



Community Conversations

The Roles of a Mental Health Professional and a Spiritual Coach

Episode 21

Host: Welcome back to the Can Do MS Podcast. This episode is part of our Community Conversation Series. Today, we will hear from psychologist, Roz Kalb, and spiritual director, Rhonda Canby, as they discuss how their disciplines overlap and what that means for people living with MS.

Roz Kalb, PhD: Hello, I'm Rosalind Kalb, I'm a clinical psychologist and I've been involved with Can Do MS for about eighteen years and the mental health care team has been a key part of all of the work that is done for individuals affected by MS. But I'm very pleased to be here today with a friend and colleague, Rhonda Canby who is a spiritual advisor and she and I are going to have a conversation about our respective roles in helping people live with the challenges of MS. Rhonda, can you tell us a little bit about yourself?

Rhonda Canby: Yeah. I was a lawyer in a big law firm at the time my late husband was diagnosed with Alzheimer's disease. I slowed my life down and tried to find meaning again in a new way and I did find that through spiritual direction. So after he passed away about four years ago, I decided to go ahead and wrap up my career and become a spiritual director. So I've studied and become a spiritual director. I've been doing that for the last few years. I also work as a hospital chaplain and I have a special affinity for families affected with neurological diseases, of course, and especially with multiple sclerosis. So I'm glad to be here today. Thanks, Roz.

Roz: That's wonderful. So let's get started.

Rhonda: So what role does a mental health professional play in the MS Health Care team?

Roz: Well, fortunately, it's a growing role and has grown over the years. So I think our primary place in the team is to help people manage the challenge of the disease with a particular focus on the emotional changes that can occur particularly depression and anxiety which are very, very common symptoms of MS. And also with the cognitive challenges or the changes in thinking memory and attention, which can affect at least 65% of people with MS. So these mood and cognitive changes obviously affect both the person who has the disease but also

family members in a very profound way. So the mental health professional is there to help educate, to help people communicate with one another about these very, very challenging symptoms and just basically to navigate this pretty tough journey that people have.

Rhonda: So how does grieving fit into a person's adaptation of a diagnosis of MS?

Roz: You know, I think that grief actually plays a very significant role. When I first started talking about grieving and MS, people were surprised because they said, "Well, what is there to grieve? Nobody's died. This is not like that kind of loss." But I think whenever a person is handed a diagnosis of a chronic unpredictable illness, it requires them to change the way they thought about themselves, to change their picture of themselves and when you have to give that up when you've taken a whole lifetime to put it together, that's a tremendous loss and individuals have to grieve over that loss before they can begin to try and put one foot in front of the other to move forward with managing their MS. The challenge in MS is that you don't just get to grieve once with a new diagnosis but you grieve every time the disease takes something away from you whether it's a cherished activity, a career, a role that you play at home or in your workplace or just anything that you can no longer do because of MS. There is a healthy normal grieving process that has to occur.

And you've mentioned in your own life that your spiritual path came out of the grief over the loss of your husband of many years. And so how would you describe the role of a spiritual advisor for somebody's living with the challenges of MS?

Rhonda: I think it starts with grief. I think that's exactly right and I lead grief workshops and I've been doing that for several years that's sort of my entree often into a spiritual direction relationship. It's exactly as you say someone hits that grief spot for maybe the 27th time in a single course of illness, but they hit that spot of grief and it often causes questioning of all of their earlier beliefs. Many of us grew up believing that God won't give me more than I can handle or as long as I'm doing good, good things will happen to me. If bad things happen it is because I deserve it. That sort of justice idea is built deeply into us and it's challenged when we have grief like this, a setback, as something that really seems grossly unfair. So I touch people often in that context of - why did this happen to me? Where is God in this? What in the world? Why am I not being rescued? Why aren't my prayers being answered? How did this happen to me? Why me? Why now? That's the beginning of our spiritual direction relationship to begin to explore that question.

Roz: I just have a follow-up question to that because I think I understand the questioning that people go through when they have that sort of belief system in their background. What happens when people don't have that sort of religious training or framework that they operate from? Is there still a role for you to try to help them to find that spiritual path?

Rhonda: Sure. Sure. The sense of meaning and purpose in life is the essence of spirituality and a sense of connection with something beyond our daily lives. So I talked to people often about connecting with nature with art, with beauty, with something that brings them out of

their present sadness and discouragement. So, yes, it doesn't have to come a religious perspective, but often there's a sense of internal justice and internal frustration that may or may not be expressed with religious terms.

Roz: So when you do this work, do you work with support partners or family members as well as someone living with the disease?

Rhonda: Yes, absolutely.

Roz: Because I know from my work that family members and support partners are impacted in a very profound way by the disease and I worry sometimes that both mental health professionals and others who work with them such as spiritual advisors have tunnel vision, right? And focus just on the person with the disease when everybody else is profoundly affected.

Rhonda: Right. Because I'm a support partner. I was a support partner for many years. I have a particular affinity for those people. I know you've worked for MS for your entire career, what is it that you enjoy about your work? What makes this fun for you?

Roz: It's true. It's been forty years, which is kind of an astounding number to me. But I think that I got involved and then got hooked because I felt so privileged to be allowed to accompany people on whatever path they took to manage MS in their lives. People are incredibly creative, resilient, hard-headed, and they just keep finding ways, creative ways to manage this. And so I think I've found it interesting, I've found it profoundly moving and I've also learned about how to live my own life because I was a lot younger when I started working MS. And I learned about how to manage losses and changes that happen to all of us as we age and I find myself all the time thinking, "I can handle this." I've learned how to handle this because I watched pros figure out how to manage changes in their life.

So if you were going to try to explain to somebody who maybe was hesitant or kind of had a negative reaction to thinking about the role of spirituality in their MS life, how would you explain to them how they might benefit from what they would hear from you?

Rhonda: I agree with you that it's a great privilege to work with people who are struggling and have struggled and have found creative ways to cope. So I guess I would see myself in the role of coming alongside someone in that journey and to work with them in whatever way is meaningful to look for language that is comfortable for them, to look for spiritual practices. When I say the word spiritual practice, I'm thinking of anything that brings you to a place of moving outside yourself to a connection with something greater than yourself. For many people, that involves meditation, maybe a prayer, maybe just getting away to a place in nature, maybe doing something creative artistically or musically. So to just work with that journey to help people find a regular way to move outside of the anxiety and depression and grief. That is so common in everyday life particularly living with a chronic illness.

Roz: It makes a lot of sense to me, I guess, and it seems very similar in many ways to the kinds of things that we as mental health professionals might do as well.

Rhonda: Yes. So, I am turning that question back to you. When are mental health professionals most helpful?

Roz: I think that it's really at times of transition. So certainly at the time of diagnosis as we've talked about, that's a major life change, it throws people off the rails for a while and they may need to work through that grieving process and figure out who they are now that this has happened and what are the next steps. But then I think that it's often when something else major changes that people find themselves coming back to talk again. So, for example, somebody who is starting a new relationship that might become a permanent partnership and they're trying to figure out how MS fits into that and how to navigate the unpredictability of the disease with a life partner, or they may be struggling when things at work become difficult and they may need to think about how to change the work that they do or do it differently. I think also other major life transitions, whether to have kids or having kids. So I think of us as coming in, sort of, as coaches and consultants and supporters when something happens that makes the ground feel a little shaky and people want to reassess their options and their priorities.

Rhonda: So, if a family member or a friend believes that their loved one with MS would benefit from seeing a mental health professional, how would you suggest that person bring it up? We know that many people resist talking to a therapist.

Roz: Yes, they do. And I think that some of that has gotten better over the years. There's somewhat less stigma than there used to be and also in MS care now, the role of the mental health person is really talked up. It is talked up by neurologists, it is talked up by nurses just to help people navigate these challenges. So I think it's really helpful to take the focus off the mental part of mental health. This is not about being crazy, it's not about being weak or somehow dysfunctional. It's about consulting with someone in the same way you would consult with an attorney or a financial planner or your dentist because this is hard and so you want to talk about your feelings, your priorities, your choices, your options in a safe environment, right? You want to be in a place where raising questions and being supported is comfortable. So you don't have to go in and talk about your whole life history and your dreams and all that unless you choose to. What you can focus on is - how do I get to the day and how do I deal with all these feelings I have which sometimes feel over the top?

Rhonda: So a conversation about that. I, as a family member, coming to my person living with MS, what might I say? Would I just describe that it's not the role that you used to imagine? It is somebody who can help you think about things differently. How would you start that conversation?

Roz: I think that's a very good way to do it to talk about a safe place, a comfortable place to just think about your feelings, your choices, your options, and to say that it's something to try,

right? You don't have to sign up for life. You can go to meet somebody and try it. If you don't like the person you try first, you can try somebody else but it's really just an opportunity to see if this is another tool that you can use comfortably to help you manage your MS. And I'll go with you. I would be happy to be part of this with you if you want me there you don't have to do it alone. I think it would help us.

So now that we've talked about a lot of these aspects of the work we do, do you see our roles as very different from one another or similar?

Rhonda: I think they're complementary. I think my role would be helping someone look interiorly to how they can cope in a better way and yours is too. You have a different set of tools that you use but I often work with people who are seeing a whole host of people. They have doctors, they have therapists, they have a whole group of people that they say, "I'm just one, I'm one member of the team is how I see it." And not every person benefits from having this team member working with them. That's fine. So sometimes I would say to someone if someone came to me and had issues that seemed more deeply psychological or about relationship building or coping with some of the issues that you focus on more, I probably would suggest that they pull in another team member. I would suggest, "Let's call someone who's a psychologist and see if we can bring that into the mix of our conversation."

Roz: I'm glad that you said it that way. We talked so much at Can Do about the healthcare team and how we collaborate with one another and work together to help folks with MS and their family members. So two think of you as on our circle of team members and pulling you in in the same way you described pulling us in so that people see our work as complementary, I really like that. So if somebody comes to a consultation with you, what does it actually look like or sound like?

Rhonda: I usually ask them to start with silence and if they have a meditation practice during our silence, they are welcome to use that. But I usually don't interfere or interrupt that. I ask them to let me know when they're feeling centered and ready to talk and then we just explore what's going on in their lives and how it's feeling to them, in their interior. I meet with people usually once a month over a long period of time so we try to track issues from the beginning at the first meeting or two, we probably would just be getting to know one another and over time, we would be talking about how the same issues may keep coming up and how we might address those in any way. I would be trying to remind them perhaps of an issue that they had talked about in a way that they had found a successful solution at an earlier time. So it's a long-term relationship with a little bit of accountability involved and a little bit of tracking so we just get to know one another, feel comfortable with one another, and raise the same issues over and over until we feel like there's really nothing more to discuss. So it's a long-term, slow, and easy maintenance kind of relationship more than a crisis-intervention type of relationship.

Roz: Great.

Rhonda: So your question makes me think about all those people who associate psychotherapy with lying on a couch and talking about their family for years and years. So how would you describe the work you do with individuals and family?

Roz: Well, it's actually similar to what you described. So I am a clinical psychologist and if people have particular mental health issues or background issues that get in their way or that are affecting their present-day lives, of course, we might talk about them. But mostly in my work with MS, I'm working with people who might never have sought out a mental health professional if they hadn't suddenly had to deal with the challenges of an unexpected and unpredictable chronic illness. So I think we sit in an office typically once a week for several weeks to get over whatever particular issue is. But what we're looking at is how they're approaching the challenges that they have. So what is this experience like for you? Have you had any similar things in the past that you have learned from that you could apply those lessons to managing the current challenge? Are you thinking about it in the most helpful way or do you really need to reframe the way you're thinking about the current challenge to make it something that you're more able to fix or change? So it's how we think about things, how we react, what kinds of problem-solving skills people are bringing to bear. Sometimes people have very good problem-solving skills, but sometimes they need to learn slightly different ones.

And, again, because I have mental health training if I think that either cognitive issues or mood issues like anxiety or depression are preventing people from doing the work they need to do to manage their lives, then we need to focus in on those symptoms and make sure that people are getting optimal treatment for them so that then they're in the best shape they can possibly be in to do the problem solving that they have to do.

Rhonda: So we're bringing in the rest of the team?

Roz: Absolutely. We are always bringing in the rest of the team. And that reminds me that as you said, it's almost never just about the person with MS, it's also about all the people who were involved. Particularly, support partners, children, sometimes parents who are struggling with how to live with this, how to help, when not to help, and just how to understand what's going on. So, for me, even if there's only one person in the room with me, we're talking about the whole constellation of people who are involved and where possible and like to work with the support partners and the families as well. Because as one person said it to me not very long ago, "This is not a me-disease, it's a we-disease," and I think that that's a really good description.

So let's hope that our listeners are convinced that you and I can each be helpful in a variety of ways. How would somebody go about finding somebody like you, Rhonda?

Rhonda: I work at a retreat center, and I also work through my church, and mostly I work with referrals now. But there is a website called Spiritual Directors International and if you go on with that website, there are sources for spiritual directors from pretty much every spiritual

tradition there might be in pretty much every part of the world. So you can find names of people and I always offered a first-visit free to just see how we fit together and I don't mesh perfectly with every single person but there are lots of spiritual advisors out there who come to the practice with very different ideas of how it should be done. So I just look for a good fit. I look for a place where we can feel comfortable together and I'm hoping that they're doing the same thing.

Roz: I am very glad we've had the opportunity to do this because I've learned a lot about how someone in your role can fit into and complement the kinds of interdisciplinary work that we talked about and do at Can Do MS. It just makes good sense to me. So, thank you.

For those people who are interested in finding a mental health professional to consult with, I think the best place to start is by calling an MS Navigator at the National MS Society. That's 1-800-344-4867 and they will be able to help you find somebody in your community. If you are struggling to find somebody who is familiar with MS in your community, anybody who is a health psychologist or has a particular focus on helping people with illness and disability that tends to be a good fit. So that's where I would start. They have access to a huge database of mental health professionals and can help you try to find somebody who's a good fit for you.

Rhonda: Thank you.

Roz: Thank you.

Host: Thank you, Roz and Rhonda, for the engaging discussion and thanks to our listeners for tuning in to this episode of the Community Conversations Podcast Series. We would also like to thank our sponsors: Biogen, EMD Serono, Sanofi Genzyme, Celgene, Genentech, and Mallinckrodt Pharmaceuticals for making this series possible. Be sure to check out the other episodes in our Community Conversation Series featuring more discussions between healthcare professionals. For additional resources, please visit www.cando-ms.org to check out our online webinars and webinar archives.

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