



**MS Learn Online  
Feature Presentation  
Program Title Here  
Featuring Maria Milazzo, N.P., CPNP**

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**>>Kate Milliken:** Welcome to MS Learn Online. I'm Kate Milliken. In our first program on pediatric MS, we learned about the issues children and teens with MS may face in the school setting and strategies families can use to advocate for services in the educational system. We'll continue our discussion on pediatric MS, focusing on transition issues teens with MS may face as they move from the pediatric medical community into adult care.

Joining us again is Ms. Maria Milazzo. Ms. Milazzo is a Nurse Practitioner at the National Pediatric MS Center at Stony Brook University Hospital. Welcome, Ms. Milazzo. So, when do you start preparing kids to actually take on their own independence in the healthcare system.

**>>Maria Milazzo:** Well, we start from day one. We really think that from the very beginning, kids have a lot of say in what's happening with them, and we really want to help advocate for them to be advocates, so teach them how to be advocates.

**>>Kate Milliken:** How can parents teach their children to be empowered and to take on a bigger role in their own healthcare?

**>>Maria Milazzo:** What we think is important is for kids to be part of the entire decision-making process, so when we're talking about an appointment, let the kids know that they're coming in, why they're coming in, ask the kids ahead of time, "do you have any questions when you go in, any things you want to talk about, do you want to write them down so you can speak about them," and when the kids get

to the appointment, to always make sure they have some private time alone, so they can speak-- when they're very little, they may not need to be alone, but to be given a voice through the visit, and to be given a voice and a choice about what we're going to do.

For a little child, it might be something as simple as, "Do you want me to examine you on this table, or sitting next to your mom?" As the kids get older, it's always important we try to pull the teens out and give them a little bit of face time alone with the different providers, so that they can speak about their concerns, their issues. Often, the kids are so worried about their parents, and may not want to speak freely in front of their parents about things that they're feeling or questions that they have.

And I think it's important that even if there are no concerns or issues, that they start to feel comfortable speaking with the providers, and so to take them down the hall to get something, or why don't we take a walk and check your vision in this room instead, you know, gives them some room to build up a confidence about themselves as they start to get older.

>>**Kate Milliken:** Is there anything else you feel that parents should expect from a healthcare provider to participate, to give this child a sense of independence?

>>**Maria Milazzo:** I think it's really important that the providers speak to the children as well as the parents, and I've had parents tell me that they were not comfortable when the child was excluded from the discussion. I've also had parents tell me that they're not comfortable when the child is the only one that's spoken to in the room, so I think we need to have that balance of speaking to the kids and speaking to the parents, but I think that it's important that parents feel comfortable and kids feel comfortable, no matter what our access to care is, it doesn't matter if we're in a specialty office like pediatric MS, or in the general pediatric office, that we need to work with our providers as consumers.

We need to work, we need to have a good, trusting relationship, and if we don't feel we have one, to talk about that, and sometimes, you know, we need to change into a place that we feel more comfortable.

>>**Kate Milliken:** Yes, like, you provide an opportunity for a teen to kind of take control. Because I think when you're a teenager, it's kind of hard to know--

you're already dealing with so many other issues in terms of maturation and hormones that for somebody to give you the opportunity to set your own stage.

>>**Maria Milazzo:** That's exactly right. I mean, that's the developmental stage the teenagers are going through, starting to think for themselves and separate a little bit from their families and start creating their own relationships, and we need to be able to see that happening in our pediatric group and our pediatric MS group. These are normal changes that teens are going through, but we need to take the next step and build that into pediatric MS with a teenager.

>>**Kate Milliken:** Even though it's a time for teenagers to have a sense of independence and really grow their independence, families are still really important in the mix, so is there anything you can kind of suggest for the families on how to facilitate this process when the child has MS?

>>**Maria Milazzo:** Yeah, that's a good question. It's something that we're really looking at at our center right now. We think that the more opportunity the kids have to care for themselves and to be participants in their care, it's very important but we have learned, and we have learned through other pediatric-onset diseases, that the family can't totally abdicate responsibility, that kids who do best are kids who are sharing responsibility with their parents, so, in the world of MS, kids whose parents are checking in, "Did you take your medicine, where-- how's your sight looking," you know, how do you feel today, is important.

Parents who really leave it all to the kids may not be doing the best-- the kids may not be doing as well as if the parents were a little bit more engaged. On the other hand, the kids need to start to develop a little independence. At 16, 17 years old, they should be able to have some bit of control over medication and administration times, preparing for medicine, rather than a parent coming in and giving the injection for the kids at that age, it's probably a good idea for the kids to be doing a little bit of that themselves.

>>**Kate Milliken:** You know, outside of the whole technical element of, you know, making sure you have your meds and making sure you stay on schedule, there's also this stigma of MS, and the general attitude about MS, and, you know, a child having a disease, so is there anything you would say from a parental perspective of how to kind of shape a kid to accept the fact they have something in their life and not be ashamed of it or just to handle it?

>>**Maria Milazzo:** Yes, that's-- I think we can learn a lot from other, again, childhood chronic illnesses in that the kids aren't sick, so, you know, my name is Jamie and I have MS, and I'm a soccer player and I'm in tenth grade, you know, it's just a piece of who the kids are rather than their whole identity, and if we can look at it from that perspective, this is just another bit of who you are, you're not sick, this isn't your defining identity, this is a piece of you, and to try to raise the kids up in that way, let them have the all the opportunities they can possibly experience, try to keep it open, try to talk about it.

We find that families who do better and children who do better are families that are able to talk about it, to approach problems head-on, rather than avoiding the problems, when we come to a crisis, whatever it is, to really look at it, try to work through it, rather than run away from it, would be a helpful way for the families to help the kids grow up with a good attitude about their disease.

It's just a piece of who they are that they'll take with them.

>>**Kate Milliken:** Great. Thank you, Ms. Milazzo. If you would like to learn more about pediatric MS, go to [www.nationalmssociety.org](http://www.nationalmssociety.org). This is Kate Milliken for MS Learn Online, and thank you for joining us.