

Learning to Understand Your Child's Symptoms

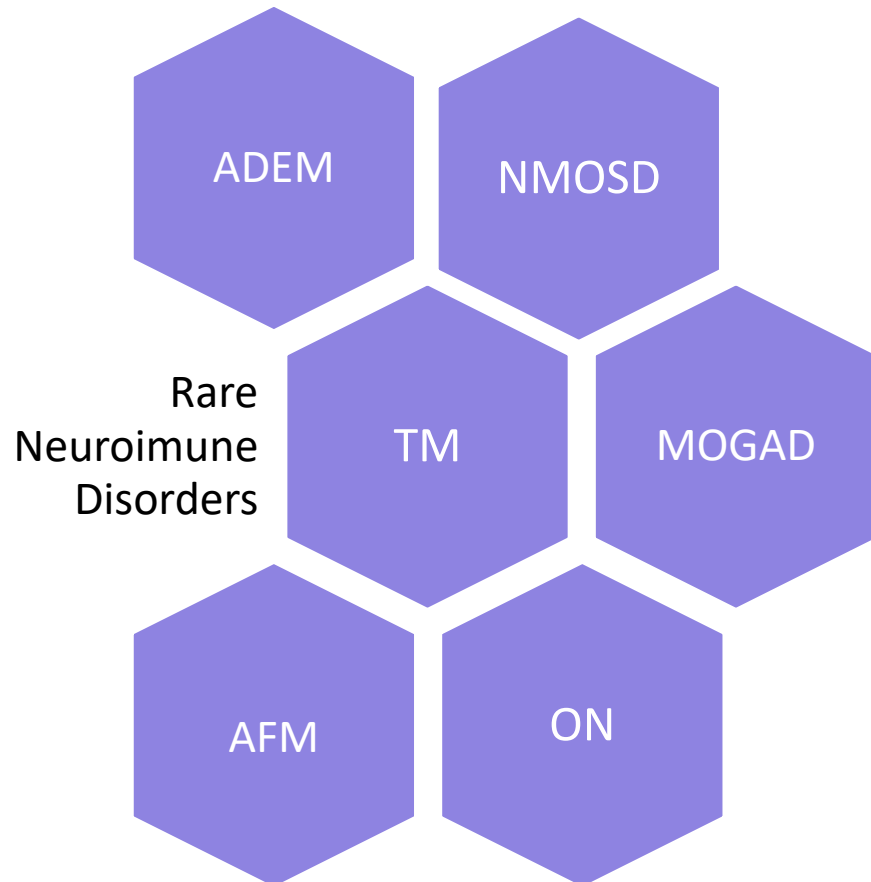
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We are all born with great potential.
Shouldn't we all have the chance to achieve it?

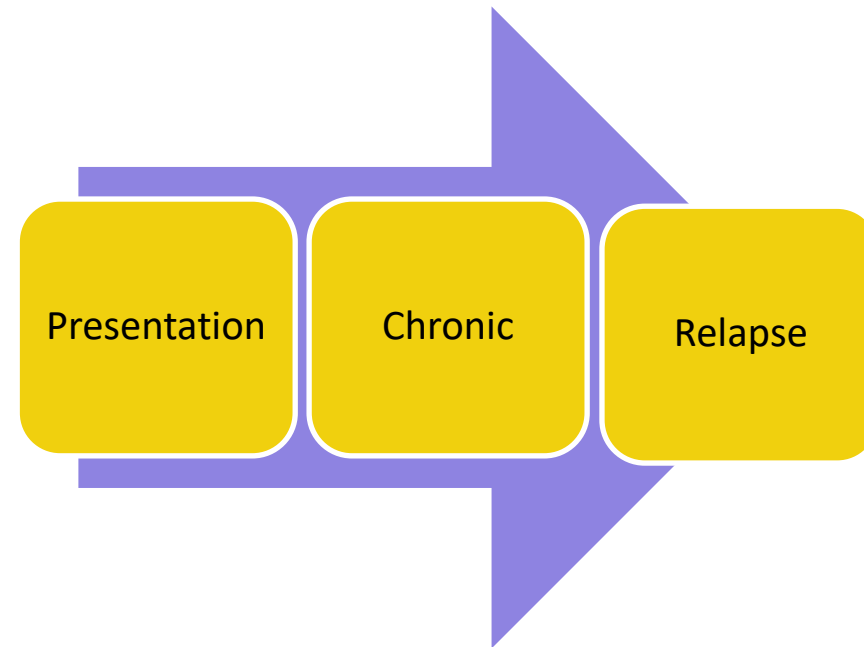


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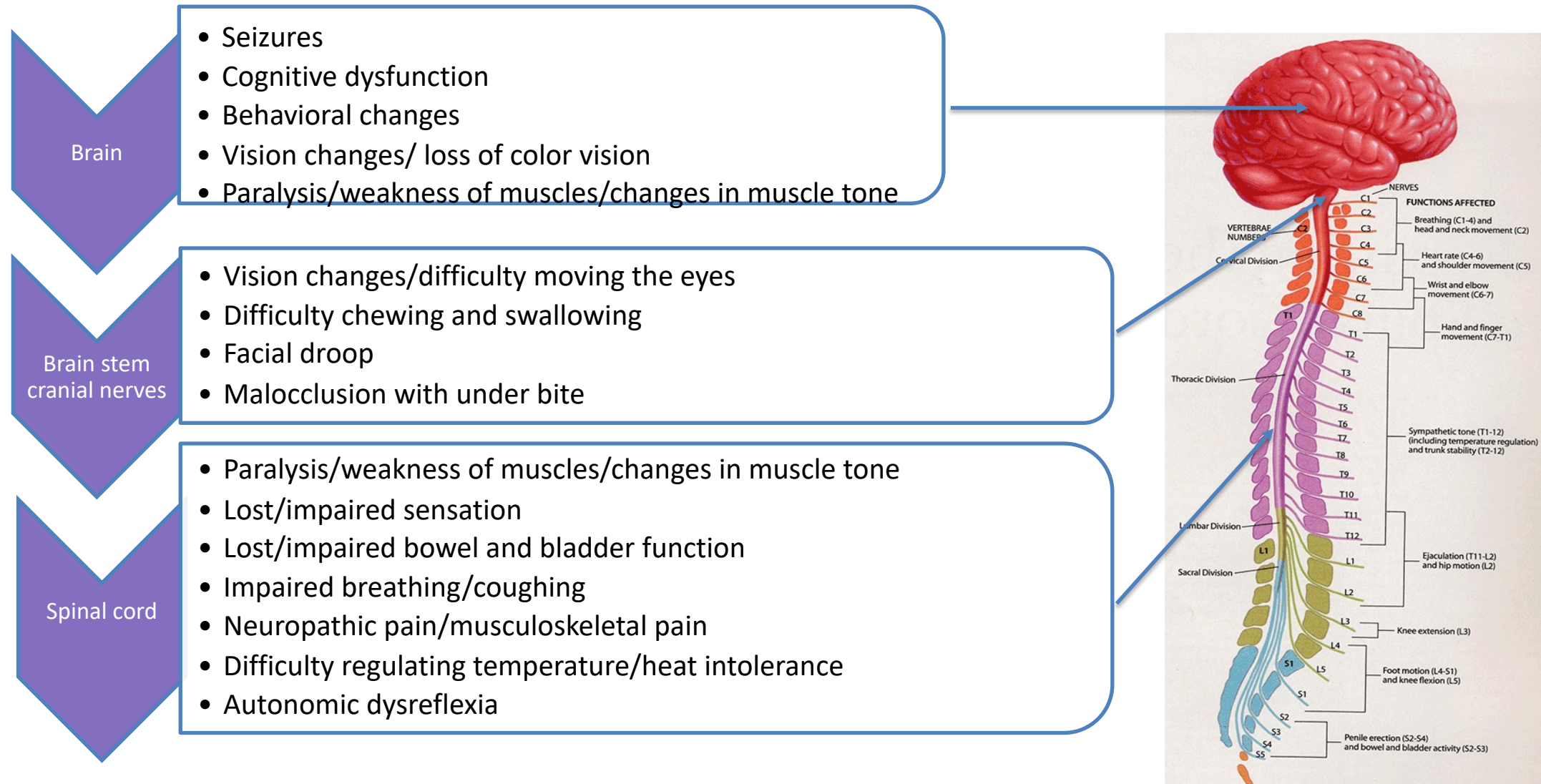
Symptoms in Rare Neuroimmune Disorders



Symptoms



Injury in the central nervous system determines symptoms



Other factors influencing symptoms

Time since onset

- Over the first 1-2 years
- Symptoms can get better or worse
- Change pattern

Age of your child

- Young children do not express some symptoms as well
- May not be able to demonstrate function

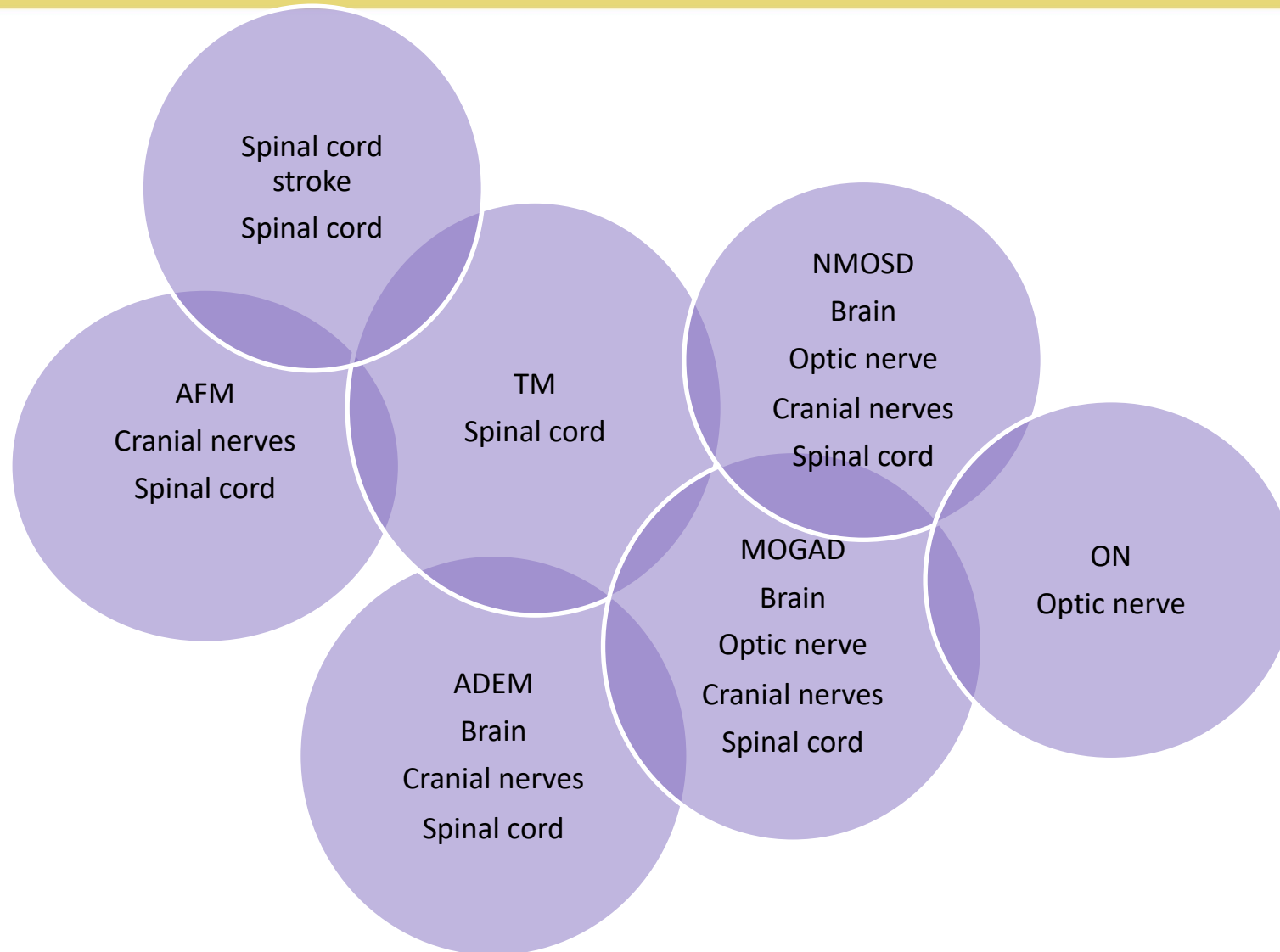
Completeness or severity of condition

Some have impaired function.
Some have no function below the level of injury

Common childhood illness, Fatigue or overheating

- Can worsen existing, familiar symptoms

Areas of injury overlap in Rare Neuroimmune Disorders



Sometimes difficult to get the correct diagnosis

May have differing opinions regarding diagnosis

Even with a diagnosis a child may have different symptoms than what is expected for diagnosis

Important

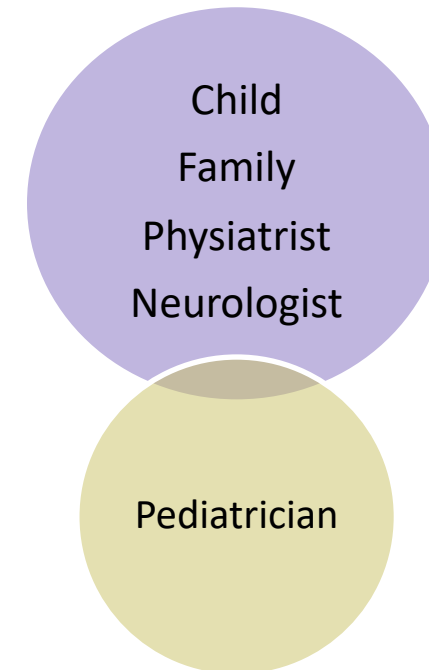
Treat Symptoms
Not the diagnosis

Symptom Management

Takes a team

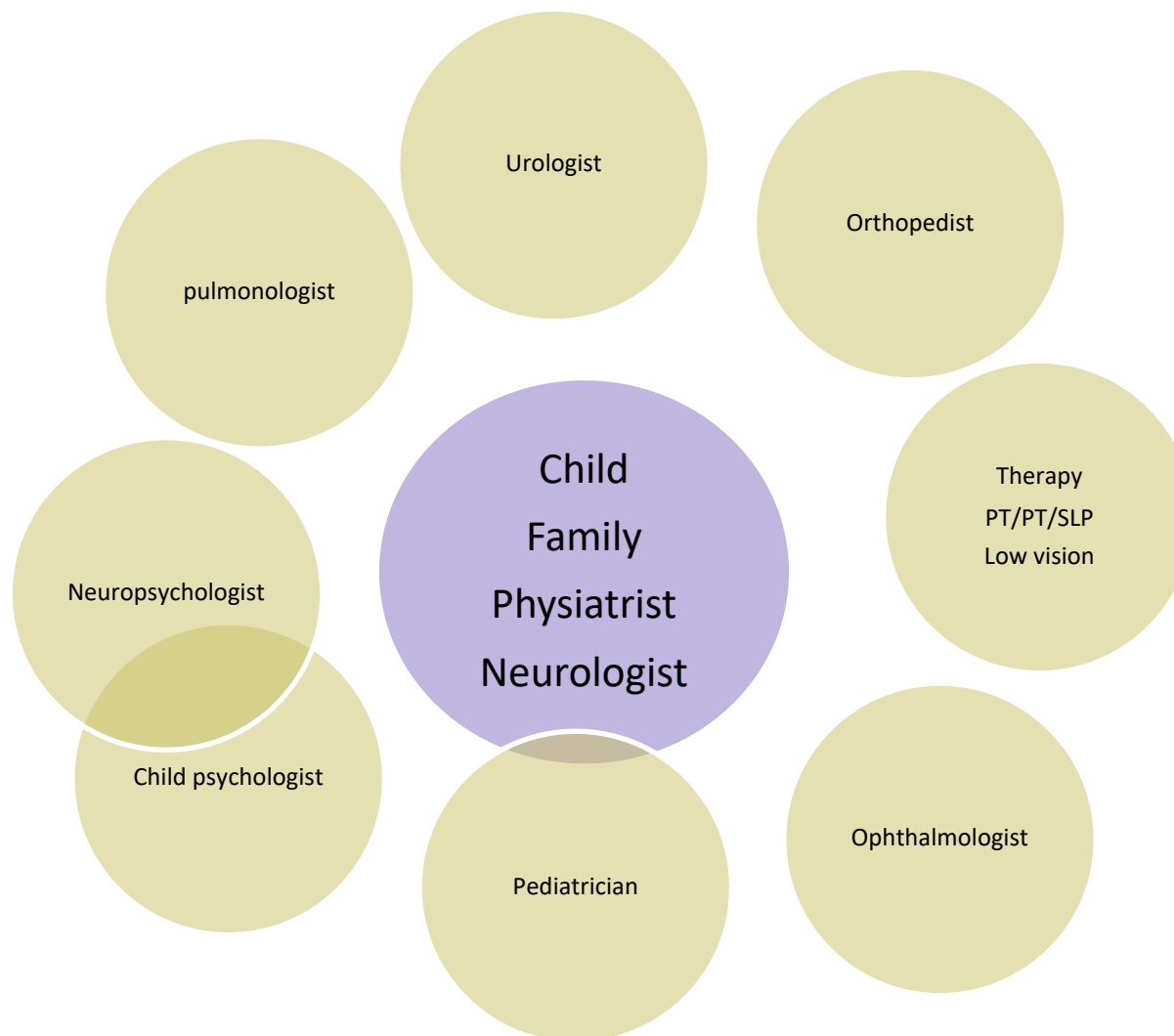
It takes a village... and team to raise for your child

- **Family and Child**
 - Center of the team
 - Identify a case manager to help obtain care and services
 - Identify a health care provider to guide you
 - Coordinate care
- **Physiatrist and/or neurologist**
 - Guide your child's overall care
 - At least annual history and physical examination
 - Monitor and treat symptoms, regardless of diagnosis
 - Provide anticipatory guidance of what to expect in the future
 - Direct rehabilitation plan: referral to therapy, equipment, orthotics
 - Referral to specialist to monitor and treat symptoms
- **Pediatrician**
 - May guide you child's overall care if comfortable
 - Well child care
 - Sick visits for generalized symptoms
 - Childhood vaccination
 - Referral to specialists to monitor and treat symptoms



It takes a village... and team to care for your child

- Specialist Care
 - Specialists may be unfamiliar with your child's rare diagnosis
- Symptoms of RND occur due to injury to the:
 - Brain
 - Brainstem/cranial nerves
 - Spinal cord
- Treatment of chronic symptoms of injury is very similar regardless of the cause.



Working with specialists/therapists/schools

I suggest describing where the injury is, caused by the RND diagnosis

My child has
Bladder problems

due to a spinal cord
Injury

caused by...

My child has
cognitive delays

due to a brain
injury

caused by...

My child has
visual problems

due to a brain
injury

caused by...

Generalized symptoms-look for other issues

- Autonomic dysreflexia (very high blood pressure)
 - Only occurs in spinal cord injury at levels around T6 and above
 - Caused by noxious stimulation/irritation below the level of injury
 - Bladder and bowel issues are number 1 and number 2 causes
 - Can be life threatening
- Increased spasticity
- Temperature +/-
- Difficulty breathing
- Changes in bowel and bladder continence
- Redness or swelling in an extremity
- Headaches
- Increased pain
- Increased fatigue

Symptoms of Relapse

Neurologist will give you prognosis of possibility of relapses and what to look for.

- If you think your child might be having a relapse, contact your child's provider or take to ED.
- New unfamiliar symptoms or symptoms in a previously unaffected part of the body, are concerning for relapse especially with mobility, sensation or vision.
- If your child is ill, fatigued or overstressed and has an increase in familiar symptoms, relapse is less likely.

Questions?

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