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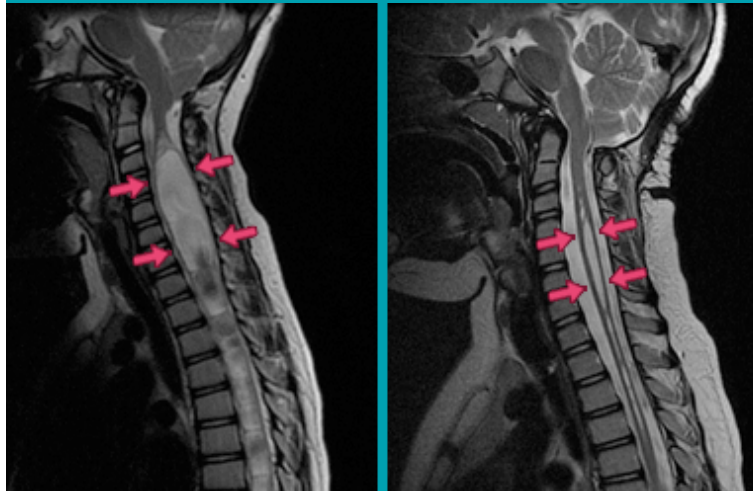
The Basics

Sharing Syringomyelia & Chiari with my Doctor

What is the Definition?

Syringomyelia and Syringobulbia

Source: National Institute of Health



○ Syringomyelia

Disease (also termed disorder) in which a fluid-filled cyst (called a syrinx) forms within the spinal cord. This syrinx can get bigger and elongate over time, damaging the spinal cord and compressing and injuring the nerve fibers that carry information to the brain and from the brain to the rest of the body. Please note: Symptoms do tend to correlate to the section of spinal cord that is damaged and nerve injury. Large and small syrinxes have resulted in symptoms and pain.

○ Causes of Syringomyelia:

Chiari Malformation, spinal cord injuries, neural tube defects, spinal cord tumors, damage from inflammation in and around the spinal cord.

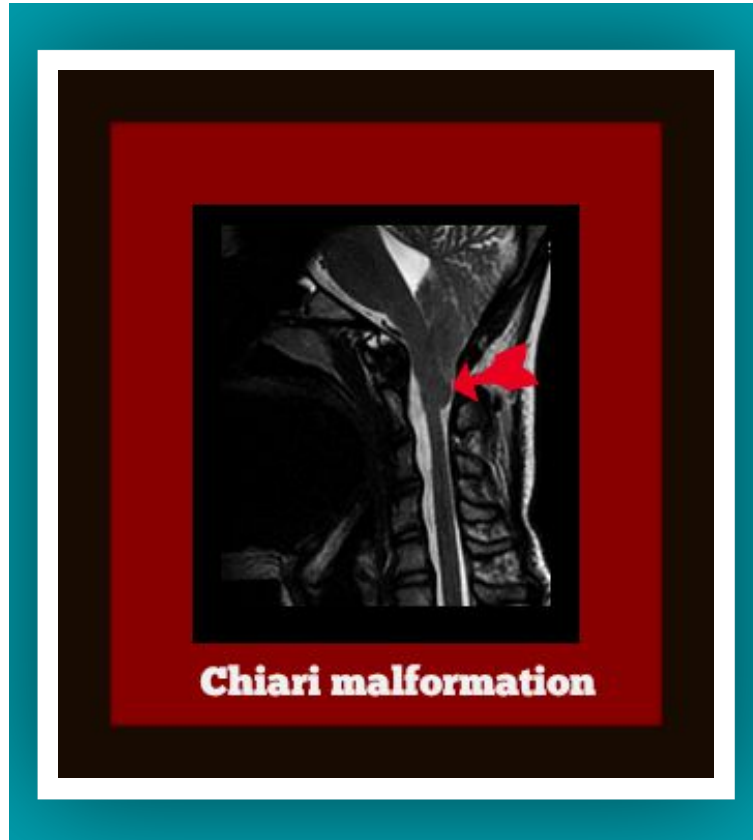
○ Syringobulbia

A term used when a syrinx has affected the brainstem. The brainstem is responsible for functions including regulation of temperature, heart rate, blood pressure, and breathing.

What is the Definition?

Chiari Malformation

Source: National Institute of Health



○ Chiari Malformation

Structural defects at the base of the skull and cerebellum, the part of the brain that controls balance. When part of the cerebellum extends through the hole at the bottom of the skull called the foramen magnum and into the upper spinal canal it is called a Chiari Malformation. This can obstruct the flow of cerebral spinal fluid, compress or injure the cranial nerves and compress the brainstem.

○ Causes of Chiari Malformation:

Neural tube defects during fetal development, excessive drainage of cerebrospinal fluid from the thoracic or lumbar regions due to trauma, infection, or disease.

Assessment Considerations:

Source: National Institute of Health

- 1 **Medical Fact: Compressed or damaged cranial and spinal nerves or inflammation in or around the spinal cord may result in complex symptoms. Over time irreversible injury may result. Damage to the cord and nerves often correlate with reported symptoms and area of pathology visualized on MRI.**
- 2 **A neurological assessment and detailed physical exam are helpful to assess for nerve injury, document reported symptoms, or changes in function.**
- 3 **Detailed family history and a comprehensive medical history can hold important diagnostic clues.**

Additional Diagnostic Findings with cases of SM and/or Chiari: Genetic history of Chiari or Syringomyelia, Spina Bifida, Hydrocephalus, Myelomeningocele, Head or Spinal Trauma, Spinal Tumors, Central and Obstructive Sleep Apnea, Autonomic Dysfunction, POTS, Diastolic Heart Failure, Cardiac Rhythm Disturbances, Intracranial Hypertension, Ehler's Danlos Syndrome, Tarlov Cyst Disease, Tethered Cord, Childhood meningitis, and Papilledema, and more!



Medical Fact: SM and Chiari

are complex. They can cause multi-system physical symptoms and moderate to severe chronic pain depending on these factors: Brainstem Compression, Cranial Nerve, Spinal Cord, and Spinal Nerve Injury. Nerve Injury and nerve compression can vary per patient.



Diagnostic Imaging

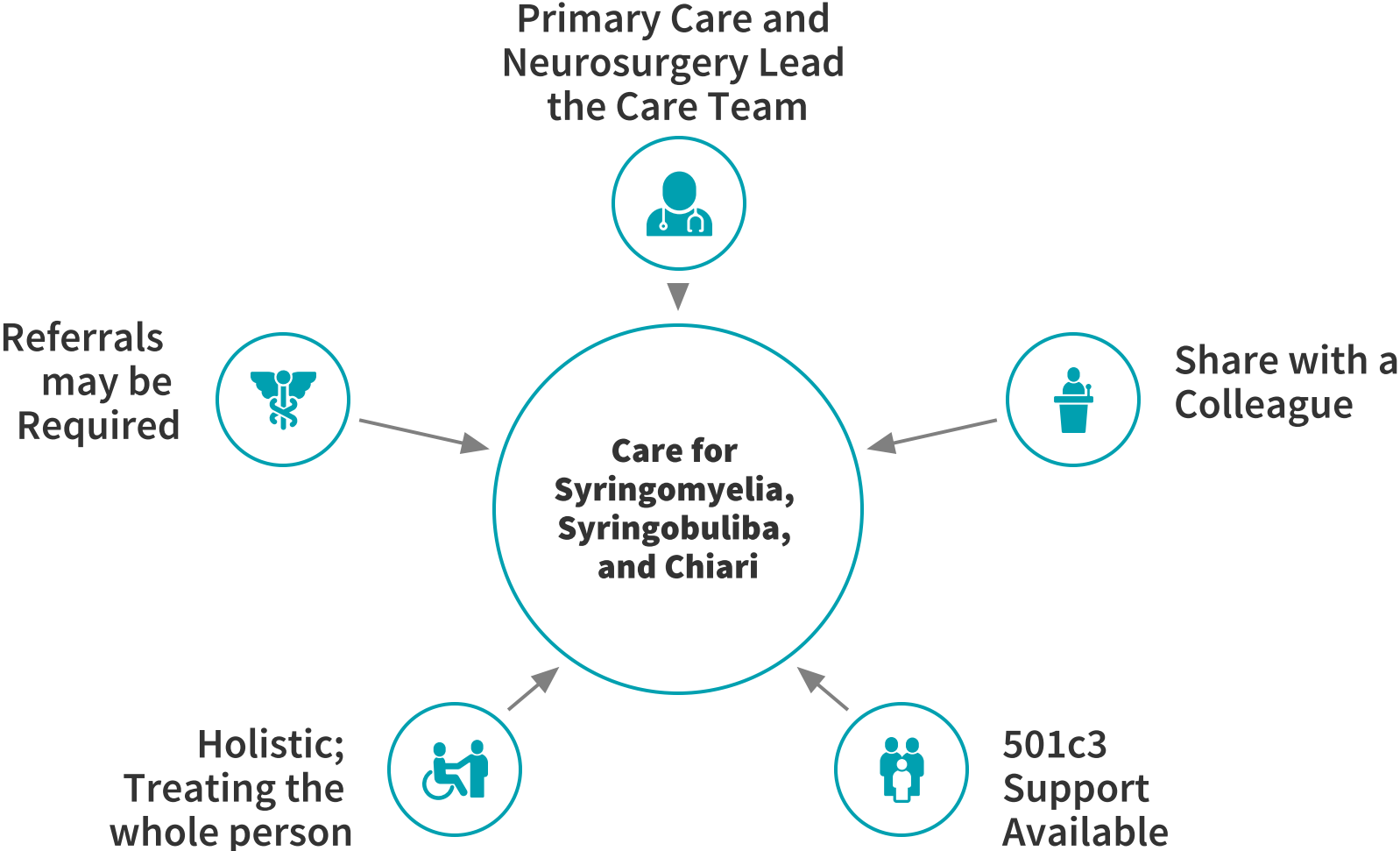
MRI imaging is the best diagnostic test to visualize Syringomyelia, Syringobulbia, and Chiari Malformation.

Radiologists are responsible to measure, document, and report all pathology on the MRI to the ordering physician.

Cine imaging is another type of MRI that is motion sensitive using a series of images in video to observe the flow of Cerebrospinal Fluid for any blockages or obstructions which can occur with Chiari, Syringobulbia, and Syringomyelia.



Treatment Team



Time is Brain and Spine!



**Syringobulbia,
Syringomyelia, and
Chiari are significant
findings.**

We support ruling out common causes for presenting symptoms first.

Time is Brain and Spine!



Delay and Inaction may result in Irreversible Injury and Poor Outcomes!

It is very important to consider the underlying diagnosis as a possible cause for symptoms once common causes are ruled out.

Time is Brain and Spine!



Additional Specialists to Consider for Example:

Syringomyelia, Syringobulbia, and Chiari can injure and damage nerves that may may adversely affect multiple body systems.

Neuro-ophthalmologist- treats papilledema

ENT-swallowing difficulties and speech

Pulmonologist- treats sleep apneas

Cardiologist- treats rhythm disturbances

Gastroenterologist- treat bowel function

Urologist- treats urinary incontinence

(All in collaboration with primary care and neurosurgery for a holistic care approach)

Time is Brain and Spine!



Selecting a Neurosurgeon

There are a small number of neurosurgeons in the world who routinely treat children and adults with Syringomyelia, Syringobulbia, and their complications.

It is important to choose a neurosurgeon who understands the conditions to lead decision making and assist a medical team with less experience treating the conditions.

An excellent neurosurgeon can help quickly rule out the need for surgical intervention vs observation. They will typically begin treatment with a minimally invasive approach.

Sources:

- 1 National Institute of Health Syringomyelia Fact Sheet
- 2 National Institute of Health Chiari Fact Sheet
- 3 Medical Resources and Research Citations
- 4 Syringomyelia & Chiari Provider Locator Tool
- 5 Syringomyelia and Chiari Complex Symptom Chart



Worldwide Syringomyelia & Chiari Task Force

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