



Can Do MS Podcast Transcript

Energy and Endurance: How Every Step Beats MS

Episode 54

Samantha: Hello! And welcome to the Can Do MS Podcast. My name is Samantha Balistreri and I'm your host. Today is episode number 54. We're going to be talking about energy conservation. I'm excited to welcome our two guests in the studio today. With us, we have Occupational Therapist, Stephanie Nolan, as well as guest Gene Caffrey. Gene is an endurance athlete living with MS. As many of us know all too well, energy conservation is a key ingredient to managing life with MS. And it's also been a crucial element to Gene's goals as an endurance athlete.

Gene, let's start with an introduction. Will you please tell us about how you were diagnosed with multiple sclerosis?

Gene: Sure. Umm, so back in 2009, uh, while training for the Florida IRONMAN, I had run into some issues, uh, in the race. Umm, we're going through the swim which is the 2 lap[?] swim, umm, coming out of the- the first lap, my legs were- were numb, uh, real spastic, and I ended up hitting the beach because my legs gave out. Umm, got up, just assumed it was something to do with the race, uh, went through the rest of the swim, got through it, got into the bike, had all kinds of problems when the bike is well, with the same cramping and spasticity. Umm, until got through the bike and got into the run, and it just got worse and worse where I couldn't feel my feet, they were numb. Umm, and by the end of the race, uh I, again, I was ignoring it just assumed it was from- from- from, uh, things that happen during the race.

And by the time I got home back to New Jersey, umm, you know, it had moved from my feet, up my legs, into my midsection, umm, to the point where, you know, every time I stop, if I was out running, it would- it would give me an electric, kind of burning [(2:00)] feeling to it. So that's what I finally stopped ignoring it and think[?] it was a- uh, an overuse training thing. Went to, umm, a neurologist that tested that day and, umm, throw the different diagnostic tests they do for me through MRI, umm, umm, MRIs they found findings of, umm, scars[?] and plaques[?] on my brain and my spine, and I was diagnosed with MS shortly after that.

Samantha: Wow. And then when and how did you first connect with Can Do Multiple Sclerosis?

Gene: So, umm, it's a funny story coz like after I was diagnosed, I started Googling exercise

and MS. Uh, endurance exercises in MS, fitness and MS, whatever I could find. And I found stories about Jimmie Heuga, and it blew me away that, you know, he had gotten it so early. He was an Olympic, uh, champion, you know, winning medals and then shortly after that got diagnosed with MS when there were zero treatments. And it really pulled me out of my funk of being diagnosed, uh, when I found out, and because I saw that he fought it with what he knew about Athletics and a- and fitness, and being healthy and it helped him, and that he went out and started helping other people.

That really got me motivated that day and told me I could- I could do it too. And it really got me focused on keeping up on my training, and if I kept it with light[?] training, it would keep me strong even if I had MS problems. And then I-I can still do what I'm doing and maybe even help other people be umm, you know, aspire to do their stuff. I also found information about something called MS Global, and that was Tyler Hamilton's, uh, organization that was taking people across the- the [inaudible], uh, taking people with MS and without MS, raising money and getting over the- these- these amazing rides and climbs. And- and on that same day, I found both of those. So that's what my fringe[?] connection to Can Do MS was.

Then, I was invited to a cycling event for MS [(4:00)] that was being headed up by Tyler Hamilton. So I went out, I got involved with it. And when I got there, I found that the charity that we were working with was Can Do MS. And it was this kind of a, umm, life-changing week, and it was meant to be and I felt it's fate, but it was what got me connected and focused on what I wanted to do from that day forward. Everything's been about riding for awareness and- and try to help everybody to live their best life with MS by inspiring and do what I do.

Samantha: That's really incredible. Yeah, your- your story and your attitude really remind me of- of what I know about Jimmie Heuga and his legacy, so that's really special.

Gene: Yeah, he changed my life without- without even meeting him, so, uh, you know, I [inaudible] one time and I told him that- I said he's just- he's just totally changed where I was at at that point. So, it's really great.

Samantha: Yeah, that's- that's awesome. And something else he was really passionate about was teamwork and we're lucky to have an Occupational Therapist here with us today. So Stephanie, welcome.

Stephanie: Hi.

Samantha: So I want to pull you in into the conversation. Umm, as an Occupational therapist, what can you help with and what can we learn from you?

Stephanie: Uh, so I feel like Occupational Therapy is such a great resource, uh, for people

with MS. And I think our biggest role would be, uh, energy conservation which is fancy for fatigue management, umm, trying to find ways to manage your fatigue by conserving as much of that energy as you can. Uh, giving you m-more energy to use throughout the day, not necessarily making more energy right there, but making it spread out throughout the day. Umm, but we can do that through so many different ways that might be using gadgets, that might be just pacing your day and kind of figuring out how and what to do and when to do it, that could be educating you and your family and your friends or other people understand a little bit better.

Umm, it can look like helping with vision, helping with heat tolerance. That's another big one and I know, uh, Gene we've talked before that- that's- that was a tough one for you.

Gene: Mmm-hmm.

Stephanie: Umm, so I think, you know OTs [(6:00)] just play a big role in so many areas, but in the overall, like improving that function with different strategies, techniques. And I think that fatigue management is like, the biggest key.

Samantha: Yeah, especially with multiple sclerosis where that's such a common problem. Uh, Gene, you're a passionate endurance athlete, and what other roles are important in your life?

Gene: Uh, well, besides the riding a bike, umm, my family, work- I'm a- I'm a salesman, uh, I've been doing that for 30 years. Um, uh, selling, umm, o-on the road, I'm driving a lot, that kind of stuff, so... B-but mainly family, health, and, uh, keeping that bike rollin'.

Samantha: Yeah, you're clearly balancing a lot of roles and I think a lot of us can relate to that.

Gene: Yup.

Samantha: Umm, and as Stephanie mentioned, energy conservation can be beneficial for anyone with them MS. Stephanie, I know this is a topic you're really excited to talk about. Can you tell us a little bit about how energy conservation can help people with MS?

Stephanie: You know, I think a lot of people, umm, when they first noticed the fatigue or experienced the fatigue, there's a- a- it's overwhelming almost and then there's this, "I have to get everything done. As soon as I wake up in the morning before that fatigue monster hits at 11 a.m.". Or something like that. So there's this, umm, strive to just cram in all these things really early on and then eleven o'clock hits, and they're like, "OK! My day is done. I-I got my eight to eleven. That's all I got, and I'm down for the count."

Gene: Mmm-hmm.

Stephanie: Umm, so I think that's like a- huge thing is, umm, really just figuring out how to make that little bit of energy you have in a day lasts longer. And- and someone once told me [inaudible] gives you a \$1 a day and like kind of imagine if you had \$1 worth of energy and had to spend that dollar very carefully and spread every penny out. How would you spread it out? And so many people spend that dollar real quick in that first couple hours of the day. They have no dollars left or they steal tomorrow's dollars or the next day's dollars and then they're out on a loan that they really can't afford. So, figuring out how to plan [(8:00)] and organize yourself to be able to manage that energy is really critical.

Samantha: Yeah, that's- that's so important. And you have a good tool for people to help remember energy conservation.

Stephanie: Yeah. So I like to use something called the 4 P's. Umm, so we separate into 4 different groups, and those are, umm, Prioritizing, Planning, Pacing, and Positioning. So we you know, break down what's priority, what needs to be done, what can be done later. Planning, how are you going to budget that dollar? How you going to plan out your hour, your day, your week, you know, in- Gene, he plans out a year ahead [laughter]. He found his races[?] and stuff. Umm, and then pacing, how are you going to pace that hour. And then positioning is things like gadgets or tools, or how you stand or sit while you do something. Umm, so, you know, those are the 4 P's and- and how you can use those to, uh, break down your energy techniques or energy saving techniques.

Samantha: And, so in other words, think ahead, use your energy wisely, and listen to your body. [music] Okay, we're going to take a moment to hear from one of our sponsors. We'll make it back, we'll break down the 4 P's of energy conservation, and learn some tips and tricks from Gene when it comes to managing his fatigue.

[music]

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[(10:00)]

So, welcome back and thanks for listening. We have Stephanie and Gene with us in the studio today. We're going to continue our chat about energy conservation. So, Stephanie tell us more, how can planning help with energy conservation?

Stephanie: So planning is really important. I like to encourage people to look at a calendar or look at a schedule for that day and write down everything you plan to do, and just kind of visualize that and when you go to plan that in this kind of bumps and little bit pacing, but we will plan that. I want people to really think about what are you doing next? How are you going to pace that? Umm, and- and write all the things- how people forget sometimes to write simple things, like bathroom breaks, or taking a nap, might need to go in there. So really looking at your day and planning ahead or just kind of going on the fly.

Samantha: Yeah, that makes sense. And I think it's- it's so different depending on how much energy you have. For Gene, you're an endurance athlete, but how do you use planning to help you with energy conservation?

Gene: So yeah, the planning is big. Umm, I have schedules that I have to follow up for work. I have schedules I have to follow for my training, you know, i-in order to be ready for event[?] I'm getting ready for. So, my work is the normal calendar that you guys all use and I-I look at it, I have everything from home in there and work. I- my wife needs me, I'll tell her to send me a mini invite, you know, it's, you know, just it's easier that way. I won't forget and then I-I work with a coach to help me plan out , uh, my week, by month, it's done every day and we-we really pay attention to every workout. And he sees how I- how it affects my body and he plans the next day, so he helps me plan. Umm, so that's, that's really good.

And without- without that, I would be doing too much, umm, you know, and I would ignore just like I did when I was first diagnosed, I would- I ignored that I was super tired and needed rest. So, he- [(12:00)] my coach helps me understand when I need rest, you know, coz like I said before, you gotta have a team, you know, my wife, my coach, my friends, t-they all helped me stay on track. And... so the tools that I'm using there are the different calendars that my coach uses in the calendars I have. And- and I try and balance all those and it's also not rock-solid plan, so I m-might have a plan that I want to follow.

Eh, but I have to be open to say, "You know, what? That would have been great to do that and I'm going to adjust that.", you know, and that's where- that's where the team that's supporting the helps me say, okay, y-you know, it's time to take a break coz when that- when that MS fatigue hits me, uh, it's the way I explain it, i-it's like no other fatigue. I-I'll be fine, and then I- there's nothing else to do but to take a nap. And I could take a nap at six o'clock at night for two hours and still go to bed at 10 and have no problem doing that and then that's how I plan and it helps me get through that.

Samantha: Yeah, thank you. And another component of planning is what equipment you bring to your training. So, how do you plan to not overheat or at least minimize your overheating?

Gene: Yes, that's- that's an ongoing learning process to figure that out, you know, and a lot of times that- that... what helps you figure it out is making mistakes, you know, I've had many races won last year where it's hot, you know, it's very hot here in North Carolina this summer. Y-you can't regulate heat with MS. And when I push it to the extremes, I've had some situations where it's just to stop me and shuts me down. So, some of the ways I-I manage that is, umm, you know, there's devices I have on my bikes and I wear heart rate monitors, I have things that could tell me how much power I'm putting out. Uh, I'm starting to look into ways to measure my core temperature so I can figure out what my level is before I hit that height where it's just going to shut me down. The other things I use within, especially when it comes to heat, which when I get overheated, then there's fatigue and then you're done, right?

Samantha: Mmm-hmm.

Gene: I work- I work, umm, by using, umm, cooling techniques and pre-cooling [(14:00)] before workout, cooling during, and then cooling after. And, you know, I searched and found companies that can help me, this company called ThermApparel, well it makes a device called the undercool vest that fits right under my- my cycling, umm, jersey and, umm, it's- you wouldn't even know it was there. And it just helps me go longer, umm, but it's not just during the event. It helps me before, helps me during, helps me after, and I find that I recover better after that. Umm, and also diet and- and hydration, t-to- to get me through t-the best I can.

And all that carries over to normal daily life too coz, you know, when I'm- when I'm doing my job, and I'm in the car sometimes, umm, you know, I got to go and see a customer and it's 105 degrees out, y-you have to balance everything not just for my endurance sports.

Samantha: Yeah, that's really important. So, cooling vest, staying hydrated, staying cool however you can...

Gene: Yeah.

Samantha: ... Are really important.

Gene: And also knowing- then... by doing it, I-I learn my limits, really. You can [inaudible] really in coz, you know, it- I might want to go at a certain effort, and try and go a certain distance, but the day might tell me it just gonna- it's not going to happen. You have to listen to your body. So...

Samantha: Absolutely. Uh, the next in the 4 P's of energy conservation is Pacing. So Stephanie, why is pacing so important with MS?

Stephanie: So we're pacing in heavy load work, some recovery work; heavy load, working recovery work. And I love how Gene when he said that, with all his endurance training, you know, he has recovery days in there. That's awesome, like his or big recovery days. You know, a lot of us, I don't have endurance training, I don't do endurance training. But you know, a recovery day on my level might look totally different than recovery down his level. Or, a recovery minute, or hour, or whatever it is. So looking at that, just organizing it; so higher activity, lower activity, high activity, low activity, and trying not to slam in all that heavy energy work first.

Samantha: Yeah, thank you for explaining that. It makes a lot of sense. Gene, have you ever poorly paced yourself and had to learn from the experience?

Gene: Many times! [(16:00)]

[laughter]

What? Whether it's worker or- or- or an endurance race. In the endurance race, it's [inaudible]. Just- just this August, umm, uh, you know, it was a 12-hour race, umm, I-I had a plan, it was working. And it was- it was involved in that Ice Fest[?] I told you about and, but it was 105 degrees out and I- it's not that like I made mistakes. I just didn't know. I learned a lot from it, you know. And it got to a point where, you know, 5 hours in I was starting to fall apart and it got to a point where I was almost getting towards heat exhaustion. And I learned a lot from that, umm, it was brutal.

And there's in many races like that. And there's been times when I've worked, you know, during a n-normal day and without exercising, where it's hectic, there's stress, and I'll get home, and it's just I'm out. And I-I'll be... t-the MS fatigue hits in which is- can't be compared to normal fatigue. So it happens all the time.

Samantha: Yeah, and I've heard you share a story a couple times that that was an experience where you really overdid it and you kind of developed a mantra that you...

Gene: Yeah!

Samantha: ... Started to come by [laughing].

Gene: I'll tell you about that. It's so- so that was when I was still, you know, we're always learning with MS but it was when I was really starting to learn, I was- I was newly diagnosed. I knew I have an MS and I knew it would taken some things away from me, but I wanted to give it a try at the marathon distance again, and I was starting to, umm train. I went out and just run and, umm, felt OK so I kept going, then I realized I was 5 miles away from home. And I realized that it was going to be a 10-mile run, and that was too far.

Eh, so I got to the, uh, turnaround point, and I was really hurting. So, when I'm- when I'm doing races, I use mantras a lot, you know, just to kind of keep my-myself focused. So, when I was running and trying to get back to home, I just started chanting in my head on the where it came from. I just started chanting, "every step beats MS" and I kept doing it or- so I'm- I'm trying to keep myself from that thinking about the [(18:00)] pain I'm in. And I'm shuffling and say, "every step beats MS" and I'm starting to feel better. And before I knew it, a mile was gone, and then another mile, and- and another mile, and I got- that time, umm, I got home, I didn't really realize that I was close to home, but then I was home.

So on that day, "every step beats MS" was a physical thing for me. It was just trying to keep me moving. Umm, but since then, I've made it my mantra for life. I-I actually have it tattooed on my leg. You know, when you finish an IRONMAN, you get an IRONMAN tattoo. I didn't do that until I got MS. I turned it into an MS tattoo and I have a [inaudible] "every step beats MS". It's on all my bikes that I ride, it's on my clothes, and when people see it, it gets me talking. Helps me raise awareness coz then I- I tell them, you know.

And that day, in the story, it was a physical step. But it's much more than that now. It's- to me, it's- it's the way you set your life up. It's- it's- i-it's your mindset and how you're going totackle the day; it ties into everything that's definitely just talked about. What is that next step going tobe to help you live your li- your best life with MS? And I try and preach that- I-I try and show that in everything I do, you know, when I make mistakes, I try and learn from it.

And I just figured, if I've got that on my body and I- and I live that way, I can then talk to people that can help me spread awareness and help us all inspire people t-to do what they need to do to get the best help. And that might mean that they're going tocome to one of your- one of your programs and set some goals. Someone's step might be, you know, "I'm going tofigure out how to do things a little easier at home" and it all just goes from there. So that's- that's what that is and, umm, I love it. I-it really helps me every day, and if I'm helping myself, then I'm helping others too.

Samantha: Yeah, I love that, too. It's- I think it's better to not put yourself in a situation where you overdo it, but when you do, [(20:01)] and when it's kind of an i-inevitability with MS, umm..

Gene: Yes.

Samantha: ... That's a great mantra to help you get through. Another of the 4 P's is Prioritizing. So, Stephanie, what are we talking about with prioritizing?

Stephanie: When we talk about prioritizing, it's- it's determining what needs to be done versus what wants to be done in the day. Umm, and I'm not telling people to get rid of

all your wants because then, life is just not fun. And I know like Gene, found a way to make all his wants work, right? He's doing this cycling and he's staying involved, and those are his wants but, umm, also figuring out how to balance those wants and needs. Figuring out, you know, "I need to go to work.", "I need to pay the bills", or "I need to see my doctor today.". Those are the things I have to do. These are the things I want to do, and I want to incorporate them in there.

But are they simple things like, "I really want to vacuum my carpet every day.". Well, and some people are, you know, Taipei[?], they say and really have to keep everything super perfect and they have this regimen or routine in it. It's hard for them to break away. And I love how you mentioned that earlier Gene, is sometimes you have to be flexible and maybe, you know, the day does- doesn't go as you planned and you have to change a little. So that's when those needs and wants can be adjusted a little bit. You know, can we skip vacuuming the carpet today? Or can we skip something that's a little less important? Is today- just- just I'm just so tired, you know, I really wanted to cook this awesome meal and have all my friends over. But is it a day to switch it up and say, hey, I might order pizza and have everyone come hang out and eat pizza. You know, it's just I can't cook that giant meal I wanted to do today. So balancing those needs and wants.

Samantha: That makes- makes a lot of sense. Gene, you're a driving salesman, you're an athlete, you're a husband, you're a father. How does prioritizing help you with so many roles in your life?

Gene: It-it really connects well with every-everything that I've learned for balancing an endurance, uh, athlete lifestyle. It just connects so perfectly. [(22:00)] The support of my family to help me get through what I need to get done, and banking on and take and accepting help from my support team is the biggest thing I think that helps me through all that.

Samantha: Yeah, helping- having other people and, umm, kind of delegating your tasks can be really a good prio- good way of prioritizing.

Gene: I-in your team- your team does that for me too, as well. Can Do MS and the MS Global family that I, that's all part of that, you know, we're all there to help each other and that's- I help other people, and the team, they help me. So it's- it's... e-every- s-sometimes it's hard to accept help. But, y-you know, if you have- if you have a surround yourself with a real team, I think- when you said that earlier in this podcast, that's the biggest thing, you know...

Samantha: Yeah, definitely.

Gene: ... To be honest.

Samantha: And then the last one we have is Positioning. So, Stephanie what is positioning mean when it comes to energy conservation?

Stephanie: I like to look at positioning as, yes, it might be the position you're in. So, maybe you sit for a shower instead of stand for a shower. Umm, and I have a lot of people who say, "why do I need to s-sit in the shower?", "I can stand in the shower.". But then they tell me when I'm done with the shower, I'm so exhausted I can't get dressed. Well, if you sit in the shower, then maybe you can get dressed. It might not even be necessarily that you're going to fall. It might be more, you're just saving that energy.

Umm, positioning could also be gadgets, you know, they have so many adaptive tools out there now. They have special knives for cutting and chopping. Umm, you could use food processors to cut or chop, right? Either just saving energy, let the machine do the work. Umm, they have clothing, that's modified. They have shoes that are easy to put on especially for people who have, umm, AFOs or braces on their feet. There's, you know, magnetic clothing. There's so many different opportunities, umm, with gadgets and tools out there.

Samantha: Yeah, I like that. Every little bit helps. So, we have Planning, Pacing, Prioritizing, and Positioning as those 4 P's to help us remember energy conservation. And it sounds like it can be helpful to everyone. Whether you're an endurance athlete or just need a little bit extra energy [(24:00)] to help you get dressed or bathed, or do something else that's important in your life. So after this conversation regarding energy conservation, for either of you, is there a key takeaway you hope others learn?

Gene: I would say just always be your own- your biggest advocate and learn. I've learned so much just for our conversations. How much that- that Stephanie is- is talking about ties into my life. Umm, I didn't know how much Occupational Therapist deal with people with MS before we all started talking. And I'm kinda blown away by it, and realize how much it- it does coming into my life. So, I think the takeaway is, you know, surround yourself with the best support team you have and- and be your best advocate, and always be willing to learn.

Stephanie: I love that, Gene. I also feel like, uh, my takeaway is often that a lot of people with MS feel like they lose control. They lose their ability to control their life and MS might be taking some of that from them. But using these 4 P's, can give them some of that control back. And you can have the power to say, "I'm going to make my schedule for the day", "I'm going to figure out what activities are most exhausting for me", "I'm going to look into these tools that might have helped me", "I might be able to say no to somebody when they ask me for extra, you know, to do something extra today that I don't have the energy to do, or I might be able to p-prioritize my day a little bit better". So, I think it just gives a little bit of power and control back in a moment of feeling like you've lost that control.

Samantha: That's fantastic. Yeah, it's a very useful conversation and a- and a helpful tool. So, Stephanie and Gene, thank you so much for joining me today on the Can Do Multiple Sclerosis Podcast. It was pleasure having you.

Gene: Thanks for having me.

Stephanie: Thank you!

Gene: It was excellent. Thank you.

[music]

Samantha: The Can Do MS Podcast [(26:00)] is made possible by the generous support of our sponsors. Thank you to EMD Serono, Sanofi Genzyme, and Genentech. And a big thank you to our listeners for tuning in. For more great resources about fatigue management, please visit CanDo-MS.org/fatigue.

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