

## Epilepsy as stigma – evil, holy or mad?

Ideas that appear very strange to us have shaped views of epilepsy throughout our history. A number of creative, but mostly ineffective cures have been attempted.

Older writings testify to the fact that persons with epileptic seizures have been discriminated against throughout history. We can hardly imagine what it was like to live with such seizures in an era when people believed that these were caused by evil spirits and that the spirits could affect or infect others (1).

A well-known neurologist has claimed that «the history of epilepsy can be summarised as 4 000 years of ignorance, apprehension and stigma, followed by 100 years of knowledge, apprehension and stigma» (2). In contemporary Norway, both children and adults with epilepsy can tell stories of exclusion because of apprehension and fear in society. The myths surrounding epilepsy are enduring, and many of them still persist (3). Doctors and health personnel should seek to de-mystify epilepsy and thus help improve the patients' quality of life.

### Many designations

Throughout history, epilepsy has been known by many names. The term epilepsy was introduced by Hippocrates and is derived from Greek «to seize, grab hold of».

Many other designations have been used: the sacred disease, the great disease, the falling sickness and many others (in Norwegian: fallsott, brotfall, fang, fangkrampe, ilske, brot, krampeslag, slau, begavning), including the wicked/evil sickness and lunacy (4).

The term «the falling sickness» reflects the belief that during a seizure, the sufferer would fall to the ground towards Hell and the Devil (5). «Fang» or «fangkrampe» refers to the belief that the creatures of the underworld would grab hold of or embrace the sufferer, and the cramps are his or her attempts to struggle free of this embrace (4).

The designation «begavning» («gift») testifies to the fact that epilepsy also was associated with special abilities, including the ability to cure others. In Norway, Knut Rasmussen Nordgarden (1792–1876) is probably the best known figure. He lived in Vestre Gausdal and went by the name Knut the Wise. People came to him from far and wide to be cured of illness (6) (Figure 1).

«The sacred disease» was used because people also believed that epileptics had contact with God. One example is Christina the Astonishing (1150–1224), also known

as Christina Mirabilis. She was a poor, orphaned peasant girl from Belgium who suffered a serious epileptic seizure at a young age. After the seizure people believed that she was dead and proceeded to bury her. Suddenly Christina called out: «The stench of the human sin is unbearable to me!» Later in life she performed a number of miraculous acts. She has become a symbol of human suffering and of the need to banish stigma and prejudice (7).

The term «lunacy» stems from a notion that mental disorders were closely linked to the phases of the moon. In Norway, the diagnosis *insania epileptica* (epileptic insanity) was used for some time. In 1925, altogether 223 persons were hospitalised with this diagnosis (8). The term «hysteroepilepsy» was coined by the French neurologist Jean Martin Charcot to describe seizures that neurotic patients suffered after having observed epileptic seizures in patients on the same ward.

### Numerous causal explanations

In Antiquity, epilepsy was regarded as a sacred disease that had been inflicted by the gods. The treatment consisted in sacrifices and religious rituals presided over by priests.

For centuries, it was believed that epilepsy was caused by evil spirits, goblins and demons («morbus daemonicus»). Epilepsy was also linked to witchcraft. A handbook from 1494, *Malleus Maleficarum* (The Hammer of Witches), claims that witches had special characteristics, including epileptic seizures (9).

Nordic folk tales from the 17th, 18th and 19th centuries show that epilepsy was thought to be a result of incidents during pregnancy. The pregnant woman should avoid being «negligent» – otherwise the child would suffer from the falling sickness. Pregnant women needed to carefully avoid anything that had collapsed. For example, they should not climb over a collapsed fence, not witness anybody who was unravelling a weave and not drop any object on the ground. If they saw someone falling over, they should invariably help them back up on their feet in order to avoid the forces of magic (1). In the village of Slåtthög in Småland, Sweden, it was said that one should take care not to pour a child's bath-

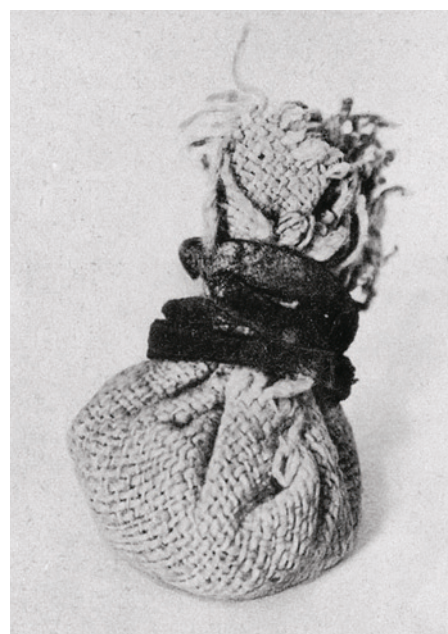
water directly out onto the ground. If so, the water would reach the creatures of the underworld, who would later seek revenge by inflicting epilepsy on the child (1).

It was also a widespread notion that epilepsy could be God's punishment for evil acts perpetrated by the sufferer or his or her ancestors.

### Numerous methods of treatment

Christianisation reinforced the belief in healing by religious rituals. The New Testament describes how Jesus healed a boy suffering from «lunacy» i.e. epilepsy: «And Jesus rebuked the devil; and he departed out of him: and the child was cured from that very hour.» (10). The most frequently used cures included prayer, fasting, sacrifices and exorcisms (driving out of demons). Certain saints were also invoked.

«Setting the disease into the ground» was a common treatment principle (4). To conduct diseases into the ground, the patient could, for example, place on the ground an arm that was twitching during a seizure. «Shoving», i.e. pulling the patient through a natural opening, such as a stone crevice or a hollow tree, could also help prevent seizures (Figure 2).



**Figure 1** Magic satchel, dated 1885. Satchels containing powerful ingredients were carried on the person, often around the neck [1, p. 86]

It was also believed that carrying an amulet or a satchel filled with dried animal organs around the neck could have a healing effect. Other forms of treatment included castration, bloodletting, leeches and craniotomy (to release evil spirits), ashes from burnt clothing worn during seizures, herbs, various metals, human and animal blood, urine and ground-up human skulls (Figure 3). The methods were ineffective at best, and directly harmful at worst (5).

In the early days of printing, herbal manuals played an important role. The books would often be blessed by the local bishop, who would specify that «this herb will help – God willing» (11).

Bromide salts were introduced in the treatment of epilepsy in Norway in the 1930s and remained in use until around 1950. The salts were often added to bread (12). The practice continued despite the fact that other and more effective drugs had been introduced. The bromide salts reduced the seizures but could have serious adverse effects, such as large boils on the skin. Unfortunately, history shows that once a treatment method has been introduced, it may be a long time before it is abandoned even though it has been proven to be harmful (5).

Lobotomy was used as a treatment method in Norwegian psychiatric hospitals from the 1940s until 1957. It is less known that persons with epilepsy were also subjected to this treatment, which resulted in varying degrees of brain damage. Some of those who did not suffer from epilepsy beforehand developed post-operative epilepsy as well as other signs of frontal lobe injuries (13).

#### «Murderous and morally depraved»

Through many centuries, certain forms of epileptic seizures, for example complex partial seizures characterised by aloofness and strange behaviour, were interpreted as madness. When psychiatric asylums were established in the 1800s, many epileptics were sent there.

In the late 19th century epilepsy was regarded as a degenerative disease. «The so-called epileptic degeneration includes development of an imbalance of the mind, moral defects, mendacity, spinelessness, often dipsomania and a predilection for vagrancy» (14).

Dell described the characteristics of persons with epilepsy thus: the patient was «insane and malevolent with a proclivity for unpredictable seizures of violence and



**Figure 2** Shoving was one of several methods used to cure epilepsy. Here a child is pulled through a hole in a tree, photo from 1922 (1, p. 31)

madness, perhaps murderous tendencies and surely moral depravity» (15). Hyperreligiosity, hypergraphia and hyposexuality have also been regarded as features of the epileptic personality (16).

Marked by the social stigma that accompanied the diagnosis, people with epilepsy have through all ages had difficulty in finding work. Many were forced to beg, others took casual work and others were on poor

relief (17). In the world at large, unemployment remains high among people with epilepsy, and discrimination in the labour market continues to be common (18).

#### Genetic cleansing and discrimination

The German psychiatrist Hans Berger, who discovered electroencephalography (EEG) in 1924, was the first to show that epilepsy was associated with abnormal electrical



**Figure 3** Bloodletting in Värmland, Sweden, 1918. Bloodletting was used as a cure for epilepsy. Drinking human or animal blood was also frequently used as a treatment method [1, p. 293]

activity in the brain. Unfortunately, this did not help change people's view of epilepsy to any appreciable extent.

In Germany in the 1920s it was assumed that 80 % of those who were living in the epilepsy colonies had a hereditary form of epilepsy (19). This era was marked by ideas of racial hygiene. Persons with hereditary diseases, including epilepsy, were to be barred from having children.

Forced sterilisations and extermination of all disabled children under the age of three were initiated. In practice, all disabled people up to the age of seventeen were killed (19).

In the period 1907–1964, altogether 60 000 persons with epilepsy were sterilised, including 30 in Norway (20). In Norway until 1969, everybody was obligated to disclose his or her epilepsy before

marriage. If such information was withheld, the marriage could be annulled (21).

The rectification of myths and misconceptions about epilepsy has been a slow process. To this day, many experience the prejudices as an additional burden which is as hard to cope with as the epilepsy itself.

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