



**MS Learn Online  
Feature Presentation  
Pediatric MS: Partnering with Your Child's School  
Featuring Maria Milazzo, N.P., CPNP**

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**>>Kate Milliken:** Hello, I'm Kate Milliken, and welcome to MS Learn Online. Parents of children with MS typically gather a vast amount of information about the disease, including how it's affecting their child now and accommodations that others have had success with outside of school. They may not, however, have a realistic understanding of how the family-school partnership can temper their concerns for their child's future.

While schools are familiar with various pediatric illnesses and disabilities, pediatric multiple sclerosis adds some particular challenges, due to the fluctuating nature of the disease, the changing needs of the child, and the disease's relative rarity among children.

In this first of a two-part interview, we'll be talking with Maria Milazzo, a nurse practitioner at the National Pediatric MS Center at Stony Brook University Hospital. Welcome to MS Learn Online, Ms. Milazzo. I really appreciate you being here. So, to start, what are some of the common challenges that children with MS have in a school environment?

**>>Maria Milazzo:** Well, pediatric MS is a very rare disease or disability that many of the schools have never had experience with, so kids and their families are battling just the unknown nature of the disease for the school. They often have to explain the fact that they have MS, that MS can happen to children, and, you know, we talk about the invisible nature of the disease, that the kids may not look sick, and so the teachers really may not have an understanding of what the kids are going through, so one of the big challenges is to really be able to educate the

school and the teachers and the staff about what MS means, what kinds of symptoms the kids may have, the difficulties the kids are facing, some days just getting to school, some days making it through the day, some days being able to get the work done, either in school or at home.

>>**Kate Milliken:** What are a child's rights regarding education?

>>**Maria Milazzo:** So, we are very lucky to have in the IDEA, the Individuals with Disabilities Education Act, which guarantees a free and appropriate education to all children in this country, so all children have a right to an education that's appropriate for their needs in the school, and the schools have an obligation to provide that education for the children.

>>**Kate Milliken:** So, MS being kind of a foreign entity in the school system, do you have any suggestions for steps for how to sort of explain what's going on to an administrator?

>>**Maria Milazzo:** Right. So, one of the big things is, the kids and the families need to feel comfortable disclosing the diagnosis to the school, so that's probably the biggest-- the first step, is to actually be able to tell the school, tell the principal, tell teachers that the child has MS. Families can choose to do that in different ways. They may not want to disclose to everybody in the school at the beginning, but it's a good idea for them to touch base with the principal and the guidance counselor, school nurses, to let them know the child has MS, and to start the dialogue.

This is going to really vary based on the age of the child. For kids in younger grades, sometimes telling the principal, the school nurse and the primary teacher is enough. As the kids move on through the school process, they're meeting so many more people in their school day, you probably need to spread that circle a little bit wider.

>>**Kate Milliken:** And, throughout this process, I'm sure there have been accommodations that have been made for individual kids within a school system. Can you think of any things that have actually been successful?

>>**Maria Milazzo:** Sure. I think, again, as soon as the kids disclose the diagnosis, the school can start thinking about what we can do. So, for younger children, we may-- one of the bigger concerns is, often the kids aren't allowed to

do all of the activities that the other kids are doing. They're afraid to let the kids play in the playground or go to gym class, so first to allay those fears. The kids have every right to be out doing their activities, and what we can do is ask the school to allow them to participate to their level of comfort, and to understand that they may have varying levels of fatigue through days or over days, and they should be allowed to play or participate on a daily basis, based on how they're feeling.

For the older kids, we want to make sure that when we plan class schedules, we can plan them around the kid's fatigue levels, and so maybe not have major academic classes first thing in the morning, maybe allow them to warm up to the day. If they have to come in a little bit late, they can maybe have their more academic classes second, third, fourth period. Maybe not have gym class first thing in the morning, so we don't fatigue and overheat first thing in the morning.

We could try to build breaks in during the day, so, alter an academic class with a lighter class, and then to make sure that teachers know that when kids are out sick or are out because of doctor's visits, they should be excused those absences. If they miss schoolwork, they should have an opportunity to catch up on the schoolwork.

But, really, the biggest thing, and the thing that worries me a lot is, sometimes schools would offer the kids to stay home and have homeschooling, and that's not something that we think is a good idea. There's so much more that happens at school besides the academics. The socialization is really the most important for most kids, and we want the kids in that environment. We want to make sure that we can make whatever accommodations are needed to keep kids in school, and happy, and having friends in school.

>>**Kate Milliken:** What's interesting about what you talk about, obviously, there's a variable degree of fatigue or, you know, a day-by-day thing, and it really does become kind of a relationship, you know, partly the teacher's responsibility to notice what's going on and make that choice, or an actual communication between the student and the teacher.

>>**Maria Milazzo:** Right. I think you're absolutely right. I think that the families and the kids really have to feel confident going into the school and talking to the school. They have the right to be at school, and the school needs to be able to meet these very basic needs that the kids have, and to really be able to have a dialogue, whether, for the younger kids, something like a communication book,

where messages can go back and forth every day from the parent to the teacher and back home again, or for the older kids, to really try to help them advocate for themselves, if they're not feeling well, to speak up, but to know that they will be respected when they speak up, and to be understood, and that they shouldn't be afraid of speaking up would be important.

>>**Kate Milliken:** You've spoken about a number of people in the school administration, the school nurse, the immediate teacher, the principal, which I would think would be kind of overwhelming for a parent, so from your perspective, if you had to pick one person to be kind of the first go-to person, who is the right person to talk to?

>>**Maria Milazzo:** You know, I think it varies based on the age of the child. You know, I think for the younger school children, touching base with the school principal is probably the best. If we want to make our initial point of contact the principal, and then we can find out based on that school district's policy, is there a committee in Special Ed, or is there a Special Ed department to be touching base, but certainly that school principal could be that first contact.

For kids that are older, again, we might want to notify the school principal, but I find that the school guidance counselors or social workers are often a good place to start that contact, and find out what is that process.

And again, speaking as a nurse, I think it's always invaluable to make friends with the school nurse, because that's the person who's going to really impact your kid's life every single day.

>>**Kate Milliken:** A child most probably has a healthcare provider. Can they be helpful in facilitating this relationship?

>>**Maria Milazzo:** I think it's really important to keep our primary care providers as part of our team, so the pediatrician is definitely someone who can help out with what's going on in the school. Because pediatric MS is rare, often children are travelling distances to get to a center for children with MS, so the MS Society has the Centers of Excellence for Kids, so parents and children may be traveling a great distance, but right in your own community is your own pediatrician or your primary health provider, and that person can really be a good point of contact for the school district.

They have a good working relationship, probably, already, with the school, so they can help facilitate, and then you can use your Centers of Excellence or your specialty care to fill in and to provide the next level of information to the school.

>>**Kate Milliken:** As-- for the older children, as they get ready for college, children with MS, are there any specific things you feel like they need to prepare especially as they go into that next phase?

>>**Maria Milazzo:** That's become an area of great interest at this point. For me, what happens is, our kids are growing up, and we realize this isn't a process that we can start in 11th and 12th grade. This is something that we need to be thinking about all along, so one, what are the child's goals for college. What's-- are they going to go away, are they going to stay and commute to a local community college?

>>**Kate Milliken:** Is it doable at all?

>>**Maria Milazzo:** Is it doable. And for most of the kids, it is doable, which is the amazing thing, but we want to make sure that the kids have accommodations in place early on. For kids to apply to college, many of them will need some sort of standardized testing, SAT, ACT, and kids are eligible for accommodations in that testing process. There are available accommodations including extra time on testing, two-day testing, so that they don't have the fatigue associated with sitting for one long test, but in order to get those services and those accommodations from the testing boards, the kids need to already have documented within the school district that they are getting accommodations through the school, whether it's a 504 or an IEP, so we need to make sure we've laid down that groundwork first and, you know, we've learned the hard way that if we wait until the last minute, we may not be able to get those accommodations.

So, think ahead, work with the school, try to have services. Even if your kids are doing great, having a 504 in place, which is sort of an understanding from the school that the child may have some medical issues that are going to impact his learning, but the kids may not-- parents are worried that the kids are going to be treated differently. The kids won't be treated differently, but having that all laid out early will enable the kids to get what they need as they move on.

>>**Kate Milliken:** Thank you so much, Ms. Milazzo. In our next conversation, we'll continue to learn more about the issues that teens with MS face as they move

and transition into the world of adult healthcare. We'll see you then. This is Kate Milliken for MS Learn Online.