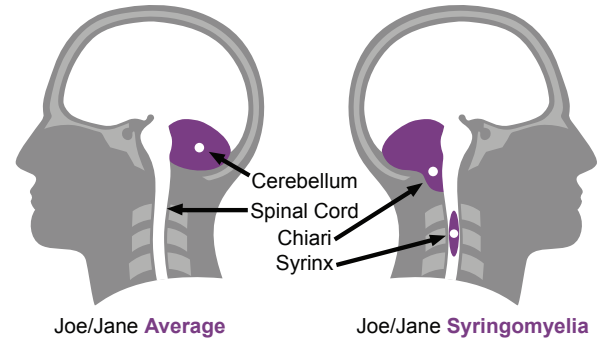


# Syringomyelia Education Sheet

**Definition:** *A serious neurological disorder where a fluid-filled cyst, known as a syrinx, develops inside the spinal cord, stretching the cord and damaging nerve tissue*

**Number of People Affected:** *Not known for sure, but estimates range as high as 200,000 people in the US; affects both children and adults*

**Cause:** *Up to 90% of cases involve a Chiari Malformation; spinal cord injury (post-traumatic SM), tumors, and arachnoiditis are other causes; exactly why syrinxes form is not known, but might involve the abnormal flow of cerebrospinal fluid (CSF), which is obstructed by a Chiari Malformation*



## Symptoms:

- Many possible, but most common are pain in the neck and shoulders, numbness and weakness in the arms, and pain and stiffness in the legs
- Other symptoms include abnormal sensations, abnormal sweating, inability to feel hot and cold with the hands, lack of bladder/bowel control, and sexual dysfunction in men
- Size of the syrinx is not necessarily related to severity of symptoms
- Condition progresses differently for everybody, but can lead to permanent nerve damage and even paralysis
- Some people have a syrinx with no symptoms

## Diagnosis:

- MRI (Magnetic Resonance Imaging) can clearly show the presence of a syrinx in the spine
- cine MRI can show whether fluid is actively flowing into and out of the syrinx
- Neurological exam is used to assess the impact the syrinx is having on the nervous system
- Prior to treatment, there is no test to say who will get better and by how much
- Some evidence that the amount of time a person has had symptoms before surgery is related to outcome, meaning the longer someone has had symptoms, the less chance they have of recovering fully

## Treatment/Surgery:

- Unless there are no symptoms, surgery is usually recommended
- For Chiari related SM, decompression surgery is used to create more space around the malformation (just like Chiari surgery)
- Sometimes, a shunt - or tube - is put in to help CSF flow around the Chiari obstruction
- Many variations on basic surgical technique, none proven better than others
- Post-traumatic SM can be very difficult to treat; sometimes the area around the injury is decompressed, sometimes the syrinx is drained directly with a shunt

## What To Expect:

- Precise data is not available, but up to 80% will experience some level of relief or at least not get any worse; about 20% will continue to get worse
- Most people will suffer from some symptoms even after surgery
- Major lifestyle modifications may be necessary
- Severe, chronic pain, which can be difficult to treat, is one of the most common long-term problems
- Recovery can be a very slow process and involve many ups and downs
- Living with SM can have a major effect on a person and their family

**CONQUER CHIARI**<sup>SM</sup>  
*From Knowledge, Strength. Through Research, Hope.*

**For More Information Visit: [www.conquerchiari.org](http://www.conquerchiari.org)**

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