

Relapse and MS Series Maintaining Employment and Emotional Well-Being During a Relapse Episode 9

Rachel: Hello and welcome to the Can Do MS Podcast. My name is Rachel Lahti and I am the program coordinator for Can Do Multiple Sclerosis. We are excited for today's podcast which is the second episode in our three-part relapse in MS series where you will learn how to manage potential relapse related challenges at home, work, and in your relationships. In this podcast, you will hear from an employment expert and a psychologist as they share strategies on how to handle a variety of work situations impacted by a relapse. The team will use real-world scenarios to provide recommendations to help you navigate the impact a relapse can have on your work life and emotional well-being. With us today, we have psychologist, Dr. Roz Kalb, and Employment Specialist, Dr. Phil Rumrill to share tips and resources on how to manage potential relapses related challenges at work. Welcome, Roz and Phil. So Phil to get us started, would you please tell our audience a bit about your career experience as it relates to MS employment.

Dr. Phil Rumrill: I am happy too, and good morning, good afternoon, good evening, everyone, whatever the case may be. It is a great pleasure for me to be here and Rachel is working with you on this, and to share this program with Dr. Kalb. I will call you Roz if that is all right?

Dr. Roz Kalb: Sure.

Dr. Phil Rumrill: I am delighted to do this and have the opportunity to work with you again so happy to be here. I have been working with people with MS for about the past 25 years or so. Currently, I am a professor of Rehabilitation Counseling at Kent State University. We trained counselors to provide vocational and other services to people with disabilities. We have had a number of research and service projects funded by the National MS Society and other organizations over the years, and MS has been an area of keen interest to me for most of my career. We have done a lot of research in the area of employment people with MS. I have done a lot of clinical and direct service work with folks with MS regarding employment and life after multiple sclerosis. And having Roz's perspective as a psychologist is really a perfect complement to what would be talking about today because the psychosocial adjustment to the disease is a major part of the ongoing employment decision and deliberation that people make. So how it affects people is psychological and social functioning, and the people around them is very, very important. I am glad we are able to look at it from both of these perspectives here in one call. I am glad to be here and looking forward to our discussion.

Rachel: All right, great. Thank you, Phil, and thanks for sharing and that is a great segue way into Roz. So Roz tells the audience a little bit about yourself.

Dr. Roz Kalb: Well, thanks, Rachel. I have still beaten by a little bit. I have been a psychologist in the field of

MS for over 30 years but I am thrilled to be doing this with him because he is one of the best-known experts in the field of MS employment and we have had the opportunity to work together in the past, and I agree with everything he said about how the issues of mood and cognition and decisions about employment go hand in hand. I am looking forward to this as well.

Rachel: Excellent. All right, well, we are really thankful to have you both with us today. So now for this podcast, we are going to present three real-life scenarios of a person or a couple going through an MS relapse. Well, then here recommendations from Roz and Phil with ways to handle a variety of work situations that could be impacted by an MS relapse. So let us get started. Our first scenario is Jeanette. So Jeanette is a 26-year-old, single woman who is employed by a busy marketing firm. She was diagnosed with MS three years ago and has been relapsed free since starting a disease-modifying therapy. But yesterday she woke up feeling exhausted and week with high anxiety. She had difficulty walking and her thinking felt sluggish and even foggy after a cup of coffee. She called in sick to work and then called her neurologist who suspects she is having an MS relapse. So now Jeanette has to decide what to tell her employer. So, Phil, does this relapse mean Jeanette should disclose her diagnosis to her employer?

Dr. Phil Rumrill: Well, not necessarily and perhaps particularly at this time at this early stage in the disease process. Number one, given the fact that Jeanette has been asymptomatic relapse-free, it sounds since her diagnosis there may not be a need. In fact, if I were working with her directly, I probably would encourage her not to disclose her diagnosis of MS at this particular time. I think I would encourage her to take sick time and normally when you take sick time, you do not have to disclose the nature of the condition. In fact under the Americans with Disabilities Act, you very rarely are required to disclose your actual underlying diagnosis of multiple sclerosis. Usually what we tell people is until or unless the person has a need for an accommodation at work related to the effects of MS, there is no need to mention the diagnosis. Sometimes you have to share with your employer certain effects of the condition particularly if it affects your job performance but we tend to encourage people early on to speak about the condition in general terms. So I am feeling tired today or I am feeling sick and therefore I am going to take the day off.

The reason why we encourage people to start by not disclosing all of their details about the diagnosis is number one, there is no legal obligation to do that. Number two, it is your right to privacy, Jeanette's right to privacy in this case, and if she volunteers more information then she is comfortable in doing, she can never get her privacy back. Once it is out, it is kind of out. But does not mean that the employer would necessarily find the fact that she is diagnosed with MS stigmatizing. But Jeanette may not be able to really articulate what it means to have an MS because for the past three years she has not been experiencing symptoms. She does not know how long this particular relapse is going to last. She does not know what her disease process is going to be owing to the unpredictable nature of the illness itself. So there is a lot of uncertainty there and I would tend to suggest that she would focus on those specific effects of the job. Pay very close attention to changes in our health status. The symptoms that Jeanette is dealing with our sort of classic MS symptoms. You are seeing the fatigue which is certainly the most common symptom of all.

You are seeing as you seem perhaps the beginning of cognitive impairments and a large proportion of people with MS experience that and those can be very difficult to accommodate the anxiety which could be due to organic changes in the brain as a result of MS. Or could be the result of the adjustment to a condition that for many people is a really lousy thing to deal with then the mobility and physical stamina those kinds of things. She is getting a wide range of symptoms but these symptoms might only last a day, they might last two days, etcetera. So erring on the side of speaking to your employer functionally about what you might need. I am feeling tired and today I would like to work at home if I could for a couple of hours. I do not have to give away your MS diagnosis, that is your privacy. As far as cognition related accommodations number of ways she could contact her neurologist, cognitive neuropsychology later on in the process

perhaps to help to identify the specific areas of cognition that she is finding difficulty with. All kinds of uses of technology from iPad or tablet, computers, and applications that can be used to compensate for memory problems, executive functioning problems, etcetera.

Visit the website to the job accommodation network for ideas about how she might accommodate the symptoms that she is dealing with right now. Perhaps more importantly than any of this is the importance for Jeanette of monitoring changes in our health status. Becoming her own best expert on how MS is affecting her and just as importantly how MS is not affecting. So looking at the ways where because you might have MS, you might have these symptoms but you are also entitled to get a cold or to get the flu or to have a headache and it may or may not be related to MS. You do not want to over attribute things that are going on necessarily to your MS but you want to pay attention to changes in your health status over time. Also, I want to pay close attention and Jeanette wants to be your own best expert about her job performance. She wants to identify problems with job performance before the employer does because there are many things that she might be able to do that may not even involve intervention from the employer before the employer brings her attention.

So understanding how MS affects your health and functioning, how it affects the way you feel, how it affects the way you think in process information. How it affects the people in your life and how it affects your job performance if you are working, and we talked about if you are working because the vast majority of people with MS are working at the time of diagnosis. So early in the disease process, the issue is really center on job retention rather than job acquisition. And as a voc rehab person, I can tell you it is much easier to help someone keep a job than it is to start a whole new job search process. So we like to get involved early in the process and what is working to Jeanette's advantages her symptoms have just started, she is been relapsefree for a while. Symptoms may be very intrusive but it does not appear, they have begun to progress at this point. She still employed, still productive. She is got age on her side because she is young and a lot of energy and so these are the things that she has to work with going forward. But it is very important to develop that kind of contingency plan for what happens during those next symptoms. But it short way to end a long answer would be to say I would not suggest she disclosed her diagnosis of MS at this particular point.

Rachel: All right, great information there Phil. So now from a different perspective, Roz, what concerns do you have about Jeanette's situation from an emotional wellness point of view?

Dr. Roz Kalb: I really appreciate Phil's very comprehensive and thoughtful answer to Jeanette's situation. I really just want to emphasize a few points that he is already touched on. For those of you who joined our relapse podcast on relationships. We talked about a relapse being a crisis in particularly for somebody like Jeanette who is been relapsed free for three years. This really must have come as a bolt out of the blue caught her off guard and I am sure is responsible in some way for that anxiety she is feeling. She woke up and did her usual MS morning body check, what is working? What is not working? So well today and found herself in a relapse. I think this is a time of crisis point when once the physical symptoms have subsided a bit. She may very well want to speak with a counselor who is knowledgeable about MS just to deal with her feelings about this unpredictable disease and how she is going to start managing that not just in her workplace but in her life and her relationships with other people. Anxiety is can be a very crippling emotional feeling and so we really want her to get help and support to deal with that. Also as Phil mentioned there is the possibility here that we are seeing the beginning of cognitive changes. Now, there can be cognitive relapses or relapses in which cognitive symptoms occur and then they may subside as other symptoms may subside after a relapse or there may be some continued cognitive change following this relapse.

We do not know yet but this would be the time for Jeanette to be screened for cognition. This would help us get a establish a baseline for her. This is how her cognition is at this point and that is the recommendation from the National MS Society. At this point, the people have a baseline cognitive screening and then get screened yearly after that. And to Phil's point monitoring her cognitive change over time if it progresses will help her plan proactively around her employment and plan on finding the treatment, the rehabilitation services, the accommodations that she might need to help her continue to be a very effective employee at her job. She may also have a lot of anxiety about the cognitive changes and her ability to continue her busy career. So again, the cognitive screening and the counseling go hand in hand here. I think we should mention that and I totally agree with Phil's advice that if you do not have visible symptoms and you do not require accommodation, there is certainly no need to disclose in the workplace. But we have met some individuals who worked in a small work setting. They were very close to their employer and their colleagues and they found not disclosing highly stressful. So this again is a very personal decision. It is important for Jeanette to know that she is not in any way required by law to disclose but in talking to the counselor particularly a vocational counselor like Phil and his colleagues. It is important for her to discuss her own personal feelings about keeping this information private in small close worked settings.

Dr. Phil Rumrill: Agreed. 100% perfectly put.

Rachel: Yes, yes. Some great tips here for dealing with an employment situation while also keeping your emotional wellness in check. Thank you for your responses, Phil and Roz. So moving on to our second scenario. We have Barb and Kyle, a married couple with one young child. Kyle is a teacher and he has already disclosed his MS diagnosis to his employer. Barb works as an administrative assistant in a law firm. So Kyle's symptoms have been relatively mild and manageable since his diagnosis. But he woke up three days ago with blurred vision, weakness on his right side, and impaired balance. His neurologist is treating the relapse and Kyle and Barb are trying to figure out how to manage until he is back on his feet. Kyle is dealing with mild cognitive changes and is now concerned about his ability to keep teaching over time. Barb and Kyle are really dealing with a variety of issues here. So how would you start addressing these challenges presented because of this relapse Phil?

Dr. Phil Rumrill: Well, I think a couple of wrinkles here that are different than Jeanette's case when is Kyle has already diagnosed his MS to his employer. He does have that entree[?] and may need to think about what. Once you have made the initial disclosure then the issue becomes what do you tell them as time goes on? What things do they need to know and what kind? Now that they know you have MS, they may attribute anything that you tell them in terms of difficulties or need for accommodation to your MS. It is important to very judiciously to think about what it is you want to share about what is going on with your health status and before you say anything to your employer, I continue to emphasize any chance I get with folk has figured as much of this stuff out for yourself as you possibly can. You do not want to put the employer to work as a service provider helping to solve the problem. They will help to solve it, many employers are willing to do that but the more information you can give them.

So Kyle wants to talk to the employer, not just about the cognitive difficulties that he might be having. He also wants to come prepared with solutions to those cognitive challenges that he is experiencing. Employers and my experience are much more amenable to providing accommodation if you give them not only the problem but the solution. So you say look I am having difficulty with this particular function of the job and here is what I think would solve the problem. That is a much more difficult thing to refuse or to get bogged down and then if you say, "I am having this difficulty and I am not sure what to do about it." So Kyle's an educated fellow, he is a teacher. He is in a cognitively intensive occupation where a mild and maybe that is a euphemism or as mild cognitive impairment because they can be very intrusive. But the beginning of cognitive impairment could be very disruptive to the job as a teacher. He is also having some

visual symptoms and on and on an intermittent basis and so there may be some technology that is required as far as that goes.

I would start by encouraging Kyle, first of all, get as Roz mentioned some screening on the cognitive stuff. Find out what is going on, find out what areas of cognition are being affected. He may not be able to articulate it, he might say my thinking feels kind of sluggish or it is fuzzy but really what he is dealing with is intermediate-term memory. What I had for breakfast this morning or yesterday? Or maybe he is having difficulty with executive functioning, the organizational sector of the brain. A cognitive screening can with a neuropsychologist, can help them to pinpoint those areas where he is having difficulty. Is he having difficulty processing information that his students present to him verbally? So is it an auditory processing issue that he is having? He has difficulty grading papers because of a slight visual impairment and he is not tracking and able to see punctuation and things like that. Is he having difficulty managing and organizing his time were are those issues? And finding out not only can the neuropsychologist help to identify those areas of cognitive impairment but also can help to identify compensatories solutions. So the beginnings of technology-based solutions, he is a teacher, he is probably as a laptop, probably has an iPhone.

Now we can start looking for applications that are commercially available, not just for people with disabilities but they make them for executives, for elderly people that can help to enhance cognition to store information verbal auditory electronic prompts instead of you having to keep track of when your appointments are there. Your tablet can let you know. There is a lot of these ways you can accommodate himself and he may want to start doing that in his life in general. I think again it gets back to that self-monitoring, early screening, preventative problem-solving, you are heading off the issue before it really becomes problematic. Being very objective and honest with himself about the areas of his work that are affected. Figuring out solutions that he can identify and at that point then bringing them to the principal to his department head or whoever his supervisor might be, and again bring them the solution at the same time. I noticed them having some difficulty with this. You know I mentioned I have MS. I am having trouble tracking things visually on my PowerPoints so I am just going to enlarge the text and if he is doing that he may not even need to mention that. Some of these technology-aids are so unobtrusive that there is no need to mention these sorts of things.

And in my remarks so far, I am talking about the kind of keeping all this information from the employer. Keep it to yourself, etcetera. Sometimes that can be very stressful as Roz mentioned. Sometimes you want to lay it out, you want the support. You need to let people know what is happening because they care about you, and that is very important too and it is a totally personal decision. My own experience tells me that people with MS will tend to over disclose rather than under disclosed. I am usually helping to keep people from telling too much and want to encourage them to be very thoughtful about that and to figure out as many solutions on their own. You want to present the solution to the employer. You do not want to put the employer to work in developing that solution any more than is absolutely necessary. So that is what I think about the employment situation in Kyle's case. Now Kyle is married and has a young child and I know Roz will have some suggestions related to the impact of MS on significant others and family. So I will stop here as far as that goes and turn it over to you Roz.

Dr. Roz Kalb: Thanks very much, Phil. And again, I want to call out some things to emphasize in all of this. It is absolutely essential at this time for both Kyle and for Barb that they have a better understanding of what is going on with Kyle that cognitively. Not everybody has to access to neuropsychologist that depends a lot on where they live, urban or rural areas. And so other good members of the healthcare team to keep in mind our speech-language pathologists who also evaluate cognition and are excellent helping people come up with workaround solutions to accommodate whatever problems they are having. And occupational therapists as well a wonderful with the kinds of technology adaptations that might be helpful to Kyle. In

working with these specialists, it will help both Kyle and Barb have a better understanding of how these problems might impact to Kyle in the workplace but also in their relationship and at home. The strategies that will work in one part of one's life can frequently be very helpful in all parts of one's life and Barb needs to have an understanding of this because this is one of the invisible symptoms of MS that is most stressful for care partners and kids.

Because they can not see it and it needs to be explained, and Kyle needs to be able to explain what is going on with him and what he needs. In terms of discussing possible accommodations with employers and with colleagues, I think the National MS Society booklet called the win-win approach to reasonable accommodations really plays out in detail what Phil has been talking about in terms of going to an employer with the solution. You want the message to be that if I have an accommodation that works for me, I can be the best possible employee for you. Or in Kyle's case, I can be the most effective teacher and so I am going to present you with these solutions and again the job accommodation network. It is an excellent source of recommendations for particular accommodations on how to implement those accommodations and the speech-language pathologist or the neuropsychologist or occupational therapist can also help Kyle come up with the suggestions. Now, because of the career that Kyle is in it is possible if the cognitive changes progress that he may have a lot of difficulty in the classroom. So it is not too early for Barb and Kyle to begin to think about what might they need to do in terms of changing their there career planning a little bit to accommodate that if Kyle ends up not being able to be in the classroom.

This would be an excellent time for him to talk to a Voc Rehab specialist just to think about ideas for possible retraining or other kinds of work where he could put his knowledge and skills together in ways that would not be as impacted by cognitive changes or visual changes if those continue. This is called planning for the worst while hoping for the best. You do not want to be caught off guard in the future. You want to have thought through how you would want to handle such an adaptation in your lifestyle if you needed to make it. It is something that Barb and Kyle need to do together because changes in Kyle's employment status might affect Barb's work as well. All of this of course can be very stressful and so again an optimal time for Barb and Kyle perhaps to sit with a counselor just to talk about their feelings about this if they are having trouble communicating with each other. They are too anxious or they are worried about upsetting each other, a counselor can really help make those conversations easier more accessible so that they can be more comfortable talking to one another. I would really encourage follow up around the cognitive symptoms but also emotional support for both Barb and Kyle individually and as a couple

Rachel: Yes, wonderful information. Thank you, Roz. So before we move on to our final vignette, I just wanted to circle back about Kyle. Kyle might have to take off of work in the short-term. So Phil do you have any recommendations on how people might handle that situation as far as what to use, leave time, sick time? Could you tell us a little bit about that?

Dr. Phil Rumrill: Yes, kind of depends on the length of time the person needs to take the length of the leave. And with MS, this is complicated because when you are having a relapse you do not know whether it is two days or a week or a month or whether your symptoms might persist over a period of time. And whether you need to leave too kind of regain your energy and rest or whether it is on a larger scale. The first thing that most people do is they would take accrued sick time as the first option and that would be if you need probably a week or less of time off. You would start by taking accrued sick time. Teachers accumulate sick time fairly in public schools accumulate a fair amount of sick time so you have that leave. Other employment situations, you do not have sick time, you just have accrued time off regardless and for any reason so it does not even have to be sick time. And sometimes for folks with MS, they find that even better, it is not stigmatizing. So you get for weeks a year, it can be a vacation, it can be sick, it can be personal, it can be whatever you want. Start by taking believe that requires the least documentation, of course, and is the least

intrusive kind of all the way around, then it can progress out to short term disability and these usually leave of a couple of weeks up to about 90 days. And after 90 days, there are long-term disability provisions that most school districts would have in place if he was going to have to disengage from the workforce kind of on an ongoing basis.

There is another at law that provides called The Family and Medical Leave Act which has been in existence now for about 25 years and also known as the FMLA. The FMLA allows employees who work for employers with fifty or more employees. So you have to be a medium, a company of that size to take up to 12 weeks of unpaid leave per year and this would be after you have exhausted your sick leave. You can take up to 12 weeks of unpaid leave per calendar year while still maintaining your job. The employer would be responsible for finding in this case a substitute teacher for that period of time. But because that leave is unpaid you would want to make sure that you have exhausted most people who want to use all of their paid leave prior to the use of FMLA. FMLA also allows you to take time off to attend to your own serious health condition is what they call their term for disability or the serious health condition of a family member. So a spouse or partner or child or parent can take time off to provide care to a person who has MS, who was a relative of theirs. It allows the caregiver to take some time off too, and we find that many caregivers of folks with MS will take family members, will take FMLA time as well. So there is a lot of options as far as time off but for a day or two here or there you use your regular accrued sick time for more time off than that you go to either short-term disability which is typically paid or FMLA which is typically unpaid.

Rachel: All right, yes. Great recommendations and not only for the person with MS but also, the person in that supportive role. So thank you so much, Phil. All right, so moving on to our final scenario. So we have Maggie and Louise who have been together for 10 years and they are in their early 40s. Louise's MS has been difficult to control and choose to experience more than one significant relapse in the last couple of years. So both Maggie and Louise are employed as nurses at different community hospitals. Louise is currently experiencing a relapse that is affecting her thinking, mobility and causing worse than usual fatigue. She needs assistance with daily activities and she and Maggie are trying to figure out what to do until things are back to normal. So Phil, what are your thoughts on Maggie and Louise's situation?

Dr. Phil Rumrill: It sounds Louise's condition is dealing with more severe symptoms across a wider range. She is having to kind of she is needing care and sounds like in the home. And so now this decision that Roz had mentioned earlier on about future planning, about when it is time to disengage from the labor force. How do we modify it for there is time to find a whole new career, etcetera. These issues really come more to the forefront in this particular case because the symptoms appear to be quite significant and perhaps progressive. Here, I would remind you also of FMLA protections if Maggie needs to take time off to care for Louise, she can do so under the FMLA. So that is a nice benefit at least while they are sorting out the need for In-Home Care, the need for accommodations in the workplace. I am guessing that if Louise's case is such that she needs assistance in the home. She is probably needing significant accommodations to continue her work in the hospital. So here the issue of accommodations becomes very important. The issue of communication with the employer becomes important here.

We also want to start talking about future planning. Are you able to continue doing this job? What are the benefits you have available as part of your employment? Do you have long-term disability benefits? What benefits could you receive from Social Security if the time comes to disengage from the labor market as a vocational rehabilitation person? I like to encourage people to stay working as long as they feel that they are able to do so. But we do know that MS on average lowers people's retirement age. People with MS stop working at earlier ages than people who do not have MS, and so understanding that practical reality even beginning the process of financial planning. So when one is early 40s, you are starting to think or thinking in more concretely about retirement and how much money you are going to have in retirement and

projecting that, and if you have a condition that might mean your retirement would come at an earlier age than it would otherwise. You have to start thinking about your overall financial plan within that context as well. So understanding the benefits that are available to you of making sure that Louise is getting the very best medical care she can. Are we alleviating as many of the symptoms as possible? So is she making this plan in her very best health status with all the treatment making sure that medication she is taking are working?

So kind of ramping up the self-management, the symptom management program, so that she is as healthy as possible back to that sort of hoping for the best but planning for the worst. So understanding your health status making sure you staying healthy when conserving your energy as much as possible. But thinking down the road and being practical and realistic about the eventuality where you might have to change jobs or disengage from the labor force. At some point, an understanding that how you make decisions regarding disability benefits and financial planning can have long-term implications for your future well-being including your health and your ability to maintain health insurance coverage and acquire treatment that you need are those kinds of things. Here we have got issues, a couple is issues that become more prominent as Louise's MS has progressed and both members of this partnership need to be actively involved, the need for open communication. Roz, I am thinking about individual and possible couples of counseling to just make sure that with the myriad of decisions that are kind of swirling about and needing for people to both be on the same page perhaps managing time off to provide care. We have kind of a complicated situation that really requires someone to arm themselves with as much information and advocacy about their health status, their benefits status, financial status, and long-term career prospects.

Dr. Roz Kalb: I could not agree with you more. They have a lot going on and one of the things that really jumps out at me is that Louise is trying to manage some very challenging changes related to her work and planning for her future as you have pointed out. At the same time that Maggie and Louise are probably beginning to deal with major shifts in their relationship where there is more hands-on assistance and caregiving required. They may be looking at a time when Louise is not able to work or bring in as much income and they have to be able to talk as a couple about how they are going to manage this. It is very stressful and I agree with you that counseling at this point is extremely important because our goal for Louise and Maggie is to help them keep a partnership that is as comfortable and nurturing for both of them, satisfying for both of them, and balanced as it has been in the past. And when there is a shift in care was one person needing more assistance from another, they really have to do some adjusting and thinking about how to keep their partnership balanced so that each person feels as though she is giving and receiving in the relationship. Also related to cognitive care the sort of goes back to what I started at talking about at the beginning in terms of getting a baseline assessment of cognition and then tracking it over time.

If one is going to apply for disability with cognition being a major factor in that application for disability. It is very important with cognition as with any other symptom that you are tracking progression over time. So that in the medical record when the doctor supports the application for disability, the doctor is able to point to a progression in the cognitive symptoms or any other symptom. So having periodic assessments every year or two will then make it possible for Louise if she needs to apply for disability on the basis of cognition to demonstrate why she needs it, how much progression has happened, and what the pace of the progression has been over time. So then they can work together as a couple and with the employer to plan for these kinds of changes and I just want to mention one very helpful resource. If you go to the National MS Society's website and look at SSD workbook. You can find a workbook that a person and the neurologist can use together when planning for a disability application so it is a challenging process. We really want you to know about this SSDI workbook and I think with all that is been said that Louise and Maggie will be able to navigate these very difficult changes.

Dr. Phil Rumrill: It strikes me Roz that MS just change at this level of intrusiveness. It changes everything, right and so the career, the relationship and no part of your life is immune to the effects of MS. Self-care has to apply all across the board and that is what makes it overwhelming in some ways.

Dr. Roz Kalb: Yes, I agree.

Dr. Phil Rumrill: And thinking about your mention of applying for disability. I often think in working with folks with MS that in order for people to get by psychologically, vocationally while dealing with MS, sometimes they have to marshal[?] what I refer to euphemistically as a functional denial. You have got to be okay, this is happening but even in spite of that I am going to persevere. The strength and courage that people have to draw upon in order to get through their daily lives can sometimes cause them to kind of minimize the effects of the illness. It is not that I am tired but not that bad or yes, I am having some trouble with cognition but I will be okay. I am okay, I am fine, right. But then when you go to apply for disability, you have to give the fullest accounting of your limitations or you are not going to be found eligible for disability benefits. There is the dissonance that goes on where the way you get through your whole life is to be, look, I am getting through this no matter what. But in order to get benefits, you have to kind of lay it out and I find people with MS are often red reticent to acknowledge the full scope of those limitations.

So knowing yourself and acknowledging the impact and the charting and progression over time. I find that something that people with MS often do not want to do because it limits their ability to sort of persevere in a way. If I really thought about how intrusive this was, I would throw in the towel and so in order to get by I have got to do that. There is that dissonance I think is in converting over to where you gotta pretend like it is not bothering you that much in order to go to work every day. But as soon as you decide to stop working, it is totally different psychology and Roz you have a more sophisticated explanation for that than I do psychologically speaking. But you know what I mean like there is that thing that happens where you have got a shift from a focus on what you do in spite of your symptoms to giving the fullest accounting of those symptoms and it is a hard shift to make sometimes.

Dr. Roz Kalb: Well, I agree with you and that is why this workbook can be so helpful because this really is a team enterprise. It is the doctor's responsibility to track symptoms and progression in the medical record with accurate input from the patient. But when you know that is being tracked by the doctor, I think it frees you up a little bit to go on about your life and do what you need to do to keep functioning at home and at work. I am hoping that people can take your advice and do both tracks what is going on with them carefully with their healthcare provider. But then focus on accommodations support networks, good communication to keep doing the things in daily life that are so important to them.

Dr. Phil Rumrill: Great point.

Rachel: Yes, and great information from both of you guys today. But unfortunately, that is all the time we have so we really hope this podcast provided our audience with some new strategies and tips on handling relapse related challenges in your work life. So thank you so much to Roz and Phil for taking it the time to share your knowledge and experience with our audience today.

Dr. Phil Rumrill: Rachel, thank you for having me and for this opportunity, and Roz always a pleasure working with you.

Dr. Roz Kalb: I agree. Thanks, Rachel, and I look forward to other opportunities to work with Phil in the future. I always learn a lot every time I hear you speak.

Rachel: This podcast is part of the relapse in MS Series, a collaborative initiative led by Can Do MS and Mallinckrodt to better understand how MS Relapses can impact your home, work, and relationships. Please remember to listen to all three podcasts in the relapse in MS series which are available on our website and apple podcasts. We also encourage you to view our relapse in MS Webinar which is available on our website, cando-ms.org/relapse. Thank you for joining us.

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