

S3E40 Transcript

Ritu Kaur: A One-Woman MS Awareness Machine

Geoff Allix (1s):

Welcome to Living Well with MS, the podcast for Overcoming MS and people with multiple sclerosis interested in making healthy lifestyle choices. I'm your host, Geoff Allix. Thank you for joining us for this new episode. I hope it makes you feel more informed and inspired about living a full life with MS. Don't forget to check out our show notes for more information and useful links. You can find these on our website at www.overcomingMS.org/podcast. If you enjoy the show. Please spread the word about us on your social media channels. That's the kind of viral effect we can all smile about. Finally, don't forget to subscribe to the show on your favorite podcast platform so you never miss an episode.

Geoff Allix (44s):

Now, without further ado, on with the show. Ritu Kaur is no ordinary woman. She's creative, accomplished, life-loving, and after getting diagnosed with MS, has made it her single-handed mission to educate people about MS to reduce the stigma around it and lessen undiagnosed and misdiagnosed cases. MS is not the same for everyone, nor does MS define a person. Only their courage and strength do. With love and kindness in her heart, Ritu has taken to spreading awareness about MS and building a community around the globe to create acceptance of MS among people with MS and their families, friends, colleagues, and society. Through her adept use of social media, Ritu is building a platform where people with MS and their supporters can get counsel and emotional support, where they feel loved, accepted, and confident.

Geoff Allix (1m 32s):

Welcome to Living Well with MS, Ritu.

Ritu Kaur (1m 35s):

Thank you so much.

Geoff Allix (1m 36s):

I believe your actual name is Surjeet. Is Ritu a nickname?

Ritu Kaur (2m 6s):

Yes, Geoff. Ritu is my nickname, but people love this name Ritu. It's just easy to pronounce. They feel that it's more comfortable for people to say Ritu. They feel that closeness to me when they call me Ritu so yes. Surjeet Kaur is my official name, but people call me Ritu as well.

Geoff Allix (2m 25s):

Okay. If you see the two names, it's the same person. There are many thousands of people around the world that know the name Ritu, thanks to the work you've undertaken to build a community around the cause of raising MS awareness. First off, could you share a little bit about your personal background and connection to MS?

Ritu Kaur (3m 10s):

Thank you so much for this wonderful introduction. When it comes to me, I was diagnosed with MS in December 2012. I got this as a Christmas gift from God. I know that it was given to me for a reason, and the reason was to help people all around the globe. That's why I took up this mission of spreading awareness. Yes, MS was unknown to me, and I was too scared. I did not know if I'll be able to see my birthday coming up the next month in January, but it all passed.

Ritu Kaur (3m 50s):

I sailed through everything. I sailed through the storms, through horrible symptoms I had, everything. I believe the support of my family and God's blessing really helped me through that. When I was diagnosed initially, I had symptoms. I had my right-side numbness. The symptoms got so bad that I could not even pick up a spoon to eat. My

mom had to feed me with her hands. I had sensitivity over my right side that even with a strand of hair touching my skin, I would scream out in pain.

Ritu Kaur (4m 39s):

All these symptoms lasted over three weeks' time and doctors could not diagnose them initially. Then I met the right doctor in Mumbai. He did my MRI and he said, "It looks like MS. We will have to do your lumbar puncture as well." It was all quick. He did my lumbar puncture; my report came within two to three days. It said I had MS. I spent Christmas celebrating it in the hospital. From the New Year, I started DMDs, which was Avonex. Ever since then, I have been on a mission to spread awareness.

Ritu Kaur (5m 19s):

The main thing here was I felt very lucky to know that I was diagnosed with a problem. I know what I had. My sister is a neuro-specialized physiotherapist. She was a valuable help with my complete diagnosis and contacting the doctors. I had guidance but what about the people who do not have people to guide them to the right doctors to meet? They are not in the right city wherein they have such qualified neurologists, especially in India. I also realized that the treatment is so expensive in India.

Ritu Kaur (6m 11s):

My one Avonex injection would cost me 10,000 rupees. How many people can afford that? There are people who have a salary of just 10,000 rupees. All those things really touched me. I said, "I have to do something." One more thing I saw, when I was diagnosed, there were so many friends and colleagues who said, "You should not talk about these kinds of problems to people. Those issues, keep it to yourself." Some of the people also said, "You should get married immediately because you can't live alone." I said, "No. Even though I have MS, I want to be independent the way I have always been. Trust me, I will prove to be stronger than I ever was." I have two challenges here.

Ritu Kaur (6m 57s):

I had to prove to myself that I am perfect. I'm fine, there's nothing wrong with me. I also had to face a society who said, "You should keep your identity hidden. You should not tell people that you have MS," because people see someone with a disease, they feel, "She has a problem. Let's stay away from that person. Maybe I'll get it. Maybe it's contagious. You never know. Maybe you'll have problems getting married. You will not get a guy who would like to marry you in the later years of life so get married immediately." Why is there so much social stigma? Why is there so much of a misconception? Why don't people come to know that they have MS for years of staying with this disease? If someone has MS, will that person ever know they have MS at the right time? Also, the expensive treatments. It was all, together, running in my mind. That's what inspired me to take up this challenge and do something.

Geoff Allix (7m 34s):

How do you think what you do fits with big organizations like MS Society around the world? How is your work different from theirs? Has it supplemented them?

Ritu Kaur (8m 17s):

MS Societies are societies. They have lots of contacts. They are politically driven. They are doing their own jobs but I, as an MS patient myself, understand what MS feels like. It's a different game altogether. How I connect to people personally is something maybe the societies cannot give. If you write a message to the MS Society, maybe one of the employees will message you. They will connect you with someone else and the other person. Yes, of course, they have more contact with doctors.

Ritu Kaur (8m 58s):

They might be able to help in more detail but what I give it to MS patients personally is precious. Tomorrow, if someone writes a message to me, I have the responsibility to answer them myself, not a second, third, or fourth person. They get answers from me. It's just me here. That is the personal connection, the personal touch, and the language I can give which the other societies do not give. Trust me, when some other patients messaged me, they

have a problem and they are in Africa, India, or any other country, even in Pakistan, or any place, I message their respective MS Societies and connect them.

Ritu Kaur (9m 45s):

This is a patient in your place, in your area, can you help them with the required doctor, required facility, medical assistance, financial assistance, or anything that they are asking for. Here, I'm a connection between the societies and the patients. Whatever I can give them personally, like mental support, I'd give them. Of course, I know that something is beyond my capability. I can't have a connection with doctors in South Africa. I don't know who to connect with. For that, of course, you must reach out to the societies.

Geoff Allix (10m 4s):

You've talked about your relationship as an individual, but you've got a community of over 17,000 people on Instagram. As well as being an individual, do you feel that there's a community between those people?

Ritu Kaur (10m 46s):

Yes, of course. There's a strong community between those people as well. What I do is I just provide them with a platform wherein all MS patients can meet and connect with each other. Sometimes, I take Zoom meetings wherein I invite people to join and we have a community forum there. People can discuss their problems, guide each other. That is one way. Otherwise, if someone has a problem, I post it on my page and there are other people answering with some tips they have to that problem. They interact with each other.

Ritu Kaur (11m 35s):

The introduction that you see on my page, I think I'm very proud of that. In fact, I know that MS Patients in my community have become such good friends, they have met each other offline, and they are like best of friends. Not just them, it was me also because I'm an MS patient myself. Even I have made friends and families all over the world now. Tomorrow, if I go to the US or UK, anywhere, I know I have a sister there, or maybe I have a best friend. That's the kind of community I have created. You can feel comfortable in that community. You have people who can understand you and love you.

Geoff Allix (11m 52s):

You're based in India. What do you see as specific challenges in India in terms of MS awareness and acceptance? Are there things that you can do to address those in your homeland?

Ritu Kaur (12m 36s):

Yes, absolutely. When I got the MS initially, I did not know MS. That is the first thing that there is no awareness about MS. When I had visited New York previously, I saw that there were banners and posters about multiple sclerosis in the metros. People could read that there is something known as MS. We do not have a banner or anything like that in India. I have not seen it, at least. The other thing is that the MS Society should shout out and see we are doing MS Walk, MS Marathon. It is also done in India but on a smaller scale. It has not given much of the media limelight.

Ritu Kaur (13m 28s):

That is something that should have been here, I feel. Initially, when people are diagnosed with MS, they don't want to talk about MS. They have a lot of fear. Like I said, to me, people are advising, "Get married," or they were saying, "Keep it to yourself. Don't share the news that you have a problem or a disease." That's the social stigma that is in India. I think that is the biggest challenge right now, but I'm happy to see that people are now breaking away from that social stigma. When I had started this stage, I started it on Twitter and Facebook initially, and then on Instagram. I saw for so many years, I had not gotten a single follower from India.

Geoff Allix (13m 44s):

You've mentioned about fear of a stigma. Is it a fear of a stigma or is there actually taboo? Do you get treated differently in India because of having MS?

Ritu Kaur (14m 24s):

Yes, it's a very important question. It is taboo, of course. That's the reason why people don't want to talk about it. They feel, "If I tell someone that I have the disease, they will not hire me." If I am a working professional, they will say, "She or he is not capable. Tomorrow, something wrong can happen. Why should we take responsibility for that person?" Of course, it's a big taboo. At the same time, the taboo gives rise to fear in a person. Once someone is diagnosed with MS, they don't want to talk about it because they don't want to be treated differently.

Ritu Kaur (15m 7s):

That's the thing. That's why people are scared to disclose that they have MS. When I had started these pages earlier on Twitter and Facebook, and then on Instagram, I did not have any of the Indian followers. Now, I'm very proud to see that I've got so many Indian followers. It really feels good to receive messages from some of the followers saying, "Thank you for being an Indian and raising this kind of awareness because this really gives us a lot of strength that someone, a person like me, is doing this social work."

Ritu Kaur (16m 10s):

This is the kind of strength I am personally giving to the Indian people, which I'm really happy about. In fact, I also do live sessions on my Instagram page, wherein I invite MS Warriors to come and share their stories. I was very happy to see that some of the Indian patients also joined my live Instagram and shared their stories, which earlier, they did not even want to talk about or accept the MS. Yes, India is a different country with lots of cultures and lots of different thoughts and different kinds of perceptions to deal with. I think it's getting quite modern now and people want to talk about the things which are once considered to be taboo. I'm just really proud to be one of them to bring that change to India.

Geoff Allix (16m 30s):

Just to change the subject, you've got a background in marketing, and you've applied some of your marketing skills to some pretty amazing awareness campaigns. There are links to all those in the show notes, as well as your social media channels. How do you think those awareness campaigns have made an impact?

Ritu Kaur (17m 13s):

Yes, I'm a marketing professional and I have done a lot of video campaigns. This was the aim of spreading awareness in a fun manner. We do see videos wherein someone comes and sees, "MS is bad. MS gives me this kind of problem. I'm having this kind of pain." We had those kinds of crowdsource videos. What about showing people a different side of MS? "Yes, I have a problem, but you know what? MS can't stop me. I still can do and achieve the dreams that I want to." That's what my campaigns are mostly about.

Ritu Kaur (17m 56s):

My recent campaign was we switched MS, which showed initially that I've got pain in my leg. I've got numbness in my leg, but the next flip of the switch was, I'm running. I'm still running in the marathon. This kind of fun campaign is actually admired. People really liked to participate in it worldwide. I've got an audience from the US, UK, Australia, India, Africa participating in these kinds of campaigns. The other campaign was "Beat MS with a campaign." It was on the similar lines that I have problems, but do you know what, I beat MS with a proper diet.

Ritu Kaur (18m 36s):

I beat MS With proper exercise. I beat MS with just music or just dancing. I think these kinds of campaigns have a very strong meaning. With these kinds of campaigns, I can actually change the perception of how MS is seen now all over the world. It is seen as a serious illness or chronic disease, but it is not seen as MS is there, but it cannot stop and cannot crumble anyone's spirit. The message of all the campaigns is this. It cannot crumble a spirit.

Geoff Allix (19m 1s):

As well as all the things you've talked about already, building community and raising awareness, you're also like me, a host of a podcast, 10 Minutes for MS, which is presumably for you and another great way to get your message out to people. What do you think that podcasts provide to advance the cause compared to other media?

Ritu Kaur (19m 45s):

I've always been talking about community building and creating awareness. This podcast is not just about awareness but it's also about education. It is about educating people about MS. That's the reason why I've got doctors worldwide talking about different factors of MS. Some doctors are talking about fatigue. The other doctor is talking about exercise. The other is talking about diet, stem cell therapy, or different kinds of treatments available. This is more focused on education. Other podcasts are also there. It is in the MS community. They are also very good podcasts talking about inspiring stories and creating awareness. Mine is totally focused on educating people about MS, which I think is very much required. In fact, I've got feedback from many people that they have learned so much from my podcast. They said, "We don't even hear from the nurses and the doctors." That's the kind of education I'm providing. The podcast is for education and my pages are for awareness and community.

Geoff Allix (20m 19s):

So, on the personal note, how do you personally find time to stay healthy and balance? Given how much time do you spend on your MS awareness work?

Ritu Kaur (21m 11s):

They say you should practice what you preach so that's what I follow. When I say that workout is important, no matter what, I have to take time even if it is late at night, even after dinner. If I have to walk, it means I have to walk. I have to clock my timing that yes, I have to definitely do two hours of workout every day, whether it is yoga, strength training, or just walking. It has to be a workout. I have disciplined myself that way. My health is my priority, so I have to take care of it. My workout schedule is very much strict as is my diet. I'm an Indian.

Ritu Kaur (21m 52s):

They say that gluten is very much of a staple diet for us because we have rotis, chapatis, parathas. Trust me, I love those. It was difficult for me to leave aside gluten and wheat, but where there is a will, there's a way. I managed to do that. For example, I replaced my gluten, my wheat with quinoa flour. We have alternatives available. Only if you want to really look for it, you will. That's how I have done. I have when taking care of my diet, my exercise, my sleep pattern. It has to be eight to 10 hours of sleep definitely.

Ritu Kaur (22m 41s):

Like I said, I give priority to my health. I stay away from stress as much I can. I do whatever makes me happy. If something is giving me stress or burden, I just want to quit that thing. I'm not a quitter, I'm a fighter I know, but my health is my priority. I don't want to disturb it in any way. Other than that, I am still on DMDs. Like I said, my first DMD prescribed by the doctor was Avonex. I'm still on that. It is a weekly injection that I had to take myself so I'm following that.

Geoff Allix (23m 3s):

You mentioned about avoiding stress but is there anything specific that you do day-to-day to keep your mental health? There's definitely a mental side to MS as well and there's a tendency for people to get depressed or feel blue. Do you do anything the day-to-day to help with that side of things?

Ritu Kaur (23m 42s):

I just feel that my positive outlook has really helped me through this journey. I believe in looking at things from a positive aspect. If something is going wrong, I see it as wrong, but if I look at the other side of the picture, maybe it's something for good. I just believe in three things. Whatever happens, it's for good. This is one mantra. The second is if God is putting you in a trouble, then it's his responsibility to take care of all of it so you don't have to worry about it. He will take care of you. You are his child, so you don't worry about anything. The third thing is, of course, my family environment is really good.

Ritu Kaur (24m 22s):

I have a very supportive family. My parents, my siblings, my husband, everybody's very supportive. They know how I am. They, themselves, help me keep my positive spirits alive. I am today, a 36-year-old lady, a woman. If you see me at home, I don't behave like anybody older than 20. I still dance and jump around in my house like I'm 20 years old. Keep yourself young with all the positive ways that you can. Meditation is really important, I have to say that. I

do 45 minutes of exercises including meditations every day. It not only calms the mind, but it will also help to gain a lot of patience and it really helps you cool down your mind. That is one thing which I think a person should follow. So, keep yourself young or by all the positive ways that we can.

Geoff Allix (25m 17s):

Well, thank you so much for being on our program, Ritu. You are truly an inspiration to the MS community. The work that you've done has helped transform the MS landscape. On a final note, if you looked forward five or 10 years into the future, what would be the single greatest change or impact you would have liked to have made with the work you're doing?

Ritu Kaur (25m 57s):

I have already started seeing the change. Like I said, I am seeing the changes that people have started accepting this as a disease that cannot stop and crumble them. I'm changing the perception of how it is seen in India. Now, people are talking about MS as a disease in India. I really pray to God that someday, this taboo just breaks away. There's no more there. There is no problem for MS patients to find jobs. There is no problem for MS patients to have partners in their life. There is no problem for MS patients to live confidently because MS is not a punishment. It is definitely not your fault so why shy away or be scared? Live confidently. I think I'm getting closer to this, and I really want to see a 100% change or total turnaround from what it is right now in the next five to 10 years.

Geoff Allix (26m 34s):

Thank you very much for joining us.

Ritu Kaur (26m 37s):

Thank you so much, Geoff, for your wonderful time.

Geoff Allix (27m 16s):

Thank you for listening to this episode of Living Well with MS. Please check out this episode's show notes at www.overcomingMS.org/podcast. You'll find all sorts of useful links and bonus information there. Do you have questions about this episode or ideas about future ones? Email us at podcast@overcomingMS.org. We'd love to hear from you. You can also subscribe to the show on your favorite podcast platform, so you never miss an episode. Living Well with MS is kindly supported by Grant from the Happy Charitable Trust. If you'd to support the Overcoming MS Charity and help keep our podcast advertising free, you can donate online at www.overcomingMS.org/donate. Thank you for your support. Living Well with MS is produced by Overcoming MS, the world's leading multiple sclerosis healthy lifestyle charity. We are here to help inform, support, and empower everyone affected by MS. To find out more and subscribe to our e-newsletter, please visit our website at www.overcomingMS.org. Thanks again for tuning in and see you next time.