

Encephalitis lethargica was an enigma throughout its one and only epidemic. All those who have concerned themselves with this disease have been impressed, above all, by its *strangeness* — no fiction author would have had the temerity to invent a disorder of such incredible clinical diversity and puzzling behavior — and then the mystery was deepened, and its solution perhaps rendered inaccessible, by its unexpected disappearance. The influenza pandemic of 1918/19 killed many more people, and polio made an especially terrifying impression as a crippling disorder of childhood, but EL retains a special place in the history of brain disease because of its peculiar acute face, the fascinating horror of its intermediate and chronic stages, and the uncertainty of both its origins and its withdrawal.

Its brief and mysterious history has seduced some recent commentators to speak of an “invented disease”, and to suggest that there was no disease ‘encephalitis lethargica’, but rather a mass of difficult cases of disparate nature and origin that were subsumed under this title as a matter of convenience, or of error. This hypothesis inevitably founders, however, upon the calibre of the investigators from the various branches of medicine and public health who concerned themselves with the disorder; while not everything that someone, somewhere called ‘encephalitis lethargica’ can be assumed to have been relevant to the disease discussed in this book, the evidence that encephalitis lethargica existed as a disorder *sui generis* is overwhelming. Any notion that it was little more than a figment of the fevered imagination of the faraway interbellum years, in any case, was clearly dispelled by the living testimony of those who suffered its neuropsychiatric grasp until the ends of their lives, still capable of attracting horrified fascination half a century after the end of the epidemic. With memory of the original disease now largely confined to paper, however, alternative interpretations of ‘encephalitis lethargica’ have since arisen, not all compatible with historical EL.

Encephalitis lethargica on film

Contemporary images of EL, eerie as they might be in their unaccustomed silence and lack of definition, not to mention the relative liberties taken by filmmaker physicians with their patients, are important documents of both the strangeness and the reality of the disease. The peculiarities of EL ensured that it was the object of several medical films during the 1920s, a period in which the relatively new medium was regarded with great interest by neurologists and psychiatrists as a means of recording symptoms for both educational and analytic purposes. Of 56 German journal publications

on neurological films from this period, no less than sixteen were concerned with EL or parkinsonism, while a further eighteen portrayed other extrapyramidal movements.¹

Among the most prolific producers of EL-related medical films were the prominent Frankfurt am Main neuropsychiatrist Karl Kleist (1879–1960) and his *Assistent* Ernst Herz (1900–1966). These films were also exported — there is a version of at least one Kleist film in which the German text boards have been replaced by English translations (these films were all silent) — but most have unfortunately since been lost. Synopses of several of their EL films were published in a short-lived specialist journal, the semi-annual *Programme der medizinischen Filmwoche* (the third and final volume [1926/27] appeared under the title *Medizin und Film*), published in Berlin by the *Unterrichts-Film-Gesellschaft* ('Educational Film Society'):

- 'Rigidity (parkinsonism) in encephalitis epidemica';
- 'Encephalitis epidemica II': postural and gait abnormalities, oculogyric crises and blinking crises, antagonist muscular tremor in chronic EL; as well as myoclonus and tics in acute EL;
- 'Encephalitis epidemica III': rigidity combined with psychologic negativism.²

The same authors also published several films on PD and various aspects of catatonia, and Herz also published a volume on his video analysis of involuntary extrapyramidal movements that included several stills from their EL films;³ Kleist prepared at least one further EL film during the late 1930s.⁴ Herz departed Germany during the 1930s, but continued to make neurologic films at Columbia University in New York, and in 1946 published (together with Tracy Putnam) an illustrated overview of this work, *Motor disorders in nervous diseases*. A particularly interesting film of acute EL, in which the hysteria-like aspect of the presentation was noted, was also reported by Friedrich Lewy in *Medizin und Film*, while Gustav Machol (Charité, Berlin) presented a 20-year-old man who had suffered oculogyric crises for the past five years, having contracted EL as a 12-year-old. Kurt Albrecht, from the same clinic, depicted both the loss of balance experienced by an EL patient when their eyes were closed, as well as curious rhythmic shifting between feet when standing, but not when sitting or lying down.⁵

Several other German clinics also prepared films of EL patients; a series concerned with this disease, for example, was produced by Kraepelin in Munich, whereby the time and expense required had motivated a co-operation agreement with the *Neue Kinematographische Gesellschaft*.⁶ Alexander Westphal (Bonn) was particularly interested in the possibilities of cinematographic analysis of movement disorders, and his film of nine chronic EL patients is still extant.⁷ Oculogyric crises were filmed by several authors, including Stern,⁸ while Johannes Kirchof produced several short films at the Charité in 1939.⁹ Interesting film records were also produced in France, including clips of EL at the Vauluse colony, and another concerning subcortical crises.¹⁰

In the USA, Simon Philip Goodhart and Frederick Tilney (Columbia University) similarly recognized the value of film for the analysis of movement disorders, and presented two film reels of 1,000 feet each (c. 16 minutes silent) to a meeting of the American Neurological Association in 1922. The first depicted movement disorders in recognized neurologic syndromes, the second those of EL. The latter included one case that resembled Sydenham chorea, and another that encompassed a combination of symptoms unknown in other any disease: athetotic limb motions together with tic-like movements of the left sterno-cleido-mastoid and rhythmic oscillations of head and trunk. In another case, the tics and other early involuntary movements had been abruptly displaced a year later by marked parkinsonism that gave the impression the patient had aged by ten years. Other features depicted in the film included unusual chewing movements, dystonia, disturbed posture and gait, cranial nerve symptoms, abdominal myoclonus, and, most interestingly a "*peculiar oculo-encephalogyric movement*", probably the first American reference to oculogyric crises and the earliest film

recording of this phenomenon.¹¹ Goodhart and Benjamin Harris Balser included 19 minutes of footage of various aspects of acute and chronic EL (22 cases) in the 1944 *Neurological cinematographic atlas* (including the self-mutilation cases discussed on p. 426 of this volume), providing an invaluable record of the disease.¹²

Other such films have, unfortunately, been lost, although it is likely that many are awaiting rediscovery in archives or other storage facilities. In 1998, for example, Virgilio Evidente and colleagues (Mayo Clinic, Rochester) published a collection of clips made between 1920 and 1930,¹³ while films prepared by Kinnier Wilson during the 1920s at Queen Square in London have come to light more recently, including segments involving three chronic EL patients;¹⁴ a film produced by Rosenow has also been published.¹⁵ Joel Vilensky and colleagues published a valuable compilation of film clips from various (mostly American) sources, including the Goodhart–Tilney films in 2006.¹⁶ Unpublished photographs of EL patients also occasionally re-surface.¹⁷

Encephalitis lethargica in non-medical literature and film

EL was a regular subject for reports in the newspapers and magazines of the 1920s. Unsurprisingly, most attention was initially directed to the threat to life posed by the disorder, with the quality of the coverage depending upon the newspaper style; as one physician commented in the *British Journal of Nursing*, it is “*the custom in a certain section of the lay press to announce under more or less sensational headlines the advent of a new disease ... this honour is conceded, for the most part, only to those conditions from which something in the nature of a scare can be elicited.*”¹⁸ As it became clear, however, that the EL epidemic was not to assume the scale of influenza, interest switched to accounts of prodigious or abrupt sleep (particularly in the United States), and of discussions of the social consequences of post-EL delinquency. EL was known well enough by the average citizen to be feared when it struck close to home, but it did not occur frequently enough to be a source of major consternation or personal concern. This sentiment was particularly widespread until the mid-1920s, before the realization dawned that ‘recovery’ from acute EL almost invariably disintegrated into lifelong incapacity at some unforeseeable point in the future.

Newspapers were also naturally attracted to the more unusual EL cases (or at least putative cases of EL), such as the 8-year-old Illinois girl who talked non-stop for 212 hours before slumping into sleep,¹⁹ or the bride who awoke when her friends arrived for her wedding.²⁰ In another of these typically American cases, a violinist had been engaged to rouse a 29-year-old New York woman:

While Hoffmann slowly drew his bow, Mrs. Mintz awakened. She recognized Schubert’s “Serenade” and a Russian song and nodded her head ... Dr. E. G. Giddings, Superintendent of the hospital, explained the theory that musical sound waves of varying length stimulated certain nerve centres that were lying inactive.²¹

Prominent people suffering EL were also worthy of attention, such as Jane Morgan, the wife of American banker John Pierpont Morgan Jr who, two years after his wife’s death, donated \$200,000 (today: c. \$2.75 million) to fund a 48-bed department for the investigation of EL at the new Neurological Institute,²² and British entomologist and banker Charles Rothschild, who committed suicide in 1923 to escape the chronic effects of the disease he apparently contracted in 1916 or 1917.²³ Others purported to have contracted EL included the astrophysicist and mathematician Edward Arthur Milne (1896–1950), the Italian poet Emanuel Carnevali (1897–1942), and the rapist Caryl Chessman (1921–1960).²⁴ The creator of *Gormenghast*, Mervyn Peake (1911–1968), is also often noted as having contracted EL as a child in China, but there is nothing in his biography to support this diagnosis.²⁵ Of particular interest for the history of neurology is the suggestion that the

promising young Sydney professor of anatomy, John Irvine Hunter (1898–1924) and the orthopedic surgeon Norman Royle (1888–1944) contracted EL in New York in late 1924 during a tour of the USA and the UK to promote their sympathectomy technique for the amelioration of spasticity. Both Australians fell ill during this journey, and Hunter died shortly afterwards in England (officially of enteric fever = typhoid); Royle survived, but in 1930 presented initial signs of post-encephalitic parkinsonism (PEP). Hunter's premature death was regarded as a major tragedy; Australian émigré Grafton Elliot Smith remarked that had "*he lived, he might have become the foremost man of science of the age.*"²⁶ The change in demeanor exhibited by United States President Woodrow Wilson during his second sojourn in Paris has been attributed to his contracting EL during the Versailles peace treaty negotiations,²⁷ but this speculation is not supported by reports of any specific symptoms; Wilson had, in any case, fallen ill *en route* to Paris, and the intransigence of his European colleagues and other health problems (including vascular disease, a recent car accident and severe influenza) sufficiently explain the decline in vigor of the 63-year-old president.

In 1921, American industrialist William John Matheson (1856–1930) developed motor symptoms, including parkinsonism, that led to New York neurologist Charles Dana diagnosing EL. This, in turn, motivated Matheson to initiate and fund a major investigation of the available therapies, the Matheson Commission, at least partly in order to find a solution for his own condition (and partly fired by his faith in the Rosenow approach). I have not had the opportunity to examine Matheson's medical file, but the clinical details cited in the literature (and the lack of relevant details in published biographical sketches) cast doubt on the accuracy of Dana's diagnosis,²⁸ the available information being more consistent with idiopathic Parkinson's disease (Matheson was 64 years old when his 'EL symptoms' first appeared).

The most prominent supposed EL sufferer was undoubtedly Adolf Hitler (1889–1945), and there is a rich literature on this question that obviates the need for a detailed discussion here. A range of symptoms that support the diagnosis are well documented on film and in the accounts of those who had close contact with him: not only the left hand tremor so evident in unedited film clips from 1945, but also increasing rigidity, micrographia, palilalia, obsessive-compulsiveness and iterative motor signs, as well as possible oculogyric crises. It is also known that the many medications he was taking during the Second World War included those normally prescribed in Germany for PEP, including the Bulgarian treatment, Homburg 680 (an alkaloid preparation based on the Bulgarian preparation), and harmine, but there could conceivably also have been employed to treat idiopathic parkinsonism. Johann Recktenwald (1882–1964), director of the Andernach asylum during the period in which it participated in the sterilization and killing of mentally ill patients, proposed in his detailed 1963 study that Hitler had suffered PEP, but dated the acute illness to 1900, the year Hitler's brother had died of measles; Dutch author P. J. Stolk (Portugaal) held 1918 as the more likely initiation date, but otherwise supported Recktenwald's position. The PEP hypothesis was more recently supported by American neurologist Abraham Liebermann on the basis of film documentation of a deterioration in Hitler's parkinsonian symptoms between 1933 and 1945; Liebermann identified the first PEP symptoms in 1933 footage. A thorough analysis of the available film material led Cologne neurologist Ellen Gibbels to the opposite conclusion, that Hitler suffered idiopathic Parkinson disease (PD). The controversy has attracted no attention in the past ten years, and it remains unresolved.²⁹

Apart from indirect allusions to the visual and psychological semeiology of EL in the German expressionist film *Das Cabinet des Dr. Caligari* (1920), references to EL in literary settings were surprisingly infrequent. The most prominent was in Agatha Christie's 1930 mystery *The murder at the vicarage*, in which the young curate Ronald Hawes had suffered EL a year prior to the events described in the novel, as related by Dr Haydock in his conversation with the vicar:

There's nothing radically wrong with him ... He recovered all right — as far as one ever recovers. It's a strange disease — has a queer moral effect. The whole character may change after it. (Chap. 14)

The physician muses that the day may come when hanging criminals will seem as abhorrent as burning witches, given that criminality may be a disease: *"Too much of one gland, too little of another — and you get your murderer, your thief, your habitual criminal."* Christie also indicated, on the other hand, that such a sympathetic view was not universal: when Haydock informs Colonel Melchett, the Chief Constable, that Hawes cannot be convicted of the murder to which he had apparently confessed, because *"the poor devil wasn't responsible for his actions"*, Melchett curtly dismisses the objection:

Sleepy sickness, eh? Always some good reason nowadays for every dirty action that's done ... Science be damned — I beg your pardon, Clement, but all this namby pambyism annoys me. I'm a plain man. (Chap. 29)

Other symptoms mentioned in passing by Christie included tics (*"Mr. Hawes's becking and nodding and crossing himself every other minute"*; ch. 1), his fatigue and inability to attend to his duties (*"various matters in his province ... had been muddled or shelved"*; ch. 4), involuntary movements (*"His hands were shaking and his face kept twitching nervously"*; ch. 15), and *"awful racking headaches"* (ch. 24); the fact that his *"whole attitude was nervous and queer"* (ch. 15) was also attributed to EL.

The depiction of Hawes was quite consistent with what might be expected of the EL interval period, and, to my knowledge, remained the only inclusion in contemporary literature of a major character with EL, despite the fact that the personality change aspect would seem to offer a number of opportunities for fictional purposes. The lethargy of EL, on the other hand, provided a metaphor that was repeatedly deployed from the 1920s onwards. An early example was the 1927 Russian short story *Letargiia* by Ivan Korvatskii: it was the account of a Russian émigré in Constantinople who awakes from nine years' sleep to discover that the nightmare of the Russian Revolution and Civil War had, in fact, been a dream, and that Russia under the Czar was now a respected world power — only to discover that his 'awakening' had been a dream. Only the title and a single line in the story allude to EL, but the influence is clear.³⁰ An English short story from 1924 involved a hare pursued by a fox, and at one point *"the hare hesitated, turned at right angles, and crossed the burn again. On the opposite bank she paused, then, as though possessed of sleeping sickness, she crawled slowly on."*³¹

This metaphor also found wider use as an expression of ennui. A New York journalist wrote in 1919: *"Central Park tempted, bock-beer signs beckoned, and that most fatal malady, 'Encephalitis lethargica', attacked. Sleeping sickness and music criticism, however, are old pals";*³² an astrological column noted that Aquarian children were energetic and hopeful, divinely human and *"not suffering from 'sleeping sickness' of the soul"*.³³ The term 'lethargic encephalitis' was also employed in the press and elsewhere as a rather obvious metaphor or insult for those who were perceived to be inactive or indolent, including, of course, governments; an American correspondent criticized the sloth of the post-War German economy with the comment that *"Germany's salvation depends as much on waking her people out of their spreading sleeping sickness as it does on getting food"*,³⁴ while Anglican leaders complained that *"the Church was suffering from what doctors called Encephalitis lethargica ... and wanted waking up"*.³⁵ 'Lethargy' had, however, been used for centuries by Protestant ministers to harangue their spiritually slothful flocks. A British parliamentarian asked in 1926 whether *"the medical profession are of the opinion that there would be a serious outbreak of sleepy sickness"* were Parliament to be broadcast on the radio,³⁶ and the metaphor is still occasionally labored today in political reporting. Republican responses to the foreign policy initiatives of the Obama administration, for example, were lampooned in the following manner: their *"spasmodic flurry of attacks, complaints, and self-pitying diatribes is so intense that they have succeeded in shuddering themselves into a state of frozen paralysis. Call it the political equivalent of encephalitis lethargica."*³⁷

This reduction of EL to ‘lethargy’ persisted unabated until the 1970s. The diagnosis of EL by a local doctor in a traveller suffering a bout of Mexican diarrhea in Sam Shepard’s 1967 play *La turista*, for instance, has little more to do with the actual disease than as a reference to the weariness of the sufferer: following the recital of an encyclopedic (and mostly confused) account of the features of the disorder, the doctor’s best advice was that “*the patient must be kept in motion and, if possible, induced to talk. The more motion the better, lest it prove fatal. Benzedrine sulphate is also useful in some patients at this stage.*”³⁸

Awakenings

The major impetus for a revival of public interest in EL was provided by Oliver Sacks’ 1973 book *Awakenings* (as well as his 1972 *Listener* and 1981 *London Review of Books* articles; see pp. 810ff.) and the 1974 Yorkshire Television (UK) documentary about Sacks’ patients, both of which were met with critical acclaim. The documentary, also titled *Awakenings*, introduced the ‘Discovery’ science television series, won awards at the 1978 American Film Festival and 1978 International Rehabilitation Film Festival. It is perhaps ironic that the documentary had still not been shown on American television as late as 2001; it was presented that year in a New York theatre in a session for medical personnel, moderated by Sacks.³⁹

The mystery of the ‘sleeping’ or ‘frozen’ patients from another time and the wonder of their ‘awakening’ generated immense public interest, attention that was not impeded by the then prevailing interest in altered consciousness in general, drug-induced and otherwise. Sacks’ EL publications were admired in some quarters for their adventurous synthesis of neurology, psychoanalysis, physics, and philosophy, and dismissed by others for the same reason. They were, in any case, eminently readable accounts of his encounters with PEP patients and of their responses to L-DOPA. More importantly, Sacks’ publications also recorded his patients’ accounts of their own experiences — “*the lives and reactions of certain patients in a unique situation*”⁴⁰ — adding a palpably human element to his depiction of an otherwise impenetrable and alien disorder. In a footnote to his discussion of the philosophy he applied to understanding his patients, Sacks described an alternative to traditional subjective and objective narrative, an approach he denoted as ‘trajective’:

There can be no reaching out into the realm of the incommunicable (or the barely communicable) unless the physician becomes a fellow traveller, a fellow explorer, continually moving *with* his patients, discovering with them a vivid, exact, and figurative language which will reach out towards the incommunicable. *Together* they must create languages which bridge the gulf between physician and patient ...⁴¹

The telling of the tale and, to an even greater degree, its interpretation was clearly modulated by Sacks’ metaphysics of health and disease, which proposed that finding a balance between one’s capacities and ambitions is crucial to individual fulfilment — his book thus sits comfortably alongside another best-seller from the same period, Robert M. Pirsig’s *Zen and the Art of Motorcycle Maintenance* (1974) — but also by his perceptions of the implications of the L-DOPA effect for science and medicine as a whole: while most neurologists saw L-DOPA as alleviating the striatal dopamine deficit that underlies akinesia, Sacks presented the drug as a key that released the patient from motor confinement and thereby broadened their psychological perspectives. Not every patient, however, could make the adjustments that were required by their expanded potential, and this failure to adapt explaining for Sacks the inability of many to derive sustained benefit from the miracle drug, which ultimately proved to be only a partial solution to an extremely complicated neuropsychiatric problem.

Sacks' insights revitalized the currency of EL both as a theme and as a metaphor. His 1973 book inspired several adaptations of its themes,⁴² the most prominent being the 1982 short 'memory play', *A kind of Alaska*, by British playwright Harold Pinter.⁴³ Deborah (played by Judi Dench in the original production) is woken by L-DOPA from her 29-year EL sleep, but is mentally still the 16-year-old she had been when her mind entered the cold, faraway place of the title. Despite passing resemblances to Sacks' Rose R. — there is also an implication that psychological factors may have played a role in Deborah's withdrawal from the world, and her dawning realization of what she has lost seems likely to motivate a return to her Alaska, echoing Sacks' views on Rose R.'s failure to accept her new reality — EL is essentially employed (in distorted form) merely as a convenient device in a psychological version of the classic legend of the sleeper who awakes to find their world radically altered and their former life irretrievable. One reviewer indeed saw the 29-year slumber less as a medical condition than as an extreme metaphor for ageing itself, Deborah reflecting the state of mind of the middle-aged person disturbed by the sudden consciousness that their life has somehow passed more rapidly than they had been previously aware: "Where did time go? What did I do while it was passing? Why did I make so little of it?"⁴⁴

A more direct adaptation of Sacks' book by Arnold Aprill (simply titled *Awakenings*) was staged in 1987 by the City Lit Theatre in Chicago, and received Sacks' approval, although other reviews of this attempt to portray his patients on stage were mixed.⁴⁵

The conceit of the long sleeper was also exploited by the 1985 American television movie *Between the darkness and the dawn*, directed by Peter Levin. The 37-year-old Abigail (Elizabeth Montgomery) awoke after twenty years' slumber caused by a "rare encephalitis" in 1964. This film garnered less than rapturous critical acclaim, being described as "a candidate for the worst television movie of the year."⁴⁶ The Britons Pete Brooks and Jeremy Peyton Jones introduced their multimedia performance, *The sleep: The strange case of sleepy sickness*, — "both an opera and a dream play" that entwined the awakening of a patient after 40 years of 'sleeping sickness' with the Orpheus myth — at the 1987 Mayfest in Glasgow. Psychological factors (the condition was perhaps initiated by sexual shock) and usurpation of the patient's autonomy by cold medical authorities also played roles in this unusual interpretation.⁴⁷ More recently, an Indian film, *Man Paakharu* (2008), appears to have offered a Marathi version of the *Awakenings* story, but I have not been able to find any information other than an interview with the lead actor.⁴⁸ On the other hand, EL was reduced to its lethargic component in *The archaeology of sleep* (Julian Beck, Living Theatre, New York; 1984), an experimental performance described by the *New York Times* as "a quasi-Adlerian, quasi-Joycean meditation on the 'millenium-old [sic] mysteries of sleep.' We know this not because of what happens on stage but because Mr. Beck announces his intentions in one of the program's several turgid manifestos."⁴⁹

The commercially most successful adaptation of Sacks' 1973 book was undoubtedly the 1990 Penny Marshall motion picture *Awakenings*, a fictionalized Hollywood version that starred Robin Williams as Malcolm Sayer (= Sacks) and Robert de Niro as Leonard Lowe (= the patient Leonard L.). The movie was lighter in tone and much more optimistic than the book, increasing the popular appeal of its otherwise tragic story. Its success also revived interest in Sacks' book, motivating publication of a revised edition. Critical appraisal was mixed: the movie and its screenplay were nominated for Academy Awards, as was De Niro as lead actor. De Niro was awarded several other critics' prizes for his portrayal of Leonard, and one reviewer hailed his performance "a physical wonder, a stony guise that gives way to a sideshow of wracking tics."⁵⁰ Sacks himself was impressed by his depiction of parkinsonian symptoms in the film, the result of De Niro observing PD patients for an extended period:

I think in an uncanny way, De Niro did somehow feel his way into being Parkinsonian. So much so that sometimes when we were having dinner afterwards I would see his foot curl or he would be leaning to one side, as if he couldn't seem to get out of it. I think it was uncanny the way things were incorporated.⁵¹

In the same 1996 interview, however, Sacks commented that at *“other levels I think things were sort of sentimentalized and simplified somewhat.”* He commented elsewhere that the Marshall film accurately reflected the emotional state of his patients, but took liberties that enhanced the dramatic effect of the situation: prior to his treatment Leonard, for example, was not the completely rigid, statue-like patient depicted in the film.⁵² The movie has indeed been widely criticized for its Hollywood saccharinity, particularly the perceived need to embellish an otherwise thought-provoking complex of medical and human elements with unnecessary romantic and other melodramatic elements. This was particularly the case outside the United States; the reviewer for the leading German weekly news magazine, for example, found that:

It may well be that the whole gruesome normality of such an asylum would be unbearable for the cinema audience; but because the film religiously submits to the taboo that a severely disabled person can certainly be wretched, but never disgusting or repulsive, it glosses over the disaster towards which “Awakenings” is headed.⁵³

Nevertheless, the film has enjoyed enduring popularity with those looking for a tale of spiritual triumph in the face of tragedy, the spirit expressed by Sayer at its conclusion:

What we do know is that, as the chemical window closed, another awakening took place; that the human spirit is more powerful than any drug — and THAT is what needs to be nourished: with work, play, friendship, family.

Sacks' *Awakenings* and the 1990 film have thus played a major role in shaping current public perceptions of EL. The irony is that they elevated awareness of chronic EL, but at the same time undermined understanding of its neurophysiological basis; Sacks himself only touched cursorily upon the etiology of the disease, encouraging the popular view that PEP *was* EL.⁵⁴

It is surprising that some commentators regarded the 1990 film as more negative (and unduly so) than the book (the reverse was clearly true), arguing that the outcome was positive for those who seized the opportunity provided by L-DOPA:

Miriam managed, by force of will, to maintain an active life and accept reality, and Frances survived the pressures and refused to allow them to dominate her, thereby validating her strong personality. The book is proof that the daily lives of these patients improved considerably for those who decided to grasp the reins of their new reality.⁵⁵

No-one would dispute that the ‘gift’ of L-DOPA placed demands upon the freed patient, but to attribute their ultimate relapse to an inability to accept these demands is as fatuous as blaming the inadequate tenacity of patients who lose their ‘battle’ with cancer.

A more realistic and helpful approach was that of Ernest Ward, an English physician who himself suffered chronic EL (see pp. 436, 491), and who commented in 1929 that his experience had confirmed the adage that *“one of the ‘pleasures of being ill’ was that it enabled the patient to realize and appreciate his friends.”* In contrast to Sack's personal writing style, Ward chose to compose his *“subjective study of encephalitis lethargica”* — the conclusion of his memoir of his life as a physician, and of *“all [its] chapters ... the most difficult and painful for me to write ... every sentence, every word an effort”* — in the third person, commencing: *“A medical man, aged 47, was attacked on the evening of January 17 with acute coryza ...”*⁵⁶ Ward concluded his autobiography with the following advice:

One is inclined to advise this patient [*that is, Ward himself*] not to face the situation too squarely, and to envisage, not the shadowy future, but rather the busy present, or even the well-filled past. Prudence and foresight are useful and estimable virtues, but those who exercise them to the utmost do not always escape disaster. Life is a game, and its chief art is to turn adversity to good account.⁵⁷

Encephalitis lethargica in more recent literature

Oliver Sacks was also clearly the model for the progressive psychiatrist Zack Busner in the 2012 novel by Will Self (b. 1961), *Umbrella*. The novel is concerned (at one level) with Busner's headstrong experimental L-DOPA treatment of chronic EL patients in the north London Friern Mental Hospital (during the EL period: Colney Hatch Lunatic Asylum) in 1970. Some of the expressions employed and specific symptom descriptions are taken directly from *Awakenings* (the woman who speaks at 500 words a minute, the impression of "maps of maps of maps", while the musings on the different speeds of the patients appears drawn from a later Sacks essay⁵⁸), and the central patient character, Audrey Death, is quite reminiscent of Rose R. The novel is a complex conflation of timelines, uninterrupted by chapter breaks and only infrequently parcelled into paragraphs, repeatedly and abruptly switching mid-sentence and mid-thought between the three time-lines of the narrative (1916–18, 1971, and 2010) according to triggers provided by word associations — or for no obvious reason at all. The descriptions of the motor phenomena of PEP are reasonable, although, unlike Sacks, Busner finds meaning in at least some of the manifold tics of his patients by analysing films of the 'enkies':

... slowed to eight, then four, then two frames, the Nouvelle Vague stares him in the face: it is only their orchestration that makes her actions appear outlandish, discretely they are all within the normal gestural repertoire — their orchestration and their syncopation ...⁵⁹

Audrey's tics, for example, are mostly related to her employment during the first World War in a munitions factory. Tics in general play a central role in *Umbrella*, the actions of other characters also possessing tic-like character (such as the incessant tapping of a 'smart phone', or people fiddling with their neck ties), thereby blurring the distinction between health and disease. The description of the onset of Audrey's disease in the novel, on the other hand, is confused, with the first parkinsonian symptoms *preceding* the lethargy, which itself appears to have been more of a febrile delirium with amnesia than acute EL — perhaps once more reflecting the difficulty in grasping the nature of this curious disorder. EL primarily served as a tool for the exploration of the ideas that Self wished to explore in his novel, most notably the 'construction' of one's individual world, rather than as a faithful representation of the disease. This direction was already present in Sacks' 1973 book, and had been repeatedly taken up by each successive adaptation. None of which detracts from the literary merits of Self's novel, nominated for the Man Booker Prize in 2012.

The grandfather of the protagonist in the 1990 debut novel by Dutch author Marcel Möring (b. 1957), *Mendels erfenis* ('Mendel's legacy'), is diagnosed with EL following his "petrification" ('*verstening*') one morning: he was abruptly seized, without prior warning (apart from "atypical dementia" diagnosed the previous year), by an amyostatic condition, his symptoms including akinesia, slowness of movement (minutes pass before he replies to his grandson's greeting, for instance), and unclear speech and handwriting. The doctor explained:

He hears us, he sees us, but he cannot break through his rigidity. His mind is perfectly healthy, but is encased in a petrified body. The world turns around him, but he stands still. A living statue, so to speak. (p. 14)

The man's wife viewed his condition as preferable to dementia: at least she need not fear that he will one day mistake her for his mother. The internal state of the ossified man was contrasted with that of his tentative grandson, Mendel:

He participated in everything and stalled. I stall and participate in everything. He was imprisoned by an absolute slowness of movement, his body became a house, hard and stock-still, and in it lived a soul lived that seethed and railed, that raged like a storm. (p. 25)

The onset of amyostasis was thus unusually rapid, but Möring nonetheless provided a fairly accurate cameo of chronic EL.⁶⁰

Childhood EL, on the other hand, was the subject of a 1990 short story by the American author Brian Booker: an account of two pre-pubescent residents of the Franklin School (see p. 459) who presented all the cold cruelty and other behavioral aberrations that were characteristic of EL children, but who are drawn to each other by a mixture of nascent sexuality, childishness, and pyromania. The outcome of a final, fiery night-time tryst remains obscure, the account shifting from doting memory to the current state of rigid, repetitive immobility, completing as accurate a portrayal of such a condition as is possible for anyone who has not experienced it personally.⁶¹

The theme of life seeping away from the young but ageing EL victim was concisely and delicately addressed in the poem ‘The twenty-five year trance’ by American poet Gary Fincke (b. 1945; prefaced by the explanation that EL “*is an acute inflammatory disease of the brain, and is characterized by lethargy, weakness, and coma*”):

All week he’s been xing
 Out lost days: nine thousand.
 Nothing will pry open
 The coma in his count ...
 Not his hands. The surprise
 Of their age. Not mornings
 So stiff he slow-paces.⁶²

The depiction of acute EL in the 2012 short story by American Marines officer Edward H. Carpenter, *Lethargica*, is less accurate than any of the other treatments discussed here. In this tale, the disease traps an American woman in her body, snatching her from her husband, a soldier returning from First World War France; his survival had depended upon her letters, which had recently ceased, and his longing to be reunited with his love.

The most unusual exploitation of EL as a theme is the Polish novel *Tańcząc z panną Garbo* (‘Dancing with Miss Garbo’), published by philologist Mariusz Kuleta in 2005. Although described as a ‘novel’, it is written as a semi-documentary re-examination of European history and culture between the World Wars under the influence of the “*epidemic of bizarre dreams*”, a conflation of historical facts and the speculative re-telling of the EL story as an explanation for not only the elusive personalities of cultural and political figures, such as Greta Garbo and Franz Kafka, Adolf Hitler and Józef Piłsudski, but also for the madness and political violence that infected Europe from the early 20th century. Although the book reads like a non-fictional, if conspiratorial work, it actually arose as a series of unconnected stories; only when they were ready for publication did Kuleta encounter the EL literature that moved him to adopt the epidemic as a linking theme. The author nevertheless insisted that almost everything in the book was true, if perhaps overinterpreted: “*it is impossible to speak of the 20th century without telling the story of encephalitis lethargica.*”⁶³ Kuleta’s book is an entertaining story, in any case, and less outlandish than other attempts to impose EL as an explanation for historical events; for instance, one author interpreted the unusual behavior of women that led to the Salem witch trials in the 1690s as EL-related, whereby she viewed EL as an arbovirus infection.⁶⁴

Other depictions of encephalitis lethargica in popular media

In 1951, science fiction Robert Anson Heinlein (1907–1988) included EL as one of the diseases that might be deployed against invading parasitic ‘slugs’ in his novel *The puppet masters*; “nine-day fever” was ultimately deployed instead, but ‘encephalitis’ was retained as the rescuing infection in the 1994 film based on the novel. More recently, the Neil Gaiman (b. 1960) graphic novel *Sandman* (originally

published in 1988) commenced with EL (conflated with African sickness) as being the result of Morpheus or Dream (= the Sandman) being imprisoned by an occultist in 1916.⁶⁵

In the Canadian television series *ReGenesis*, about scientific investigations by the 'North American Biotechnology Advisory Commission' (Toronto) of mysterious events and disasters in the present day, the pathogen of EL proved to be a widely distributed human retrovirus (it is discovered that the virus has since been integrated into chromosome 11 of the human genome) that is re-activated in US military personnel in 2006; the symptoms of the re-awakened disease included headache, flu-like symptoms, and mild fever, developing further to blurred vision, severe muscular pain, slowed physical and mental responses, as well as sleepiness ranging to coma. This is the only reference to EL in a science fiction setting that in its clinical presentation even resembles the historical disorder, although a number of details were incorrect: the reference to two million fatal cases during the 1920s, the matching of the retroviral sequence with that of the EL virus (isolated from a corpse exhumed in Spitzbergen), the (disappointed) expectation that the acute disease could be treated with L-DOPA.⁶⁶

EL has also been the subject of occasional documentaries. Apart from the 1974 Yorkshire Television program on Sacks' patients, the two most important have been the BBC1 documentaries *Prisoners of the forgotten plague* (1998; 30 minutes) and *Mystery of the forgotten plague* (2004; 60 minutes; part of the *Medical Mysteries* series). *Prisoners* briefly related the story of 1920s EL and its outcome, including the life of one its victims, Philip Leather, as well as the Sacks story. British virologist John Oxford discussed the possibility that EL might have been caused by the influenza virus, and could thus return. Oxford also discussed this in the second part of the BBC2 *Horizon* program *Pandemic*, described on the video packaging as a "drama-documentary [that] attempts to predict how the next influenza pandemic will hit us." This possibility was seemingly confirmed by the described case of Becky Howells, a 23-year-old woman who had reputedly contracted the disease in 1993; her neurologist had seen several more cases since. *Mystery of the forgotten plague* also commenced with the Howells case, but took the 2004 paper by Dale and colleagues as its focus, concentrating on the auto-immune hypothesis of EL. The material accompanying the program included a lot of the inappropriately dramatized information commonly associated with current discussions of EL, including the claim that "in the 1920's an incurable disease that turned ordinary people into living statues caused global panic", and that "during the outbreak, nearly a million died, and millions more were left frozen inside their useless bodies, in institutions."⁶⁷

The Becky Howells case provides a link with the recent 'acute encephalitis lethargica' cases discussed in the previous chapter, being the first to attract attention in the non-medical press.⁶⁸ At about the same time, 17-year-old Sophie Cameron suffered encephalitis and then a cardiac arrest that resulted in severe brain damage, robbing her of speech and mobility. This inspired the foundation of the Sophie Cameron Trust in 2004, which raised funds for encephalitis research until 2010.⁶⁹ These and similar reports not only confirmed in the popular mind the identity of historical EL and contemporary EL-like syndromes in Britain, but also blurred to some extent the distinction between EL and encephalitis in general. The widespread impression of EL today is consequently a confused *mélange* of sketchy knowledge of the original disease and more recent cases of acute encephalitis. In particular, there was no apparent link between Ms Cameron's tragic case and EL; but this does not, of course, devalue the work of the Trust: indeed, supporting research into a contemporary disease, rather than into an extinct entity, is of more practical benefit, particularly as investigations of rare conditions often struggle to find funding. The problem is that denoting two separate diseases as 'encephalitis lethargica' can be confusing, and not only for non-medical people, particularly with respect to outcome: the sometimes frightening aspects of current 'encephalitis lethargica' cases are alarming enough for parents without adding the fear that their child might one day resemble the characters in *Awakenings*.

The end

O that a man might know the end of this day's business ere it come! But it sufficeth that the day will end, and then the end is known.

Brutus, in Julius Caesar, V, i

In 2002, Philip Leather, reportedly the final survivor of the EL epidemic, died at the age of 82 years in Yardley Wood Hospital (Birmingham), attended to the end by his 81-year-old sister Jean. Philip had been a wonderfully creative child and self-taught pianist, but from the age of six years had begun to withdraw from the world. His behavior deteriorated over the following years; he was walking with a stoop and his eyes were partially paralysed by the time he was 12 years old, and communication had been reduced to the barest minimum. He finally hid beneath his bedclothes for three days, signaling to his parents that he was in real trouble: diagnosed with EL (presumably contracted during 1920/21) by no less than George Auden, the inaugural School Medical Officer in Birmingham and authority on childhood EL, Philip was admitted to the Hollymoor Mental Hospital at the age of eleven years, a hospital with no children's ward, and with no hope of cure. As life moved on outside his room, he remained largely immobile and silent, although something of his mind remained alive: he enjoyed ice cream and beer throughout his life, and when this was forgotten at one of his later Christmas parties, he burst into tears.⁷⁰

By the time Philip died, almost ninety years had passed since EL first appeared in Europe, and its cause was still unknown, as was the reason for its rapid retreat. But there is no doubt that the EL epidemic played a major role in the development of the clinical and laboratory neurosciences between the World Wars: it was intimately involved in the conceptualization of the extrapyramidal motor system — defined according to both its functional and biochemical features (the presence of high iron levels) — resulting in the “*dethronement of the motor cortex, or at least the elimination of its motor autarchy.*”⁷¹ EL thereby uncovered the significance of the substantia nigra for motor control, and of the basal ganglia in general for the generation of basic motor patterns that underlie the smooth execution of voluntary motor activity:

To put it crudely, the neostriatum and pallidum would be, in a dynamic sense, the empowering element, the motor cortex the nuanced, differentiating, regulating component. With respect to their content we could — always with the reservation that one may ever speak of the localization of mental phenomena — regard the striatal ganglia as the repository of the motor memories of the history of our species, and the cortex as the archive of the acquired motor memories of the individual.⁷²

Parkinsonism itself attracted more interest as a result of the epidemic, no longer seen ‘merely’ as a regrettable feature of ageing, and PEP demonstrated that rigidity, akinesia were separate if associated phenomena. EL also polished concepts of ‘encephalitis’ and inflammation in the brain, including the roles filled by the newly described microglia.

EL also made it clear that there could be no absolute demarcation of the motor and mental capacities of the brain: the two areas of function with inextricably entwined, exhibiting an interdependence that questioned the wisdom of separating clinical neuroscience into two discrete fields. The psychiatric aspects of motor disease and the motor features of psychiatric disorders had been subject to investigation since the late 19th century, but EL provided more clinical and pathological data regarding this consanguinity than could previously have been imagined. The similarities between certain EL-related states and schizophrenia could not be overlooked, including the troublesome symptom of catatonia (although, ironically, efforts to distinguish EL-related psychiatric symptoms from those of schizophrenia resulted in motor symptoms being largely expunged from definitions of ‘genuine psychosis’ by the late 1930s), while its even more frequent production of ‘hysterical symptoms’ — particularly the litany of involuntary, iterative motor symptoms of the chronic phase, all bizarre and most previously unknown: “*oculogyric crises ... disturbances of tongue and mouth*

*movements in the form of complicated, automatisms ... respiratory spasms ... yawning, laughing, shouting, barking attacks ... hand rubbing, paper plucking, clothes tearing ... pants rubbing, scratching, finger fumbling ... compulsive walking and running ... compulsive lateral deviations of the head, manège movement-like rotations of the body about its axis when attempting to walking ... the inability to sit still, compulsive acquisitiveness ...*⁷³ — contributed massively to the final dissolution of hysteria as a nosologic entity, particularly by exposing the role of extrapyramidal and brainstem centres in the production of these symptoms.

Other symptoms of the chronic phase then regarded as unique to EL — the character changes of younger patients, bradyphrenia — further demonstrated that personality, criminal inclinations, and other behavioral abnormalities could have defined organic roots. Although it had been recognized earlier that a large proportion of the prison population — probably the majority — suffered from mental dysfunctions or abnormalities of varying degrees, there was an underlying assumption that this was primarily the result of poor breeding and upbringing. It was now frighteningly clear that the mental faculties and social behavior of any person could be dramatically altered by an infection or by a neurologic lesion, even when that person was both aware of and repugned by this transformation.

Taken together, EL forced recognition of the critical significance of the brainstem — mesencephalon and diencephalon — both in the vital functions of the living organism, supporting and providing clinical corroboration of the important basic research then being undertaken in laboratory animals, as well its crucial participation in the emotional and mental life of the individual. The pathogen of EL, as a virus that could seemingly infect the mind, had undermined concepts of the will, of volition, as a single, unitary function, let alone as a localized faculty, and promoted concepts of consciousness as a phenomenon that was not the preserve of any single brain region, and certainly not entirely attributable to functions housed in the cerebral cortex. The lessons of this disease also suggested that sleep — itself clearly no longer a single function controlled by an on/off switch in the brain, but instead the complex co-ordination of several linked but autonomous cortical and subcortical rhythms and functions that could be separately disturbed by disease — attention, and consciousness were linked but distinct functions, and that fibres coursing through the central grey of the brainstem, as well as other subcortical structures, were critically involved in the elaboration of higher mental functions presumed to be the preserve of the cortex. The failure to identify cortical lesions in schizophrenia were now less surprising in light of the dramatic personality and cognitive effects of an infection that generally produced detectable lesions in the brainstem. On the other hand, EL provided major insights into the impact of motor capacity upon mental functions and drive, but also of emotion and mood upon motor performance; that is, into the indissoluble union of psyche and soma in health and disease.

The EL epidemic also reinvigorated discussions of infectious etiologies for both neurologic and psychiatric disorders, including multiple sclerosis and schizophrenia. Further, although the major research path pursued appears to have been misguided and ultimately a dead end, investigation of the herpes hypothesis of EL significantly advanced knowledge in both laboratory and clinical microbiology, including the emerging field of virology, while the epidemiology of EL, like that of polio and epidemic meningitis, once more underscored the central role that could be played by healthy carriers in disseminating disease. It is doubtful that understanding of the herpes virus — including its access to the nervous system and its ability to lie dormant in nerves — would have accrued so quickly without the impetus to its investigation provided by EL, and this knowledge assisted the investigation of the many new encephalitis types that emerged towards the end of the EL period and afterwards.

EL was a source of great controversy throughout the 1920s and 1930s, not least because solutions to the many puzzles it posed were so elusive. The period between the two World Wars was among the richest and most productive in the history of the neurosciences, and EL was critically involved in both

providing data for and demonstrating connections between various aspects of brain function that were discussed with such passion at this time.

The human cost of the lessons afforded by EL should not be forgotten; as MacNalty commented, at a time when the epidemic was waning, but when it still remained uncertain whether EL would not yet return in full force:

The study of encephalitis lethargica has made many problems in neurology and physiology plain; but the existence of this tragical disease in our midst is a heavy price to pay for the acquisition of new learning. Sir Thomas Browne wrote: "Some will allow no diseases to be new, others think that many old ones are ceased; and that such which are esteemed new will have but their time". But even if this last is true of encephalitis lethargica, it behoves us all to endeavour to shorten the time of visitation. You will have gathered from what has been said how serious is the disease and how deplorable and frequent are its after-manifestations.⁷⁴

The Würzburg psychiatrist Richard Geigel was equally divided about the insights provided by EL:

Whoever is but a scientist and not a doctor, who has a brain but no heart: such a person can indeed experience an unalloyed joy over the quite significant enrichment of our knowledge regarding the basal ganglia and its neighborhood, the extrapyramidal system, that the new malady has delivered us.⁷⁵

Economo concluded his 1929 monograph with a discussion of the lessons learned from the epidemic. Vegetative functions, the neural mechanisms of sleep, extrapyramidal motor control and muscular tone, models of consciousness, personality and volition, neuroses and psychoses: it seemed that there were few areas of neuroscience in which concepts were untouched by the experience of the phenomena of EL:

EL has not only has not only altered the fundament, to some extent, of much of our neurological knowledge, but has also provided completely new foundations for our understanding of normal and pathologic mental phenomena ... the dialectic combinations and psychological constructions of many ideologues will collapse like houses of cards if in future they do not take account of these new fundamentals ... Many elaborate constructions of speculative thinkers will disintegrate in the face of what, for the physician, are commonplace facts. It is to be hoped that this will not provide yet another reason for these theoreticians to simply ignore them.⁷⁶

Economo believed that the impact of EL upon neuroscience was such that the disease would never be forgotten, even should it prove, as it then seemed, that its time as an epidemic disorder had ended. EL was, however, indeed largely forgotten within a generation of its vanishing. Diseases rarely impose themselves upon the public memory as much as political events, with their well delineated chains of events and identifiable lead characters. This is all the more true for a 'vanished' disease such as EL: while the occasional review recalling its strangeness might evoke some interest, a disease that no longer threatens anyone is easily consigned to the archives. Many of the lessons learned during the EL period were also shelved, at least temporarily: the biological holism epitomized by EL was soon to lose its integrity, as its merciless and irrational melding with race theory and political ambition in Germany discredited biological psychiatry for two generations. It is to be hoped that the revival of neuropsychiatry will foster understanding and tolerance, as anticipated by its progenitors prior to 1933, not the desire to eliminate all that is atypical, less socially acceptable, or 'unworthy'.

Encephalitis lethargica was not the first disease to seemingly appear from nowhere. Freiburg psychiatrist Alfred Hoche cited the example of general paralysis, which seemed to have arisen during the early 19th century, although the infection that causes it, syphilis, had existed in Europe since the end of the 15th century; and acute syphilis itself had undergone a massive transformation during its initial decades in European bedchambers.⁷⁷ The sudden profusion of other encephalitides from the late 1920s provided an even more relevant example of the unexpected and abrupt emergence of 'new' disorders, not to mention the more recent AIDS epidemic. There have also been other instances of diseases disappearing — it is some time, for instance, since the once ominous SARS virus has made itself noticeable, and the precipitous decline in the incidence of rheumatic fever (and the associated

heart disease and other consequences) in the Western world since the early 20th century remains unexplained.

But it is also possible that the ‘encephalitis lethargica virus’ that caused so much trouble and aroused so much interest for a decade has itself never really disappeared, but simply assumed a form or lifestyle that renders it invisible or uninteresting; viruses generally only attract our interest when they threaten us or the animals or plants we value. We do not know why EL came or why it departed, or even which ‘virus’ was the source of its power. We should perhaps just be grateful that encephalitis lethargica appears to have disappeared for good, as the question as to whether we should fear its return cannot be sensibly discussed without knowing more about whose return we are dreading.

Notes

1. Podoll & Lüning 1998; these authors did not consult the two journals mentioned in the next paragraph. For scientific film during this period see also Kleist & Pittrich 1936; Podoll 2000.
2. Kleist & Herz 1925/26, 1927a,b.
3. Herz 1931.
4. Kleist & Pittrich 1938.
5. Lewy 1927; Machol 1927; Albrecht 1927. The Lewy film is available via the Wellcome Library catalog (<http://library.wellcome.ac.uk>). The journal issue in which the Machol film synopsis appears is dated ‘1927’, but the patient came to the clinic in May 1928; further, Machol cited two 1928 references, including Stern’s monograph.
6. Kraepelin 1923.
7. Podoll 1995; see also Westphal 1926.
8. Fischer 1926; Stern 1927; von Stockert 1929.
9. Kirchhof 1941a-c.
10. Miller & Simon 1927; Halban & Rothfeld 1934.
11. Goodhart 1922.
12. Goodhart & Balsler 1944. Some of the Goodhart–Tilney films were also published as Krusz *et al.* 1987, and were discussed by Cartwright in 1995 (pp. 72–80), who saw the influence of their colleague Herz in this work.
13. Evidente *et al.* 1998.
14. Burn 2011; Reynolds *et al.* 2011.
15. Claassen & Boes 2009.
16. Vilensky *et al.* 2006.
17. Martin 1983; Evidente & Gwinn 1998.
18. Gordon 1918. The author’s own advice, however, was not terribly helpful: “*at present there is nothing whatever to justify a scare ... it is best avoided by not worrying about it, and by seeing that children and young adults get as much fat as they can.*”
19. ‘Girl sleeps after talk of 212 hours’. *Chicago Daily Tribune*, 14 February 1921, p. 1; cf. *JAMA* 1921.
20. ‘Guests rose bride from sleeping malady. ...’. *New York Times*, 2 February 1921, p. 3.
21. ‘Violin notes ended sleeping sickness: Mrs. Dora Mintz soon to leave hospital, where she had slept since last October’. *New York Times*, 21 January 1920; p. 24.
22. ‘Mrs J. P. Morgan has sleeping sickness. ...’. *New York Times*, 19 June 1925, pp. 1, 11; ‘Mrs. J.P. Morgan dies at her home isolated from kin’. *Washington Post*, 15 August 1925, pp. 1, 5; ‘Sleeping sickness fund from Morgan. *New York Times*, 22 March 1927, p. 29.
23. Ferguson 1998, p. 971 (based on the recollections of Rothschild’s daughter). The obituary in the *London Times* (15 October, p. 14) referred only to his “indifferent health” and “depression”.

24. Milne: McCrea 1951; Carnevali: Carnevali & Boyle 1967; Chessman: Chessman 1954, pp. 29f.
25. Sahlas 2003 has suggested that dementia with Lewy bodies was more likely. Peake developed parkinsonism in his late 40s.
26. Elliot Smith 1924.
27. The usually cited source for this claim is Weinstein (1981, pp. 336–339), but he mentioned EL only in passing, and then only because he regarded the shift in demeanor of the president to have been more persistent than postgrippal asthenia.
28. See, for example, Kroker 2004 (Kroker, however does not question the diagnosis).
29. Recktenwald 1963; Stolk 1968; Walters 1975; Lieberman 1983, 1996, 1997; Gibbels 1994, 1995a; Redlich 1999; Guerrero 2003; and the video compilation Gibbels 1995b.
30. Korvatskij 1927.
31. Batten 1924.
32. James Gibbons Huneker, 'Encephalitis lethargica'. *New York Times*, 25 March 1919, p. 11.
33. Mary Blake, 'Aquarius'. *Washington Post*, 15 February 1931, p. A1.
34. Charles A. Selden, 'Food relief is temporary'. *New York Times*, 14 March 1919, pp. 1f.
35. "'Sleepy sickness" in the church; shortcomings of the laity'. *Times* (London), 22 October 1925, p. 10.
36. 'House of Commons: Broadcasting of parliamentary speeches'. *Times* (London), 16 March 1926, p. 8.
37. Poulos 2012.
38. Shepard 1968, act 2.
39. Wendy Lesser, 'Seeing 'Awakenings' with its real-life cast'. *New York Times*, 21 January 2001 (Arts), pp. 41, 44.
40. Sacks 1973, p. xi.
41. Sacks 1990, pp. 225f. (footnote). See also discussion by Hawkins 1993.
42. Sacks reviewed adaptations of *Awakenings* to date in Sacks 1991, pp. 367–386.
43. Originally produced as part of the *Other Places* trilogy: Pinter 1981.
44. Benedict Nightingale, 'Time passing'. *New Statesman* (London), 22 October 1982, p. 36.
45. Reviews: Richard Christiansen, 'Medical cases get an awakening on stage'. *Chicago Tribune*, 11 September 1987, p. A4; Hedy Weiss, 'Sacks awakens the theater to science. Doctor's tales have allure for the stage'. *Chicago Sun–Times*, 4 October 1987, p. 5.
46. John J. O'Connor, "'Between the darkness and the dawn", on NBC'. *New York Times*, 23 December 1985, p. C16.
47. Reviewed: Noel Goodwin, 'The Sleep. Gardner Centre, Brighton (Brighton Festival), May 15'. *Opera* (London) July, p. 119f. An extract of the 1986 Brighton Festival performance is available at <https://www.youtube.com/watch?v=V9-o6krPX4Q>. (accessed June 2015).
48. Padukone 2008.
49. Frank Rich, 'Theater: The archeology of sleep'. *New York Times*, 19 January 1984, p. C14. Detailed description of performance: Neff 1984.
50. Rita Kempley, The dawn of man. 'Awakenings': Robert De Niro and Robin Williams in a tale of medical magic. *Washington Post*, 11 January 1991, p. D1.
51. Dwight Gardner, 'The last curious man'. *Salon* [website], 24 December 1996. <http://www.salon.com/1996/12/23/sacks961223> (accessed June 2015).
52. See Wiltshire 1994.
53. Urs Jenny, 'Steh auf und wandle!' *Der Spiegel* (Hamburg), 11 February 1991, pp. 196–199 (here: p. 198).
54. For discussion of Sacks' approach to writing on medical subjects: Wiltshire 1991.

55. Serranía 2007. The same author remarked that “*Oliver Sacks himself commented that the film was a good image, or the portrayal, of the emotional situation of his patients. This assures us that we are not seeing an adaptation of a story but a faithful reflection of reality*”, perhaps indicating more about her confusion of levels of reality than the quality of the performance.
56. Ward 1929, pp. 280–291; here, p. 280.
57. Ward 1929, p. 291.
58. Oliver Sacks, ‘Speed. A neurologist’s notebook.’ *New Yorker*, 80 (2004), nr 23, pp. 60–69.
59. Self 2012, p. 137.
60. Möring 1990.
61. Booker 2000.
62. Fincke 2000.
63. <http://franzkafka.ovh.org/prace/recenzja5.htm> (accessed July 2012); Kuleta 2005.
64. Carlson 1999.
65. *Sandman*, #1, ‘The sleep of the just’ (1989), reprinted in Gaiman 1995. Dream, incidentally, escapes his captor in 1988.
66. Series 2 (2006), episodes 11 (‘Fishy’), 12 (‘Lethargica’), 13 (‘The end’).
67. ‘Mystery of the forgotten plague’. *BBC News*, 27 July 2004: <http://news.bbc.co.uk/2/hi/health/3930727.stm> (accessed September 2012).
68. See, for example, Jemima Harrison, ‘Woken from the dead’. *Times* (London) 15 July 1998 (magazine), p. 78, 79, 81.
69. Judith Cameron, ‘In a world of chronic illness. Five years ago, a rare brain infection left Sophie, a bright teenager, wholly dependent on full-time care.’ *Daily Telegraph* (London), 20 February 2004, p. 26.
70. Biographic sketches: David Charters, ‘Lost boy with gift for the world’. *Daily Post* (Liverpool), 15 January 2003, p. 14; Nick Craven, ‘He was a child prodigy and brilliant pianist ...’. *Daily Mail* (London), 2 January 2003.
71. Hoche 1923.
72. Hoche 1923. See also Bonhoeffer 1923; von Economo 1929, pp. 221–230; Willer 1929; more recently: Hoenig, 1987; Cheyette 1995.
73. Steiner 1927. This is an excellent contemporary review of the lessons drawn from the experience of EL by Heidelberg neurologist and neuropathologist Gabriel Steiner (1883–1965).
74. MacNalty 1926.
75. Geigel 1925, p. 239.
76. von Economo 1929, pp. 229–230.
77. Hoche 1923.