



## **Relapse and MS Series**

### **From Hospital to Home: Preparing Yourself and Your Home**

#### **Episode 8**

Rachel Lahti: Hello and welcome to the Can Do MS Podcast. My name is Rachel Lahti. I am the Programs Coordinator for Can Do Multiple Sclerosis. We are excited for today's podcast, which is the first 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 members of The Rehabilitation team as they share tips on how you can prepare yourself and your home after a relapse. The team will use a real-world scenario to demonstrate the transition from the hospital back to your home after an MS relapse occurs.

Rachel: With us today, we have physical therapists Mandy Rohrig and occupational therapists, Juliann Hanson to share their experiences, resources, and healthcare professionals that can help you prepare yourself and adjust your home life when you experienced a relapse. So Mandy, would you please tell our audience a bit about your working experience as it relates to MS?

Mandy Rohrig: Certainly. Thank you, Rachel. Hello, everyone. I am excited to be able to visit with you all today and to talk with Juliann. Clinically, I work in an outpatient physical therapy setting where I specialize in helping people with MS and their families as well as people who have balance issues. Also, I am on the programs team at Can Do Multiple Sclerosis where I work as a senior programs consultant. Thanks, Rachel.

Rachel: And Juliann, would you tell us a little bit about your experience?

Juliann Hanson: Giant and welcome everybody to the podcast. Like too, I am excited to be a part of this and to have a discussion with Mandy about how to transition back into the home and after a relapse. I work in Castle Rock Colorado. I have a private practice. I have worked with Can Do MS for the past 15 years as a program consultant. I also specialize in neurorehabilitation, particularly in recovery with multiple sclerosis and doing a bodywork technique called 'myofascial release'.

Rachel: Great. Well, thank you ladies for both being here with us today. So now before we get into our discussion, Mandy, would you describe what a relapse is and what it looks like.

Mandy: Sure. So, relapses which are often called 'exacerbations' or 'flares' are generally characterized by new symptoms or worsening of existing MS symptoms. By definition, these symptoms must last 24 hours at least 24 hours as being separated from the most recent attack or the most recent flare exacerbation by 30 days. For example, perhaps you have a lot of numbness and tingling in your legs. If that seems to get worse and last longer than 24 hours, that may signify that there may be a relapse going on. Relapses or exacerbations whatever you prefer to call them, are generally followed by periods of partial or complete recovery. The symptoms during this time can disappear or some symptoms can persist and become permanent relapses

can be mild and people can recover within days or weeks. Symptoms can often be quite severe, interfere with function, can be ongoing, and last many months and this is often when the rehabilitation team, physical therapists, occupational therapists, and speech therapists become involved. For more involved relapses, a neurologist may also recommend some types of treatment. While sometimes more mild relapses, they just simply may resolve on their own. But Juliann, can you share with us a little bit about how the rehabilitation team helps people with MS manage their relapses?

Juliann: Yes, absolutely Mandy. As many mentioned just a moment ago, the rehabilitation team typically comprises three professionals. That would be your physical therapist, an occupational therapist, or speech-language pathologist or therapist. Depending upon the type of symptoms that you have with an exacerbation or relapse. You may see all three of those professionals. You may see just one of those professionals or any combination of them. Typically, rehabilitation or general treatment is aimed at symptom resolution. If the symptoms seem to be hanging around for some time, an adaptation. So that the symptoms do not interfere with your life as much as they may be. For instance, if strength or coordination is something or balance has been something that has been affected by the relapse, we would be looking at re-strengthening and coordination exercises that bring you to back up to what we would call a baseline or a previous baseline. That is usually where you were functioning. Before, a relapse may have started. You would be working with your team. Deciding how you were doing in your progress as you are going through your rehabilitation. Rehab emphasis will likely be directed according to the severity of the exacerbation and can last anywhere from what week or a couple of visits to maybe a month or two.

Juliann: Fatigue management would be a big part of any kind of Rehabilitation approach. Because fatigue can sometimes be a big factor in coming through an exacerbation. Many there is such a thing as a 'pseudo-exacerbation'. How do those differ from an actual relapse?

Mandy: I am glad you asked that question, Juliann. A true relapse or a true exacerbation differs from a pseudo-exacerbation generally by time. So again, a true exacerbation must last 24 hours at a minimum, while pseudo-exacerbations are often reflecting their symptoms. For example, a bladder infection can cause increased sex activity. Or perhaps heat whether it be environmental heat or just an increase in core temperature as a result of exercise can cause worsening fatigue or worsening weakness. But the difference is once that aggravator is removed, whether the bladder infection is treated or whether you can go to a cooler environment, then that symptom that was irritated returns to its baseline presentation. But, I think what is important is if there is any question as to whether or not you are experiencing a relapse, contact your physician. They can help you distinguish what is going on. Whether it is a pseudo-exacerbation or a true exacerbation that needs to be managed.

Rachel: Excellent. Thank you both for sharing that informative information there. So now that we are all on the same page with what a relapse is and some general treatment options, I like to present a real-life scenario of a couple going through a relapse. And then, we are going to hear some recommendations from Juliann and Mandy on how you can prepare yourself and modify your home life after a relapse occurs.

Rachel: So, we have a couple in their 40s, Lucy and Michael. Lucy has been diagnosed with MS for seven years now. Both her and her husband Michael are full-time employed. They have two children in elementary school.

Lucy's first relapse occurred at the time of her diagnosis. It presented in visible symptoms like fatigue, depression, and cognitive changes. Currently, Lucy is in the hospital with her second relapse. This one is presenting changes in her motor skills and challenges with typing, cooking, writing, and helping her kids with homework. She is also unable to walk well and uses a walker to help with drop foot and fatigue. Lucy is

about to be discharged from the hospital. Juliann, what do you recommend she does before she leaves the hospital?

Juliann: It is a good question, Rachel. She is likely going to be scheduled to see an occupational therapist in the hospital.

Rachel: Right. That sounds like a really good opportunity for Lucy. What do you think that visit with the occupational therapist looks like? What kind of tools might they recommend?

Juliann: Often in the inpatient setting or what we call the acute care setting of the hospital, you may only have one interaction with the occupational therapist, and that maybe the assessment. What will happen in that assessment is the occupational therapy will come in and see Lucy and see how she is doing in terms of her basic mobility and our basic skills for getting around in the room, getting her clothes on and off, doing basic grooming tasks? They are going to be looking at how does her strength play into that. It has coordination. How does her balance look out of that evaluation with her?

Juliann: They may often recommend some tools that she can go home with it will make her safer. It could be something like a raised toilet seat or a shower chair. It could be something like a Reacher for helping her with getting dressed if her balance looks a little shaky at the moment for getting things up off the floor or what have you so. They would make a recommendation also at that time for what kind of assistance she might need upon returning home.

Or what they would recommend in terms of any kind of a rehabilitation flow for her. Whether that be with health care or outpatient therapy. Now while Lucy is there, she should also have the opportunity to meet with the physical therapist. So Mandy, what does that visit with the PT look like?

Mandy: Yeah, so at times in an inpatient setting or an acute care setting, the patient may only see PT one time which may be similar to occupational therapy. There is certainly some overlap between the occupational therapist and what the physical therapists prioritize. What we both prioritize is what Juliann describes the safety, we prioritize mobility and access within the home in this type of setting.

Mandy: Generally, a person with MS should not expect to go home with a comprehensive exercise program to help them return to their previous level of function. But rather, they might just get a few exercises that help lead to that next stage of therapy. But a PT would evaluate those gross motor skills such as walking, balance, coordination, and strength. And then make recommendations in the home environment. For Lucy, we would recommend probably a walker to help her manage her drop hood and make certain that she is safe with walking in the home. We would also probably recommend other tools that Juliann also alluded to shower chairs and other devices that can be used in the kitchen or the bathroom to just ensure that safety and appropriate fatigue management. But I think, overall, it is important to remember that any of the tools recommended by physical therapy or occupational therapy at this stage are familiar. They may be quite frightening for some. But they are tools that will help Lucy and other similar, in a similar situation, to stay safe and stay mobile as she can recover. Often, these devices are only temporary. So, people need to keep that in mind as they move forward.

Rachel: Great job. Now, we have an idea of what it looks like while Lucy is at the hospital. Lucy is going to be coming home and she has a walker. Just as a few reminders, she had experienced changes in her motor skills, challenges with cooking, writing, and helping her kids with homework. Again, she is unable to walk well and is experiencing drop foot and fatigue. So Juliann, what can Lucy do to make sure she is safe in her home when she gets there?

Juliann: Right exactly, Rachel. It sounds with Lucy's symptoms upon her return home like it might be pretty overwhelming for her. There is a lot of changes in her. In going into this transition and home, she probably has a lot of questions. How am I going to get back to my usual routine of things?

Juliann: It is important to note that the fact the very first thing is too important to note that this is a transition and that expectations are that she will be getting better. The other thing for I would encourage her to know is that she does have support from the medical community and to rely upon that support reach out to that support as she makes this transition. Most likely, in the flow of things these days, she will be recommended to have a home health occupational therapist come into her home. Buying Large [?] that person will start within a short period with her getting back home, so maybe within a day or two. Within that day or that first day or two before she sees a professional. Keeping in mind the advice that she was given by the therapist in the hospital is a good idea. Also, just kind of taking an assessment of her own home and removing any obstacles that might get in the way. Rearranging furniture if need be and picking up floor rugs that might get in the way now that she is using a walker. Even though that is temporary. Making her pathways through the home as comfortable and easy as possible. Because that is going to help her manage the fatigue and some of the overwhelmingness is coming home.

Juliann: Once she starts with the outpatient therapist, they will be a lot more specific in forming a plan together with her. Getting her started in specific rehabilitation for the exact needs that she has. This is where some of the strengthening and coordination exercises will become much more specific for her. The occupational therapist is going to be concerned with how is she doing in cooking and what specific problems is she having with cooking? Is it the coordination issues with cutting and chopping or lifting and carrying. So they will not brainstorm together and troubleshoot. That may be another time when some work tools or adaptations can be recommended. So that she can begin resuming her normal life and her normal chores as soon as possible. Again, some of these solutions or adaptation may be temporary and be just a part of her transition as she will be returning to her baseline level of tier.

Juliann: This often may take a short amount of time where she has a home health therapist for maybe a week, maybe two or three visits. If an exacerbation is mild, it may be one or two visits and then the therapist will recommend an Outpatient Therapy Program.

Rachel: All right, great information from the occupational therapist side. But now Lucy, she might also need to work with a physical therapist when she is at home. So Mandy, what would the first visit with an Outpatient Physical Therapist look like?

Mandy: Thanks for asking, Rachel. I think, again, it is important to know the different levels and different stages of Rehabilitation. Juliann spoke wonderfully about Home Health Physical Therapy. Often, one of our Rehabilitation rather than Home Health Rehabilitation, once people get through that then they are often referred to as an outpatient setting.

Mandy: A first Outpatient Physical Therapy visit would often involve a comprehensive evaluation, strength walking, or wheeled mobility as applicable, balance, coordination, sensory input such as visual-motor input and touch sensations, body awareness, or movement awareness. It is a very thorough comprehensive evaluation of where that person is at, at that time. Lucy and I would have lengthy conversations about her previous level of function. Our current mobility at work home within the community.

It is really important for me as a physical therapist to understand what her goals are, what activities are important to her, and what she is been able to do or what she desires to return to after the relapse.

Mandy: PT sessions can be as often as three times a week or as little as once a week. Again, that debate and

that varies depending on the severity of the relapse as well as the goals that she might have. But, a typical session might involve exercises, activities to help optimize that movement, and help Lucy achieve those goals support. For example, if she wants to help minimize her foot drop, which would be a priority for her so that she can avoid tripping on the carpet in the living room. We may do different strengthening exercises, different stretching exercises, and talk about how to restore the proper basic mechanics to help her minimize that foot drop. But, I would also like to add a common challenge with exercise prescription during a relapse knowing how hard to work during exercise. People feel very different there. They are trying to learn how to exercise in a body that is evolving, and that feels very unfamiliar. The ceiling and this sensation can be frustrating for patients as well as their families. The general rule that I like to follow or encourage people to think about is something called a two-hour rule that if you do not feel as good as two hours after exercise as you did before you started, then you did too much. In other words, you should feel back to your baseline within two hours or so after an exercise routine. But I would again encourage people to talk with their physical therapist and their occupational therapist to help them understand when to clue into certain symptoms that would send signify that they have simply done too much exercise.

Rachel: All right, great. Great information to explain the rehab team's role in adjusting a person back into their home life. Now, for those who do not have access to an occupational therapist or a physical therapist, how can you utilize your current health care team or other resources when you are recovering from a relapse. Juliann, would you want to take that?

Juliann: Yes, you bet I would. I would also like to just thank Mandy for going over. When it did discover when you have worked too hard. Because that is such a tricky thing and can feel very frightening if you have kind of overdone it a little bit. That two-hour rule is such a great tool for understanding how hard to work. So, thank you for that, Mandy.

Juliann: If you do not have access to an occupational or physical therapist in your community, and if you are feeling a little lost about being at home or you feel like you might need some more support, it is a good idea to talk to your neurologist, your primary care physician, or nurse practitioner. They may have access to individuals in the community who can specialize in some form of rehabilitation or give you some support. It is important at this point to know that you can reach out and access some support.

Juliann: It is also important to know if you have — Let us say Lucy gets home and she is just not doing very well. Maybe she was just charged from all services. She feels like she is struggling not making a lot of headway toward getting better. Then, that is a good reason to contact your primary care physician or your neurologist and say, "You know, things just are not going as smoothly as things are not going well. I think I need a little bit more support." Often, it is us, the clients, or the patients, that can advocate the best for ourselves. We know where we are about our baseline to how we are feeling now. I encourage people to advocate for themselves and ask for assistance rather than quietly trying to struggle through a relapse.

Rachel: And Mandy, did you have any feedback? Other than on how to utilize your health care team or other resources?

Mandy: I think that is an excellent recommendation that Juliann just made about encouraging people especially during this time of uncertainty and unpredictability. Encouraged people to have their voices and to be their advocates. So, thank you Juliann for sharing. I would also add that people can find individuals who understand or specialize in MS Care by contacting the National MS Society. The phone number is 1-800-5 MS. When you called that number, you will be connected with a call center and you will speak with someone called an MS Navigator. They can help identify those people in your area who would be able to help you in this particular situation. Other resources would be the American Physical Therapy Association or

the American Occupational Therapy Association. Those two organizations can also help you identify physical therapists and occupational therapists respectively who specialize in neurological rehabilitation.

Mandy: I would also like to add for those folks that maybe do not have immediate access to information or just want a little bit of information about relapses and how to modify your home can do a message of some wonderful recordings webinars, specifically, with tips of how to manage your home and how to make modifications that may suit your needs.

Rachel: All right. Great information, Ladies. Thank you. So now, let us kind of go back to Lucy. Both Lucy and her husband are working full-time. Are there any options to help Lucy get to and from rehab since her husband Michael is working full-time? And Juliann?

Juliann: Family Medical Leave Act or FMLA is something that is going to be discussed in our next podcast in the series. I think that will be a really important one to tune in just to see how that transition can be supported. Because it is going to be a very big transition. Once you come home, both people are expected to be working full-time. Time management becomes a real issue at fatigue management. It becomes an issue and important at this point time. Briefly, I would like to discuss driving modifications for most people especially for those who live in the Western United States driving is an enormous piece of being independent. So getting to and from work, taking the kids to and from school, and after school activities. When driving is something that has been impacted. It can take a chunk out of how somebody feels about their recovery and also their independence.

Juliann: I want to mention that there are driving modifications that can be made to a car and really to how a person interacts with their car. Generally speaking, they can be temporary in their usage. Most people's will if they are only going to need temporary assistance, will put in a support network for driving so that may be accessing a carpool within the community or your child's school system. It may be arranging rides for yourself that have been offered via fan friends or family to get to and from appointments or to and from work. More permanent driving modifications are usually when people are going to need them for a long time.

Juliann: I think what is important for people to know is that they are out there and that they are extremely effective. You can have modifications made to your car whether that is hand controls or a lift system to bring a scooter into your chair. Then, there is financial assistance for getting those kinds of modifications to your car. I think it is an important thing to discuss.

Juliann: As an occupational therapist for one of my favorite topics is fatigue. Fatigue management for Lucy and her husband Michael at this stage is going to be critical for them. The most important thing I want to bring about right now is that fatigue management thinking and tools at this stage need to be very flexible. That is an important piece of this in terms of mental and physical recovery. To know that from day-to-day, you may need to use different strategies. From week to week, you may need to use different strategies to manage fatigue and that is okay. It is preferable because as Lucy regains control, strength, and balance, she is going to be able to utilize different strategies.

Juliann: At the very beginning of her recovery and at the very beginning of her coming home, she is going to have to utilize a lot more strategies. Things like sitting down when she is doing meal preparation, sitting down to shower or bathe, accepting assistance from people maybe to do grocery shopping and those kinds of things. As she regains her strength, motor, control, and balance, she can start resuming some of those chores. The communication for her with her family number and with her support network is really important. And I think the most important thing I would recommend is keeping that line of communication

very open for Lucy to be easy to talk about what she does need and talk about what she does not need almost daily just so that her support network can be utilized for her to maximize her recovery.

Rachel: Excellent. Yeah. Great information. Fatigue management and driving modification communication all very important things to keep in mind when dealing with a relapse recovery. So now, we do not want to forget about Lucy's husband Michael and providing some support for him during his changing role during this relapse. Mandy, how can rehab support Michael?

Mandy: I think rehabilitation can support Michael in two general ways particularly in the outpatient setting when Lucy is participating in rehab. That is the time when he can hopefully have a little rest though. He can go off and do something that he needs to do. Whether be it self care for himself or run some errands for the family. But that would give him a chance to have some time independent of caring for Lucy.

Mandy: But, I would also encourage him to separate the conversation. Because he is living with MS too. he is living with MS in a slightly different way. But, he is living with MS. My guess is this relapse has shaken his world. I would encourage him as a side to seek out that another support. Whether it be through the National MS Society or through some resources that Can Do MS that has four support partners to kind of learn, digest, and figure out how this looks for him now that they have experienced this significant relapse.

Mandy: And to echo what Juliann had said, I think it rehab also offers the opportunity for Lucy's husband to understand how and when to help. How and when to allow Lucy the opportunity to try and to do something independently in her own home. Or, when it is like, "Hey, Lucy. I have got to help you with this so that we can keep you safe." But opening that line of communication and rehab being that facilitator and that guide for what activities need assistance and what activities can be done independently. And again as Juliann alluded too often, these roles are temporary. Often, it is very important again to emphasize communication and have open conversations with one another.

Mandy: I would also like to add one other thing. We have not spoken about the children, right? They have a couple of kids. They are probably wondering, "Hmm, what is going on with Mom? Like a lot has changed for her." I think as a rehabilitation team, we are privileged with a lot of time with our patients, right Juliann?

Juliann: Yes.

Mandy: It is an opportunity for us to also give education to the parents of other resources on how to communicate and how to talk with their children with these changes that Mom may be experiencing. Especially, if they are old enough to understand and ask questions about it. The National MS Society does have some resources for how to talk with children and how parents can talk with their loved ones about what is going on with their MS.

Mandy: I think that utilizing and encouraging Lucy and Michael to utilize their Rehabilitation team is an awesome suggestion. During Lucy's Rehabilitation, it might be a good time for Michael to have a bit of a break maybe run some errands. But I think at the very beginning and maybe periodically maybe once a week or so during Lucy's Rehabilitation, it might behoove Michael and Lucy to attend an entire session together. Even if Michael is included in her rehab session, maybe for the first 10 or 15 minutes. In that way, they can bring up maybe if there is a thorny issue that has arisen Lucy. Michael has taken over a chore. Maybe that Lucy would like to take a trip back in charge of or maybe just smooth out some communication. Experienced therapists can help them facilitate that for them. That is one of the suggestions I would make for Michael.

Mandy: During this time to we as you said, we need to discuss the Children's role in all of this. One of the things that were mentioned is that Lucy is usually helping the kids with their homework. That is usually her role. And maybe due to fatigue or source of cognitive symptoms and her exacerbation, she is not doing that as often. It is stressful than now, obviously, that the kids are not getting what they need.

Mandy: Tapping into your Community Resources is a really good idea. Whether that be fellow parents or often schools will have after-school tutoring assistance available. Or even an after school program where children can have access to their teacher, that might be a time to tap into that resource. Preparing the kids and talking openly in the family about what is going on. That an exacerbation is usually temporary. Involving the children in that conversation, involving them in home chores to help Mom out can often be very helpful. Rather than kind of everybody kind of going into hunger mode and doing things for themselves. Keeping an open line of communication, reaching out to the community, or family and friends can be helpful at this point.

Rachel: Excellent. Developing your support network, utilizing your rehab team, and making sure you have a focus on communication all key pieces to make note of when you are recovering from a relapse Thank you both for emphasizing those key areas. Now to close out our discussion on relapse has and how they affect your home life, what advice would you give to those living with relapsing-remitting MS who are fearful of the effects of a relapse? And Juliann, would you want to take that first?

Juliann: Yes, you bet. So probably the first thing I would say is a plan for unpredictability which sounds a little bit ridiculous like it is unpredictable by nature, right? How do I plan for that? If you are approaching something with the idea that you can put a plan in place or that no things are going to be unpredictable. Maybe a little bit up and down and having several strategies in place beforehand to deal with that as it comes along can give you a lot of peace of mind. It gives you a lot of flexibility in your thinking. It gives you a lot of resources. Because stable resources from which to draw to whether those unpredictable situations.

Juliann: I think it is really important if people have not started putting a support network in place to begin loosely conglomerating a support network. That could be anything. That can be becoming familiar with the Can Do MS website that can be familiar with the National MS Society. That can be talking to friends or family about what you might need. The idea is that people can fluidly step in and step out as you need in setting up those expectations with your friends or family. Sometimes you may need some help with grocery shopping. Sometimes you might need some help with home chores or with driving. In many circumstances throughout being a rehab therapist, people will tell me that friends our family want to be able to help. Often, when we, as individuals, make the suggestion "Hey, I could use your help with grocery shopping or taking the kids to swimming lessons or whatever." People are delighted to be able to jump in and help. If you can drive that, it can be the peace of mind for you and peace of mind for your support network. It is usually much less frightening to go through something difficult if you have some sort of a plan and that plan can shift. But Mandy, what would you recommend in this instance?

Mandy: I like your recommendation of planning for unpredictability, right? To echo your comments Juliann, unpredictability can be a lot less frightening if those plans have been discussed. Well, in advance and the army of people who can be successful at the tasks that you ask them to help you with an ease that anxiety for everyone involved. I would also agree with everyone, some generally speaking people and friends, who want to help during that time of crisis. But to make those important decisions in that crisis mode does not necessarily lend itself to the best decisions. I think it is important to make those plans well in advance. Again, I would also echo that those resources beyond just your friends and family can also include your health care team. Those trusted resources like Can Do MS and the National MS Society can also provide a lot of those



connections and help you just reassure people as they are navigating this unfamiliar territory. It is a frightening territory both for the person living with MS and their loved one.

Mandy: Everything is less frightening if you have a plan for that unpredictability.

Rachel: All right. What a great discussion. Thank you both to Juliann and Mandy for being here today and sharing this really valuable information to help those living with MS prepare for the effects that relapse as can have on one's home life. So thank you again, Ladies.

Juliann: And thank you so much, Rachel, Can Do MS, and Mandy. It is been a productive conversation. I enjoy the opportunity to discuss situations that can be challenging for people. I am looking forward to having further conversations in the future.

Mandy: And I was also like to thank Juliann, Rachel, and Can Do MS and all of our listeners. We wish you all health and happiness. Thanks for joining us.

Rachel: This podcast is part of the relapse and 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 and MS series which are available on our website and apple podcasts. We also encourage you to view our Relapse and MS Webinar, which is available on our website [cando-ms.org/relapse](http://cando-ms.org/relapse). Thank you for joining us.

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