

# Common Questions About Chiari



## Is Chiari Fatal?

*In general Chiari 1 is not considered fatal, in that survival rates are not discussed. However, through social networking, it is becoming unfortunately clear that deaths associated with Chiari may be more common than once thought. While there are reports in the literature of rare sudden death associated with Chiari I due to breathing problems, surgical complications, suicide, and shortened life due to associated health problems also need to be considered. To date, the impact that long-term symptoms, especially chronic pain, may have on life expectancy has not been studied.*

## Is Chiari Genetic?

*Research has identified more than 100 families with multiple affected members, implying that at least some cases are genetic in origin. However, it is not known what percent of cases are, and what genes are involved. Currently, there is no genetic test for Chiari, but Conquer Chiari continues to fund research in this area.*

## How Many People Have Chiari?

*Chiari is more common than many people think. Conquer Chiari estimates that 1 in 1,000 people have Chiari, which translates to more than 300,000 people in the US alone. According to the American Association of Neurological Surgeons, there are over 10,000 Chiari surgeries each year.*

## Who Gets Chiari?

*It is generally believed that Chiari affects people of all races. There are some indications that it affects more women than men. Symptoms can develop at any age, but people are usually diagnosed as children or as adults in their late 20's or early 30's. As recognition of Chiari grows, it is being diagnosed in children more frequently.*

## Does Size Of The Malformation Matter?

*Traditionally, Chiari Malformation has been defined as the cerebellar tonsils descending more than 3-5mm into the spinal cord. However, research has shown there is not a strong correlation between the amount of descent (or herniation) and severity of symptoms or surgical outcome. Some people with herniations of less than 3mm are extremely symptomatic, while others with quite large herniations are symptom free. However, people with very large herniations are more likely to be symptomatic. Because of this confusion researchers are looking for other quantifiable indications of symptomatic Chiari.*