

APPENDIX 1

History of epilepsy

Misunderstandings about epilepsy can be found throughout history and still exist in many cultures around the world. Epilepsy has been depicted in literature for centuries with the first reports occurring around 2000 BC.¹ The explanation of epilepsy has ranged from a religious, sacred experience to one of demonic possession or a curse.

The first scientific explanation of epilepsy generating from the brain was detailed in a text titled *On the Sacred Disease*, written around 400 BC and included in the Hippocratic Corpus.* This piece of literature is thought to have started the understanding of epilepsy as scientific, rather than religious or spiritual. It depicts epilepsy as a medical condition, noting the “sacred disease” has no relation with the divine, but is explained instead by the accumulation of phlegm in the brain.

Despite the description in the Hippocratic Corpus, explanations of epilepsy tied to religion persisted,² as shown in a review of epilepsy during the Middle Ages, the Renaissance, and the Enlightenment.³ The review notes that the primary view of epilepsy during the Middle Ages was one of superstition, most notably endorsed by some religious authorities. The predominant theory was that those with epilepsy were possessed and a religious intervention was the only cure. Epilepsy in the Middle Ages was also thought to be contagious, leading to those with epilepsy being shunned and facing social discrimination. An isolation hospital for people with epilepsy opened in France in 1486, named St. Valentin, after Saint Valentine, the patron saint of epilepsy.³

In the 18th and 19th centuries, the broader acceptance of epilepsy as being a medical condition helped to create an understanding of its pathology and dissolved the idea that it was a religious or

* A collection of Ancient Greek medical works associated with Hippocrates and his teachings. The exact authorship of these books is largely unknown.

spiritual condition. This led to the introduction of medical treatment with some of the first therapies for epilepsy. A review of epilepsy research from the same time noted several treatment options, including ingesting substances such as bromides, indigo, belladonna, mistletoe, zinc oxide, and chloroform.⁴ Intentionally causing fevers, bloodletting, and surgical procedures involving creating holes in the skull also occurred during this time.

Medical advancements and research have come a long way since the early history of epilepsy, but it is still not completely understood, leading to the continued stigma of the disease, even today. (“Stigma” refers to negative and unfair beliefs people have about something.) In 2019, the World Health Organization, in partnership with various epilepsy organizations, published a comprehensive report, “Epilepsy: a public health imperative,” noting this stigma and discrimination. This report encourages improving knowledge and raising awareness in schools, workplaces, and communities. Enacting legislation to uphold human rights standards can help prevent discrimination in this group of individuals.⁵

Addressing the stigma often associated with epilepsy can be best done through education. Knowing what to say to others about epilepsy, particularly for children, can help empower them to not be embarrassed or ashamed of their condition. This education should be provided not just to the individual with epilepsy but the entire family.⁶ Increasing education is shown to decrease negative attitudes toward epilepsy. Still, misconceptions and myths exist today.⁷

References

- 1 Magiorkinis E, Sidiropoulou K, Diamantis A (2010) Hallmarks in the history of epilepsy: Epilepsy in antiquity. *Epilepsy Behav*, 17, 103–108.
- 2 Magiorkinis E, Diamantis A, Sidiropoulou K, Panteliadis C (2014) Highlights in the history of epilepsy: The last 200 years. *Epilepsy Res Treat*, 2014, 1–13.
- 3 Diamantis A, Sidiropoulou K, Magiorkinis E (2010) Epilepsy during the Middle Ages, the Renaissance and the Enlightenment. *J Neurol*, 257, 691–698.
- 4 Sidiropoulou K, Diamantis A, Magiorkinis E (2010) Hallmarks in 18th- and 19th-century epilepsy research. *Epilepsy Behav*, 18, 151–161.
- 5 World Health Organization (2019) Epilepsy a public health imperative [pdf], Geneva, Available at: <<https://www.who.int/publications/i/item/epilepsy-a-public-health-imperative>> [Accessed September 13 2024].
- 6 Guilfoyle SM, Wagner JL, Modi AC, et al. (2017) Pediatric epilepsy and behavioral health: The state of the literature and directions for evidence-based interprofessional care, training, and research. *Clinical Practice in Pediatric Psychology*, 5, 79–90.
- 7 Beghi E (2019) Social functions and socioeconomic vulnerability in epilepsy. *Epilepsy Behav*, 100, 1–4.