

# THE HORTON CHAPEL PROJECT

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# A Short History of Epilepsy

Despite encountering extreme prejudice throughout the ages, many famous people from all over the world defied the physical effects and negative attitudes arising from the epilepsy. They led nations, armies and religions, or produced incredible literature or works of art. Julius Caesar, Joan of Arc, Alexander the Great, Czar Peter the Great of Russia, Pope Pius IX, the writer Fyodor Dostoevsky and the poet Lord Byron are just a few of many prominent figures from history who are believed to have had epilepsy. These gifted individuals and millions of people living with epilepsy every day have given lie to the fallacy that the illness has its roots in insanity or always limits the abilities of an individual.

The condition of epilepsy derives its name from the Greek word 'epilepsia', which means 'to take hold of' or 'to seize', although the oldest detailed account of epilepsy is contained in a Babylonian textbook of medicine kept in the British Museum, dating as far back as 2000 BCE. The condition was at that time believed to arise from the supernatural, and the physical manifestations of seizures indicated possession by evil spirits or gods. Treatment was therefore also largely a spiritual matter. Even the Bible gives an account of Christ casting out a devil from a young man with an illness believed to be epilepsy (Mark, 9:14-29; also in Matthew and Luke) and in Europe St. Valentine has been the patron saint of people with epilepsy since medieval times.

In a treatise named 'The Sacred Disease', written before 440BCE and attributed to Hippocrates, the contrary view was propagated that epilepsy was not sacred, but rather a disorder of the brain. This was a revolutionary view at the time and did not begin to take root in the medical world until the 18<sup>th</sup> or 19<sup>th</sup> century. During this period treatment was based on a sensible lifestyle, involving regulation of diet, regulation of excretions and physiotherapy. This was augmented, where appropriate, by herbal medicines.

The Middle Ages saw a reversion to the supernatural view of the origins of the condition, when seizures were viewed with fear, suspicion and misunderstanding. Those with the condition were cast out of their community, subjected to vilification, punishment or at the very least the attachment of an unwarranted social stigma. Treatment included offering sacrifices and subjecting sufferers to exorcism. Herbal medicines, such as belladonna, henbane, mistletoe and foxglove were also used, but these could be extremely toxic if given in excessive doses, so the remedy often was worse than the ailment.

The first effective anti-epileptic drug was potassium bromide, the use of which was first recorded in 1857 by the Victorian obstetrician Sir Charles Locock. This drug and variants of it (such as bromide of strontium, administered to residents of the Ewell Epileptic Colony)

became widely used in North America and many European countries during the second half of the last century. With the introduction of phenobarbitone in 1912 and phenytoin in 1938, drug treatment options for the control of seizures were improving slowly. By the 1960s more was known about the electrochemical charges within the brain, especially the required balance between the excitatory and inhibitory neurotransmitters, so using this information many new drugs aimed specifically at the treatment of epilepsy were developed.

Such targeted drug development was made possible in large part to the emergence in the 19<sup>th</sup> century of a new medical discipline known as neurology. Epilepsy began to be increasingly viewed as a neurological disorder, attributable to electrochemical discharges of energy into the brain, as opposed to being a psychiatric condition. This theory was expounded in 1873 by John Hughlings Jackson, an eminent London neurologist, who theorised that such discharges in the brain were the root cause of epilepsy, resulting in what he described as 'the dreamy state' in the patient.

With the development in 1924 of electroencephalography (EEG) by Hans Berger, a German psychiatrist who used EEG to record "brain waves", it was now possible to show the location and patterns of wave discharges, to identify the different types of seizure and from the 1950s onwards, expand the possibility of using neurosurgery as a treatment.

The last few decades have seen the development of different types of neuroimaging such as computer tomography (CT), positron emission tomography, magnetic resonance imaging (MRI) and MRI spectroscopy, all of which can detect lesions within the brain. Such lesions can develop as the result of trauma, tumour or infection within the brain, but can also arise from congenital and degenerative issues all of which have the capacity to cause epilepsy. Without such modern diagnostic tools the search for the cause and treatment of epilepsy would be much more difficult.

#### BIBLIOGRAPHY – HISTORY OF EPILEPSY

[www.journals.lww.com/neurotodayonline/Fulltext/2005/01000/Epilepsy\\_](http://www.journals.lww.com/neurotodayonline/Fulltext/2005/01000/Epilepsy_)

[www.epilepsiemuseum.de/alt/body\\_therapieen.htm](http://www.epilepsiemuseum.de/alt/body_therapieen.htm)

[www.epilepsy.org.uk/about/st-valentine-epilepsy-patron-saints](http://www.epilepsy.org.uk/about/st-valentine-epilepsy-patron-saints)

Highlights in the History of Epilepsy: The Last 200 Years. Emmanouil Magiorkinis, Aristidis Diamantis, Kalliopi Sidiropoulou, Christos Panteliadis. Hindawi, Volume 2014, Article ID 582039, 13 pages  
[www.doi.org/10.1155/2014/582039](http://www.doi.org/10.1155/2014/582039)

<p>The Falling Sickness: A History of Epilepsy from the Greeks to the Beginnings of Modern Neurology, <u>Owsei Temkin</u> Volume 4 of Publications: 1st ser., Monographs, Johns Hopkins University Institute of the History of Medicine <u>Softshell Books</u> JHU Press, 1994</p>
<p>A Disease Once Sacred. A History of the Medical Understanding of Epilepsy - M.J. Eadie, P.F. Bladin, P.O. Box 276 Eastleigh, SO50 5YS, England: John Libbey &amp; Company Ltd, (2001)</p>
<p>An Introduction to the Life and Work of John Hughlings Jackson: Introduction. Med Hist Suppl. 2007;(26):3–34.</p>
<p>Epilepsia, 44(Suppl. 6):12–14, 2003 Blackwell Publishing, Inc. © 2003 International League Against Epilepsy</p>
<p>Seizures as imbalanced up states: excitatory and inhibitory conductances during seizure-like events. <u>Jokūbas Žiburkus</u>, <u>John R. Cressman</u>, <u>Steven J. Schiff</u>. 01 MAR 2013 <a href="https://doi.org/10.1152/jn.00232.2012">https://doi.org/10.1152/jn.00232.2012</a></p>

# Epilepsy Colonies Throughout The World

## Germany

The first purpose designed colony for the care of people with epilepsy, the Rheinisch – Westphalian Asylum for Epileptics, was founded in 1867 in Bielefeld. The Industrial Revolution severely reduced the opportunities for work for many of workers, so it followed that those with epilepsy would find employment even more difficult to obtain.

The Westphalian Provincial Council, Christian industrialists and members of the clergy saw that these changes created severe hardship for those already considered unsuitable for employment because of their epilepsy, so purchased a farm to give work for three men with epilepsy in a safe, contained environment. The intention was that by giving them vocational training, they might later be integrated into mainstream employment.

It soon became apparent that this aim was largely unachievable for residents of the colony (by now known as Bethel) because of their physical or mental symptoms. A programme of expansion within Bethel was started and by 1884 the colony comprised 18 farmhouses, workshops and other buildings. The colony was now self-sufficient, with enough living accommodation for both men and women and various different trades and occupations being carried out by the patients. This expansion continued and by 1897 the colony was home to 1522 patients from all over Germany.

Although Bethel provided a safe and productive environment for those with epilepsy, it was not until decades later that any effective treatment of the condition was introduced, in the form of sodium bromide as an anti-convulsive drug. The nature of care provided by the Bethel, from inception to the present day has changed considerably; the Bethel Epilepsy Centre is still considered a flagship in the provision of treatment of and research into epilepsy.

## United States of America

The first dedicated facility for the care of epileptics in the USA was the Ohio Hospital for Epileptics at Gallipolis and opened in November 1893. It was established on the model of the Bethel Hospital in Germany, which was held in high regard internationally as a groundbreaking concept in the care of epileptics.

Hitherto those afflicted by epilepsy found themselves consigned to poor houses or other state institutions. The Ohio facility comprised 5 large ‘cottages’ each housing 250 patients,

where a homely atmosphere was developed so patients did not feel they were being institutionalised and where they could maintain some sense of privacy.

The provision of day rooms, churches, schools and an amusement hall, as well as nourishing food (regarded as key to improving the condition) and adequate clothing did much to improve the demeanour of the patients. Those who were physically able could engage in work at the farm, laundry and workshops.

Over the decades successive regimes adopted different scientific views and treatments for the condition. In 1950 and again in 1979 the colony changed both its name and function, aimed at serving a broader range of persons with developmental disabilities.

#### Chalfont St. Peter, Buckinghamshire

The main source of treatment for epilepsy in the United Kingdom at the end of the 19<sup>th</sup> century was provided by the National Hospital for the Paralysed and Epileptic in London. As with the founders of colonies in Bielefeld and Ohio, staff members were aware that epilepsy often made obtaining employment difficult if not impossible, and as a result those with epilepsy often found themselves housed in a workhouse or asylum.

In 1892 the National Society for Employment of Epileptics (NSEE) was established by a group of London philanthropists and medical men, with the aim of establishing a colony along the lines of facilities already existing abroad, to foster a more humanitarian approach to the social problems of epilepsy

After a period of fundraising, in 1893 the Society purchased Skippings Farm, near Chalfont St. Peter. In order to establish the colony quickly, facilities were rudimentary at first, with two large iron huts for accommodation and a horse driven pump to provide water. The first 14 male residents moved into the premises in July 1894.

Later, more permanent dwellings and workshops were built, providing facilities for both men and women. The men undertook work such as bricklaying, carpentry, plumbing and painting, whilst the women were engaged in laundry, fruit picking and haymaking. It was considered to be a beneficial part of their treatment to be out in the fresh air and gainfully employed. This being said, the colonists were expected to pay 10 shillings per week towards their keep if they or their families could afford it, and if not the sum would be provided by an annuity fund.

Buildings continued to be added to what had effectively become a village and in 1909, after the construction of a school and suitable accommodation, children were also admitted to the colony for the first time. The name, layout and functions of the buildings changed over

the years but it still had a total of 550 patients by the 1950s. In 1957 the school closed as a result of falling numbers and the remaining children transferred to a building in Lingfield, Surrey, run by a charity now called Young Epilepsy.

In 1965 the first resident doctors were appointed to the centre, which coincided with a time of great advances in the treatment of epilepsy. Much research was carried by the staff at the facility and the Chalfont Centre, supported by what is now known as the Epilepsy Society, is considered to be a centre of excellence for the diagnosis and treatment of the condition, enabling those with epilepsy to live as independently as possible.

BIBLIOGRAPHY – EPILEPSY COLONIES
Epilepsy Center Bethel, Bielefeld, Germany: Grewe, Philip et al.
The Story of a Colony for Epileptics Sellers, Edith. The Contemporary review, 1866-1900; London Vol. 62, (Nov 1892): 683-691. <a href="https://search.proquest.com/openview/fc6a5539b1f68c64/1?pq-origsite=gscholar&amp;cbl=729">https://search.proquest.com/openview/fc6a5539b1f68c64/1?pq-origsite=gscholar&amp;cbl=729</a>
Kissiov D, Dewall T, Hermann B. The Ohio Hospital for Epileptics-the first "epilepsy colony" in America. Epilepsia. 2013;54(9):1524–1534. doi:10.1111/epi.12335
The Ohio Hospital for Epileptics—The First ‘Epilepsy Colony’ in America: Djem Kissiov, Taylor Dewall, and Bruce Hermann, PhD Department of Neurology University of Wisconsin School of Medicine and Public Health Madison
The History of Epilepsy Society <a href="https://www.epilepsysociety.org.uk/history-epilepsy-society#.XQPUoNQrKt9">https://www.epilepsysociety.org.uk/history-epilepsy-society#.XQPUoNQrKt9</a>
Epilepsy & Behavior, Volume 76, S17 - S20 01/09/2017  <a href="https://www.epilepsybehavior.com/action/showCitFormats?pii=S1525-5050%2817%2930596-6&amp;doi=10.1016%2Fj.yebeh.2017.07.023">https://www.epilepsybehavior.com/action/showCitFormats?pii=S1525-5050%2817%2930596-6&amp;doi=10.1016%2Fj.yebeh.2017.07.023</a>
<a href="https://www.bmj.com/content/2/1774/1502.1">https://www.bmj.com/content/2/1774/1502.1</a>
Lost Hospitals of London – Chalfont Centre for Epilepsy <a href="https://ezitis.myzen.co.uk/chalfontcentre.html">https://ezitis.myzen.co.uk/chalfontcentre.html</a>
A Visit to the New Colony for Epileptics (Skippings Farm nr Chalfont St. Peters) <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3775289/#">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3775289/#</a>

# Ewell Epileptic Colony



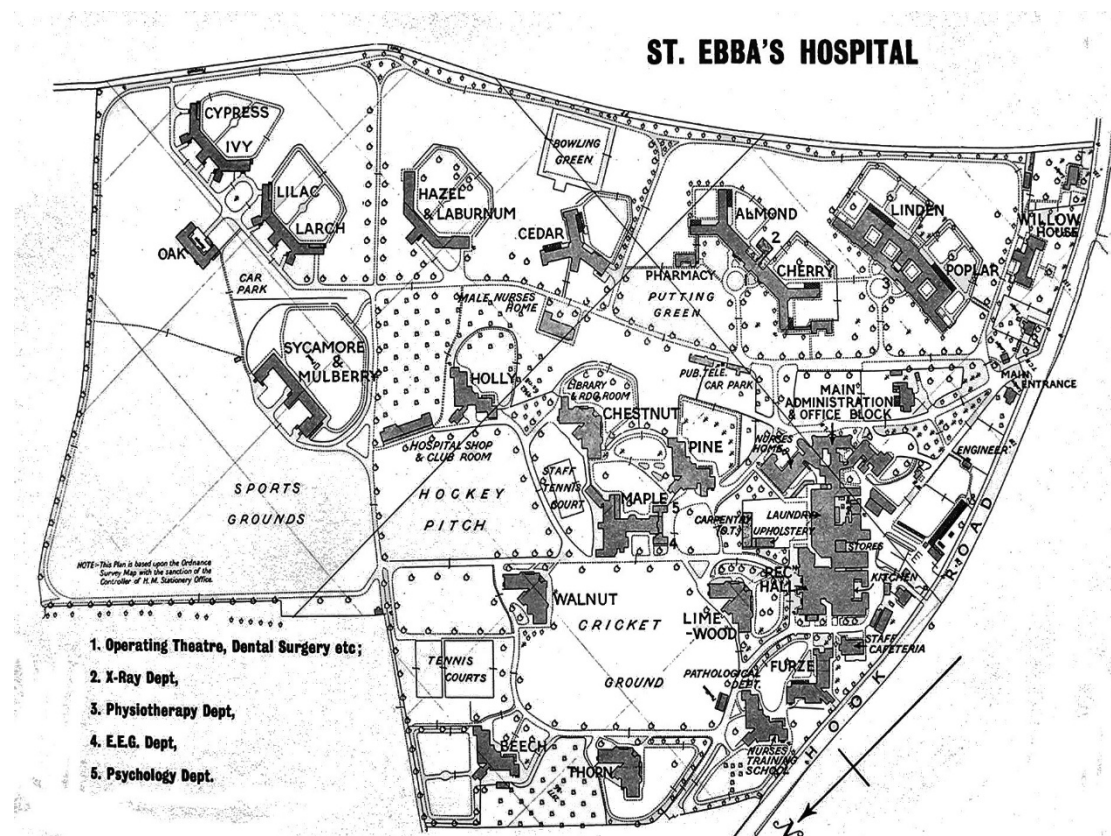
Ewell Epileptic Colony was opened in July 1903 and was the third group of buildings which comprised the Horton Estate, known later as the Epsom Hospital Cluster. Unlike the colonies previously mentioned, which relied on private funding or philanthropic donations, Ewell was funded by the London County Council (LCC) and supported by council rates if a patient or their family was unable to pay. If a patient came from outside the LCC area, the fees for their treatment were billed to their home council and patient files were marked up accordingly, in order to ensure compensatory payment was pursued. The records show that 326 patients were admitted in the first year.

By the time the Colony had come into operation, attitudes towards epilepsy had changed and there was a growing perception amongst the medical profession that epilepsy was a form of neurological rather than psychiatric illness. The LCC Asylums Committee decided that patients with a mild form of the disease with no signs of insanity would benefit from colony life, so the concept for the Ewell Colony was born. The admissions records for the



Ewell colonists still invariably showed the initial diagnosis of patients as 'insanity with epilepsy'

The aim of the colony was to provide an environment where patients could live in a setting which was less institutionalised and where they accessed gainful employment and fresh air, far removed from the atmosphere some must have previously encountered in an asylum or workhouse in Victorian London. Medical care for the condition of epilepsy was primarily the administration of bromide of strontium, which was effective to a certain degree in suppressing or reducing the instance and severity of seizure. Great emphasis was also placed on the importance of a well-regulated diet and exercise in an open-air environment. Regular bowel movements were encouraged and if not forthcoming, were remedied by use of laxatives or enemas. Although constipation did not cause the condition of epilepsy, it did seem to exacerbate the occurrence of seizures. Colonists were weighed on a regular basis to ensure that they thrived and the number of seizures they experienced was also recorded, with a distinction being made between diurnal and nocturnal occurrences, the latter seeming to be more frequent in a number of patients.



The buildings of the Colony were designed by the architect William C Clifford Smith, who was responsible for all of the LCC's institutional design. The development comprised 8 one storey villas, covering 20 acres of the 112 acre site and widely dispersed between other buildings which provided services such as laundry, boiler house and storeroom facilities. The total cost of construction on opening was £98,000. In 1909 another two villas were added to the site, which had previously been farmland. Patient numbers had by now risen to 429.

Each villa had accommodation for 38 male patients, with a veranda and porch enabling them to have access to the open air, regardless of the weather. Female patients were accommodated in a separate villa housing 32 patients, which connected to an administration block, kitchen and hall used for dining and recreation. A cricket pitch and sports field provided outdoor recreational facilities, forming a type of central village green. Instead of following the Victorian trend where such premises were given the name of financial patrons or ward numbers, the villas were each named after trees, thereby attaching a bucolic air to the premises.

The intention of the LCC Asylum Committee was always that the Colony would be self-sufficient, with the patients being engaged on the farm, in the grounds or in workshops, where they crafted simple items such as wire brushes. Female patients were more often engaged in the laundry or kitchens. Although taken from a post WW2 plan, the above diagram shows the layout of the villas, auxiliary buildings and facilities amongst which the Colonists lived.

In 1918 the Colony became the Ewell War Hospital, providing desperately needed facilities to treat the mental wellbeing of soldiers returning from the World War I. The Colonists were either transferred to other parts of the Epsom hospital cluster or moved to other institutions within the LCC. It can only be imagined what an effect this would have on patients used to the calm atmosphere of the Colony, especially if they were moved to closed institutions and treated alongside patients who had severe psychiatric illnesses.

In 1927 the Colony buildings reverted to the LCC, after which it was renamed the Ewell Mental Hospital. Further changes in accommodation and purpose occurred and in 1938 the hospital changed its name for the final time to St.Ebba's Hospital.

#### BIBLIOGRAPHY – EWELL EPILEPTIC COLONY

St Ebba's Hospital, Epsom, History  
[www.exploringsurreypast.org.uk/themes/subjects/disability-history/epsom-cluster/st-ebbas/](http://www.exploringsurreypast.org.uk/themes/subjects/disability-history/epsom-cluster/st-ebbas/)

Lost Hospitals Of London – St Ebba's Hospital  
[www.ezitis.myzen.co.uk/stebba.htm](http://www.ezitis.myzen.co.uk/stebba.htm)

ST. EBBA'S

<a href="http://www.countyasylums.co.uk/st-ebbas-hospital-epsom/">www.countyasylums.co.uk/st-ebbas-hospital-epsom/</a>
Epileptic Colony, Ewell, Surrey. (2003) British Journal of Psychiatry, 183(2) 174 – 174.doi:10.1192/bjp.183.2.174-a <a href="https://www.cambridge.org/core/journals/the-british-journal-of-psychiatry/article/epileptic-colony-ewell-surrey/DAAD0117D491CC752FB5269857A3E741">https://www.cambridge.org/core/journals/the-british-journal-of-psychiatry/article/epileptic-colony-ewell-surrey/DAAD0117D491CC752FB5269857A3E741</a>
Historic Hospitals - An Architectural Gazetteer <a href="https://historic-hospitals.com/english-hospitals-rchme-survey/surrey/">https://historic-hospitals.com/english-hospitals-rchme-survey/surrey/</a>
The Langdon Down Museum of Disability – The Five Hospitals that made up the Epsom Cluster – St. Ebba <a href="https://langdondownmuseum.org.uk/research/u3a-research/2014-long-stay-institutions-for-people-with-learning-disabilities/the-five-hospitals-that-made-up-the-epsom-cluster/">https://langdondownmuseum.org.uk/research/u3a-research/2014-long-stay-institutions-for-people-with-learning-disabilities/the-five-hospitals-that-made-up-the-epsom-cluster/</a>
London County Asylum, St Ebba's Epileptic Colony <a href="https://thetimechamber.co.uk/beta/sites/asylums/london-county-asylum-st-ebbas-epileptic-colony">https://thetimechamber.co.uk/beta/sites/asylums/london-county-asylum-st-ebbas-epileptic-colony</a>
Epsom Hospital Cluster <a href="http://www.epsomandewellhistoryexplorer.org.uk/HospitalCluster.html">www.epsomandewellhistoryexplorer.org.uk/HospitalCluster.html</a>
Ewell Epileptic Colony <a href="http://www.asylumprojects.org/index.php/Ewell_Epileptic_Colony">www.asylumprojects.org/index.php/Ewell_Epileptic_Colony</a>
Black and white photograph and diagram taken from Surrey in the Great War website, originally from Surrey History Centre ref: 6380/1/8/1 <a href="http://www.surreyinthegreatwar.org.uk/category/health-welfare/war-hospitals/?post_type=story">www.surreyinthegreatwar.org.uk/category/health-welfare/war-hospitals/?post_type=story</a>

# Stories of the Early Ewell Colonists

The majority of the information recorded in the following profiles is taken from contemporaneous notes made by staff during the time the patients spent in Ewell Epileptic Colony. As such there will be descriptions, attitudes and actions which would not be considered appropriate today. These have been included to give an accurate representation of prevailing social conditions.

## Ada



Ada had the distinction of being the first female colonist registered in the large heavy binder of records of female admissions to the Ewell Epileptic Colony. She was 39 years old when she was admitted on 8<sup>th</sup> September 1903. Her diagnosis on arrival at the Colony was recorded as 'epileptic imbecility with increasing mental enfeeblement'

Ada was born in 1864 in Notting Hill, London, 4<sup>th</sup> in a family of 3 brothers and 3 sisters. Her father was an upholsterer, living in Fulham, and the census returns until 1901 all show that Ada still lived with the family. She described herself as home schooled, but had never been able to find long term employment. She gave details of her maternal uncle as next of kin, her parents both being deceased by the time of her admission to the Colony. The visitors' book shows that her uncle, a cousin and one of her brothers visited her on occasion, giving the impression of a caring family. Given the distance from their homes in North London and the lack of public transport, these visits must have constituted a substantial sacrifice of time and money on their behalf.

Ada's history of epilepsy began when she was less than 1 year old, when her seizures were slight at first but as frequent as 5 times a day. She received treatment for almost 20 years at Queen Square, London which when established in 1859 was called The National Hospital for the Relief and Cure of Paralysis and Epilepsy. She also had the misfortune to have spent time in the Fulham Workhouse Infirmary, as her family undoubtedly had no money to pay for treatment. After time in the workhouse, the Ewell Epileptic Colony must have seemed a quiet and comfortable home, with fresh air, good food and medical care.

Ada's case notes whilst she was at the Colony indicate that she was very violent during seizures and took a long time to recover, often being gloomy and bad tempered afterwards. She had a moderate knowledge of current events, had good reactions, and was truthful and sociable, with a high sense of propriety. She could produce needlework of a high quality, give the current date, her full name, correct names to the months of the year, and multiply 3 times 13, despite 'her appearance suggesting imbecility'. Current attitudes would consider imbecility a harsh and unacceptable label to apply to someone who laboured under the physical and mental effects of a debilitating illness.

Little seemed to alleviate Ada's symptoms and throughout her time in the Colony she had an average of 3 seizures a week. For treatment she received regular doses of cod liver oil (constipation was believed to exacerbate seizures) and bromide of strontium, a chemical compound of crystalised powder which was the contemporary anticonvulsant treatment.

Unfortunately the records after 1910 are incomplete for Ada, although she was still shown as an inmate of the Colony in the 1911 census. She may have been transferred to another of the hospitals in the Epsom cluster when the Colony was converted into a hospital for WWI soldiers in 1918, but she died later that year and was buried in the Horton Cemetery.

## BIBLIOGRAPHY – ADA

Surrey History Centre records relating to the Ewell Epileptic Colony, Ref 6292/27/8

BMD and census records - [www.ancestry.co.uk](http://www.ancestry.co.uk)

History of Queen Square Hospital

[www.ucl.ac.uk/ion/alumni/queen-square-alumnus-association-newsletter-issue-12/queen-square-history-national-hospital](http://www.ucl.ac.uk/ion/alumni/queen-square-alumnus-association-newsletter-issue-12/queen-square-history-national-hospital)

Reed CAL. Constipation in Causation of Epilepsy and Migraine.

JAMA. 1916;LXVI(12):912. doi:10.1001/jama.1916.02580380062034

DeGiorgio CM, Miller PR, Harper R, et al Fish oil (n-3 fatty acids) in drug resistant epilepsy: a randomised placebo-controlled crossover study *Journal of Neurology, Neurosurgery & Psychiatry* 2015;86:65-70.

Pourmasoumi M, Vosoughi N, Derakhshandeh-Rishehri SM, Assarroudi M, Heidari-Beni M. Association of Omega-3 Fatty Acid and Epileptic Seizure in Epileptic Patients: A Systematic Review. *Int J Prev Med*. 2018;9:36. Published 2018 Apr 5. doi:10.4103/ijpvm.IJPVM\_281\_16

Use of Bromide of Strontium in Epilepsy: *Br Med J* 1895; 1 doi: <https://doi.org/10.1136/bmj.1.1794.1089> (Published 18 May 1895) *Br Med J* 1895;1:1089

## George

George was born in 1855 in Marylebone, London, the youngest of 3 children. His father was a West End theatre stage hand, who died aged 44 years, his cause of death being attributed to a ruptured vessel in the head from the strain of winding up heavy stage curtains. Despite losing his father at such an early age George thrived, becoming an expert French polisher, earning good wages, marrying and fathering 6 children, who ranged in age from 6 to 30



years. The Visitors Book for the Colony show that he was visited on numerous occasions by members of his family who travelled from as far away as Essex and Nottingham to see him.

The condition of epilepsy did not become apparent in George's life until he was almost 50 years of age. Prior to this his only serious illness had been scarlet fever and he firmly believed this was the trigger for his new condition. Contemporary medical opinions (Gowers and Sieveking) draw links between the 2 conditions but later research notes that seizures experienced during scarlet fever are not necessarily symptomatic of epilepsy.

The first treatment George received for his epilepsy was upon admission to Colney Hatch Lunatic Asylum in December 1904. A year later he was allowed out on trial for a period of 6 weeks but then began to experience even more severe seizures. Colney Hatch was severely overcrowded and lacking in accommodation after a serious fire in 1903, so George was lucky to be transferred to the Colony in April 1906, where conditions were much better.

The picture of George taken on admission shows a well-nourished, well-dressed man with groomed hair and moustache. He gave a good account of himself when a case history was taken but he had little recollection of his admission to Colney Hatch or the events leading up to it. He became by turns tearful, trembling or irritable as he was interviewed, and claimed he had a bad memory. It was noted that he indulged in alcohol and sexual activity to excess but did not have syphilis. It was not uncommon for case notes to contain moral judgements on the lifestyle of the patients.

George settled into the Colony well and was described as being useful when employed in mending and polishing furniture. Unfortunately, he sustained several tool injuries when

caught unawares by seizures, so by 1908 he was transferred to the Colony farm, where he appeared to enjoy his role.

His seizures were by now becoming more frequent and violent and happened mostly at night. He suffered shaking of the limbs, foaming at the mouth and hallucinations. Understandably these episodes left him upset and confused for long period afterwards and he sometimes was not aware that he had seizures. His case notes make it clear that, having been fit and healthy until the age of 49 years, he found the diagnosis of epilepsy hard to accept. There seems to have been little medical intervention, other than the administering of laxatives and enemas, so George had to endure the very unpleasant symptoms of his illness.

George's condition began to decline on the 7<sup>th</sup> April 1913, when he became 'agitated, aggressive and resistive' On 11<sup>th</sup> April he was confined to bed, showing signs of 'fits, stenorous breathing and rigidity in the legs' An enema was given, 'with good result'. He then fell into a coma, his blood pressure dropped and he finally died in the early hours of 12<sup>th</sup> April 1913. His cause of death was recorded as granular kidney, recent encephalitis (inflammation of the brain) and a large central haemorrhage of the brain. He is buried in the Horton Cemetery.

#### BIBLIOGRAPHY – GEORGE

Surrey History Centre records relating to the Ewell Epileptic Colony, Ref 6292/27/2/184

BMD and census records - [www.ancestry.co.uk](http://www.ancestry.co.uk)

Colney Hatch Asylum

[www.barnet.gov.uk/libraries-old/local-studies-and-archives/pocket-histories/finchly-friern-barnet-and-totteridge-0](http://www.barnet.gov.uk/libraries-old/local-studies-and-archives/pocket-histories/finchly-friern-barnet-and-totteridge-0)

Sieveking E. (1858) *Epilepsy and epileptiform seizures: their causes, pathology and treatment.* John Churchill, London

National Institute of Neurological Disorders and Stroke. University of South Florida School of Medicine: "Psychogenic (Non-Epileptic) Seizures," Selim R. Benbadis, MD, and Leanne Heriaud, RN, authors. WebMD Medical Reference Reviewed by [Neil Lava, MD](#) on May 05, 2019

Gowers, William R. "Clinical Lectures On The Borderland Of Epilepsy: Vertigo." *The British Medical Journal*, vol. 2, no. 2377, 1906, pp. 128–131. JSTOR, [www.jstor.org/stable/20290513](http://www.jstor.org/stable/20290513). Accessed 6 Feb. 2020

Shorvon SD. (2011) Historical introduction: the causes of epilepsy in the pre molecular era (1960 – 1960) In Shorvon SD, Andermann f, Guerrini R (Eds) *The causes of epilepsy. Common and uncommon causes in adults and children.* Cambridge University Press, Cambridge, pp1-20

Reed CAL. Constipation in Causation of Epilepsy and Migraine. *JAMA*. 1916;LXVI(12):912. doi:10.1001/jama.1916.02580380062034

Records of Horton Cemetery burials - Epsom & Ewell Historical Explorer [www.eehe.org.uk/](http://www.eehe.org.uk/)



## Edith

Notes relating to Edith's admission to the Colony in 1904 reveal that she knew nothing about her parents or even how she came by her name. Her only piece of luck was having



been born in St Pancras, London in 1869, so she qualified for a place in the Leavesden residential school, one of several St Pancras Industrial Schools. These were established in 1868 in Abbots Langley for the education and welfare of pauper children in the parish and Edith spent her entire childhood there.

Conditions at the school were very comfortable in comparison to those prevalent amongst the poor in Victorian London. The children were well fed and had regular exercise, including swimming. The school had a general infirmary for treating 'ophthalmia, ringworm, eczema and other non-infectious conditions', together with a separate building for infectious cases. A dentist also attended the school three times a year. School work

was built on literacy and numeracy and religious education. Towards the end of their formal education, the emphasis shifted to practical skills which could be easily translated into employment in service, factories or other trades in the outside world and indeed Edith was fortunate to be employed in service straight from school.

Edith suffered her first seizure at the age 15 years but it is not known if or how this was treated. The first mention of medical treatment as an adult comes after she suffered a seizure in the street in Greenwich and was taken to Maidstone Asylum (also known as Barm Heath). She later transferred to the Ewell Epileptic Colony, where her admission details note a scar on her left inner arm from bloodletting or venesection, at this time regarded as an effective treatment for epilepsy. Otherwise she was in good health with no deformities.

Her moods were described as emotional or hysterical and she could be ill tempered or abusive to staff and other patients, though her record notes some of this behaviour might be 'due to injudicious management on behalf of her nurse'. Unsurprisingly, these traits seem to immediately precede or follow clusters of seizures, which are recorded as having occurred 13 times in the 3 months following her admission. She describes pains in her head which feel 'like a lot of spiders' crawling around. The only note of treatment given is the prescription of 30g of bromide of strontium 3 times a day and regular doses of cascara laxative. Its frequent use with other patients within the colony would tend to indicate that constipation was considered a trigger for seizures.



Edith is described as a useful worker, being helpful to the housemaids and porters on the Colony and working variously in the laundry, kitchen and Medical Officers' quarters. She obviously impressed previous employers with her industriousness, one of whom, Mrs M Osbourne of Wandsworth wrote to the Colony asking for a trial in her care with a view to discharge. This was carried out successfully and Edith returned to the Colony after the month away looking very well indeed. She was discharged from the Colony on 24<sup>th</sup> February 1906, having spent 30 months as a Colonist.

Later entries in her record note that she was in service in Kingston to Mrs Sutton, the wife of a boot maker and that in 1910 she married and was doing well.

#### BIBLIOGRAPHY – EDITH

Surrey History Centre records relating to the Ewell Epileptic Colony, Ref 6292/27/8/22

Leavesden School - <http://www.workhouses.org.uk/StPancras/#Records>

BMD and census records - [www.ancestry.co.uk](http://www.ancestry.co.uk)

Roche A. The Bromide of Strontium in Epilepsy. Br Med J. 1895;1(1794):1089.

Reed CAL. Constipation in Causation of Epilepsy and Migraine.

JAMA. 1916;LXVI(12):912. doi:10.1001/jama.1916.02580380062034

## Llewellyn

Although Llewellyn was not strictly a Colonist (the Colony closed in 1918), his journey through epilepsy to West Park Hospital has been included to illustrate that even by the 1950s the condition still attracted the same stigma as it did when the Colony opened in 1903.



Llewellyn was born in Bristol in 1890, the youngest of 4 children whose father was a clerk of works with HM Prison Service. The 1911 census shows that Llewellyn was a student still living with his parents in Bristol. One of his sisters was a headmistress of a girls' school in Bristol, the other a nurse/midwife who worked in a munitions factory hospital during WWI. His brother was a chemical engineer who spent most of his career abroad.

Llewellyn was a staunch Baptist, much involved with activities within his church and in 1921 he and his wife were married at a Baptist chapel in Cardiff. They settled in the city, where they both had family connections, and their only child Philip was born there in 1923.

The first indication of Llewellyn's illness was his listing as a patient in the Northwoods Private Hospital in Bristol in the 1939 Register, his occupation being shown as a retired clerk of works. This hospital was first established in 1832 as The Northwoods Lunatic Asylum for those who could afford to pay for treatment. The name of the hospital was altered on a number of occasions but the number of patients who could afford treatment waned and it finally closed in 1948.

The burden of payment for Llewellyn's treatment which fell upon his wife must have been considerable, given that she was living without income and supporting her son through school, university and theological college. There are indications that both sides of the family rallied round with financial support but ultimately lack of funds may have necessitated Llewellyn's move to West Park Hospital as a rate aided patient, i.e. being paid for by his home council of Cardiff. By now his son Philip was also living and working in Surrey.

Llewellyn was admitted to West Park Hospital in 1944, where his diagnosis was recorded as 'insanity with epilepsy'. It would seem that even this late into the 20<sup>th</sup> century, epilepsy was still not regarded as a neurological disease. It is noted Llewellyn had suffered seizures since 1927, when he was 37 years old. Patient records for Northwoods cannot be traced and those for West Park are sparse, so it is not known what type of treatment Llewellyn received for his condition. He died in West Park Hospital in 1952, the cause of death being recorded as status epilepticus, a condition where seizures do not stop or one seizure follows another without the person recovering in between.

When Llewellyn's grandson Richard began researching his family tree in 2010, he was surprised to find that his grandfather had died in Epsom, where Richard had lived for almost 30 years. He contacted other distant family members who knew of Llewellyn, but knew nothing of his illness.

The informant on Llewellyn's death certificate in 1952 was his son, Philip, by then a Church of England curate in Chertsey. It is likely that he conducted his father's funeral service at Woking Crematorium in December 1952, after which Llewellyn's ashes were scattered in the Keats Garden. Philip was a kind, compassionate man, who served as Chaplain at Canehill and Netherne Psychiatric Hospitals in the 1960s and 70s, but it seems that the stigma of having a relative die in a mental hospital was such that he could not mention it, even to his own family. The photograph of Llewellyn and the pipe he is seen smoking were found in Philip's desk after he died, on the same day as his father Llewellyn but 38 years later.

#### BIBLIOGRAPHY - LLEWELLYN

Surrey History Centre records relating to West Park Hospital Ref.6294/7/58

BMD, Census & 1939 register – [www.ancestry.co.uk](http://www.ancestry.co.uk)

Definition of status epilepticus - [www.epilepsysociety.org.uk/status-epilepticus#.XjgNwdSLSt8](http://www.epilepsysociety.org.uk/status-epilepticus#.XjgNwdSLSt8)

Photograph – Llewellyn's family records

Woking Crematorium records

# Epilepsy Today

Epilepsy still affects over 600,000 people in the United Kingdom and a further 87 people are diagnosed with the condition every day. There are no preventative measures to avoid the onset of epilepsy and because many different factors (brain injury, tumours, genetic and development issues) can trigger seizures, there is no known cure for people already with the condition. Advances in drug development and techniques in neurosurgery have however been able to reduce the severity and frequency of seizures. By being prescribed the correct type of anti-epilepsy drug, figures from the UK charity Epilepsy Society estimate that 70% of people with the condition can have their seizures fully controlled.

Alongside drugs and neurosurgery, other measures such as the adoption of a ketogenic diet, a special high-fat, low-carbohydrate diet, has been found to help to control seizures. This treatment is approved by the National Institute for Health and Care Excellence (NICE) but the adaptation requires careful monitoring by a doctor or dietician.

After much debate and campaigning, medical cannabis was finally made legal in the UK in 2018. This legislation allows specialist doctors under certain circumstances to prescribe it to treat epilepsy. The substance contains hundreds of natural chemicals, but most important is cannabidiol (CBD), which does not produce the 'high' associated with cannabis. The efficacy of the other natural chemicals is still under review.

More difficult to treat are the perceptions and attitudes that people with epilepsy face on a daily basis. In 2014 at a symposium in London, epilepsy expert Dr Sallie Baxendale criticised the media and social media for 'perpetuating outdated myths and misconceptions that fuel the stigma around epilepsy'. She further made the point that 'news coverage of epilepsy often reinforced negative attitudes' and 'the entertainment industry relied on overly dramatic stereotypes to represent the neurological condition'.

There are many organisations in the UK connected to epilepsy support, all of which place an emphasis on the psychological and social needs of those with the condition. The ultimate aim is to enhance quality of life and eliminate discrimination for those who have epilepsy. The Equality Act 2010 has gone some way to achieving this aim by setting legal requirements on issues surrounding employment, health care provisions and education. It also prohibits direct and indirect discrimination on the grounds of disability. Whilst epilepsy is not automatically considered a disability, if the condition has a 'substantial and long-term effect on an individual's ability to do day to day activities', the criteria are likely to be met.

One of the main support groups in the UK, The Epilepsy Society arose from principles established in 1894 at the first UK Epileptic Colony at Chalfont St. Peters. Although methods of operation have changed since then, their mission now aims to 'enhance the

quality of life of people affected by epilepsy by promoting public awareness and education, by undertaking research and by delivering specialist medical care and support services’.

In Surrey, the major provider of specialist services for young people with epilepsy in the UK is the charity Young Epilepsy, which is based at Lingfield. It carries out research, diagnosis, assessment and rehabilitation for children and young people, as well as information and support for parents. The premises comprise a school, college and residential facilities. A large part of its work is also aimed at raising awareness and increasing understanding of epilepsy.

Also in Surrey, The Meath Epilepsy Charity has premises near Godalming and provides residential and day centre services for people with severe epilepsy. Its aim is to ‘enhance the lives of people who have complex epilepsy and related disabilities’. This is done in part with a social enterprise initiative called ‘Changing Perceptions’. Visitors will find a café, a home interiors shop and workshops where residents ‘upcycle’ donations of unwanted furniture. These are then sold in the shop and any profits go straight back to the charity.

All around the world, March 26<sup>th</sup> is designated Purple Day and is aimed at raising awareness of the numbers of people affected by epilepsy. The concept was started in 2008 by Cassidy Megan, a young Canadian girl with epilepsy and fundraising events are held internationally to highlight the condition. Lavender has been recognised as the international flower of epilepsy because it is said to symbolise isolation and loneliness, often associated with epilepsy. Supporters and participants at fundraising events are asked to wear purple to draw attention to the cause.

BIBLIOGRAPHY – EPILEPSY TODAY
<a href="http://www.epilepsy.org.uk/info/what-is-epilepsy">www.epilepsy.org.uk/info/what-is-epilepsy</a>
<a href="http://www.epilepsy.com/learn/treating-seizures-and-epilepsy/dietary-therapies/ketogenic-diet">www.epilepsy.com/learn/treating-seizures-and-epilepsy/dietary-therapies/ketogenic-diet</a>
Thomas RH, Cunningham MO: Cannabis and epilepsy. Practical Neurology 2018;18:465-471.
<a href="http://www.nice.org.uk/guidance/ng144">www.nice.org.uk/guidance/ng144</a>
<a href="http://www.legislation.gov.uk/ukpga/2010/15/contents">www.legislation.gov.uk/ukpga/2010/15/contents</a>
<a href="http://www.epilepsysociety.org.uk/epilepsy-stigma-worse-than-seizurest-26-06-2014#.XkbO-NSLSt9">www.epilepsysociety.org.uk/epilepsy-stigma-worse-than-seizurest-26-06-2014#.XkbO-NSLSt9</a>
<a href="http://www.youngepilepsy.org.uk/about-us/what-we-do/">www.youngepilepsy.org.uk/about-us/what-we-do/</a>
<a href="http://www.purpleday.org">www.purpleday.org</a>
<a href="http://www.meath.org.uk/wp-content/uploads/2019/03/Epilepsy-leaflet-March-2019.pdf">www.meath.org.uk/wp-content/uploads/2019/03/Epilepsy-leaflet-March-2019.pdf</a>