



**MS Learn Online  
Feature Presentation  
Planning Ahead While Living with Primary-Progressive MS  
Dorothy Northrop, MSW, ACSW**

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**Tracey>>** Hi I'm Tracey Kimball

**Tom>>** and I'm Tom Kimball. Welcome to MS Learn Online. Planning for the future is something we should all do. But it's especially important if you have primary-progressive MS.

**Tracey>>** Dorothy Northrop is the Vice President of Research and Clinical Operations for the National Multiple Sclerosis Society. She joins correspondent Rick Sommers to talk about what people living with primary-progressive MS can do to plan for the future, or what is commonly referred to as "life planning."

>>**Dorothy Northrop:** Well, we often talk about life planning when it comes to living with a chronic illness. Actually, it's a good term for any of us, but particularly when you have a chronic progressive disease, you want to be able to anticipate future needs that might arise, and figure out how you're going to meet those needs. And that's basically the task of life planning.

So, it's really anticipating changes that might come, whether it's in terms of employment or income or family support or health, either of the person

with MS or the caregivers. It may be trying to reduce your medical costs in the future, limit your financial liabilities, and just basically figure out how are we going to be able to continue to have the person with primary-progressive MS continue to be as independent as possible and to have control over their life?

I think what happens is that when we don't plan, we often end up in crises, and all of a sudden we have a problem and we don't know how we're going to go forward. How are we going to get through this day? We have something that fell apart that we thought we had arranged, and then our options and choices become much less. So, the more we can anticipate what might happen and be prepared, I think that puts the person with the primary-progressive MS and their family in the driver's seat, and they can really have some control over how things are going to be handled.

>>**Rick Sommers:** Along those lines, how can one with primary-progressive MS plan for their medical care in the future?

>>**Dorothy Northrop:** Well, certainly how one receives medical care is going to be critical if you have a chronic progressive disease. So, you're going to want to make sure that you are able to access all of the clinical services you're going to need to be able to maintain independence and feel as well as you can. You're also going to want to maintain control over your health care. You're going to want to make sure that you're going to be making those healthcare decisions. And probably the third goal is to make sure that you're reducing your out-of-pocket costs as much as possible, because it's very expensive and there's a lot of needs that arise with MS.

So, I think people need to be very aware of their disease. They need to learn very carefully what their disease is and what they can anticipate. And they need to have some good, honest conversations with their doctor and other healthcare professionals so that they can anticipate what might come along in the future medically.

They also need to be very savvy in terms of their health insurance coverage and their choices, because today it's not like you're handed your health insurance policy. You have to make choices, and so you want to make sure that you're getting the coverage you need to see your specialist, to get the various interventions and drug therapies that you need. And today you often have to make the choice. It's not made for you. Sometimes it costs more as a premium to have a higher health insurance plan, but for someone with a chronic condition, it may be something that's going to save a lot of money in the long run.

So, I think people need to be very educated consumers about the healthcare system and about how they can go about making sure that they're going to get all the care that they need.

And I think finally, in terms of decision-making for healthcare, there often is a time that all of us have to face where we may not be able to make that decision at the time it needs to be made. And so it's very important to kind of look ahead and set forth advance directives about what you want to have happen if you were not conscious and needed to have some medical intervention. And you may want to think of someone that you want to make decisions for you, if you're not in a position to make that decision.

And these are all things that all folks should be really doing, but I think when you're dealing with a chronic progressive disease, you just want to make sure you are as prepared as possible.

>> **Rick Sommers:** And along those lines, how does somebody with primary-progressive MS plan for their future financially?

>> **Dorothy Northrop:** Well, financially, it is a very big road for folks with a chronic progressive disease like MS. We know that MS is a very expensive disease and that there is a lot of costs that come to it, whether it's costs in terms of medical care, in terms of support services, or whatever. So, financially planning is incredibly important, and we usually need professionals to help us with that, frankly, because it's very complex.

So, you want to really be tapping into a financial planners and elder law attorneys and community care managers; anyone that can kind of help to negotiate those systems.

You want to be able to anticipate possible costs in the future. You want to be able to handle your assets and your income and your expenses in a way that's going to give you the best protection. So, there's a lot of thought that needs to go into how you balance your dollars.

There's sometimes opportunities to set up trust funds that can assure someone can get care later, but it has to be done within the legal framework of a state. So, you usually need to have professional assistance in making those decisions. But it will pay off in the long run, because you will be prepared.

And I think the other thing financially is to learn about the different services that one can be eligible for based on their needs. There are a lot of dollars out there now for home and community-based services, and it's important for people to know what makes them eligible for those services. Because there may be financial decisions they can make today that will assure that they will be eligible for those programs when they need it. So, looking ahead and anticipating what's going to happen financially is really a very critical piece of living with primary-progressive MS.

>> **Rick Sommers:** How can somebody with primary-progressive MS plan for the potential need of long-term services?

>> **Dorothy Northrop:** Well, usually when we think of long-term services, we're often thinking about needing more personal assistance. Usually when we talk about long-term care, we're talking about someone who may need help with activities of daily living, whether it's bathing or dressing or toileting or transferring, or whatever. So, as one looks ahead to the potential of needing more hands-on care, I think again it becomes a family dialogue, to really look and see what can we do within our family to make sure that we can give the hands-on assistance that's needed?

And then they may need as a family to make a decision that maybe we need to go outside of ourselves for this help, whether it's paying for services or having additional friends and neighbors help. And so it's kind of, again, looking at planning and thinking ahead, what might we need? Let's have everyone onboard as to how we go forward. Let's get our family members to look into the possibilities. What do we know is out there? Many families don't know what services are available, and so let's get our crew of family out there and find out about these different resources, so that if we do need them, we'll know exactly where to go.

**Tracey>>** Health care, insurance, financial planning ... issues that everyone needs to think about, and they're especially important for people with primary-progressive MS.

**Tom>>** It makes me think that maybe we should check in with our financial advisor and go over a few things.

**Tracey>>** Good idea Tom, let's do that. If you need an advisor to work with, or if you have any other questions about planning for your future, contact your local chapter of the National MS Society.

**Tom>>** And we'll see you next time.