



**National
Multiple Sclerosis
Society**

**MS Learn Online
Feature Presentation
Planning for Life with MS
Dorothy Northrop, MSW, ACSW**

Tom>> Hello, I'm Tom Kimball

Tracey>> And I'm Tracey Kimball. We're glad you've joined us for this program on Life Planning.

Tom>> Exactly. It's something we all need to do, whether or not you have MS.

Tracey>> But for those of us with MS, it's especially important. Correspondent Rick Somers sits down with Dorothy Northrop, who is vice president of research and clinical operations for the National MS Society.

Tom>> They talk about areas of life planning that are especially important when living with MS.

>>Rick Somers: Dorothy, planning for the future is something that most of us have tried to do, and I say that with quotation marks around it. Most of us have tried to plan for good things -- marriage, buying a house, having a family, etc., etc. Then the diagnosis of MS comes up and wallops us. Talk to us about what life planning is and

how it's incorporated and how it's changed when somebody is dealing with MS.

>>Dorothy Northrop: Well, life planning is really looking to the future and kind of anticipating what needs might be there, and then trying to figure out how we might meet those needs, if they come up. It's not saying that the problems are going to arise, but it's more saying let's be prepared. No matter what happens, we want to have some control of this.

And we know that there's always changes that can happen. Changes can happen in terms of income that we didn't anticipate. We could have a dip in our health status or our caregiver could have a dip in their health status and all of a sudden not be able to do what they were doing before. There can be all kinds of different things that come into our lives that we just don't know how to anticipate. So, we want to think about those possible changes and say, well, if that happened, how would I deal with that?

And some of the changes can almost be -- you almost know they're going to come. For example, if you have teenagers that are going to leave the home and they're doing a lot of help in the home, then you know that if they do go away to college, we're going to need to figure out, then, how we're going to deal with this. So, it's those kinds of questions that we look at. What if this happens, or when that happens, how will we be prepared?

And I think you also want to make sure that you're handling your risk in terms of financial risk. You want to make sure that you're protecting your assets and looking at what's going in with your finances so that you're protecting yourself and giving yourself as much financial stability as possible. You want to think about how do we keep ourselves as independent as possible? And that might open up areas like home modifications, technology, things that we may need to look to now to make sure that we can do what we want to do and lessen as much as possible any hands-on care. Because there are so many things that are available now, where people can be

independent and control their own environment, and get out of their house easily, and be able to go out.

But you have to plan. You have to figure out how you're going to pay for these things, and you have to kind of anticipate so that you're not surprised. Because there's nothing worse than surprises. You don't want to get into a situation where all of a sudden you have to figure out what you're going to do -- you know, Aunt Sophie can't come over like she always does, and what are we going to do now? Who do we call? How do we handle that? And the more you can anticipate those situations, the more you're going to be in control of the future.

>>Rick Somers: Let's talk specifically about life planning financially and the impact that may have.

>>Dorothy Northrop: Well, it is very important if one is just diagnosed, and all the way through the progressive disease, really, to make sure that one is looking ahead to what the financial needs might be. And there is certainly expertise out there to help with that.

We use a lot of financial planners who are very skilled at looking at where a person is now and where they want to be in the future, and how to get them from one point to another. There are a lot of elder law attorneys, and they are specialized in knowing state regulations and entitlements, Medicaid, knowing where you might be able to be eligible for services.

So, it's important to kind of figure out how do you protect your assets? How do you make sure that you're maximizing your income, taking all those tax deductions that you need to be taking? And then also planning for when you might have more expenditures down the road, and how do you make sure you have the dollars to do that?

So, it's very important to get some professional advice on that and to look ahead in terms of changes, particularly, that might occur. If

you're employed, what happens when you're not employed? If you're getting income but you know it's going to be reduced at a certain point, how will you handle that? So, it's incredibly important to really be thinking and not just being caught by surprise when these things happen.

>>**Rick Somers:** Specifically, are there tools and resources that come to mind?

>>**Dorothy Northrop:** There are a lot of tools out there that can help people begin to get a sense of where they are financially. The National MS Society has many different resources that can help people start thinking about this: books that are geared to helping them look at where they are now, different entitlement programs, how you might hire someone to help you later, if you need it, and so on.

So, there are a lot of very practical workbook-type of tools that are available. And the more people can start to really put down on paper where they are now, and then start looking at where they want to be, then they'll be on the road. You really need to know where you are now before you know where you can go. So, there are very practical steps that people can take in this regard.

>>**Rick Somers:** That's a nice snapshot of financial advice. How about medically planning for the future?

>>**Dorothy Northrop:** Well, again, when you're talking about medical needs and you have a clinical issue, you have a disease, you want to make sure that you're getting all of the healthcare that you need. So, you want to make sure that you have access to not only care for your MS, you want to get care for your primary healthcare and making sure that you're well; you want to be able to go to specialists when you need to. And a lot of that will depend on insurance, frankly, because that's where we are in this day and age. So, a lot will depend on your insurance coverage.

And so probably one of the most important things people need to do is be very familiar with what their coverage is, and if they have choices in terms of making a selection of a plan, that they really look at it carefully. Because even though it's something that might cost less now, if you look down the future, you may find that it's not going to cover things that you really need. You want to be able to get to your specialist. You want to be able to get a team approach to your MS.

So, it's important that people really analyze their health insurance coverage and make selections that are based on not only their needs now, but what they might need in the future, so that they feel like they can go forward and take care of their clinical care whatever way they need to have it done.

>>Rick Somers: Dorothy, speaking of health insurance, it's something that very few of us know a whole lot about, and I'm going through the process now where I'm shopping and trying to incorporate some of the things you discussed already. Give me some more specifics.

>>Dorothy Northrop: Well, the health insurance world is very complex, so it is very, very hard to figure it all out. I think that now it's even more challenging because many times people have a choice in what plan they choose for their health insurance. Even at the job there may be three or four plans. So, it's very, very important that people really look into each of those plans and see exactly what it covers and what their costs are. Because they range, and a plan that has a low premium may end up having a lot more cost later. And something that seems more expensive now in terms of a premium may give you access to specialists and out-of-network doctors, and really enable you to go to wherever you want to go and not have too much out-of-pocket costs.

So, it's really important that someone analyze their health insurance and make choices that are based on what they need. So, it's really paying attention to detail when it comes to those health insurance policies. It's not fun, but it really is important if one wants to make sure that they have some security for the future.

>>Rick Somers: And trying to anticipate those needs, which is impossible with MS, but somehow just trying to gauge, looking at the big picture, keeping your eyes in the prize, so-to-speak.

>>Dorothy Northrop: That's absolutely right. You really want to make sure that you're looking ahead, and that you are going to create your environment so that it's going to help you be the best you can be in terms of your medical condition, your wellness, everything. This is so important. And, of course, equipment is huge. Rehabilitation is huge. These are areas that are often a struggle to get coverage for, and so people need to be very clear, work with their doctors, make sure they're advocating for their needs, and making sure they're within a plan that, if they can be convinced, will pay for it.

Tracey>> Thinking about the future may not always be pleasant, but it's so important. And thinking about it is only the first step. As Dorothy points out, we all need to take charge of our lives and make plans for the future future regarding finances, insurance and medical support.

Tom>> Other areas to plan for include Employment, home modifications, and long term services; these are all situations that can change over time, and we need to plan for them.

Tracey>> Exactly! Check out the National MS Society website to find additional information on life planning. To get there click on the resources button below.

Tom>> Thanks for joining us today. We hope to see you again soon!