

Learning to Understand Your Child's Symptoms

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[00:00:00] **Lydia Dubose:** Today we are joined by Janet Dean from the Kennedy Krieger Institute. Thank you, Janet, for joining us.

[00:00:13] **Janet Dean:** Hi there. Thank you! So today I was asked to talk about learning to understand your child's symptoms. So, kind of the first thing I did was I wanted to look up symptom, what the definition of symptom was. And a symptom is a physical or a mental problem that a person experiences that may indicate an illness or condition. Symptoms cannot be seen and do not show up on any medical tests. So, some examples of symptoms are pain, headache, stomachache, or fatigue.

[00:00:49] So I was thinking that's not quite exactly all that our children have. So, I looked up another medical term called a sign because we often talk about signs and symptoms. And a sign is something found during a physical exam or from a laboratory test that shows that a person may have an illness or a condition. So, examples of signs are weakness, maybe muscle weakness, vision problems, cloudy urine, or temperature.

[00:01:15] So what I'm really going to do is talk about both signs and symptoms that our children have. And they're just going to be used interchangeably. And I'm going to try and because this is a very diverse spectrum of symptoms with these rare neuroimmune disorders, I'm going to try and see if I can just help you navigate and figure out how to get the care that you need for your child's symptoms. So first, there's symptoms at presentation. And I'm not going to talk about that at all because those are being talked about in individual sessions.

[00:01:52] Then there are chronic symptoms that our kids live with every day that hopefully will stay stable and are important for you to become familiar with. And then there are symptoms that might indicate relapse or other illness if your child has a condition that may relapse that you need to understand when to seek treatment.

[00:02:15] So, first I want to talk about just what determines symptoms. So, where the injury in your nervous system, your central nervous system is, is going to determine what symptoms your child has. So, for example, if your child has symptoms or injury in the brain, your child may have seizures, cognitive dysfunction, behavior changes, vision changes, loss of vision, paralysis of muscles, or changes in muscle tone could come from the brain.

[00:02:46] The brain stem, which connects the spinal cord, and the brain has control for vision too. Mostly with difficulty, kids may have difficulty moving their eyes, difficulty chewing or swallowing, may have facial droop, malocclusion or an underbite with their teeth, or from brain stem. And lastly if there's injury to the spinal cord, the spinal cord will result in paralysis, weakness in muscles, changes in muscle tone, lost or impaired sensation, lost or impaired bowel and bladder function, impaired coughing, breathing, or clearing secretions. Some children needing a ventilator to help them breathe.

[00:03:27] Neuropathic pain, which is the tingling, burning nerve pain. Some of the general musculoskeletal aches and pains. Children may have difficulty in regulating their temperature and have heat intolerance, and children with autonomic dysreflexia may have, children with spinal cord injury may have autonomic dysreflexia, which is something that only occurs in children with spinal cord injury.

[00:03:54] So what I'm not going to address the treatment of all these specific symptoms. Over the next 3 days, there's going to be various people that are going to address pretty much all of these symptoms. And again, what I'm going to focus on is, how do you put together a team to help you manage these symptoms? And identifying when you need to seek help.

[00:04:17] So other things that influence symptoms include the time since the onset of your condition. Over the first 2 years, symptoms will change before they become fairly stable. Some may improve, and some may change patterns, such as some people, kids may start with flaccid muscle tone, and it changes to spastic muscle tone and then stabilizes.

[00:04:43] The age of your child makes a difference. Makes it different to see what symptoms your child has. For instance, young children can't tell us where they hurt or if they hurt and may just be crying or irritable. Some children may not demonstrate a function because they're not old enough. For example, you may not see learning difficulties until children get older and school is placing more demands on them.

[00:05:08] Completeness or incompleteness of the condition will affect symptoms. Some children have maybe just impaired sensation or movement below the level, say, of their spinal cord injury, and some may have complete paralysis below the level of their injury. And then, on top of that, common childhood illness such as colds and flus or fatigue or overheating or stress can worsen the familiar symptoms that your child may have.

[00:05:47] So then there's other things that make learning your own child's symptoms can sometimes be difficult. As was talked about earlier today, sometimes getting a diagnosis is difficult. And then sometimes families I know have different diagnoses from different experts, and sometimes these conditions, such as transverse myelitis, acute flaccid myelitis, and spinal cord stroke all cause a spinal cord injury but have a different pattern of injury.

[00:06:26] And then even with the diagnosis sometimes a child may have different symptoms than what is expected from that diagnosis and because they just, all kids don't follow all the rules. So, the important part of this is that you need to get to know what your child's symptoms are and then the professionals that you work with need to really treat your child, treat their symptoms, and not treat the diagnosis, per se.

[00:06:56] And it will take a team to be able to treat all the symptoms that your child has. So, we've all heard the term, it takes a village to raise a child. Well, with children with neuroimmune disorders, it takes a team to care for your child. And of course, the family and the child is at the very center of the team and what, as a family unit, I suggest that you do is you need to identify a healthcare provider that can be in there at the middle of the team with you to help assist you in coordinating your child's care.

[00:07:33] Another thing that you might do is identify a case manager from the insurance company by calling your customer care service number on the back of your card. Sometimes you can obtain a nurse, often a nurse case-manager that can help navigate the insurance system.

[00:07:50] Generally, the professionals that are in that center circle with you are either a physiatrist and/or your neurologist. And often physiatrists and neurologists are working together to help guide the care of your child. You need to see those professionals at least annually to have a history and physical, and children that are young or children that have conditions that may change, or relapse need to keep in close contact with these folks.

[00:08:22] Your physiatrist or neurologist are going to monitor and treat symptoms. They're going to provide anticipatory guidance, or what to expect in the future, and they're going to direct your rehabilitation plan. They're going to make referrals for therapy. They're going to make prescriptions for equipment and bracing. And then they're going to refer to the specialists to monitor your child and treat symptoms.

[00:08:44] Some of you may be fortunate enough to have a pediatrician who is very comfortable treating your symptoms, but often pediatricians really are not. But they are an important part of your team. You'll need to really be able to see them for just well-childcare. They can be your local contact for sick visits such as if your child has a cold or a urinary tract infection. They can provide childhood vaccines, and then they can also help you with referrals to specialists in your community if the physiatrist or neurology specialist you see is outside of your community.

[00:09:26] So the specialist care. Families sometimes tell me it's frustrating because specialists may be unfamiliar with your child's diagnosis. And there may be a big team of specialists for some children that need to participate. But remember what I said, is that the symptoms of your rare neurologic disorder occurred due to an injury to the brain, the brain stem, or the spinal cord. And often if the treatment of the chronic symptoms that your child has, or injury is similar regardless of the exact cause of your child's injury.

[00:10:07] So what I suggest to my children when you're working with my family is when you're working with specialists, medical specialists, therapists, or schools that may not have specific expertise in your child's condition, that you describe where the injury is and what your rare neurologic disorder that causes it.

[00:10:27] So for example, if a child has bladder issues I would say to the urologist, "My child has bladder problems, or a neurogenic bladder, due to a spinal cord injury caused by transverse myelitis." Or if working with the school people, you may say, "My child has cognitive delays due to a brain injury caused by neuromyelitis optica or acute disseminated encephalomyelitis, or my child has visual problems due to a brain injury caused by neuromyelitis optica or optic neuritis."

[00:11:09] So I think, what I find is this at least gives professionals that don't have specific expertise an area to start. Because they probably treated somebody with a traumatic spinal cord injury or spina bifida. That's more common. So, this can get kind of the ball rolling with your specialists.

[00:11:33] Other symptoms, then. Once you've got somebody managing your familiar symptoms, you may have generalized symptoms that can help guide you when you need to look for other issues that may occur as a result of the familiar symptoms. So autonomic dysreflexia only occurs in people with high spinal cord injuries, T6 and above, and the end result is very high blood pressure. If your child has an injury at this level, be sure that you talk with your health professionals because this can be a life-threatening condition in how to manage and treat this.

[00:12:17] Children with spasticity, if they have increased spasticity could have a urinary tract infection, an ingrown toenail, or other things that may be causing the spasticity. For some children, fever is not a very good indication of illness. Some children it can be fine, a fine indication. You need to understand how that works with your child.

[00:12:41] Children that have weak muscles, that have difficulty breathing, you may be looking for symptoms of pneumonia or asthma or something like that. Changes in bowel and bladder continence would lead you to think about urinary tract infection or constipation. Redness or swelling in extremity. You would want to look for things like a broken bone or a blood clot in the leg. Headaches, increased pain, increased fatigue can be signs of many different things and you will get to know those from your child.

[00:13:18] And then lastly, symptoms of relapse. So, neurologists will be able to give you the prognosis of the possibility of a relapse and what to look for. Some conditions have a higher possibility of relapse, and others have a very low possibility of relapse. The most important thing is if you think your child might be having a relapse, contact your child's provider or take them to the emergency department.

[00:13:45] So, if your child has a condition that is susceptible to relapse, any new or unfamiliar symptoms or symptoms in a previously unaffected body part are concerning for relapse. Especially with regards to mobility, sensation, or vision. So, for instance, if your child has muscle weakness in their lower extremities, and they have weakness now in their upper extremities, you definitely want to seek medical attention from your neurologist or from the emergency department.

[00:14:21] If your child is ill, such as they have the cold or a flu, they're very fatigued or overstressed and have an increase in familiar symptoms, such as they have more weakness in their legs than usual, then a relapse is less likely. It will take a while for you to get to understand exactly what your child's symptoms are, and you'll do a lot of contact with your neurologist to begin with until you're very comfortable at sorting those things out.

[00:14:55] So the take home message from my presentation is, you need to learn what your child's specific, familiar symptoms are. You need to identify a team leader and a good team of professionals to manage your symptoms, and you need to learn what symptoms can be managed at home and what symptoms you need to seek additional medical care. And I'll answer any questions if there are any.

[00:15:19] **Lydia Dubose:** Thank you so much. I know somebody had put in the chat that it's very helpful wording that you gave. And I was just thinking that as well. It's almost like a formula for how to speak to your provider. That's really helpful.