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Routine Procedures May Lead to Cervical Instability For Those With hEDS

Data from the Chiari1000 indicates that between 10-15% of female Chiari patients have also been diagnosed with hypermobile EDS (hEDS), a connective tissue disorder that results partly in hypermobile and fragile joints. A recent case series publication from the Center for Complex Disorders in Rhode Island highlighted the risk that hEDS patients may face with what is generally considered routine medical care.

The authors highlighted the experience of 8 women with hEDS who were seen at their center in 2024 and 2025. The women had no previous history of cranio-cervical instability (CCI) but each of them developed CCI related symptoms after a medical procedure that involved extension of the neck (backward bending or chin up). The symptoms started after a dental procedure for three of the women and after appendectomies for two of them. During procedures that require intubation – the placement of a tube into the trachea to assist with breathing – the neck is routinely placed into extension for potentially long periods of time. The same is true for many dental procedures.

For half of the women, CCI symptoms developed 5 days or less after the medical procedure and for a majority it was within a week. Symptoms included occipital headaches, dizziness, ringing in the ears, clicking or grinding of the neck during movement, and brain fog. All the women were evaluated by neurosurgeons and CCI was confirmed on either MRI or CT. In every case there was no imaging indication of CCI prior to the medical procedures.

After performing a literature review, the authors believe this is the first report of neck extension during procedures leading to CCI in the hEDS population. While this type of study can't prove causation, the imaging is a strong indicator that the neck extension was more likely than not responsible. Based on this the authors caution hEDS patients to discuss neck placement with their medical providers before dental procedures and undergoing anesthesia.

Source: Lee C, Sutherland S, Chopra P. Craniocervical instability after inadvertent neck hyperextension in Ehlers-Danlos syndrome: a retrospective case series and literature review. *BMC Neurol*. Published online March 24, 2026. doi:10.1186/s12883-026-04801-z

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