Dysautonomia

What is it?

Dysautonomia (**dis-aw-tuh-noh-mee-uh**) is a condition that may occur if a person severely injures their brain. You may also hear this called **thalamic storming, sympathetic storming, autonomic dysfunction syndrome, or just simply "storming."**

Our brain controls many automatic things that we are unaware of such as breathing, heart rate, blood pressure, and body temperature. After a severe brain injury, the ability to control these automatic functions may be impaired. A person may have exaggerated and unexpected responses to normal stimulation such as moving, being touched, loud noises, or pain. "Storming" may also occur "out of the blue" without a known cause. It is unclear why this occurs. It is thought that after a brain injury, the different parts of the brain are not properly working together. This causes an overreaction to the brain's natural stress response. This is also called the "fight or flight" response.

What happens in the hospital?

If your child has suffered a severe brain injury, they most likely will require a high level of medical care and be admitted to the intensive care unit. There is no way to predict the amount of time your child will be in the Pediatric Intensive Care Unit. Once they are stable enough they will transfer to a regular hospital room.

Your child's doctors may order additional blood tests or images. These tests and images help determine what is the cause of the symptoms. Symptoms of dysautonomia may look like an infection, seizures, and withdrawal. There is not a test that tells the doctors your child has dysautonomia. The diagnosis is based on your child's symptoms and by ruling out other causes.

What are the symptoms of dysautonomia?

Often the signs of dysautonomia do not show up until after your child is coming out of a coma. Your child may be sedated with medicine because of the brain injury. These signs may also show up after they are weaned off the medicine. As a child becomes more awake you may see some or all of the following symptoms associated with dysautonomia:

- Agitation.
- An increased temperature (hyperthermia).
- Excessive sweating (diaphoresis).
- An increased heart rate (tachycardia).
- An increase in breathing rate (tachypnea).
- Increased muscle tone, tightness, and arching (spasticity).
- Dilated or large pupils.
- Increased blood pressure (hypertension).
- Posturing. This is abnormal flexion or extension of a child's arms and legs.
- Dystonia. This is when muscles spasm and pull on the body incorrectly.

These reactions may occur several times a day. They may be a brief episode to longer lasting events. There may or may not be an obvious trigger that started these events.

How is Dysautonomia treated?

A variety of actions may be useful in treating these episodes. Certain medicines may also be helpful.

Goals for treating dysautonomia

1. Decrease the frequency
2. Decrease the length
3. Decrease the severity of the episodes

Many parents find treating dysautonomia frustrating. There is not a way to stop the episode completely. It may be very hard to see your child so agitated. During this time many family members feel helpless. **Remember you and other family members are a valuable member of the team.**

Things you and your child's healthcare team can do to help:

These simple tasks focus on decreasing over stimulation, improve your child's comfort, and minimize possible irritants or triggers.

- Create a quiet and calm setting for your child.
  - Use soft quiet voices and low lighting.
  - Hold conversations outside your child's room.
  - If tolerated, play soft calm music for short periods of time.
- Limit the number of visitors to a few people and for short periods of time.
- Encourage sleep and rest periods between activities.
- Reorient your child frequently.
  - Tell your child they are in the hospital.
  - Tell your child what time of day it is.

Things your child's nurse will do for your child:

- Ensure your child is getting plenty of fluids and nutrition.
  - A feeding tube or IV may be used to provide the needed fluids and nourishment, and prevent dehydration.
  - Your child will have increased nutritional needs due to fluid loss through sweating and an increase in the bodies activity.
- Control your child's pain and discomfort.
  - Change the position of your child often to help with comfort and prevent skin breakdown.
  - Give pain medicine before activities that may cause discomfort.
  - Minimize tight or twisted clothing or bunched blankets.
  - Remove blankets. Use cold packs or cool washcloths to decrease their body temperature.
- Manage bowel and bladder elimination.
  - Prevent constipation and promote regular bowel movements.
  - Change wet or soiled briefs frequently.
  - Make sure your child is emptying their bladder.
- Group your child's hospital cares together, if possible.
  - This includes taking your child's vital signs, performing exams and other treatments, and giving medicine.

What kind of medicine will my child be given?

Medicine is used to help reduce how often your child has a dysautonomic episode. Medicine is also given to reduce the severity of the episodes. Your child may be given more than one medicine to help control some of the symptoms. There is no medicine to "cure" this condition. These medicines help by reducing your child's heart rate, blood pressure, temperature, agitation, and muscle stiffness. Other medicine may be used to help manage their pain, help with sleep, or assist with bowel regularity.

Your child's medical team works hard to find the right combination of medicine and interventions that may help control these events.

How long will the symptoms last?

Dysautonomia typically gets better over time as the brain heals. These symptoms can last for a few days or weeks. The effects of a brain injury are different for every child. It is important to remember that with time, care, and effort most children will improve. Our goal is to minimize disability and prevent complications. We will also maximize what your child can do while recovering. Dysautonomia is a stage in your child's healing process.

We will give you additional education regarding the complications and potential longer lasting effects from a brain injury.

Who else is on my child's team?

There are many experts to help your child to heal after a brain injury. It may seem overwhelming when there are so many healthcare providers involved. Each member of your child's team will help to determine the best level of care and treatment for your child.

The following are some of the different healthcare providers or services that may work with your child:

Rehabilitation physicians: Rehabilitation physicians are doctors that specialize in brain injuries.

Neurosurgeons: Neurosurgeons are a type of surgeon that diagnose and may perform surgery on a person's brain.

Neurologists: They are a type of doctor that diagnose and treat brain injuries and disorders.

Physical therapists (PT): Physical therapists work on movement and the coordination of your child's body. They are trained to assess and help your child with large motor movements such as getting out of bed, standing, and walking.

Occupational therapists (OT): Occupational therapist are trained to assess and help your child with fine motor movements such as gripping a pencil or picking up small things. They also help with ADL's (activities of daily living) such as dressing, grooming, and hygiene.

Speech therapists. Speech therapists are trained to assess and help your child with talking, speech, and cognitive function. They also may assess your child's ability to swallow foods and liquids.

Pediatricians: Pediatricians are doctors that are responsible for your child's care.

Trauma Service: This service is a multidisciplinary healthcare team of experts trained to assess, diagnose, and treat a child with severe injuries.

What if I have more questions?

Ask your child's doctor and nurse any questions that you have about your child's care and condition.