



## **Healthy Relationships and Living with MS: A Program for People Living with MS and Their Partners & Families**

Presented by: Elizabeth E. Nager, MSSW, LICSW

### **Marie LeGrand:**

Hello and welcome to the MSAA's live webinar, Healthier Relationships and Living with MS, a program for people living with MS and our partners and families. I would like to take this opportunity to thank you for joining us this evening. I am Marie LeGrand, Director of Education, Health Care Relations and Grant Management for MSAA and your host for the program this evening. We are extremely grateful to have Elizabeth E. Nager with us, who will be presenting on this important topic. And we are pleased to bring you this program that will focus on strengthening and fostering healthy relationships, as well as for couples and families impacted by MS. We will explore living with MS and the effects on marriages and relationships.

Now, during this webinar, Elisabeth will discuss tools for coping with stress and understanding MS, as well as strategies to help with communication. This program is for educational and informational purposes only and does not constitute as formal recommendations. Please do speak with your doctor or health care provider if you have any questions or concerns.

So as you may know, MSAA is a national nonprofit organization dedicated to improving lives today for the entire community. Some of our free services include a national helpline, equipment and cooling products, MRI funding and online community webinars, and many more free programs and services available to people living with MS all across the country.

Please visit our website to experience our COVID-19 and MS Pathfinder tool, which provides ongoing updates and resources on the coronavirus. Also, please know that MSAA has extended our helpline hours to 8:00 PM Eastern between Mondays and Thursdays.

To learn more about these and all of the ways in which MSAA improves lives today, please visit our web site at [mysaa.org](http://mysaa.org). Or you can also call us at 1 (800) 532-7667, extension 154.

Now, throughout tonight's program, you will have the opportunity to ask questions by typing them into the chat box. We encourage you to submit questions throughout the program, and we'll do our very best to answer your questions during the Q&A portion of tonight's webinar. At the end of the program, we ask that you please complete a brief survey. Your feedback is extremely important and will help us in developing future programming and content. A link to the survey will be included in the chat box.

Without further ado, I would like to introduce our speaker for this evening, Elizabeth. Elizabeth specializes in working with people diagnosed with MS and provides therapy for individuals, couples and families. She has led groups for both people newly diagnosed with MS and people experiencing progressive MS, as well as for care partners. In addition to working with people who have MS, she also works with patients with other neurological diseases. Elizabeth enjoys working with people who are motivated to create healthier patterns of coping to their current life challenges. I will now turn it over to Elizabeth. Elizabeth, welcome.

**Elizabeth E. Nager:**

Thank you so much. And thank you to the entire MSAA organization for organizing this program tonight. And thank you for everyone who has signed on for this program. People's lives are busy. Time is short for everyone. And I truly appreciate everyone who has signed up. So with that, here we go.

Healthy Relationships or Living with MS. Relationships are complex and they take work. You meet someone and the beginning is fabulous. You feel special and totally accepted for who you are. Everything in the beginning, including the romance and sexual attraction, is great. The other person seems perfect in every way. And you have so much in common. But over the course of the weeks or months, the differences start to appear and the magic starts to fade as the other person becomes more real. But if the two of you have common interests, common values and common goals, and you are both willing to do the work to keep the spark alive, I believe that you can have a happy and fulfilling relationship for decades to come.

So there have been studies that look at people who come from poor family dynamics where possibly there was abuse in the parents' marriage. Potentially the family life was extremely abusive. And it showed that as these kids get older and become adults, it is possible for kids from even these very, very poor backgrounds to have a good, happy marriage. So what makes the difference from the people who repeat their parents' marriage and the people who do so much better and transform their own marriage to something that is very positive? And the difference is the kids who are successful become adults who truly want something different, something that is better.

So today we're going to talk about how to create happy, healthy relationships. We're also going to discuss stress management techniques to ease the stress that so many people living with MS feel on a day to day basis.

So let's start with defining what is a healthy relationship. Now, I know many people will create the definition by simply looking into Webster's dictionary. I did not do that for today. I came up with my own definition. I put quite a bit of thought into this, that what exactly is a healthy relationship. And what I came up with is, I believe a healthy relationship is a partnership where each person can say that their partner has my back. Both partners will feel safe, secure, protected, accepted, cared for, and loved. That is my definition of a healthy relationship.

So I'm going to look at another study here that I find fascinating, and this study looked at long term marriages and looked at marriages that ended in divorce and they studied which couples fought more. Marriages that lasted long term or marriages that ended in divorce. And when I ask people, what do you think? Which of these relationships fought more, the marriages that ended in the divorce or the marriages that kept going for decades? Most people will say to me, well, it should be the marriages that ended in divorce. But since you're asking this question, it must be a trick question. So therefore, I'm going to answer it was the marriages that lasted long term. Those were the couples who want more.

In reality, what the study found out is that both groups of people fought the same. The number of fights was the same between marriages that went on and marriages that ended in divorce. So what was the difference? The marriages that ended in divorce, the fights never got resolved, and the marriages that continued, the couples were able to find a resolution to the fights. They were able to find closure that was acceptable for both people. Let's go to the next slide here.

So how do you make your relationship better? And the short answer is you want to make your relationship a priority. In a relationship, I believe there are three entities. There is you, me, and we. And at times, for the sake of a healthy relationship, you need to give up the "me" for the sake of "we". So I'd like you to think about, are there times that you were able to give up what you wanted to do for the sake of a marriage? And what was the outcome there? What is the impact on your relationship when you are sometimes able to give up "me" for the sake of "we"?

So based on 40 years of being a therapist, I've come up with a list of questions that I believe are important for each partner to ask themselves. So this is going to be kind of a long list. This is what I'm used to doing as a therapist, is asking questions. So in order to create a healthy relationship, do you see you and your partner as a team? And do you work well together as a couple? I want you to think about what are your strengths as a couple. Do you support each other? Are you kind to each other? Are you polite? And do you express appreciation for each other?

My husband and I many years ago spent dinner with some friends and they had young kids. And over the course of dinner, I asked my husband to please pass me something. And when he handed it to me, I said, thank you. And a few minutes later, over the course of dinner, either he asked me or I asked him again to please pass something. And one of us given, we said thank you. And it was interesting that one of the little kids at that point said, why do you say please and thank you to each other? You don't need to do that, you're family. And I thought, oh, my goodness, what are the parents teaching their kids? That there's no reason to be polite in a family. That's not what I recommend. I recommend compassion and sensitivity in a relationship; that you treat your partner as well as you would treat any stranger that you meet.

Do you try to understand your partner's perspective and do you know what is important to your partner? In the course of your relationship, do you negotiate when there's a disagreement? Do you try to create win-win situations, or win-win, excuse me, solutions when problems or disagreements arise? Do you collaborate? Next slide, please.

Are you maintaining an intimate relationship? When was the last romantic time that you had together? And what is stopping you from creating this again? We all need intimate connection. And I believe both physical and emotional intimacy can continue as long as you prioritize talking openly and in a respectful way, and that you are flexible and creative when looking at options. Think about a time when you felt intimacy that was not sexual. What was that closeness all about? I want you to really think about that. There are times when we can feel emotional intimacy with all our clothes on, right? Not even touching each other. I believe intimacy can strengthen a relationship even when life does not go as planned. Bodies change over time. We are affected by aging hormones, poor diets, lack of exercise and certainly stressful circumstances, including living life with MS. But I believe we can still have emotional and physical pleasure through hugging and cuddling, holding hands, or any touch in addition to making love that feels satisfying and loving. Whether your MS is mild or severe.

As a couple, how do you deal with stresses? Sadness, frustration and anger are going to happen for both partners, especially when living with a chronic illness. And because a relationship is

two individuals from two different backgrounds, at times, of course, you will disagree. So how do you handle this?

Do you take responsibility for changing when you see negative patterns in the relationship versus expecting and waiting for your partner to change? It's easy for some people to complain about issues to the point that they don't even think of potential solutions to problems in the relationship. It's so much easier to blame the other person. But what happens when we look at our power and our ability to create change? What happens when we ask, is my relationship headed in the right direction? What am I doing to make my relationship what I want it to be?

How am I nurturing my relationship? What am I doing that will help my relationship to absolutely be the best it can be, and what behaviors do I need to either add or remove to make my relationship better? The goal is to change any negative patterns so that we're not having the same fight 5 years from now, 10 years from now, 20 years from now, I've seen couples that literally, 30 years later, they are still having the same fight. Remember when I said that study, who fights more, marriages that go long term or marriages that end in divorce?

It's that ability to resolve fights so that 30 years later, we're not having the same fight or ending up in divorce. Improving your relationship takes time and effort. But we can do this, we are capable of this. We can set goals to improve. And then work at these goals. And with determination and a belief in our ability to change what we can, we are able to make our relationships better. So we're going to switch here a little bit to stress management.

So when do we feel stress? In general, for most people, it's when we feel like we have no control over what is happening, when we see few or no options, or the stress is long lasting and unpredictable, like, of course, living with MS. Or lastly, when there are several sources of stress that are happening at the same time.

And over time, we will all be challenged with frustrations and losses. It is truly gut wrenching to get a diagnosis of MS, or to hear that relapsing remitting MS has turned into secondary progressive. And MS does not happen in a vacuum.

But there are always multiple stresses happening at the same time simply for the fact that the MS doesn't go away. There are the common stresses of family dynamics, work stresses, house chores, in-laws, finances, the furnace breaking down, getting a flat tire when you're late for a meeting. Right? The kids coming down with being sick right when you're about to leave on vacation. Stresses happen and MS adds an additional layer of stress with the changes and losses that happen both big and small. So we need to think about how do you feel stress.

And the common ways that people feel stress include being irritable, having headaches, stomach aches, tight muscles, low mood, anger, fatigue, insomnia, or wanting to sleep way too much to escape, or having nightmares. Some people under stress feel all alone and some, on purpose when they are stressed, will isolate themselves. But most people know when they are under stress and the stress level has become way too high. So what we want to do is manage the stress load by developing good coping skills, which will increase our ability to be resilient.

But why is resilience important? Because resilience is our ability to bounce back when the stress level becomes too high. Now, certainly there are coping skills that are not healthy, and the coping skills that are not healthy, I think we could all list things, but, but the obvious ones, too much alcohol or drugs, gambling, eating either just too much in general or too much junk

food, eating all the wrong things that we know are going to make us feel lousy, and not talking. Next slide, please.

So for both the person with MS and their partner, here are some ideas to manage stress in a positive way. You want to allow time for reflection, you need to be able to ask yourself, "What is missing from my life? And what would it take for my life to lead fulfilling, meaningful and productive"? In the beginning with MS, most people feel like it is impossible to have a fulfilling life. But I believe it is not only possible, but that is the goal we should strive for.

It's important when we're under stress to make time for friends and to call them when you're feeling down or stressed. Now oftentimes people will say, oh, I've got great friends, but I don't call them when the stress level becomes too high because I don't want to be a burden. Except what would you want from your friends? And how would you feel if your friend let you know months later that they never let you know that something big was happening in their life, but they didn't call you because they didn't want to be a burden to you? Wouldn't you feel that that your friend did not include you when something big was happening in your life?

There was a study done in 2015 that actually looked at loneliness and social isolation. And it was fascinating, in the negative sort of way, fascinating. But they said loneliness and social isolation increases the chance of premature death by fifty percent. Fifty percent - think about that. Social isolation and loneliness can increase your chance of premature death by fifty percent. It also found that being isolated and being lonely is as damaging to your health as smoking 15 cigarettes a day. Terrible. Absolutely terrible. But we need to reach out to friends. We need to have that sense of community.

Another way to cope with stress is to write in a journal. This is a way to get those feelings out rather than bottling them up. You need to be able to identify your strengths. What is worked in the past? What happens when you... when you look at what has worked in the past? We don't always need to reimagine and create a new wheel.

I want you under stress to look at pursuing your passions and the activities that you love, those things that you absolutely lose track of time when you look up in two or three hours have gone. How fun! When was the last time that you truly had fun? And this is obviously harder in a pandemic, but not impossible.

I want you to be able to prioritize your days and pace yourself. This is important for everyone, but especially people with MS. I know oftentimes people who have MS and have limited energy will try and do everything in the morning and just push, push, push as their energy level is still high. But what we actually know is if you pace yourself, for example, if you work for forty five minutes and take a break for ten, and work for forty five minutes and take another break for ten minutes, that your energy level will actually last longer into the day and you will get more done during the day than if you just push really hard for three hours, and then done for the day. I want you to focus on making yourself a priority. You cannot be a good partner if you do not make time for yourself.

And this is, again, true for both partners. And the classic example is when we're flying, and the announcements at the beginning of the flight is if there is a problem and those oxygen masks, come down, put on your own oxygen mask first before you try and help other people. You will be a better help to your family if you take care of yourself first. I mentioned before, you need to make your relationship a priority. Make time for your partner. Make time to communicate. Not talking in a relationship can be misinterpreted as not caring.

And that's the last thing that most people want. You could be encouraging without coming across as nagging or blaming. And certainly no name-calling or bullying. Recognize that you do not have to be perfect, and that it is fabulous to be able to ask for help, and especially if you ask for help in front of your kids, you're going to role model, that it's OK to ask for help. Look at your ability to adapt to change. Are you rigid or flexible when it comes to necessary changes? For example, with MS, if you were told that it was probably a good idea to self, to start doing a self tap, or to start using a cane or a walker, how did you adapt to this?

Now, obviously, these things are very difficult. But did you absolutely say, no way, I'm not doing this? Or did you take some time to process and slowly integrate these changes into your life, knowing that these are tools to have a better quality of life? You always want to be looking for ways to improve your life. You need to be more assertive. Do you say yes to every request, or can you say no to people when life gets too busy or when your energy level is down?

For stress management, you want to be exercising on a regular basis. An exercise can be anything - you can walk, bike, yoga... I've got a client who puts on the music and dances in her living room for exercise. Exercise, we know, helps your ability to sleep, helps your energy level, even though lots of people will say, I'm too tired to exercise. If you truly work exercise into most days, you will find that your energy level is better. It will improve your mood. It will improve constipation. And exercise also decreases the pain perception that certain people feel by releasing endorphins into their body. Exercise also helps memory by increasing the blood flow to the brain.

It's important to get enough sleep. How many people stress and just stay awake way too late watching TV or online. We want to get enough sleep and it's recommended that the sleep be from approximately 10 o'clock at night to 7:00 in the morning. I see way too many people that quit working with their MS and their sleep cycle gets pushed further and further back to the point that they're going to bed on a daily basis at 2:00 or 3:00 in the morning and waking up at noon. Our bodies are meant to go to bed when it's dark and to wake up when the sun comes up. Poor sleep has been linked to dementia, obesity, cardiovascular disease and diabetes.

And the truth is, with MS, we are all still vulnerable to other diseases. If we get less than six hours of sleep for one night, it can disrupt our physical and mental well-being. And the research shows that if we get less than six hours of sleep for three nights in a row, it will have changes on our emotions. It can increase the negative emotions and decrease the positive emotions, and it will increase the severity of any physical symptoms that you are having.

We also need to drink more water. This is critical for everyone, and especially for stress management. Dehydration causes plenty of problems that many people attribute to their MS. Dehydration, even slightly hydration can cause people to feel tired, can cause people to have trouble concentrating and poor energy. And don't all these symptoms sound like MS symptoms? Drinking not enough water can also create headaches and can create moodiness in people. And I just want to add that many people almost have a sense of pride that they can take pills with only the tiniest sip of water or no water at all.

When you take your medication, you always want to take your pills with a full glass of water, not just a tiny sip, because if you continue with just a tiny sip of water, the pills are not getting down far enough and you will eventually wind up with acid reflux. And you do not want this on top of your MS.

It's important to not skip meals because food is energy for your body. And I always recommend that people look at their diet and try and improve your eating by 10 percent. Can you improve the good stuff by 10 percent? More fruits, more vegetables, and can you decrease the junk food by 10 percent? And there's tons of information now on the gut, the microbiome, and I'm not going to get into that now, but I recommend that you go online and look up the gut microbiome and there's some more information that's just coming out related to MS and what we eat. I think it's important. Obesity in adults with MS is associated with more rapid disease worsening and disability. It's important to keep our weight in check. And more importantly, that I just found out, is that childhood and adolescent obesity, which is determined by a BMI of 27 or higher, actually doubles the risk for kids to be diagnosed with MS. It is critical that as a family, that you eat healthy.

If you can, to help with stress management, it is helpful to get out in nature. It is helpful to listen to music. That both of these help decrease the negative emotions and increase the positive.

It's important to be honest about your attitude, certainly in the beginning when people are diagnosed with MS. It is absolutely normal to feel shock and sadness with that unexpected diagnosis. However, years later, are you still feeling "poor me"? And are you coming across to others as a victim? And does there need to be a change? I think it's important to look at that.

It's important to recognize that you always have options. Even if that option is "what is my attitude?" You need to make sure that your choices support your goals. For example, if your goal is to be healthier, then you want to make sure that you're buying healthy food and you want to make your goals reasonable and specific. For example, if you want to lose weight, the goal might be I'm going to lose five pounds in the next month. And how am I going to do that? Again, eating more fruits and vegetables, decreasing portion sizes.

And last for stress management, it's important that we acknowledge gratitude. Just as hard things happen in life, there are also good things happening all the time. And I recommend that you try and find three things to be grateful for every single day.

So sometimes feeling overwhelmed is actually more than stress. Sometimes it falls into the category of being depressed and we don't have time to go into that today. But I just want to make sure that I say there is help for depression. But you need to let people know, whether it's your doctor, your neurologist, your primary care doctor. You need to let people know. So this was all for families... excuse me, for individuals and couples. So let's get into families.

Healthy family patterns. Do you eat dinner together? Tons of research about the positive things that happen when families eat dinner together. Do you play together as a family? And this can be boardgames puzzles, card games, reading together, going biking.

Do you have family traditions? And what are those traditions and this might be as simple as specific recipes for certain holidays? Do you do chores together as a family? For example, many discussions, positive discussions, have happened over doing dishes together and how fun to get out as a family and be raking leaves or shoveling snow together.

Don't be afraid to hug your kids. Like adults, kids feel connected through touch. And be each other's cheerleader, give each other compliments, both in public and private. Look for the funny moments in your family and always, always nurture a spiritual side. This can be through organized religion or just acknowledging gratitude and blessings.

So let's get specifically to kids now. When do you tell your kids about MS? I believe you do this when kids are young. This is now the normal for your family. So you want to tell your kids very young, because this is the normal that your kids will be growing up with. I've had patients come to me and they've said, "Well, I think my kids are too young." How old are your kids? 10, 12, 15? I believe you start age 2, 3 and 4. And just like sex, you explain MS in language that kids can understand. Kids always have two questions. One, "is the most catchy?" "Am I going to get it?" And the answer is no. It is not contagious. And kids always worry, are you going to die from MS? Because kids want to know, are they going to be taken care of? For kids, you want to keep routines as normal as possible.

And always, always keeping an open door that kids can come and ask you any question about MS, that no question is off limits. And as kids get older, they're going to have different questions and they're going to process MS differently. And so, again, you want to keep that open door that it is always OK to talk about MS.

Kids will pick up on their attitude about coping with MS from their parents. I had one woman who came in and she's the most angry woman that I have seen in 40 years of being a therapist. And she described her daughter as being so angry. And I thought it couldn't be any other way because her daughter was picking up on mom's attitude. So be aware that kids can pick up on your attitude. Kids can also try and take on that parental role. And so it's important that you realize what the kids are doing. Keep your eyes open for this and make sure that kids are still getting out with their friends and having fun. Kids also can get depressed, so you want to look for the signs, which can be isolating, lower grades, nightmares, or kids just not having fun, or not seeming like themselves. But I also want to stress that just because a parent has a chronic illness does not mean that kids have a problem with it. Kids can be incredibly accepting and be resilient if they are shown how.

So in conclusion, MS brings changes, a lot of changes, to the person diagnosed and to the entire family. And it's easy to focus on all the negatives that MS brings. But I believe it is not all negative. By acknowledging what was lost while recognizing still what is possible, values get clarified, relationships can get stronger, and the focus of life can become very clear. So my goal for you is to have a good goal, satisfying life, which I believe is possible while living with MS.

So I want you to remember what you do matters. Everything you do makes a difference. And the little things count. So one final thought, before we take questions, is that if this all seems overwhelming, I'd like you to consider this quote by Mary Anne Radmacher: "Courage does not always roar. Sometimes courage is the quiet voice at the end of the day saying, I will try again tomorrow."

Marie?

**Marie LeGrand:**

So thank you so much, Elizabeth, for the very informative presentation. So I wanted to just chat a little bit more and discuss what it means to have healthy relationships while living with MS. So if you look online, you'll see different articles on coping with life, including stress and depression, as well as what it means and how people have different ways in which to cope. So can you talk just a little bit about coping with life and when both partners have different styles of coping?

**Elizabeth E. Nager:**



Great question. So I think it's important to first recognize that even in long term relationships, you're never going to be a clone of each other, that we need to recognize that, of course, there are going to be differences.

And sometimes one person is a talker and one person tends to be more quiet. And so it's looking at developing those positive patterns of how can you work together? How can you come together again as that team and so that the different styles of coping do not create fights?

**Marie LeGrand:**

OK. OK. Now, as far as experiencing different forms of stress every day, and most often people have to make important decisions on issues. So what if a couple is not comfortable talking about those important issues? Where would they start?

**Elizabeth E. Nager:**

So, I would say that, for example, after like a talk like this. Right? That would be a time to say, "So what was important to you? What did you get out of this? Was there anything that struck a chord for you?" After going to a doctor's visit together, that would be another time to say, "Boy, that was really important. What was stressful for you? What did you get out of the meeting with the doctor that we need to talk about?" Even talking - I had a time, "Boy, we have a neurologist appointment coming up in a couple of months. Maybe we can sit down together and start making a list, because I'm wondering if we both have the same questions." And sometimes even it's just sitting down and saying, "Boy, it's been a long time since you were diagnosed with MS, I think it's important that we sit down and talk about how are we doing? How are we doing as a couple?" But always starting with a question. I think that's the way to come together and to not start a fight. That it's asking the other person, how are you doing? Is there anything that's been on your mind and is there anything I can do to help you? I think those are critical questions to ask. That, again, shows that you truly are a team and dealing with living with a chronic illness.

**Marie LeGrand:**

Okay. Thank you. Now, I know we talked a little bit about depression, but not much. But depression is a common symptom of MS, as we know. So what if a person believes that their partner is depressed? What can they do?

**Elizabeth E. Nager:**

Right. So first of all, let me say that depression happens in the general population at approximately 17 percent. In people who are living with MS, the statistic goes up to 50 percent. So part of this is the stress of living with a chronic illness. And there's relatively new research that shows that the MS itself can cause depression. So it is critical that people remember help is available. It starts by talking as a couple. But if that is not enough, it may mean getting into counseling or it may mean getting on medication. And depending on the level of depression, if it's mild depression, it can be either just medication or just therapy. But if it is more moderate or severe depression, what the research says is that it is the combination of both where you are going to have the best results with depression. So as a partner, the best thing you can do is to be encouraging and supportive of your partner getting into therapy. And oftentimes I will see a couple, and sometimes it's easier for the one person who's depressed to have that first session with their partner. And afterwards, we may do alone, we may do together, it may be some combination. But showing as a partner that you absolutely support the person with depression, that you are behind them 100 percent in getting help.

**Marie LeGrand:**

Good points. Thank you. So let's shift a little bit and talk about intimacy. How would someone open up a conversation with their partner about intimacy?

**Elizabeth E. Nager:**

You know, I think talking about intimacy, for how much sex we see online, in movies, in advertising, we are surrounded by sex. But it is still awkward to bring up talking about intimacy. So I think sometimes if there's a nice beginning, for example, seeing a movie. Right? And afterwards, boy, what did you think about that? Or that scene reminded me of..., or that scene triggered something that I've been thinking of, or I had a conversation with someone, or I read an article. But that can make it a little bit easier to talk about sex and certainly bringing the subject up when you are both calm, not after a fight, when the kids are away, but just saying, I want things better between the two of us, or I'm missing this part in our lives, and I'm wondering what we can do. Again, looking at there's a problem. What is the solution that we can work on together? Because even working on the problem together can bring you closer in an intimate relationship.

**Marie LeGrand:**

Thank you. So last question regarding intimacy. So intimacy does involve emotional factors as well. So what can a couple do together to reclaim their intimacy?

**Elizabeth E. Nager:**

So I find that sometimes it is the most simple things in the beginning. Sometimes it's just remembering to be polite to each other, again sitting, watching a movie and holding hands, putting your hand on your partner's leg. It's starting by just having the most innocent touch. That is a reminder that we are a couple. It can be out of the clear blue. Giving your partner a hug and saying, wow, I missed this part of our relationship. But starting with very, very small steps. It's not going from having no sex for years and then saying, boy, let's have sex tonight. It's starting with very simple, simple but powerful messages that I miss you and I miss this part of our relationship.

**Marie LeGrand:**

Thank you so much, Elizabeth. So we're going to go ahead and turn it over to our audience for Q&A. And the first question that we have focuses more so on family. So what do you do if you are divorced, with teens and MS? The individual mentioned I have no friends close by and have tried online dating with very little success, no social circle of friends where I live, I mainly read, watch TV, yoga, meditation, and various sessions just like this one. So what would that individual do? Someone who's divorced with teens and living with MS?

**Elizabeth E. Nager:**

So the first thing I would say, even if you live in a smaller area or an area, and especially now during the pandemic, where you cannot find an MS group in person, there are now groups online, but you absolutely need to be in contact with other people with MS and meet some other people who also have teenagers. And I would say online right now is going to be probably one of the best options. Having teenagers is tough anyway. And with being divorced and having a chronic illness, you want to make sure that you're not getting overwhelmed. And part of that is having that support network. So the fact that this person has even done as well as they have with taking care of themselves, I think is absolutely wonderful. But I would probably try and find some MS groups online. And I have had some clients who have had great luck with this, and they've gotten to be absolutely great friends, that it's been a great source of support for them.

**Marie LeGrand:**

Okay, thank you. Now, for family members and friends and for many individuals, friends are part of their family circle, and they may not always understand the effects of MS symptoms. I've heard from individuals who have said that MS, you don't look sick, though you have MS. Right?

**Elizabeth E. Nager:**

Right. Exactly.

**Marie LeGrand:**

So how would an individual go about in speaking to their loved ones about their MS?

**Elizabeth E. Nager:**

So I would probably equate it to another disease that is invisible. For example, diabetes, high blood pressure, arthritis. And I think it's harder, especially if people are younger, that if you're diagnosed with MS in your 20s, 30s, 40s, again, the common ages to be diagnosed with MS, there are not so many people with chronic illnesses. But as you start to age, your friends will start to be diagnosed with invisible diseases also. And so I think to be able to equate it to other invisible diseases, to say that, boy, I know someone else who is diabetic and you would never know from looking at them either, or someone else has high blood pressure, and you would never know by looking at them either, but explaining that invisible nature of having a chronic illness.

**Marie LeGrand:**

Thank you. So it can be easy for someone to blame themselves. How can a person get out of the habit of blaming themselves for things that are not in their control?

**Elizabeth E. Nager:**

Oh my, right?

**Marie LeGrand:**

Right. That's a tough one.

**Elizabeth E. Nager:**

That's a tough one, right? One of the techniques that I like to do and that I like to recommend to people is each time there's a negative thought, or you know you're getting into that unhealthy pattern, blaming yourself, whether it's blaming yourself for something you did or didn't do. Boy, anything that is negative, that you try and give equal time to something positive. For example, boy, I ate like crap last night. I can't believe there I blew it again. My goal was to really try and be healthier. And I can't believe I blew it again. But remind yourself, first of all, that we don't have to be perfect. And maybe dinner was bad, but breakfast and lunch the day before, that you actually did a great job of eating healthy. That each time you find yourself going into the negative, I did something wrong, to find an equal number of things that you did right. It's breaking that pattern. And even the pattern of negative thoughts can be broken, but you need to give equal time to the things that you did right. And it might be also at the end of the day, as you're reviewing your day and saying, boy, I did this, this, this wrong, that you say and I also did this, this and this right. That you give yourself credit.

**Marie LeGrand:**

Good point. So how does a person... specific question, how do I make time for myself?

**Elizabeth E. Nager:**

You know, for all of us, life is so busy that it sometimes is squeezing in small amounts of time, but making it quality. I have one client that again, she had a big family and it certainly is not my style, I'm not a morning person, but she woke up at 5:00 in the morning, because the kids, everyone was waking up at 6:00. She woke up at 5:00 in the morning, went for a walk, and then was able to have a cup of coffee and do some reading before the rest of the family got up. But it was finding that worked for herself. That was... she found that it just started the day in a great way. I had one couple that the kids knew that when they came home from school and before, and this was before the pandemic, so they were still going to school, that before dinner they had to go to their rooms because mom and dad had 20 minutes to just talk themselves. That the kids had to skidaddle - mom and dad had privacy for 20 minutes before dinner. It's finding ways to sneak in, whether it's 15 minutes, whether it's a half hour, whether it's going for a walk, whether it's waking up early, whether it's on the phone with a good friend. But it's critical that you find those ways to have time together because you will be way more energized. And I believe you'll be a better quality partner and parent if you find that time for yourself. And part of it starts with saying, I deserve this time and not feeling guilty for taking that time for yourself. You deserve it. And you will be a better quality parent and partner. And I believe overall you will just feel healthier if you take that time for yourself. Good question.

**Marie LeGrand:**

Yes. And now there are some individuals who may feel guilty when they think about taking that time for themselves. So can you offer any suggestions on how to not feel guilty, perhaps?

**Elizabeth E. Nager:**

And again, feeling guilty, some people feel selfish for it. I would say do an experiment. Try to take one month where you say, I'm not going to feel guilty. I'm going to do everything that I know is important for me and see how you feel at the end of the month if you truly do everything you can to take care of yourself. Just monitor yourself. Are you that better a partner or parent when you take that time for yourself, do your own experiment. You know, I'm suggesting a month, even if you do it for a week, see how you feel when you truly with a great frame of mind saying, I'm doing this for me because I deserve it. See what happens.

**Marie LeGrand:**

Thank you. And in just the last question that we have, how do I know when I'm helping a person too much?

**Elizabeth E. Nager:**

Helping too much? What I have found is most people will say something. I will hear the expression, my partner is smothering me. They're suffocating me. I know they're doing it out of love. I keep saying you're doing too much. You know, I think you need to go to bed earlier. I think you need to rest. I think you need to say no to another obligation. But most people with MS have a sense of when they're doing too much. And if the person with MS really is truly doing too much, where they're absolutely exhausted at the end of the day, more days than not, then I would recommend asking a question, even though it's done out of love, if you say, oh, I see you again and again and again, you're making poor decisions, even though that's out of love, it comes across as nagging. Where if you ask the question, what do you think? Do you think you're doing too much? The conversation, I think, will go much smoother and there will be a better outcome to that conversation.

**Marie LeGrand:**

Wonderful. Thank you so very much, Elizabeth, for the wonderful presentation. Thank you so much for your time. This has been an amazing and insightful program. Do you have perhaps any last words for our viewers?

**Elizabeth E. Nager:**

I do. I do. Again, if you want to put on that last slide, once again, it was that quote by Mary Anne Rademacher. And also just a couple of things that I want to emphasize. I would encourage everyone to ask themselves, what do you want for your best life? What are you doing to create this best life? And it is never, ever too late to begin making the changes to make your relationship better.

**Marie LeGrand:**

Wonderful, wonderful, absolutely wonderful. Well, thank you so much once again for your time. This concludes the website, the webcast, I should say. Tonight's webinar was recorded and will be made available on our website at [mysaa.org](http://mysaa.org). Please do visit MSAA's calendars of events for our upcoming webinars.

On behalf of MSAA we would like to thank Elizabeth once again for the great presentation. And we would also like to thank you for joining us this evening. Please consider completing the brief survey which will appear on your screen momentarily. Know that we are thinking of the entire MS community and hope that you and your families continue to stay safe.

Thank you and have a good night.

**Elizabeth E. Nager:**

Thank you also so much.

**Marie LeGrand:**

Thank you.