C h a p t e r

3

The Palsy without a Name: Suffering with Paraplegia 1395–1868

"Believe me, there is no cure for this illness; it comes directly from God."

Godfried de la Haye, Dutch court physician, 1396

What Is a Disease Before It Gets a Name?

Since people suffered with a relapsing and progressive neurological disease in the centuries before Charcot gave that disease a name, it is instructive to see how such people were regarded, how they and their physicians regarded the disorder, and what therapies were offered.

Lidwina of Schiedam, Holland, had features of a recurrent and progressive disorder over 37 years. She took joy from her misery, believing that she was sent to accept suffering for the sins of others. Her plight brought attention from the community and from prominent officials, and a cult developed around her even before her death. Not all were impressed by the physical nature of her disorder, but some modern writ-

ers have suggested that she suffered from the illness we now recognize as multiple sclerosis (MS).

Other disease reports, too brief to be convincing exist, but the case of Margaret Davies of the Parish of Myddle is certainly suggestive. She also had a 20-year progressive lameness that a prominent surgeon recognized as a slow progressive disorder that would not respond to the many remedies she sought from the apothecary. She eventually became bedridden, her limbs paralyzed and contracted.

There is no doubt that Augustus d'Esté, grandson of George III, had MS. His condition was documented in poignant detail in his diaries and notebooks over the 26 years of his disease. This documentation helps us understand how the disease of someone with access to the best medical care and the outstanding consultants of his age was managed.

Heinrich Heine, the German poet, also had a chronic progressive disease that probably was MS. Though he had access to all available medical services, he progressed to death in two decades, aware to the end of the loss of physical ability, but still able to compose great poetry. He is another that we will list as having "possible MS."

Mrs. Margaret Gatty, a talented early Victorian children's writer and naturalist, came late to her literary career, just as she was developing the early signs of a recurrent and progressive neurological disease. She also saw many prominent physicians, and, unbeknownst to her, was described in *The Lancet* by her physician as someone who had developed a neurological disorder from overexertion.

It is evident that the biological process of MS has been with us for many centuries. We are not sure if it is increasing, or if its patterns are changing. Examination of the earliest cases that resemble MS can be instructive, revealing how chronic neurological disease was viewed and managed in an era when illness had a systemic rather than a focused pathological concept. Many of the cases suggested in the medical literature as early examples of MS can only be regarded as possible cases because of sketchy details; they are worth mentioning because they are so frequently raised in discussions of the history of the disease.

Lidwina the Virgin

One of the early but uncertain reports, often put forward as the earliest recorded case of MS, relates to the "strange disease of the Virgin Lidwina." Although confounding issues of religious fervor characterize her symptoms, aspects of her case led some to consider that she might have been suffering from MS in the four decades prior to her death in 1433.[1]

Lidwina was born on April 18, 1380 in Schiedam, Holland, the daughter of a laborer, and one of nine children. She was healthy and active as a child and teenager, but in the winter of 1395–96 developed an acute illness from which she gradually recovered. On February 2, 1396, she was feeling better and her friends encouraged her to go skating on a frozen canal. She fell while skating and broke ribs on the right side. Healing was slow and it was thought she had an internal abscess in the area of the fracture. She had difficulty walking and used furniture for support. She was described as having violent lancinating pain in her teeth, which may have been trigeminal neuralgia.

Figure 3.1(a) The virgin Lidwina of Schiedam (1380–1433) fell while skating at age 16. She had an illness over the next 37 years that had many of the features we would now identify as multiple sclerosis, but the diagnosis must remain as "possible MS." She is the patron saint of figure skaters. (Woodcut from "Vita alme virginis Lidwine" by Jan Brugman, 1498. Original book is in the "Koninklijke Bibliotheeks' Gravenhage, The Hague, Netherlands.) (Courtesy of Dr. Robert Medaer.)

Figure 3.1(b) Dr. Godfreid Zonderdank, physician to the Count of Holland, tells the parents of the poor prognosis of Lidwina's condition. She is lying in bed with leeches over her abdomen as a form of therapy. The physician is pouring the urine sample that was viewed to assess the prognosis and this gesture indicates he has concluded the prognosis is grave. He advised against attempting a lot of therapies for such a condition, as it would be of little help and just impoverish the father. It was an illness that comes from the hand of God. (Woodcut from "Vita alme virginis Lidwine" by Jan Brugman, 1498. Original book is in the Koninklijke Mibliotheeks' Gravenhage, the Hague, The Netherlands.) (Courtesy of Dr. Robert Medaer.)

Figure 3.1(c) Instead of medical treatments, the physician advised that the Count of Holland instead provide the parents with two golden guilders to provide her for support and care. (Woodcut from "Vita alme virginis Lidwine" by Jan Brugman, 1498. Original book is in the Koninklijke Mibliotheeks' Gravenhage, the Hague, The Netherlands.) (Courtesy of Dr. Robert Medaer.)

Figure 3.1(d) After the bones of Lidwina were examined in 1957 by A.G. De Wilde, of the University of Leiden, a reconstructed portrait was made from the appearance of her skull by A. Mutsaars. (Courtesy of Dr. Robert Medaer.)

Her parish priest, Father John Pott, visited regularly and suggested she join her suffering with that of the Lord.[2] Some three years later, she realized that she was called to be a victim for the sins of others. Her suffering would be her joy, and she even took steps to increase her discomfort, such as sleeping on planks instead of her feather bed. She said she would reject recovery even if it could be achieved by praying one Hail Mary.

She became blind in one eye, the other became sensitive to light, and she spent much of her time in bed, able to move only her left arm as she suffered with an "unbearable neuritis" in her right shoulder. By the time she was 19, her condition had improved, but she could walk only with difficulty; she developed paralysis in her right arm as well as more sporadic pains. There is mention of a split face and hanging lip, which may refer to facial weakness, but some of the descriptions suggest a deep cut down the bridge of her nose, which could have been due to self-mutilation. Soon she was unable to walk and had to be carried. She also had some loss of sensation and eventually developed sores, which may have been pressure sores (decubitus ulcers).

Her pious suffering gained public attention, and many physicians were consulted, including the prominent Andrew of Delft. Word of her plight reached William VI, Count of Holland and his wife Margaret of

Burgundy, who sent their own physician, Godfreid de la Haye,*[3] who reported that this disease was incurable because it came directly from God. Any attempts to cure her would just impoverish her father, and would do no good; even Hippocrates and Galen would be helpless in this situation. Butler's *Lives of the Saints* (1990) ascribes this statement to Andrew of Delft, and it indicates the sense of hopelessness this disease produced, in an age when prognostication was the most prized talent of physicians, and when the initial classification of conditions separated those that could be cured from those that could not.[4]

Lidwina's illness continued and her pious acceptance of worsening symptoms impressed everyone. Over the years, she had increasing pain and weakness and had difficulty swallowing, first solid food and, later, liquids. The disease progressed slowly with occasional periods of improvement.

Beginning in 1407, she experienced supernatural visits, ecstasies, and visions in which she participated in the Passion of Christ, saw purgatory and heaven, and visited with saints. During these "ecstasies," she had improvement in her sight and was more mobile. Although a cult grew around her when she was alive, not all were so impressed. Fr. Pot was eventually replaced by a new priest, a skeptical newcomer who felt she was a hypocrite. He refused to give her communion and asked the parishioners to pray that she be delivered from her diabolical hallucinations. Only intervention by the local magistrates prevented him from being run out of the parish. An ecclesiastical inquiry declared Lidwina to be of good faith, and she was again permitted communion. Further trials came to her as many members of her family died while she was lingering in her quiet, dimly lit room.

As a mythology was growing around her, townspeople said her putrefying body gave off a fragrant perfume, and the room, always dark, emitted such a glow that some raised the alarm of a fire. In the last years of her life, she was going blind; she was said to take little sustenance except communion, and to sleep little. Both stories are difficult to credit

*He is sometimes called Godfreid Zonderdank, or Sonderdank, but *zonderdank* is a nickname that means, "don't mention it," which he repeatedly said to the many poor who thanked him in the streets for curing them without charge, "as did Sts. Cosmas and Damian."

in their extremes. For example, it was said that she had only communion as sustenance for the last 19 years of her life and did not sleep for the last seven years. Enthusiastic, exaggerated reports and myth building by those who revered her saintliness make interpretation of her condition difficult for the historian. For instance, the official document prepared by the municipality of Schiedam in 1421, 12 years before she died, declared that at that time, she had not had anything to drink for seven years.

Her condition worsened further and she died on April 14, 1433 after 37 years of suffering. A year later, a chapel was built over her grave. Through the efforts of the son of Godfreid "Zonderdank," a hospital was built on the site of her home.[5] A cult developed around her memory and she was eventually beatified by the church. An ecclesiastical commission declared her experiences to be valid, and she was said to be a "prodigy of human suffering and heroic patience."[6,7]

Lidwina's bones were found in 1947 and a 1957 analysis at the Laboratory of Anatomy and Embryology of the University of Leiden indicated changes in keeping with paralysis of the legs, and probably of the right arm.[8]

The first document commenting on Lidwina was an official document dated August 4, 1421 in which Jan van Beieren, Count of Holland, acknowledged a letter from the Schiedam local authorities about her disease and stated that he had seen the young woman.[9] Details of her illness came from her biographer, the Franciscan Priest Johannes Brugman (1400–1473), who acquired information from relatives, her priest and confessor, local clerics, and other "reliable persons." Another biographer, Thomas à Kempis, wrote *Vita Lidewigis Virginis* some 15 years after her death, based on the information published by Brugman. An incunabulum of 1497, *T'Leven van Liedwy die Maghet van Scyedam*, was written by a relative of Lidwina, who lived with her for two years. There is also a biography of her in Hubert Muffel's *Les Saints* (1925).

Dr. Robert Maeder considered her case according to current diagnostic criteria for MS and concluded that the diagnosis is definite. He pointed out that she seemed to have abnormalities in the central nervous system, symptoms and signs characteristic of MS (paralysis of legs and her right arm, facial weakness, blindness of different degrees in both eyes,

sensory change, and later swallowing difficulty); a variable but progressive disease course over 37 years; he noted no other evident way to explain the disorder. The violent lancinating pain in her face was probably trigeminal neuralgia, a condition that almost always means MS in a young adult. Even the onset after her fall on the ice could be explained. If it was an abscess, Maeder argues the infection may have precipitated the attack of MS that paralyzed her legs. Another possibility is that this was a fall due to leg weakness, and the painful chest and subsequent paralysis were due to a transverse myelitis with band-like pain in the chest, interpreted as an internal abscess because of the local pain.

Although it is often said that the plight of Lidwina is the first known case of MS, I am convinced that the evidence suggests elements of marked religiosity, mysticism, histrionic behavior, and even self-mutilation. Although there may have been an underlying neurological disease, the diagnosis must be left open.

Saint Lidwina (variously spelled Lydwyna, Ludwyna, Liedwy, Lidewigis, and Ludwine) was canonized by Pope Leo XIII in 1890. She is listed in *Lives of the Saints*, with "saint day," April 14. *Online Saints* lists her as the patron saint of sickness, and because of her fall while skating, she is also the patron saint of figure skating. The United States Figure Skating Association has a medal featuring a picture of Lidwina.

Halla, the Drummer Bock, and Will Coffin

A less credible case, because of the paucity of information, is the case of Halla in the Icelandic saga of Thorlakr.[10] This information was found by Dr. Margaret Cormack. A woman named Halla developed an acute illness with loss of the sight of both eyes, and on the next day, she lost her speech. She made a vow to God and to the Bishop Thorlakr for intercession; if cured, she would walk to Skalholt, fasting and saying prayers. On the third day, a candle wick was put around her head and she began to experience a return of sight; she had recovery of speech on the feast of St. Michael. The miracle is said to have occurred somewhere between 1293 and 1323, but no other information is available. This is scanty evidence for MS in an era when powerful emotions were associated with religious belief, but I mention it because it appears in the literature of MS.[11]

Another case with incomplete information is that of "the drummer Bock," described in a paper by C.J.T. de Meza in 1810 and discussed by Stenager, who suggested he might have had MS.[12] When describing the beneficial effects of electricity on seven conditions, de Meza outlined the course of illness in a young drummer named Bock. Beginning in 1789, he had "arthritic seizures," and paralysis of the right arm and leg. His subsequent recovery over six weeks is ascribed to electrical therapy. Stenager also refers briefly to a Danish report of a case of a "peculiar, ordinary paralysis" in a person who had accompanying mental changes.

Another possible case of MS comes from the detailed casebooks of Dr. John MacKieson of Prince Edward Island, Canada. (Personal communication, Dr. David Saunders.) In 1837, he documented Will Coffin, a 37-year-old who had persistent dimness of vision associated with some head pain and falling. Coffin had experienced similar visual symptoms three years before, as well as double vision and unsteady gait. When MacKieson saw him, his vision was improving, but he had tinnitus. He had more visual difficulty when he looked to the side, suggesting an ocular paresis or an intranuclear ophthalmoplegia. He was treated with

Figure 3.2 C.J.T. de Meza described the case of "the drummer Bock," a young man who had a transient paralysis of the arm and leg who recovered after a course of electricity. (From: Stenager, Egon. A Note on the Treatment of Drummer Brock: An Early Danish Account of Multiple Sclerosis? *J Hist Neurosci*, 1996; 5(2)198.)

Figure 3.3 Dr. John MacKieson. (Courtesy of Prince Edward Island Public Archives and Records Office, No. 2398-8d and Dr. David Shepard.)

venesection, blisters, purgatives, cold cloths to the head, and warmth to the feet. Two and a half months later, he had recovered from this second episode of neurological symptoms.

Margaret of Myddle

The delightful *Antiquityes and Memoyres of the Parish of Myddle* was written by Richard Gough (1634–1723) between 1700 and 1706, although the date on his hand-drawn cover is 1700, the year he began his project.[13] This is one of the most interesting typographical and geneological books ever written, but it remained unpublished for over a century, and the first printing was from an imperfect copy; an accurate copy did not appear until 1875.

The author, Richard Gough, an elderly man of the parish of Myddle, described the parish and the objects of interest in his village. In a unique approach to local history, he then proceeded to discuss the occupants of each pew in the church. In pew 7, sat the family Davis, of the tenement of Vicar Gittens. Thomas Davis, a weaver, had a wife, Margaret, who had a lameness that progressed over 20 years. Gough says:

> *"When hee removed to Myddle, Thomas Davis, a weaver who now lives att the Wood Lesows by Myddle Wood, came to bee tenant to it. Of him I have spoken before, but somewhat I must say of his wife; Margaret the wife of Thomas Davis dyed on the 17th of this instant,*

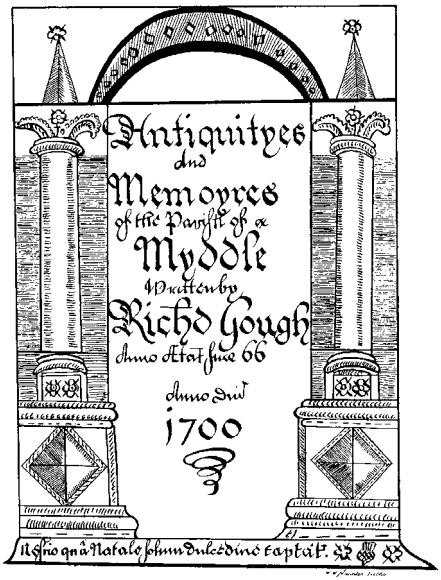


Figure 3.4 Front cover of *Antiquityes and Memoyres of the Parish of Myddle* by Richard Gough. *County of Salop, 1700*. Shrewsbury. Adnitt and Naunton, 1875. He drew the cover when he started to work in 1700, accounting for the date, but it was completed in 1706.

January, 1701. Shee tooke cold in childe-bearing, above twenty yeares before her death; shee was seized therby with paine and lameness in her limbs, and made use of severall remedyes for curing therof, butt all proved ineffectual. At last, as shee was in an Apothecary's shop buying ointments and ingredients for fomentations my uncle, Mr. Richard Baddley, an able chirurgeon, saw her and asked her how shee gott her lamenesse: shee sayd by taking could in child-birth. Then says hee spare this charges and labour, for all the Doctors and Surgeons in England cannot cure it. Thou mayest live long, butt thy strength will still decay. After this shee went to lytle more charges, only when King James II, came his progresse to Shrewsbury, shee was admitted by the King's Doctors to goe to His Majesty for the Touch, which did her noe good. Shee was forced to use crootches almost 20 yeares agoe, and I thinke it is now 10 yeares since shee grew so weake that shee was faine to bee carryed in persons' armes. About two years-and-an-halfe before her death, shee kept her bedde continually; shee was bowed soe togeather, that her knees lay cloase to her brest; ther was nothing but the skin and bones upon her thighs and legges. About a yeare-and-a-halfe past, her thigh bones broake as shee lay in bedde, and one of them burst through

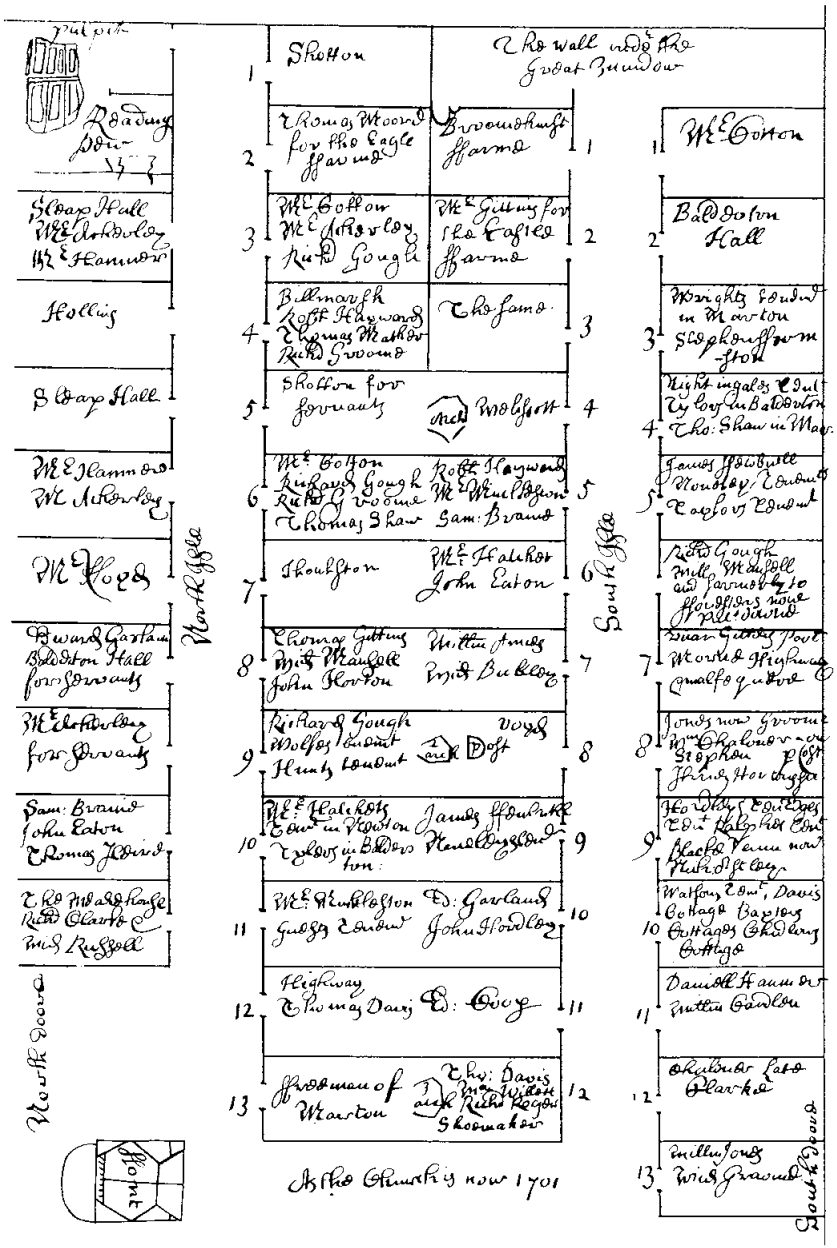


Figure 3.5 The drawing of the pews in the church in Myddle. Thomas Davis and his family sat in pew 7, on the South (right) wall, in the pew for the tenants of Vicar Gittens' tenement. From *Antiquityes and Memoyres of the Parish of Myddle* by Richard Gough. *County of Salop, 1700*. Shrewsbury. Adnitt and Naunton, 1875.

the skin and stood out about an inch, like a dry hollow sticke, but there was noe flesh to bleed or corrupt; shee could stir noe part of her body save her head and one of her hands a lytle. When shee was dead they did not endeavor to draw her body straite, butt made a wide coffin and putt her in as shee was. I heard one say that was present att laying her in her coffin, that as they layd her downe one of her legge bones broke and gave a cracke, like a rotten sticke; and it is not to bee forgotten that the Vicar Gittens, seeing that Thomas Davis had a great charge of children, and his wife lame upon his hands, did give him his house and garden rent free while hee lived in itt:"

"Habet in adversis auxilia in secundis commodat
Non est donum quod pauperi datur sed foenus"

Gough does not relate whether two pigeons came to roost on the house two weeks before death and then left, as locals sometimes noted; which he "had knowe them doe three severall times."

Margaret Davis developed a progressive lameness recognized by her doctor as one that would last a long time and be incurable; this progressed to paralysis of her legs and then her arms, with later contractures and pressure sores, and death after two decades, suggesting the diagnosis of "possible" MS.

William Brown, Hudson's Bay Trader

A plausible case for the diagnosis of MS can be made in the case of William Brown, a 19th-century Hudson's Bay trader. Born in Ayrshire, Scotland in 1790, he was sent by the Hudson's Bay Company to be company trader at York Factory, on the shores of Hudson's Bay. In 1811, at age 21, he began to experience weakness in his legs and some visual problems. He found it increasingly difficult to carry out his duties. When he felt he was too weak to withstand the rigors of a long survey assignment, he sent a replacement in his stead. For this he was censured by Governor Simpson, who felt Brown was neglecting his responsibilities. He had an intermittent and progressive disorder with visual symptoms, weakness, and gait difficulty. His symptoms progressed and he was eventually

relieved of his post and returned to Scotland to be cared for by his family. He died a few years later. In a differential diagnosis for the condition in this young man, MS would lead the list.

Augustus d'Esté

There is no doubt of the cause of the relapsing and remitting neurological symptoms and progressive disease of Augustus d'Esté (1794–1848), the grandson of George III and cousin of Queen Victoria.[14,15] His disorder was documented in his diary between 1822 and 1848 and in an almanac of 1847–1848.

King George III was very unhappy when he learned of the clandestine marriage of his son, Prince Augustus Frederick, Duke of Sussex, to Lady Augusta Murray, which took place in the Hotel Sarmiento in Rome, later repeated in a London ceremony. When word of the marriage came to the king, he had the marriage annulled, a power he possessed since the marriage of a royal heir to the crown required the monarch's consent, and he had not given it. He then ordered the son to leave for the Continent. By this time, however, there was a child of the marriage, young Augustus, who was made illegitimate by the annul-

Figure 3.6 Augustus d'Esté (1794-1848). This portrait by the famous miniature painter Richard Cosway, is signed and dated 1799, when d'Esté would have been five years old. Although it is not certain that this is d'Esté, it has long been said to be him, and the age of the child seems correct. (Courtesy of the Royal College of Physicians, London.)

ment. The young boy was raised in England by his mother, abandoned by his royal father.

While attending Harrow, Augustus contracted measles at age 14, late for childhood measles, an observation that would be of interest a century and a half later. He was vaccinated against smallpox by the method of Lady Mary Wortley Montague a few years before Jenner published his method. He later served with the VIIth Royal Fusiliers. His military career was marked by disinterest, immaturity, and arrogance, says his biographer, but he managed to attain the rank of lieutenant-colonel.*[16] He served in America and was present at the defeat of the British near New Orleans in 1815.

He was later given a knighthood, but that did not appease him in his unsuccessful appeals to four monarchs, a prime minister, and the House of Lords[17] to establish his links with the royal family as the legitimate son

Figure 3.7 Augustus d'Esté with his sister, Emma. The original painting hangs in the Edinburgh Portrait Gallery. (Courtesy of the Royal College of Physicians, London.)

*Firth characterized him as extravagant, argumentative, difficult, careless, and selfish, borrowing from the servants and developing "a relationship" with Mary, the housemaid. As we shall see, he was more mature and sensitive as the years went on and he had to deal with his increasing limitations.

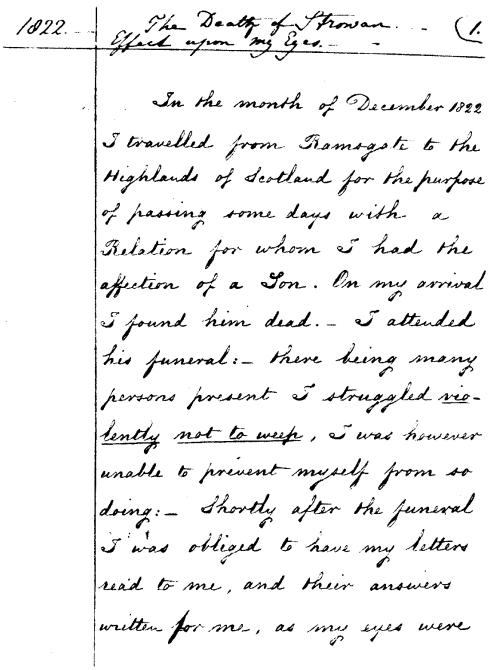
of the Duke of Sussex. Even more frustrating, however, was the progressive and puzzling illness that began when he was 28 years old.

Augustus kept a diary beginning in 1822; on the first page of this diary, he described blurring of vision after leaving the funeral of a beloved relative. He felt the blurring was due to his attempts to suppress tears, but his vision deteriorated to the point that others had to read for him. Fortunately, his vision gradually cleared without treatment. Visual blurring recurred twice over the next few years, and he consulted Dr. Henry Alexander, surgeon oculist to the Queen. After his second episode, a year after the initial blurring, he was sent to a spa at Driburg, where he

Augustus d'Esté's Debility

"At Florence I began to suffer from a confusion of sight: - about the 6th of November the malady increased to the extent of my seeing all objects double. Each eye had its separate visions. - Dr. Kissock supposed bile to be the cause: I was twice blooded from the temple by leeches: - purges were administered; One Vomit and twice I lost blood from the arm: one of the times it was with difficulty that the blood was obtained. - The Malady in my eyes abated, again I saw all objects naturally in their single state. I was able to go out and walk. - Now a new disease began to show itself: every day I found gradually (by slow degrees) my strength leaving me: I could clearly perceive each succeeding day that I went up and down the staircase with great difficulty. When I slapped myself sharply on the loins (though only momentarily the effect) yet for the time it increased my strength. - A torpor or numbness and want of sensation became apparent about the end of the Back-bone and the Perinaeum. At length about the 4th of December my strength of legs quite left me, and twice in one day I fell down upon the floor in attempting to go the closed stool without assistance; I was obliged to remain on the floor until my Servant came in and picked me up. I remained in this extreme state of weakness for about 21 days, during which period I fell down about 5 times (never fainting) from my legs not being strong enough to carry my body. I never once fainted or had any sort of fit: - debility, extreme debility was the only cause of my falling."

Augustus d'Esté, October 17, 1827[18]


1822. The Death of Strowan (1.
Effect upon my Eyes.

In the month of December 1822 I travelled from Ramsgate to the Highlands of Scotland for the purpose of passing some days with a Relation for whom I had the affection of a Son. On my arrival I found him dead. – I attended his funeral: – there being many persons present I struggled violently not to weep, I was however unable to prevent myself from so doing: – Shortly after the funeral I was obliged to have my letters read to me, and their answers written for me, as my eyes were

Figure 3.8 Page 1 of d'Esté diary begins in 1822, in which he describes the first episode of visual loss, so that his letters had to be read to him. He believed the visual loss was due to his efforts to suppress tears at the funeral of a relative. (Courtesy of the Royal College of Physicians, London.)

said he "drank steel-water, bathed in it, and douched my Eyes with it:–my Eyes again recovered."

In 1827, he complained that the heat of the country was intolerable and he developed visual loss and double vision. In the next few years, he developed numbness in his legs and difficulty walking. He consulted a Dr. Kent, who did not agree with the previous therapies and recommended that he "eat beef steaks twice a day, drink London Porter and Sherry and Madeira wines." His legs were to be rubbed twice a day with brushes and his back with a liniment made of camphorated alcohol, opium, and Florence oil. He was pleased to write in his diary: "This new system succeeded completely. Every day I found strength returning." This is the hopeful observation of many patients taking a variety of treatments for MS in a disease that waxes and wanes. He continued to have his legs rubbed with flesh brushes, but discontinued the back rubs, sub-

stituting slaps on the back by the open hand of a servant. He later took up horseback riding, a common therapy in the 17th and 18th century.

A Milan physician treated him for pain in the area of his kidneys with a counterirritant plaster that aimed at producing an eruption of the skin over the area. This was of no help, so he switched to flannel bandages as hot as he could tolerate. He took baths and a wash of sulphate of zinc and aqua plantaginis. He was treated with herbs and flowers and daily shower baths. He took 20–30 drops of valerian twice a day mixed in the herbs.

On the recommendation of his father, he saw a number of prominent physicians including Sir Astley Cooper,*[19] Dr. W.C. Mattin, physician to the Westminster Hospital, Dr. Kent, and Mr. Pettigrew. He followed

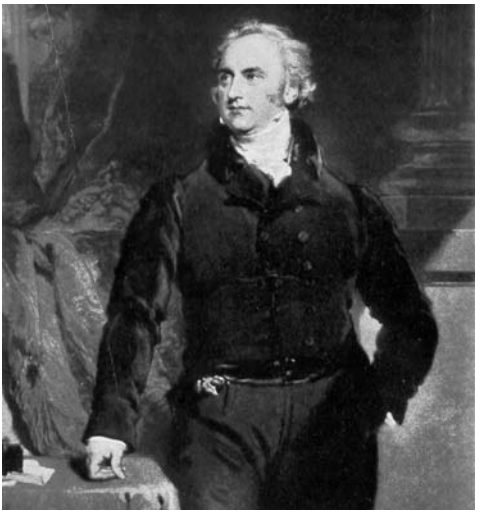


Figure 3.9 Sir Astley Cooper was one of the physicians called in consultation for the paraplegia of Augustus d'Esté. He was a much loved teacher and admired surgeon and consultant. As was the habit in the early 19th century, he was called upon as often for medical consultations as surgical, and tended the King for his gout. Another of d'Esté's physicians, Sir Benjamin Brodie, said Cooper had an income greater than any other physician or surgeon of that day. This portrait is a reproduction of the engraving by cousins after the painting by Sir Thomas Lawrence. The original is in the Council Room at the Royal College of Surgeons. It was subscribed for by his pupils in 1812 when Sir Astley was 46, but was not finished until some years later. (Reproduced with kind permission of the President and Council of the Royal College of Surgeons of England.)

*Sir Astley Cooper was a prominent London surgeon and teacher who had few original ideas but was said to be a better teacher and operator than any other, graceful and careful in everything he did. He himself said he had a flair for diagnosis but was not a good operator where delicacy was needed.

their prescriptions and also took up sea bathing. At the seaside, he developed a liaison with a young woman, but noticed that his "acts of Connection" lacked a "wholesome vigor." He consulted a Dr. Courtenay who passed bougies and a metal catheter into his penis and gave him some medicines and pills that proved beneficial. He later underwent a course of electricity, as well as tepid douches to the loins and sacrum. Following this, he was treated with a course of galvanism with disappointing results. He derived more benefit from a trip to Scotland where he was "much braced and invigorated by the Highland air." He found the horseback riding and walks to be helpful, and he continued the waters, warm baths, douches, and the visits to various spas.

By 1840, 18 years after the onset of his disease, he made a note in his diary that he was no longer using any measures for the improvement of his health or for the restoration of his vigor and strength, presumably because of disappointment with previous treatments. At this point, he read a book on hydropathy and decided to visit the celebrated Vincent Priessnitz,*[20] who thought his infirmity originated in the nerves. D'Esté was treated five times over two days with the application of wet sheets and friction and walked about wearing a wet cincture around his waist.

He next consulted Sir Benjamin Brodie, and John Scott, a surgeon who prescribed tincture of lyttae or Spanish fly, which seemed to have little effect. Prescriptions over the next few years included zinc sulphate, Spanish fly, strychnine, quinine, silver nitrate, and stramonium. Later he developed vertigo, but other than a little brandy with water, he took no medicines. Scott consulted with his colleague John Farre; they agreed the diagnosis was "paraplegia," a condition that can be active or passive, functional or organic, and can be "very imperceptible." They agreed that d'Esté's paraplegia was of the passive phase, which could remain for a long time in the functional form, and the transition to an organic form had not yet been confirmed. Healing would require improvement in the

*Vincent Priessnitz (1799–1851) was said to be the founder of hydrotherapy, although water therapy was an ancient approach to healing. It was said that he "owed his wonderful experience to his ignorance of medical science." Six years younger than d'Esté, he had a hydrotherapy building in Gräfenberg at the time d'Esté consulted him.

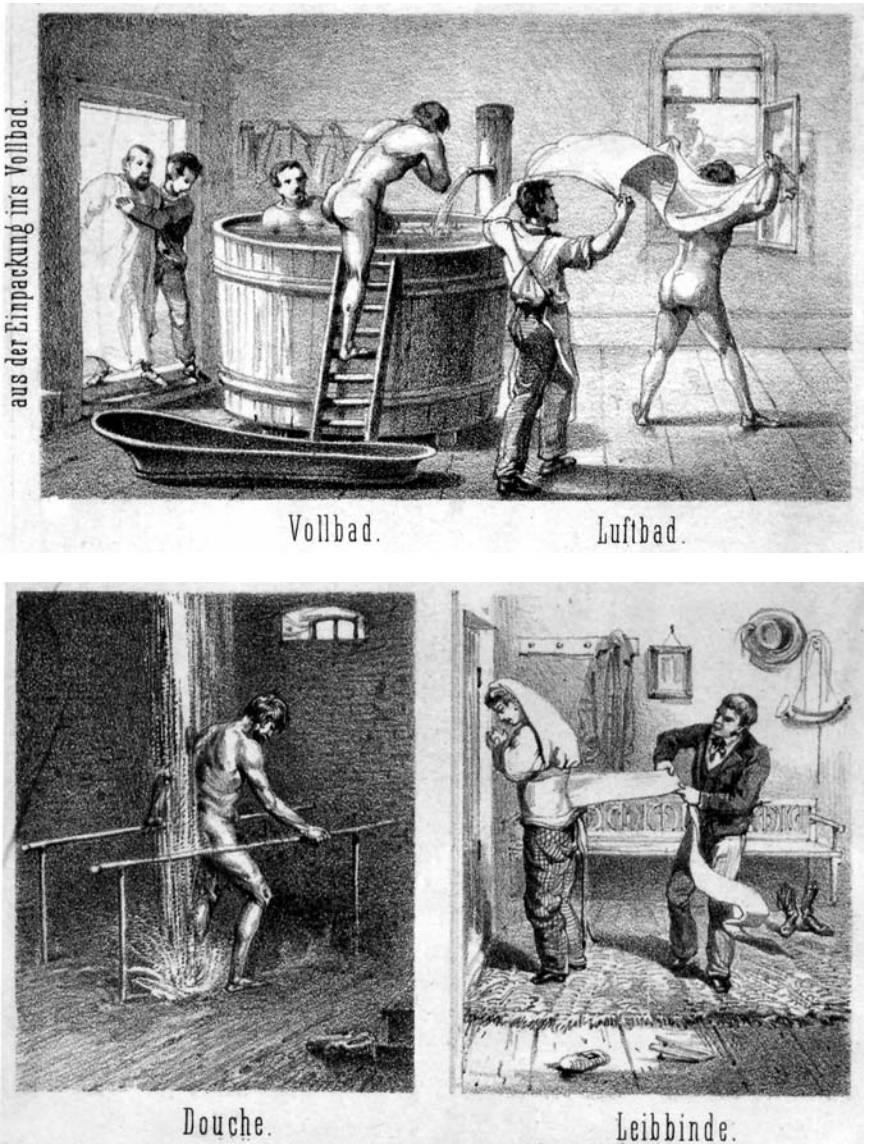


Figure 3.10 The establishment for cold water cures in Gräfenberg, founded by Vincent Priessnitz in 1822. The regime he applied to his patients, including Augustus d'Esté, made no concessions to the gentle or weak. Prints by E. Gaskell. (Courtesy of the Wellcome Library, London.)

Figure 3.11 Sir Benjamin Collins Brodie also saw Augustus d'Esté in consultation and recommended tincture of Lyttae and Spanish fly, which, unfortunately, had little effect. (Courtesy of the Wellcome Library, London.)

circulation, but because the illness is in the patient, it can frustrate the best medical therapy. They suggested he control his diet, keep his emotions calm, and keep his heart quiet. The therapy would be iron, mercury, and a period of rest in Brighton.

John Scott recommended that d'Esté ride a horse every day as long as he could, and walk as long as possible. Mercury was added to the regimen, and there was another course of electricity, which d'Esté felt was making him worse. He was seen in consultation by Sir Richard Bright in February 1844 and agreed with increasing the amount of iron in his medicine. By this time, he was walking poorly, some days buoyed by how well he was doing, other days anxious and alarmed at how weak he could be. His handwriting became shakier and many of the earlier diary sections are by an amanuensis.

He begin to write in a volume of *Simpson's Gentleman's Almanac and Pocket Journal* for 1847, recording on the left his daily visits, making comments on the weather, and evaluating church sermons he heard. On the right were compulsive recordings of his walks around his rooms, timed to the fraction of a minute by a chronometer that he took pains to keep in repair.

Sept 27 - "I rejoice to write that I have walked in my rooms 50 min."

Sept 29 - "Alas! I only walk in my room for 28 3/4 min."

The diaries reveal that d'Esté was a sensitive man, dealing courageously with his failing strength, and delighting in the visits of friends and family. He worried about the health of a friend with dropsy who was kind enough to come to the door to see him, recognizing that he was unable to negotiate the stairs. He was so concerned with the results of the Irish famine that he sent the proceeds of the sale of his phaeton, which he had been advised to sell. He then got around in a bath chair, but found his leg spasms and fatigue were so marked that he was only comfortable in bed. On the last page of his diary, for Monday, December 17, we sense his positive nature, and his euphoric mood:

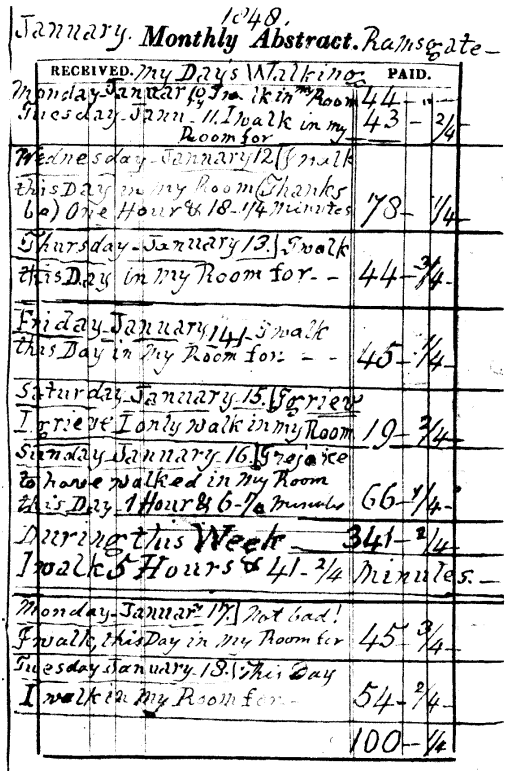
> *"Having received a Present of Indian Moccassins I put them on: - and I walk in them without my Left-Foot, which some time ago always turned outwards at the Ankle joint unless supported by a Steele-Upright, showing any disposition so to do - surely this is a decided Improvement! Thanks to The Almighty!"*

Augustus d'Esté died in 1848 and was buried in the d'Esté mausoleum in Ramsgate, whose design he had spent a great deal of time supervising. On the mausoleum is a tablet outlining the details of his parent's marriage, and the sad consequences of the Royal Marriage Act that would not allow his legitimacy.*[21]

There is adequate detail in the diary to make a conclusive diagnosis of MS. This was a young man who developed a recurrent and remitting neurological disease characterized by repeated visual loss, diplopia, sensory change, intermittent and progressive paralysis in his legs, bladder difficulty, and impotence. There was a remitting progressive course to death in 26 years—a characteristic picture of MS.

The diary of Augustus d'Esté was found during a 1940 wartime drive for paper at the Letherhead School for the Blind, that had been taken over as a sector hospital.[22,23] Douglas Firth published an outline of the life

*The likely reason the marriage was not legitimized was that another royal heir, the Prince Regent, also had a clandestine marriage to a Mrs. Fitzherbert, with two children resulting, but he later married Princess Caroline. If d'Estés parents' marriage was declared legitimate, then so would the clandestine marriage of the heir to the throne, which would give George IV a Catholic wife and a charge of bigamy. And the children of the first marriage would then have more claim to the throne than Queen Victoria.


January. 1948. Monthly Abstract. Ramsgate.

RECEIVED. My Days Walking. PAID.

Monday January 12 I walk in my Room 44 - ¼
Tuesday Jan. 11 I walk in my Room for 43 - 2/4
Wednesday January 12 I walk
this Day in my Room Thanks
be) One Hour & 18 - 1/4 Minutes 78 - ¼
Thursday January 13 I walk
this Day in my Room for - - 44 - 3/4
Friday January 14 I walk
this Day in my Room for - - 45 - ¼
Saturday January 15 I grieve
I only walk in my Room 19 - 3/4
Sunday January 16 I rejoice
to have walked in my Room
this Day 1 Hour & 6 - ¼ Minutes 66 - ¼
During this Week 341 - 2/4
I walk 5 Hours & 41 - 2/4 Minutes.
Monday January 17 Not bad!
I walk this Day in my Room for 45 - 3/4
Tuesday January 18 This Day
I walk in my Room for - - 54 - 2/4
100 - ¼

Figure 3.12 A page from the account book that Augustus d'Esté recorded his activities such as the duration he could walk around his apartment, which varied from 19 ¾ minutes to 78 ¼ minutes. His total for the week was 341 ½ minutes. He had a clock to record his walking in fractions of a minute and took pains to have this clock in good repair. (Courtesy of the Royal College of Physicians, London.)

of d'Esté in 1941 and in a monograph in 1948, using available account books, letters, and manuscripts. The diary is now in the collection of the Royal College of Physicians in London, which also has a file on d'Esté compiled by R.R. Hughes of Liverpool.*[24]

The diaries of Augustus d'Esté illustrate a remarkable saga of medicine and therapy as practiced in the early 19th century, and the moving story of a young man trying to understand and cope with a relentless disease.

*Although Dr. Firth clearly was rescuing the documents from being pulped in the wartime paper drive, when the masters of Letherhead School for the Blind, where the document was found, were made aware of the diary in the Royal College of Physicians of London, they demanded its return, suggesting it was stolen and inferred that legal action would be taken. A diplomatic lunch, offered to the principal of the school by the Harveian Librarian, and a walk around the new facilities of the College, led to the agreement that the diaries were in better hands there. Many of the papers referred to by Firth are now untraceable and were probably borrowed from members of the Murray family. Why the diary was at the Letherhead School for the Blind is unclear.

Heinrich Heine, the Poet in his Mattress Grave

The works of the German lyrical poet Heinrich Heine (1797–1856) inspired music by Schubert, Schumann, Mendelssohn, Liszt, Berlioz, and Gounod. His poems inspired two of Wagner's operas, the *Flying Dutchman* and *Tannhäuser*, the Oscar Wilde libretto for Richard Strauss' *Salome* and Adams' ballet *Giselle*. His poetry is admired in every language, perhaps even more in France than in his native Germany. Even in England, a country he did not much like, he ranks second only to Goethe in the list of great German poets.[25] His reputation was a subject for heated debate in Germany in recent times and "whipsawed" during the discussion of the German–Jewish question. Interest in Heine is increasing, and although he died nearly a century and a half ago, his grave in Paris is covered with birthday floral tributes each year.

Heine was born in Düsseldorf on December 13, 1797, the oldest of four children of Jewish parents who were initially not able to receive permission to marry. Like his mother, he had frequent migraine headaches. Despite the assistance of a rich uncle, his entree into business as Harry

Figure 3.13 Heinrich Heine (1797–1856) as a young man by Horitz Oppenheim, 1831, Deutsher Litteratur in Bilderen. (Courtesy of Heinrich-Heine Institut, Düsseldorf, Landesbildstelle Rheinland.)

Heine and Co. went bankrupt after a year. He then changed careers and studied law. To avoid religious persecution of Jews in Germany at the time, and since he was not a practicing Jew, he accepted baptism in 1925 and took the name Heinrich. He was politically active with a manner that was abrasive and outspoken.[26]

During his 20s, he suffered from severe migraines and recurrent depressions and went to spas for relief. The neurological illness of interest began much later, with a transient "palsy" of two fingers on his left hand in 1832, when he was 35. Dr. Ferdinand Koreff (1783-1851) was consulted. Two years later, Heine had a bout of depression and visual complaints, but recovered.[27] In 1837, his left arm was weaker and he had sudden bilateral loss of vision, beginning in his right eye, which became blind in a few hours, and then in the left, until he could see very little. His condition improved over the next two weeks, but worsened again in three months, before improving again. Six months later, he had an episode of double vision, followed by some worsening of his vision. He then described having giddy turns, which caused objects in his vision to vacillate, and gave them a greyish, partly silver color. The prominent ophthalmologist Dr. J.

Figure 3.14 Heinrich Heine (1797–1856) as a young poet. He began to have episodic and later progressive neurological symptoms when he was 35 years old, dying 24 years later. Etching by Ludwig Emil Grimm, 1827. (Courtesy of Heinrich-Heine Institut, Düsseldorf, Landesbildstelle Rheinland.)

Sichel applied leeches, which improved his vision. E.H. Jellinek speculated that a fundus picture in Sichel's successful *Traité d'Ophthalmie* showing the optic atrophy in a 45-year-old patient may have been of Heine.[28]

In 1841, his vision worsened and then improved, but he became depressed and developed more neurologic symptoms, including right facial weakness, diplopia, pain in the eye, and numbness down the left side of his body. He complained, "Moreover the left eye is feeble and hurts, does not often agree with the right, and this causes a confusion of sight which is much more intolerable than the darkness of full blindness."[29] It was said that, despite his youthful promiscuity, he became impotent soon after marriage that year to Mathilde, an illegitimate 19-year-old girl.*[30,31]

Much of the information about Heine's illness comes from correspondence with his brother Max, a physician. During the course of his illness, Heine was treated by numerous physicians with a number of therapies including spas, purges, sulphur baths, bloodletting, morphine, leeches, iodine mixtures, laxatives, diets, enemas, and cutaneous oint-

Figure 3.15 Heinrich Heine's wife "beloved Mathilde." Her real name was Crescence Eugénie Mirat Heine. She regularly dismissed physicians to her husband if she didn't agree with their recommendations, and when one criticized her care, she gave him a black eye and then dismissed him. Photograph ca. 1845. (Courtesy of Heinrich-Heine Institut, Düsseldorf, Landesbildstelle Rheinland.)

*Mathilde was Heine's name for her, but her name was actually Crescence Eugénie Mirat. Although Critchley gives her name as Grisette Matilde Mirat (Critchley), this is undoubtedly a misnotation from a comment in Aikens biography of Heine (1924) that refers to her as this typical Parisian grisette.

ments applied over an incision that was kept open on the nape of his neck.*[32] Although he complied with their advice, he did not place much faith in the efficacy of his treatments. His wife had even less, and she gave the prominent physician Dr. Leopold Wertheim a black eye and dismissed him for his criticism of her care. In fact, she chased all the physicians away except the Hungarian Dr. David Gruby.†

In 1843, Heine developed ptosis of the left lid, hyperesthesia of the left side of his face, and left facial weakness. In 1844, he had three episodes of deteriorated vision, and was blind for a period of four weeks. In another episode the next year, he became paraparetic and had to stay in bed. He tried spa therapy, but his condition worsened and he then became incontinent. He described the spa bath tubs as a kind of coffin, and his time in the baths as a period of preparation for death.

In 1845, he experienced bilateral ptosis, worsening gait, and further visual deterioration; the next year, he developed numbness around his mouth, loss of taste, and difficulty with swallowing and speech. His gait continued to worsen and he referred to his "paralysis, which like an iron band pressed into the chest," a description of the band-like sensory level of a spinal cord lesion. In 1847, he had right facial paralysis, cramps, and incontinence. On September 20, he wrote to Princess Beliojoso that his feet, legs, and lower torso were paralyzed and that he was unable to walk. He made a moderate recovery, but in 1848, he described his ultimate physical collapse on his last walk, looking at the Venus de Milo in the Louvre. He felt she was looking down on him with wistful sympathy, saying, "Can't you see I have no arms and can't help?"

He felt he was like a fading, drooping flower, not yet completely withered. He was having symptoms of paralysis of his right arm, sensory loss, neuralgical pains, dysarthria, right-sided ptosis, facial weakness,

*In the 18th and 19th centuries, it was a common practice to drain off noxious humors by a continuous drainage. A draining incision could be open by inserting into the wound a seton, a small stone, pig hairs, or an inverted skin flap. Such incisions might be kept draining for years, as was the case with Samuel Johnson, the English lexicographer, whose childhood neck incisions for scrofula are visible on his death mask.

†Gruby arrived in Paris from Vienna, where he received his MD and studied anatomical pathology under Rokitansky. He was a prominent microscopist in Paris, but gave up research for private practice.

A Free Mind in a Rotten Body

"...a sick man is always counting on better days. My mind is free, and clear, and even cheerful. My heart is sound, almost sound enough to be eager for and greedy for life, and my body is so paralyzed, so rotten. It is as though I were buried alive. I see no one and talk to no one." (April 25, 1848)

"I have been here in the country for the last twelve days, wretched and beyond all measure unhappy. My illness has increased to a terrible extent. I have been completely paralyzed for the last eight days, so that I can only lie on the sofa or on my bed. My legs are like cotton and I am carried about like a child. I have the most terrible cramps. My right hand is beginning to wither and God knows whether I shall ever be able to write to you again. Dictation is painful because of my paralyzed jaw. My blindness is still the last of my ills."

Heinrich Heine
Letters to Julius Campe, June 7, 1848

altered taste, and trouble swallowing. In addition, he lost weight, was constipated, and had respiratory complications. Visitors noted his thin muscles, deformed feet, and contractures. Rumors that he had died appeared in the American press. From then on he lived in a hospital, in what he called his "mattress grave" (*Matratzengruft*). He said that he read every medical treatise he could find that related to his condition so that when he reached Heaven, he could lecture upon the futility of physicians who tried to deal with spinal disease. Dr. Gruby again took over his treatment in 1849 and was able to bring him some relief of symptoms. Heine was treated periodically by a "Black woman" who cauterized his spine to relieve his distress and pain. Remarkably, he was still writing. He described his state as:

> *"This living death, this unlife … my lips are paralyzed like my feet, the tools of eating are also paralyzed as well as the channels of excretion. I can neither chew nor shit, and have to be fed like a bird…"*

He had pain and shock-like sensations and was developing pressure sores. He wrote to his mother in July 1851 saying that during hot weath-

Figure 3.16 Heinrich Heine looking down. Drawing by Ernst Benedict-Kietz, 1851. (Courtesy of Heinrich-Heine Institut, Düsseldorf, Landesbildstelle Rheinland.)

er, his eyes were worse. He had often commented that he was better in cold weather.

Visitors, including Alexandre Dumas, *père*, Béranger, Gautier, Gérard de Nerval, Taillendier, and Berlioz, were distressed by the disintegration of the body of this great poet. Noting later that the German politicians were distancing themselves from the politically outspoken Heine, Dumas said that France would be happy to adopt him.

One frequent visitor was Elise Krinitz, who went by the pen name Camille Seldon. Heine called her his "lotus-flower," and sometimes *La Mouche*, because of the fly on her signet ring. She had a history of a period of paralysis and treatment in a London mental institution, and had answered an advertisement for someone to read to him, a task beyond the abilities of Mathilde. Heine was entranced by her elegance, her fluency in German, her voice, and her intelligence. We know little more about the woman who brought him intellectual stimulation and comfort when he was, in his words, feeling like a withering flower in his mattress grave. She inspired some of his best poems; the last was "für die Mouche."

By this time, he was using morphine and opium often and in large doses for his pain and spasms, but tried to keep his head clear.* Although

*One of his poems is called "Morphine."

A Poet's Sense of Loss

"Alas, fame, once sweet as sugared pineapple, and flattery, has for a long time been nauseous to me; it tastes as bitter to me now as wormwood. … The bowl stands filled before me, but I lack a spoon. What does it avail me that at banquets my health is pledged in choicest wines, and drunk from golden goblets, when I, myself, severed from all that makes life pleasant, may only wet my lips with an insipid potion? What does it avail me that enthusiastic youths and maidens crown my marble bust with laurel wreaths, if meanwhile the shrivelled fingers of an aged nurse press a blister of Spanish flies behind the ears of my actual body? Of what avail is it that all the roses of Shiraz so tenderly glow and bloom for me … when in the dreary solitude of my sickroom, I have nothing to smell, unless it is the perfume of warm napkins."

Heinrich Heine, 1855
On hearing his poems had been translated into Japanese

the quality of his writing and poems never faltered, he was often under a "desolate narcosis" and in a "doped wilderness." At one point he said, "I have at this moment so much opiate in my body that I hardly know what I am dictating." He often felt despondent, writing, "Sleep is good, death is better—of course, best of all would be never to have been born." In *Aus der Matratzengruft* (from the mattress grave) he wrote: "For seven years now I have been rolling about on the floor with bitter excruciating infirmities, and cannot die!"

Always conscious of his public, he wished them to appreciate his plight but not pity him, and he refused the offer of a public subscription to raise money for his expenses. He could have used the money, but did not want this to be the way he was remembered. A friend asked if he had made his peace with God. He answered: "Don't bother yourself. God will forgive me—that's what He's there for."[33]

He wrote that he had two rooms: "the one I die in, and the grave." He died in 1856 at age 59 of respiratory complications, 24 years after the onset of his illness. His poetry lives on, and his popularity and importance are increasing. There were four new biographies of Heine in 1997, exploring mostly his political influence. Although his lasting fame is as a

Figure 3.17 Heinrich Heine (1797–1856) during the years of his neurological illness. He was noted to have ptosis and the hand holding his head may also be holding his right eyelid elevated. Pencil portrait of Heine by Marcellin-Gilbert Desboutin, ca. 1853. (Courtesy of Heinrich-Heine Institut, Düsseldorf, Landesbildstelle Rheinland.)

poet, he said he cared little about this, and wished to be buried with a sword and remembered as one who fought for liberty.

Germany has had a hesitant appreciation of Heine, even in his own time, but he was quickly embraced by France and even by England, a country he detested.* Heine indicated in his will that when he died, his body was not to be transported back to Germany, as he did not want to be buried there; his grave is in Montmartre in Paris. Despite his feelings for Germany, the land of his birth, his memory lives on in a university, an institute, and a medical center in Düsseldorf, all named after him.

Stenager[34] suggests that it was unfortunate that Heine did not live long enough to consult Charcot, who gave his great lectures on MS 12 years after Heine's death, but as we will see, Charcot had a negative view of therapy for this disease, so it is unlikely that he would have had much to offer.

Heine's disabling illness baffled historical diagnosticians for 150 years and the arguments have not ended. Putnam[35] and others felt Heine had MS, but still others have suggested he might have had neurosyphilis, amy-

*Heine had visited England but even though he was not lacking in ego, he disliked the English for their egotism and their mechanical church-going piety. He said that God would surely prefer a blaspheming Frenchman to a praying Englishman. Despite this, many of the prominent and admiring biographers of Heine are English.

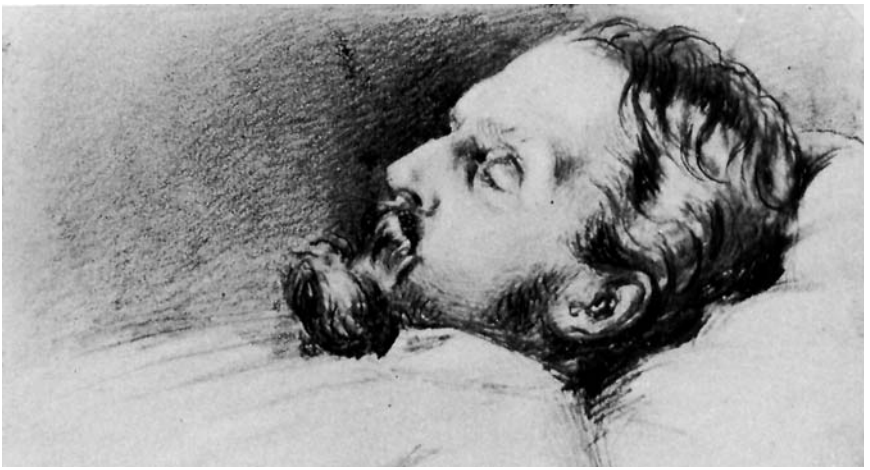


Figure 3.18 Heinrich Heine (1797–1856) on his deathbed. He spent the last years of his life on his "mattress grave." Watercolor and pencil drawing of Heine on his deathbed by Seligmann. (Courtesy of Heinrich-Heine Institut, Düsseldorf, Landesbildstelle Rheinland.)

otrophic lateral sclerosis, sarcoidosis, encephalomyelitis, porphyria, spinal muscular atrophy, chronic polyneuropathy, and spinal tuberculosis.[36] Heine himself thought he had syphilis contracted in his promiscuous youth, and Critchley felt this opinion was about as definite as it could be without serological confirmation.[37] The psychiatrist Nathan Roth reviewed the differential diagnosis, and provided details and psychoanalytical musings about Heine's complex love life, but concluded he had porphyria.[38] Stenager discussed the many differential diagnoses, but leaned toward neurosyphilis, as did many authors in the 19th and early 20th centuries.[39] Certainly Heine's expulsion from school for breaking the rule of chastity, and his frequent use of prostitutes in Paris and London seemed contributing factors to the suspicion of syphilis. Despite all these arguments, the pattern of his recurrent symptoms over 24 years suggested to Schachter,[40] Putnam,[41] Kolle,[42] Stern,[43] Fredrikson,[44] and Jellinek[45] that MS should be strongly considered.

Did Heine have MS? The recurrent nature of the visual loss and the paraplegia, his impotence and incontinence, the recurrent brain stem symptoms, Lhermitte's sign, Uhthoff's phenomenon, heat sensitivity, and the relentless progression due to a constellation of symptoms common to MS occurring over 24 years makes this a plausable diagnosis. One would

only hesitate because ptosis is rare in MS, but not undescribed as it is noted in cases described by Charcot, Althaus, Jellinex, Sparks, Zenker, Grauck, Edwards, Osler, and Hammond. Heine's clarity of mind to the end is unusual, but again, not out of the question in someone with symptoms primarily related to the spinal cord, brain stem, and optic nerve. His life and letters have been sifted repeatedly in support of one diagnosis or another, and it is unlikely that other helpful medical details will come to light. Given the evidence, I would conclude that the diagnosis is "probable MS."

Lighthouse Stevenson

One of a remarkable group of Scottish Stevensons, lighthouse keepers for generations in many of the great lighthouses of Scotland and the Hebrides, was Alan Stevenson (1807–1865), an uncle of Robert Louis Stevenson. He was a poet, friend of Wordsworth and Coleridge, fluent in six languages, classical scholar, pioneer in optical technology, and the "architect of one of

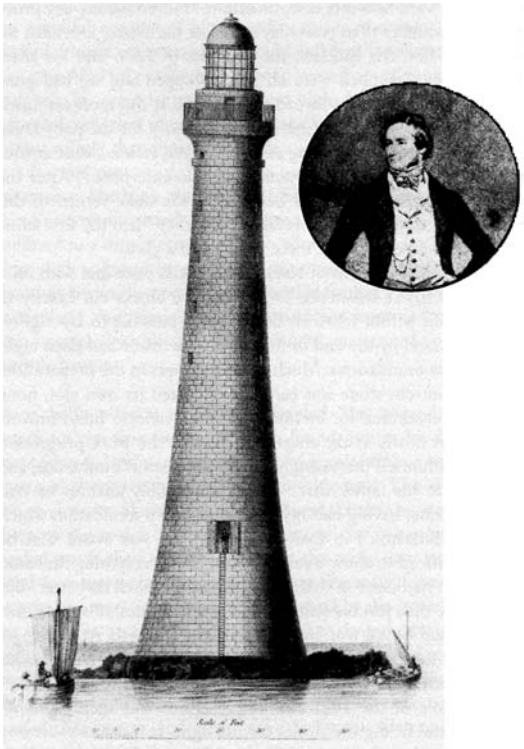


Figure 3.19 Alan Stevenson (inset) in the only known portrait, with the great Skerryvore Light, completed in 1844, said at the time to be one of the great engineering feats of the age. Stevenson was a member of the many generations of "Lighthouse Stevensons," who designed and operated many of the lighthouses of Scotland and England. He began in mid career to develop symptoms of weakness and fatigue and had many episodes of a relapsing and progressive neurological disease that caused his early retirement. He was an uncle of author, Robert Louis Stevenson.

the most exceptional structures ever built."[46] He supervised 35 lighthouses, but began to complain of marked fatigue. Early in his career, he had periods of illness that confined him to bed. Travels to France and examination of Leonor Fresnel's research on lenses suggested to him concepts that eventually changed the lighting methods in Scotland's lighthouses. Alan Stevenson went on to design some of Scotland's most remarkable lighthouses, including Ardnamurchan and Skerryvore.

"I am still grievously afflicted by Drowsiness," he complained in 1844 at age 37. Soon after, he wrote that his suffering was extreme, and described his symptoms as rheumatism. He recovered, but a month later complained that he was again tired and ill. His letters described his symptoms variously as rheumatism, paraplegia, and lumbago. His biographer, Bella Bathurst, felt he was suffering from MS. Lack of improvement forced his return to Edinburgh to seek treatment from his brother-in-law, Dr. Adam Warden. He began to reduce his workload and to frequent various spas. A poet in his free moments, he began to translate the "Ten Hymns of Synesius" from the original Greek, and wrote in the introduction, "it pleased God in 1852 to disable me, by a severe nervous affliction," and said translating the hymns "helped to soothe my pains." As his disease worsened, he was able to do less and less for the many lighthouses he supervised. He had to retire in 1853, and submitted letters from his doctors that indicated he suffered from an unusually severe form of paraplegia. As he continued to worsen, he felt his disease was due to his past sins. Bathurst said, "Alan was aching away the remainder of his life in expensive spa towns, paralyzed by poverty and self-doubt as much as by his own enforced inactivity." He died 21 years after the onset of his relapsing and progressive illness.

Margaret Gatty, Victorian Writer

> *"Then you see I wage daily warfare with myself when I feel sad at my disablement from even the simplest action."*
>
> Margaret Gatty, January 9, 1870

Margaret Gatty (1809–1873), a naturalist and author of popular children's books, probably had MS. Although she lived past the time of Charcot's

Figure 3.20 Mrs. Margaret Gatty, Victorian novelist. Her successful career as a children's writer and naturalist began at age 41, the year her neurological symptoms first appeared.

lectures, and was published in the medical literature, the end of her life came just at the time of the first English publications on MS as an identifiable entity in *The Lancet*.

Mrs. Gatty was the founder of the popular publication for children, *Aunt Judy's Magazine* and author of a successful five-volume *Parables from Nature*, and also wrote a respected guide to *British Sea-Weeds* (1863).[47] Her writings have survived less well than those of her better-known daughter, Juliana Horatia Ewing (1841–1885).*[48]

Her interest in natural sciences began when she fell ill in Hastings in 1848 and her sympathetic doctor loaned her books that excited her interest in seaweeds. The nature of that illness is unclear, but her daughter reported that in 1849, both her writing career and her first neurological symptoms began. Margaret Gatty's writing career began, at age 41, at the same time she experienced symptoms that she called a nervous disorder affecting her general system. Continuing complaints caused her to consult a physician in London in 1860, but he declared her "organically sound," as she apparently had no obvious outward manifestations of dis-

*Her daughter's middle name alludes to the fact that Mrs. Gatty's father was chaplain to Admiral Nelson.

ease. She was clearly uncertain about this conclusion, writing in her diary: "but still one must believe the Drs. know something."

In the next breath, she wondered about the possible benefits of trying homeopathic therapies. Nine months later, she wrote that her hand was tremulous and "losing its cunning." Her illness was at first intermittent, causing her to remain in bed for days due to attacks of "muscular or nervous rheumatism." She repeatedly visited Dr. Thomas King Chambers and was relieved to have him call the cause of her problem, "atrophic degeneration of the muscular fibers from overuse so my troubles have at any rate got a fine name!"

She began to write with her left hand and complained of pain in the paralyzed arm and shoulder. The fourth volume of her *Parables from Nature* was written with her left hand. Doctors said her condition would ultimately recover, even though she had the symptoms for many years. Despite this reassurance, she continued to deteriorate and was referred to a London surgeon, who recommended a leather sling and a splint for her arm. Her left arm weakened though, and in the habit of many MS patients, she assumed this was the result of overuse because of the weakness of her right hand.

Mrs. Gatty seemed unaware that Dr. Chambers had described her condition in a presentation to medical colleagues and later in a publication in *The Lancet* as muscular atrophy due to excessive physical effort.[49]

Chambers concluded that the weakness in her arms was due to overwork, which did not allow renewal of the nerve forces needed by muscles, so that no new store of muscular substance could be laid in and the muscle would degenerate into elastic fiber and finally into pale fatty tissue of low vitality.[50,51] Chambers' use of the term *atrophy* described muscles that were weak and paralyzed, though there was no loss of muscle bulk or obvious thinning.

In the *Renewal of Life*, Chambers outlined his therapeutic approach, "restorative medicine."[52] He expressed little interest in neurological disorders except sciatica and hysteria, but believed in the use of iodides for any diseases of the nervous system, including hysteria, feeling the iodides would renew the nerve sheaths to health. In his Harveian lecture of 1871, he said that all diseases add to the body substances that need to be reduced, opposed, assisted, neutralized, or concentrated.[53]

Lecture XXIX on Muscular Atrophy

"M., age 54, has lived an active literary life, writing much and well. Her vigor of constitution is shown by the menses only lately beginning to grow scanty and irregular. But she has a theory of corporeal discipline not reconcilable with rational physiology. She has thought to compensate for the exhaustion of mental labor by violent physical exertion, and has been in the habit of occupying her leisure by furiously digging her garden with a masculine spade, and mowing her lawns, not with one of the new elegant machines, but an old fashioned scythe. The consequence is that her good right hand has lost its cunning, and a letter she sent to seek my advice was scrawled with the left. The principal atrophy is in the deltoid and triceps muscles (those used in mowing), which are painful when moved, but not when pressed. She cannot raise her arm by independent efforts above the level of her waist, and it 'feels out of joint if she tries to force it.' Friction, brandy and salt, mustard, etc. have only made her worse. Her arm is now by my advice tied up, and she is taking quinine and steel and cod-liver oil in small doses."

Thomas King Chambers
The Lancet, 1864

In 1863, Mrs. Gatty developed a pain in her face she thought was due to dental problems and wished to have her teeth removed. Chambers suggested this course would make her worse rather than better. She persisted and wanted to know if there was not someone who could remove them to relieve the pain using chloroform.*

> *"In short this affair has made me so like a village old woman that I feel quite one of them when I visit and listen to all their aches & pains & histories of tumbles & sprains & rheumatism with a fellow feeling imagination only never allows one."*
>
> Margaret Gatty, November 21, 1863

*The pain in her face was probably trigeminal neuralgia, often thought to be dental when it appears in MS patients. Trigeminal neuralgia in a person under age 55 is almost always due to MS.

Dr. Chambers recommended a spa and rest for her weakness, suggesting she go to Bath in the winter. Unable to write and having trouble walking due to weakness and curling of the foot muscles in her right leg, Mrs. Gatty was still reassured by doctors that she might recover. In fact, only her left arm recovered somewhat and the surgeon Mr. Hawthorn felt her condition temporary and due to her "time of life." Mrs. Gatty spent much of her time on a couch, able to walk a little but venturing outside of the house only in an invalid chair.

In 1868, the year of Charcot's lectures on MS, she consulted Dr. Radcliffe, "a paralytic and nervous Dr. who told me there was no doubt whatever about my case: that it was spinal: a want of blood in the spinal cord. And he ridiculed the idea that it was degeneration of the muscles!" Drs. Chambers and Paget ridiculed Dr. Radcliffe, and still spoke hopefully of recovery.

Later, Mrs. Gatty's speech became affected, and she fell more often. Hawthorn noted that cold weather caused her leg muscles to tighten. She had an attack of "liver illness" and her condition deteriorated further. Repeated spasms and jerking of her legs caused great discomfort and her feet began to curl into permanent deformity.

Mrs. Gatty's illness had a variable course, which moved from one arm to the other and then affected her legs. She had a recurrence of a painful "tic" in her face and speech difficulty. After many attacks, "which perfectly disabled me without making me ill," she became progressively worse and confessed she was willing to try anything, even quackery and mesmerism.

Hawthorn now informed her that Dr. Chambers had mentioned her case in his lectures some six years earlier.[54] She was pleased, noting in a letter that "Dr. C. seems to consider it quite a peculiar case," and was buoyed by his confidence in her diagnosis.

In August 1870 she wrote, "You must prepare to see me unable to hold up my head—I tie it up sometimes." Her legs were weaker, although she felt her left arm somewhat improved. A few months later, she noted she was failing despite massage of her spine night and morning.

By January 1871, she noted regretfully that "there was nothing definite except the undeniable fact that I am getting lamer gradually." Her

arms felt a little stronger but her hands were weaker, preventing all writing. She saw a notice about the benefits of oxygenating the blood and wrote to Mr. Hawthorn who prescribed a medicine he felt would have the same effect. Her leg and foot spasms got worse. She noticed slowing of movements, such as combing her hair, patting the dog, and brushing her nails, but maintained a positive attitude. She said there was a woman at St. Leonards who was worse afflicted, and could not even swallow. She, on the other hand, could go out in a bath chair: "I am a complete cripple and feel very weak, but not in bad spirits."

Mrs. Gatty had attendants who turned her repeatedly during the night, which distressed her, but she added that although she was sad to have these services, she could afford them, and if she were a poor person, she certainly would be in dire straits. She continued to weaken though "Enry" (Mr. Hawthorn) kept insisting she was better and felt she would improve after her deterioration during a bout of pneumonia. After a further year of complete disability, she developed a respiratory infection and died on October 4, 1873.

Mrs. Gatty originated the idea of financially supporting cots for sick children at the Great Ormond Street Hospital, and over the years, her readers contributed to many cots in that and other hospitals. There was an outpouring of support from her readers in all parts of the world to funnel more beds in her memory. This idea of endowing beds in hospitals was taken up by many institutions, and these cots are a lasting memorial to a magnificent Victorian.

Summary of the Early Cases

In every era, patients have suffered with conditions not fully understood or effectively treated. Within the concepts and views of their day, physicians proceeded as best they could, and were as confident as we are today dealing with an incompletely understood condition. Multiple sclerosis still has many mysteries, and time will show how similarly we are struggling, as they were, to understand and help our patients.

Therapies did not change much over centuries, even after the disease was framed and named. We will see that the therapies of the 19th centu-

ry were continued into the 20th century. Although most doctors did not feel the therapies altered the course of the disease, they provided some relief or hope to patients. There was always a desire to offer something to those who suffer.

It is interesting how the illness of many of these early cases lasted 20–40 years, while many later medical writers felt the illness lasts about 8–12 years. This probably indicates that the most serious, advanced, and progressive cases were the experience of the consultants in clinics and hospitals. Those doing well, or with mild disease mostly cared for themselves. Margaret Davies was hardly a mild case, but her condition still lasted two decades, despite disability and pressure sores.

The cases just outlined are examples of disorders of the nervous system that resemble only MS. That only a few are known over a number of centuries should not suggest the disease was rare, or any less common than today. Patients with the disease were regarded differently in different eras and with different nosologies. The concept of disease, particularly of the nervous system, caused patients with many forms of neurological disease to be viewed as having nervous disorders, brain disease, palsy, paralysis, infirmities, or creeping paralysis.

That we can recognize cases before doctors became interested in the disabling disease characterized by scattered lesions throughout the central nervous system just emphasizes that the disease was there. Was it less common in the 15th or 17th century? We cannot tell; MS patients would have been mixed in with those suffering from other disorders. It is hard to find definitive data that the number of cases of MS have increased much in the century and a half since it was recognized. Even correcting for our refined clinical classification, recognition of milder and benign cases, and newer diagnostic tools such as spinal fluid examination, evoked potential tests, and MRI, the apparent stability of the disease suggests it has probably been part of the social fabric for a very long time. As Compston said, it has been more an epidemic of recognition, rather than a epidemic of increasing cases.[55]

References

1. Maeder R. Does the history of multiple sclerosis go back as far as the 14th century? *Acta Neurol Scandinav*. 1979;60:189-192.
2. *Butler's Lives of the Saints*. Thurston HJ, Attwatter D, eds. Vol II. Westminister: Christian Classics; 1990:95-98.
3. Ibid, p. 95.
4. Ibid, p. 97.
5. Ibid, p. 98.
6. Delaney JJ. *Dictionary of Saints*. New York: Doubleday and Company Ltd.; 1980.
7. *The Book of Saints*. London: Adams and Charles Black; 1966.
8. Maeder R. Does the history of multiple sclerosis go back as far as the 14th century? *Acta Neurol Scandinav*. 1979;60:189-192.
9. Ibid, p. 189–192.
10. Poser CM. The Dissemination of Multiple Sclerosis: A Viking Saga? A Historical Essay. *Ann Neurol*.1994;36:S231-243.
11. Anonymous. Thorlaks saga. In: *Byskua Sogur*, Editiones Armagnaenae series A, vol 13.2. Copenhagen: John Helgason; 1978.
12. Stenager E. A Note on the Treatment of Drummer Brock: An Early Danish Account of Multiple Sclerosis? *J Hist Neurosci*. 5(2):197-199.
13. Gough R. *Antiquities and Memories of the Parish of Myddle, County of Salop, 1700*. Shrewsbury: Adnitt and Naunton; 1875 (Also Centaur Press, 1968).
14. Firth D. The case of Augustus d'Esté (1794-1848): the first account of disseminated sclerosis. *Proc Royal Soc Med*. 1940–1941;34:499-552.
15. Firth D. *The Case of Augustus d'Esté*. Cambridge: Cambridge University Press; 1948.
16. Ibid, p. 17.
17. d'Esté A. Application to the House of Lords. *The Jurist*, 1844. Vol V(i) II, 793.
18. Firth D. *The Case of Augustus d'Esté*, p. 26-27.
19. Hale-White W. *Great Doctors of the 19th Century*. London: Edward Arnold, 1935.
20. Metcalfe R. *Life of Vincent Priessnitz: Founder of Hydrotherapy*. London: Metcalfe London Hydro Ltd., 1898.
21. Hughes RR. File on Augustus d'Esté. MS 107; 17/1/68, London: Royal College of Physicians.
22. Firth D. The Case of Augustus d'Este (1794-1848): the first account of disseminated sclerosis. *Proc Royal Soc Med*. 1940-41;34:499-52.
23. Firth D. *The Case of Augustus d'Esté*. Cambridge: Cambridge University Press; 1948.
24. Hughes RR. File on Augustus d'Esté. MS 107; 17/1/68, London: Royal College of Physicians.
25. Sammons JL. *Heinrich Heine. A Modern Biography*. Manchester: Carcanet Press; 1979.
26. Reed TJ. Happy Return? Heinrich Heine: the last German poet of the eighteenth and the first of the twentieth century. *Times Literary Supplement*. October 10, 1997;3-4.
27. Stenager E. The Course of Heinrich Heine's Illness: Diagnostic Considerations. *J Med Bio*. 1996;4(1):28-32.
28. Jellinek EH. Heine's illness: the case for multiple sclerosis. *J Roy Soc of Med*. 1990;83:516-519.
29. Ibid, p. 518.
30. Paty DW, Ebers GC, eds. Critchley M. Four illustrious neuroluetics. *Proc R Soc Med*. 1969;62:669-673.
31. Atkens HG. *Heine*. New York: EP Hutton; 1929.
32. Murray TJ. The Medical History of Doctor Samuel Johnson. *The Nova Scotia Medical Bulletin*. 1982; June/August:71-78.
33. Critchley M. Four illustrious neuroluetics. *Proc R Soc Med.* 1969;62:669-673.

34. Stenager E. The course of Heinrich Heine's illness: diagnostic considerations. *J Med Bio.* 1996;4(1):28-32.
35. Putnam TJ. The centenary of multiple sclerosis. *Arch Neurol Psych*. 1938;40(4):806-813.
36. Stenager E. The course of Heinrich Heine's illness, p. 28-32.
37. Critchley M. Four illustrious neuroluetics. *Proc R Soc Med.* 1969;62:669-673.
38. Roth N. The porphyria of Heine. *Prog Psychiat*. 1969;10:90-106.
39. Stenager E. The course of Heinrich Heine's illness, p. 28-32.
40. Schachter M. Un illustre malade: Le poète Henri Heine, *Paris Med*. 1933;(suppl 1):vi-viii.
41. Putnam TJ. The centenary of multiple sclerosis. *Arch Neurol Psych*. 1938;40(4):806-813.
42. Kolle K. Die Krankheit von Heinrich Heine. *Der Hautartz*. 1964;15:162-164.
43. Stern A. Heinrich Heines Krankheit und seine Ärzte. In HeineJahrbuch. Düsseldorf: Heinrich Heine Institute; 1964:63-79.
44. Fredrikson S. Letter to the editor in response to Stenager and Jensen. *Perspect Biol Med.* 1991;32:312.
45. Jellinek EH. Heine's illness: the case for multiple sclerosis. *J Roy Soc Med*. 1990;83:516-519.
46. Bathurst B. *The Lighthouse Stevensons*. New York: Perennial (Harper Collins); 1999.
47. Maxwell C. *Mrs. Gatty and Mrs. Ewing*. London: Constable; 1949.
48. Drain S. Margaret Gatty (1809-1873). In: *Victorian Britain: An Encyclopedia*. Mitchell S, ed. New York: Garland; 1988.
49. Chambers TK. Lecture on muscular atrophy. *Lancet*. 1864;96.
50. Chambers TK. *Lectures: Chiefly Clinical*. London: John Churchill and Sons, 1864.
51. Review of TK Chambers' lectures: chiefly clinical. *Lancet*. 1875;1:545.
52. Chambers TK. *The Renewal of Life: Clinical Lectures Illustrative of a Restorative System of Medicine*, *Given at St. Mary's Hospital.* London: Churchill; 1863.
53. Chambers TK. *Restorative Medicine: the Harveian Oration 1871*, with two sequels. Philadelphia: Henry C. Lea; 1871.
54. Chambers TK. Lecture on muscular atrophy. *Lancet*. 1864;96.
55. Compston A. The story of multiple sclerosis. *McAlpine's Multiple Sclerosis*. London: Churchill Livingstone; 1998:3-42.