

Many Non-Surgical Patients Stable at 12 Months

One of the most pressing needs of the Chiari patient community is more data regarding what happens if someone doesn't have decompression surgery. Now, the UK Chiari I Study has found that patient reported quality of life on average does not get significantly worse over the first year following diagnosis. The UK Chiari 1 Study involves 24 care centers and is collecting data on both adult and pediatric Chiari patients during their Chiari journeys.

This part of the project included 148 adults (age 16+, average age 32) and 44 children (average age 11). Eighty percent of the study participants experienced headaches with slightly more than half being typical Chiari strain headaches. Twenty percent of the children had scoliosis. Interestingly, 9% of the pediatric cases had a family history of Chiari compared to only 3.4% of the adult cases.

In contrast to what is seen in the US, only 12% of the group underwent decompression surgery. The purpose of this analysis was to see how the self-reported quality of life for the 88% who didn't have surgery changed over the following year. At the time of diagnosis, the adult group scored significantly lower on all eight quality of life domains than population norms. The domains included physical functioning, physical impact on daily activities, bodily pain, general health perception, vitality, social functioning, emotional impact on daily activities, and mental health. However, at the one-year mark, none of the quality of life scores had declined significantly from the initial assessment and scores for social functioning and bodily pain actually improved significantly.

The pediatric participants were given a different quality of life survey which measured physical, emotional, social, and school functioning. While the surgical patients scored lower than normal, the non-surgical pediatric cases were not significantly different from population norms. And for the non-surgical patients the scores were significantly different at the one-year mark.

Slowly but surely more data is being accumulated that will benefit Chiari patients (and parents) as they face the often difficult decisions involving potential surgery.

Source: Piper RJ, Afshari FT, Soon WC, et al. Quality-of-Life Outcomes in Adults and Children With Chiari 1 Malformation and in Those Managed Without Surgery: A Prospective, Multicenter, Observational Study. *Neurosurgery*. Published online September 9, 2025. doi:10.1227/neu.0000000000003718

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