



**MS Learn Online  
Feature Presentation  
Medical Self Advocacy: Palliative Care Primer  
Featuring Maura Del Bene, NP-P, ANP**

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**Tom:** Hi I'm Tom Kimball

**Tracey:** And I'm Tracey Kimball. Welcome to MS Learn Online as we continue our series on Medical Self Advocacy.

**Tom:** This time the subject is palliative care.

**Tracey:** I think it is safe to say that palliative care is a topic that few of us know much about and for those who do, it's often misunderstood.

**Tom:** And yet it seems to be a great tool available for many people with MS. Medical correspondent Kate Milliken spoke with Maura Del Bene, who is a palliative care nurse practitioner with the Lawrence Hospital Center in Bronxville New York. What is palliative care? Ms Del Bene explains.

**>>Maura Del Bene:** Palliative care is a specialized area of medicine that addresses care of patients with diseases that are progressive, chronic or terminal in nature. It could begin at the time of diagnosis and continue on through a person's life journey. It can be provided simultaneous with the disease-modifying treatments. So, it's there to accentuate symptom management, really focusing on improving quality of life for the individual and their family throughout their disease process.

**>>Kate Milliken:** If somebody, a person with MS, is there a certain point where they would take on the palliative care?

>>**Maura Del Bene:** I think that palliative care is a perfect dovetail to MS care, traditional MS care that's available in that you're working with individuals who not just only know MS, but they know other disease processes. And they know how to manage advanced symptoms that are refractory or resistant to typical treatments. And that's a problem with MS.

The chronicity, the progression of the disease often renders people with difficult symptoms of pain, urinary and bladder incontinence, maybe some cognitive deficits. These are areas that we need to dovetail together and team up together, MS Care Centers and palliative care.

When you live with MS, you acquire other disease processes through your lifetime, heart disease, pulmonary disease, cancer. These make life even more complex, and the medical management and decision-making much more advanced. And that's where palliative care can really dovetail nicely, again, with the MS Care Centers.

>>**Kate Milliken:** What I know about palliative care is it's a thing that comes into play when you're really at the end of the spectrum, but is that necessarily true?

>>**Maura Del Bene:** I'd have to disagree. I think originally palliative care was synonymous with hospice care. Hospice care is palliative care, but palliative care is just good management of advanced disease that is either a consequence of the disease or its treatment. And it can carry through with your journey till the end of life culminating in hospice care.

But we're really trying to work hard at moving people upstream, because there is planning that needs to be done, decisions that need to be put into place, and a supportive care environment that travels with you along the way in many different settings. Not just in an outpatient clinic setting, but at home, when you're in the hospital for other issues. MS doesn't go away when you go into the hospital for appendicitis, or when you have a colon resection because you have challenges with cancer.

Long-term care facilities. In many different locations, palliative care specialists are sprouting up to help people with chronic and progressive disease processes.

>>**Kate Milliken:** So, when you talk about multi-disciplinary care of MS, how is this different? I mean, I know you've spoken about how it dovetails onto

certain parts of it. But if I was a patient with MS and I was at a phase where I might be looking into this, where do I find it? How is it different, and how do you kind of --

**>>Maura Del Bene:** I think as a consumer, as a person living with MS, you know where your MS treatment team can take you, where they've been supportive, and where they are identifying where they're having challenges as well. And I think that's when you both have to go out of the box and say where else can we turn to? Who else can help us be more creative with addressing my symptoms? I understand these are the traditional ways of doing things, but are there things that we haven't addressed or looked at?

I need more support. These are triggers that people say. My pain is really not better improved; we've been working on it for a few weeks or a few months. I think when you feel like you need extra expertise coming in, as a consumer you can say let's try and look at a palliative care service.

They can be found throughout the country now. That is the beauty of the growth of the palliative care movement, not just being at the end of life, but being upstream from the time of diagnosis.

The Center to Advance Palliative Care in New York City has a consumer website called [www.getpalliativecare.org](http://www.getpalliativecare.org). And you can go in and look under your state and see where there are listings in hospitals or outpatient settings, where you can find a palliative care service provider.

I'm also assuming that if you call your Department of Aging in your local area, you can find information on palliative care.

**>>Kate Milliken:** So, what has been the most exciting thing for you watching this whole kind of part of the process develop.

**>>Maura Del Bene:** I think the best thing is to always get more resources, more information, and more symptom control to people living with any type of disease, particularly with MS. Large populations, young people across their life spectrum, this is just one aspect of their lived experience. And it can either be something that we help really manage optimally and help them live the highest quality of life possible.

Because it's not terminal, people will live a very long time. And with that length of time, gives more opportunities for losses: losses of confidence, loss of function, loss of symptom control. And I think if we can team together to maximize people's symptom control, support and education, within the mission of the MS Society and the MS Care Centers around the country and the world, I think that palliative care can enhance all of that.

**>>Kate Milliken:** Tell me about the costs involved with palliative care.

**>>Maura Del Bene:** Similar to any doctor's visit or appointment that you would have. Many times hospitals, if you're in an inpatient setting, their service is part of their hospital system of delivery. Right now I work in a hospital, they don't bill for my services. I'm part and parcel with being a patient at that hospital if you need palliative care intervention.

In an outpatient setting, commercial insurances pay for them. They just bill differently. They don't bill under the diagnosis of MS; they bill under the diagnosis of pain and symptom management issues that they're addressing.

**>>Kate Milliken:** So, you've talked about kind of generally what palliative care is. Can you give an individual kind of example of somebody in terms of somebody with MS, why they would hire a traditional doctor? Why they would hire you or your service, what each parts address?

**>>Maura Del Bene:** I can think of a gentleman who was 62 years old, living with MS for about 12 years. He at that point was nonambulatory. He had limited function of his upper extremities and had intermittent challenges with speech. At times his speech would be relatively clear but low volume because of respiratory weakness. At other times his speech would be slurred and almost unintelligible. He had difficulties with pain as a consequence of his immobility. He was no longer to get to his care providers as easily. His local internist -- his neurology care providers, excuse me.

His local internist, who managed his intermittent infections that occurred because of the MS, the advanced stage, or because of the immobility, called me into the hospital setting once and said, "He's not dying, but I don't know what else to do for him, but he's got challenges."

And we met and over a few weeks we were able to identify areas, like I said, the pain, the immobility, the respiratory dysfunction, and the speech disturbance.

And we talked about ways in which those issues challenged his quality of life and his functional ability, but also ways in which he hadn't been identified -- ways in which those areas had not been identified, on how to improve them. His pain was part of the disease. They did what they could for him, they told him to take certain meds, but they didn't really address and probe it longer because his speech wasn't always able to identify all of his experiences.

He wasn't able to get to the centers that provided advanced symptom management. So, we became that team for him. And we identified other areas in the community that could help him with augmentative communication devices, changes in his mobility, his seating mobility so that he didn't have as much pain. And we started a whole different pharmacologic routine for him.

**>>Kate Milliken:** Wow! Why do you think people confuse palliative care and hospice?

**>>Maura Del Bene:** Because I think as a healthcare community, we always want to cure people, and it's hard to talk about the inevitable, that we are all going to die, whether we have diseases or not. And as physicians we're trained to cure people, and that transition is very hard. Now, that's changing in medical school, academia and curriculums now. But I think on the whole, people want to be cured. People want to live as long as possible. But what they want to live with is good quality.

And I think that's where the shift from hospice care to palliative care, and defining those terms as different really can support that goal. Quality of life while living with disease, and helping you make the best decisions you can. And it's not about dying; it's about living with disease.

**>>Kate Milliken:** What would you describe the way you kind of move forward with patients?

**>>Maura Del Bene:** I think sad is not addressing the person's needs. It's not giving them all of the opportunities available to them, in helping them maximize their access to those opportunities. I think every achievement that we can make with improving a person's symptoms and helping them live better changes this from a sad situation to a fantastic opportunity.

**Tom:** That example of how palliative care impacted that man with MS was fascinating.

**Tracey:** Yes it was. It seems that palliative care can address all the different needs a person with MS may have and how one need may impact another.

**Tom:** Our third episode on Medical Self Advocacy deals with the topic of disability care centers. Be sure to check it out.

**Tracey:** Thanks to Ms. Del Bene for helping us understand palliative care, and thank you for joining us for MS Learn Online.