, I have read quotes from patients living with MS who in 2023 believe that they cannot have a family if they're living with a diagnosis of MS. That's powerful and it tells us that, that we have a lot of room to go when it comes to addressing not just the science of how to have a child in the face of chronic illness, but even how to make that conversation more accessible and some of those assumptions or beliefs that are allowed to bloom without a dedicated conversation give us room to focus our efforts for patients going forward.

[(19:41)] Stephanie: I just think your approach is so inspiring how you've seen this gap in your patient's care. You've advocated it, you've advocated for it at the federal level, you're doing

research to help address this really important topic. So if other people are also feeling inspired by what you've shared here today, how can they learn how to participate in research studies or advocate for this important issue?

[(20:11)] Dr. Suma: I would say there are two good ways to approach that. The first would be asking your healthcare provider and even though they may not be the ones who are leading up the studies, they may be able to point you in the direction of someone who is. Many of the trials these days that are currently underway trying to answer these questions are multicenter clinical trials. And so the second location I would direct people to is clinicaltrials.gov, which is an online database of all registered clinical trials underway. It's always a good idea to search there under multiple sclerosis and pregnancy or multiple sclerosis and breastfeeding or even what other topics you may be interested in and get a sense of where these trials are taking place. Just know that sometimes the trials can be registered offshore and I've found patients who said, who have come to me and asked me for a referral to Germany because that's where things are being done, uh, most abundantly in this space. But there's a good momentum underway and I think over the next couple years we'll see more and more registered clinical trials for this specific work.

[(21:25)] Stephanie: Thank you so much again for being here and for sharing your expertise and your passion.

[(21:30)] Dr. Suma: Thank you for having me. I am happy to be here and I'm happy to share what we know and our approach so that our patients can approach some of these questions with a little bit more information.

[(21:46)] Stephanie: I'd like to say thank you to all of our listeners for joining us on this episode of the Can Do MS podcast. We hope you learn something that will help you on your journey. If you like today's episode, please give us a rating and review on Apple Podcasts or wherever you listen. Your support truly helps. We'd also like to thank Biogen and all of our generous sponsors for the support of the 2023 Can Do MS Podcast series. Thank you and until next time, be well and have a great day.

[END]

This podcast is made possible thanks to the generous support of the following sponsors:

