



DISABILITY RESOURCE TOOL

Worldwide Syringomyelia & Chiari Task Force is a 501c3 nonprofit organization. We are led by nurses and physicians who advocate for men, women, and children with Syringomyelia, Syringobulbia, and Chiari Malformation. Our mission is focused on worldwide education to support excellent patient care in direct care settings. We provide educational tools and resources to support understanding about the complex nature of SM and Chiari to serve as an educational resource for decision making in determination of disability. Please feel free to contact us with any questions you may have about the information provided in this resource.

Introduction

Syringomyelia is a disease that is identified when cysts (also termed syrinxes) are identified inside of the spinal cord by MRI exam. It is defined as both a disease and a disorder. The presence of the cysts whether large or small (size is irrelevant) can damage the spinal cord, compress and injure the spinal nerves that supply many body systems resulting in widespread symptoms and moderate to severe pain. Surgery may alleviate progression in some cases. However, damage and symptoms may remain after surgery; even if a syrinx resolves; depending on how long there was injury to the spinal nerves and the spinal cord. The National Institute of Health provides two fact sheets as a general overview for both Syringomyelia and Chiari Malformation here:

<https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Syringomyelia-Fact-Sheet>

<https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Chiari-Malformation-Fact-Sheet>

<https://rarediseases.info.nih.gov/diseases/7725/syringomyelia>

Targeted Resources

- New Teaching Video about the basics of SM and Chiari with downloadable tools here: <https://www.wstfcure.org/syringomyelia-and-chiari-educational-tools.html>
- Spinal Nerve Presentation: <https://www.wstfcure.org/syringomyelia-slideshow.html>
- Syringomyelia FAQ: <https://www.wstfcure.org/syringomyelia-faq.html>
- Complex Symptoms Chart- details symptoms associated with specific nerve damage and areas of pathology that you may find particularly useful here: <https://www.wstfcure.org/syringomyelia--chiari-complex-symptom-chart.html>
- Medical Citations Page on our website as well with helpful medical publications and research articles: <https://www.wstfcure.org/medical-resources-and-research-citations.html>

Symptoms

Can match up with the area of pathology (syrinx location) inside the spinal cord. We will summarize a few symptoms here:

Cognitive changes, intracranial hypertension (headaches, nausea, visual changes), papilledema and vision loss, obstructive and central sleep apnea, difficulty walking, numbness/tingling to extremities, autonomic dysfunction (temperature, blood pressure, respiratory, and heart rate changes), moderate to severe pain, cardiovascular palpitations and tachycardia, gastrointestinal changes regarding constipation and/or excessive need to use the bathroom, problems with urination, and sexual dysfunction. Paralysis and incidence of death have been reported. Depression can occur associated with loss of job, loss of financial stability, and difficulty finding a provider who is knowledgeable about the disease.

There are numerous neurosurgeons worldwide. However, there are few expert neurosurgeons in the United States who actually treat patients on a daily basis with these medical conditions. We hope to increase understanding about how Syringomyelia and Chiari impact the lives of patients day to day with spearheading targeted educational tools for the public and medical disciplines and through the launch of a natural history registry.

Disability

An individual's decision to apply for disability may be based on the addition of medical complications or co-existing conditions that are linked to their underlying SM or CM. Individuals with a diagnosis of SM and Chiari may have no disability or they may have mild, moderate, or even severe disability. Each case should be reviewed individually. We have discovered that in cases where there is a favorable ruling for disability; attorneys received education about SM and Chiari to represent their client a few weeks prior to the case, and judges were allowed to review the educational information about the disease processes ahead of the actual hearing date. Syringomyelia and Chiari can be complex and an individual may have multiple co-existing complications. Please don't hesitate to contact us by phone or email with any questions you may want to ask.

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