



Comprehensive Care and MS

DEBORAH CHANDLER

Comprehensive care is care that provides a holistic approach to the patient, related to the condition. It addresses all of the needs of the patient, both physical, emotional, psychosocial.

DR. ROSENBERG

Comprehensive care is a concept that's used for complex diseases like multiple sclerosis.

KATHLENN COSTELLO

It's about the person with MS at the center, and then it's about the various professionals that are needed, including physical therapy and other rehab professionals, neurology, primary care. Psychiatry may be necessary. Social work, pharmacists, vocational counselors. It may look different for different people, depending on what their needs are in Multiple Sclerosis. Nurses and nurse practitioners are often involved in Multiple Sclerosis care. If someone chooses to become a nurse practitioner additional education is necessary. Both groups are going to be involved in education and, uh, management of, uh, medications, the side effects of those medications, helping someone understand their disease, providing support for that individual, providing referral in the community for the individual so that they have the support and resources that they need.

CHANTEL KEYS

My name is Chantel Keys. I'm 23 years old. I was diagnosed with multiple sclerosis at the age of 15. I went to my primary doctor first, and he referred me to a neurologist, who then had me do an MRI. My symptoms vary. Sometimes it's headaches, but it's not as intense as it was in the beginning when I was first

diagnosed with MS. I have tingling and numbness sometimes, especially in my legs.

DEBORAH CHANDLER

There are three basic care needs of the patient. The medical care includes disease modifying therapy, acute relapse management, and then symptom management...So, we go through all the medicines so they understand the pluses and minuses of those....At that point, it becomes a partnership. So, we're able to actually discuss with them, which one would fit the better lifestyle.-If it doesn't work there are other options, and I always try to give them hope that there is something else down the road should one not work. A lot of times with these medicines that we're giving, they don't make them feel well, but they slow down the disease progression. Symptom management would include those things like physical therapy, occupational, speech therapy.-Urologists, neuropsychologists, all of the other ancillary services that help meet those patient's needs when we can't meet them ourselves. If we need to coordinate care, be it referrals, we'll make that happen. If it's medicines we'll make that happen, whatever the patient needs. And then the final part was relapse management.

PATTY BOBRYK

We need to know you as a person, and what you're willing to be able to do, and can tolerate doing, and being able to share that with us, just puts in place a better plan, a plan that you can follow. You feel empowered to follow through with the treatment plan, if you're engaged in that treatment plan. So, that's really important that your care is not being dictated to you, that you're in the driver's seat and that you're going to be able to say, you know what I can do this, but I can't do that. Do I have any other options? Can we talk about that? Wellness is an important piece in your overall treatment plan for your MS.... If you're not taking good care of your overall health, that can have a negative influence on your MS. Somebody who is not taking care of good nutrition, and good sleep habits, and making sure they're staying hydrated, those things can all have negative impacts on your MS symptoms. So, we want to make sure that wellness is the important piece in your overall intervention. We also want to decrease your risk factors for other things that might occur in your life like heart attacks, stroke,

diabetes to make sure that we decrease the risk for those throughout the course of someone's lifetime.

CHANTEL KEYS

I see my primary doctor for routine checkups. It's kind of nice, sometimes he's like maybe it's an MS symptom. So sometimes I have to contact the MS center just to verify or to let them know. So, he's aware of my MS, and he lets me know if maybe I should contact them versus my primary doctor. At the center, I see Dr. Rosenberg, and I also see Ms. Chandler. When the doctor comes, they ask how I'm doing, and is anything changed, how are my medical symptoms, how's life going? Do you have any concerns or any questions that you want answered? And they don't mind, because sometimes I come with a long list of questions. I normally bring any medication that I may have gotten from my primary doctor that I may be on along with the pills that I'm – the vitamins that I may be taking. So, they will have an update of what medications I'm taking. And it's normally just weight, eye vision, do a strength test. They like to see how my balance is, so I do a walk down the hall, and I balance on one leg, and we just talk about any symptoms I've been having lately. And how's life going basically with MS.

DR. ROSENBERG

MS affects the patient, but hits the whole family. The family is so important... there is a tremendous need for education among the family members. There has to be understanding of the nature of the disease.

DEBORAH CHANDLER

It's important for patients with MS to realize that unfortunately they don't always have just MS. They usually have a lot of other what we call comorbidities. So they might have hypertension. Other issues, thyroid disorders, bladder disorders that aren't related to MS, and it's important that they follow up with their primary care and get routine primary care as well. all of the basic needs are important as well, flu shots included, pneumonia vaccines, etc.

PATTY BOBRYK

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your life like heart attacks, stroke, diabetes to make sure that we decrease the risk for those throughout the course of someone's lifetime.

DEBORAH CHANDLER

Wellness is very important in MS. We need the diet to be as good as possible. We need the exercise to take place. Exercise improves fatigue, and fatigue is a huge part of the patient with MS. Of course if they can maintain a healthy weight, it's going to put less stress and strain on their joints, and again, less issues for the patient down the road. So a lot of times we will refer the patient to physical therapy and get them a needed home exercise program that they can do.

PATTY BOBRYK

The ultimate goal for rehab in general is to have somebody strive to the highest level that they can function at. Rehab can help set those goals and work towards those goals..... we attack it from whatever direction we have to or that we can in order to support the individual in whatever function or task that they want.

DR. COHEN

Mood and cognition go very close, hand-in-hand. So, we're addressing both of them at the same time, because one can affect the other and vice versa. As this person's brain changes over time, because of the disease process, emotional changes will occur. If we don't address those, the person will not get better. You want people to understand and buy into the care that they're getting and you want to be able to connect with them emotionally. And in order to treat a person, you have to understand that a person is much more than MS.

CHANTEL KEYS

Just because you have MS doesn't mean the world stops. You still have to take care of yourself. So, when it comes to other symptoms or things, make sure you write it down and keep a notebook, and make sure you keep the time, so if you have numbness or shaking, write the start period and write when it ended. I need to be proactive when it comes to setting appointments and staying on top of my MS, and my other health as well.

PATTY BOBRYK

Oftentimes in individuals with MS, those well visits, those primary care needs, often fall by the wayside, because they are spending most of their time and their energy managing their MS symptoms and going to their neurologist.

DR. ROSENBERG

It helps to have a neurologist who has particular interest or expertise in multiple sclerosis. MS affects the central nervous system. That's the brain, the spinal cord, and optic nerves. As everyone knows the central nervous system is involved with every aspect of the body. And patients with MS frequently develop difficulties in other areas beside multiple sclerosis.

DEBORAH CHANDLER

So if the patient doesn't have, or the person doesn't have the resources close by, the first thing they should do really is contact The MS Society, because the MS Society can not only give them neurologists that perhaps treat MS in the area, but also MS support groups in the area. Those two really are the key. If you've got a neurologist that's willing to treat MS, that's very important. And then the support group will say, this is the best urologist in town. This is the psychiatrist that go to. Here is the rehab center that really knows about MS, and in that you can build your own network.

CHANTEL KEYS

Yes, I'm constantly learning about MS. I get emails about new things that's going on, new events that may happen, new medications that are coming out, are being tested. So, it keeps me on my toes to stay active, and to stay on point when it comes to new information, because time flies by. Life doesn't stop with MS. So, you still have to continue to live, and there are healthy ways to live. I'm looking forward to a cure one day with MS. It's going to come one day, just patience and time. Until it comes just continuing to do everything that I know I need to do, stay on top of my medications, stay active, keep up the daily stretches. Attitude has a lot to do with MS.

