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Simon Shorvon: The Idea of Epilepsy

A Profound Journey through History

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The great master in the large field of epilepsy, Professor Simon Shorvon from the University College London Queen Square Institute of Neurology, where he has studied and taught as a clinical academic for over four decades, recipient of many outstanding awards, offers us a present in form of a 750 pages book on the idea of and on the many ideas on epilepsy in the modern era – perfectly (as usual) and beautifully published by Cambridge University Press.

The first section of the book titled «The voyage of the good ship Epilepsy» is introduced by the illustration «On her journey from 1860 to 2020, rocked by the currents of science, medicine, society and the person with epilepsy» by the artist David Cobley, who has been the first appointed artist in residence in the early 1990s at the Chalfont Centre for Epilepsy. Simon Shorvon acknowledges thankfully, that the artist «kindly agreed to produce a series of illustrations for this book, giving a layman's view of what it

must have been like to live with epilepsy at various times in the century. His brilliant and well-crafted illustrations perfectly catch the emotional consequences of epilepsy». The black and white illustrations are indeed well worth being looked at and examined, however, the core of the book is the particularly well written text. Clearly organized in three sections whereby section two titled «A plague upon your epileptic visage» embellishes the chronological order with gripping subtitles and thoughtful and well-referenced discussions: «1860-1914: the birth of modern epilepsy»; «1914-1945: ...the catastrophe»; «1945-1970: ...the new world order»; «1970-1995: ...in a globalized world»; and «1995-2020: ...floods are too recent».

Epilepsy is understood as a neurological disease but extending beyond a medical disorder. Its complex scientific, societal and personal significations and meanings provide a symbolism deeply embedded in the culture of humankind, incorporating other themes

besides those of medicine. The author has a vast knowledge and experience in medicine and in the humanities as well. In applying those, he does not isolate epilepsy and deprive it of its deeper meanings. Epilepsy is considered a 'paradigm of the suffering of both body and soul in disease' with its broad and deep connections. Of the nonmedical themes three stand out in particular: the involvement of science, the impact of societal trends on epilepsy and finally, the often harrowing personal experiences of individual sufferers. These themes are entangled, but each one is key to making sense of the meandering nature of epilepsy's journey, the often illogical conceptions adopted, and the sometimes inefficient or harmful practices employed. Simon Shorvon admirably succeeds to tackle these topics in much depth and detail providing insights into his vast and astonishing wisdom, and his descriptions, so carefully balanced and thoroughly referenced, are stimulating to read and to reflect upon. When

medicine is understood as the art of transforming natural science into human experience, science becomes entwined in social, political, economic, and psychological issues, and the result is the heart of any epilepsy history. On the side of the societal impacts of capitalism, social democracy, legislation, public attitude, and last but certainly not least, the social concepts of heredity are mentioned and discussed in much detail. The impact of epilepsy on the individual manifests most notably in prejudice and restriction of rights, the individual's sense of identity, stigma, and affect and confidence influencing many facets of the personal and public existence. As a well-known and acknowledged neuro-historian (he was the librarian of the Royal College of Physicians for many years), Simon Shorvon is underpinning all this in the weight of the past: «There is history in all our endeavors; and it is the past which provides the context for the present». To ignore the history of medicine is a form of illiteracy that condemns us not only to misunderstanding the present but also to bungling (an English word not so commonly used but exactly fitting in this context) the future.

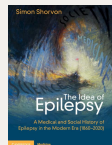
First aim of the book is to lay out a chronological story; to provide quasi a ship's log for a straightforward narrative history. However, it is admitted that many 'facts' are far from absolute, and that the appearance of a fact can change depending on scale, time, and perspective; they are, as always, relative, subjective, and dependent on context. «Facts of medical science are not immune to truth's elasticity» and need to be viewed in a matrix that includes the influences of societal, economic, and political trends, personal circumstance, and contemporary intellectual fashion. Meanings are dependent on the cultural trends of the time. Neither truthfulness nor honesty can be taken for granted in contemporary medicine and science. Despite such blurred edges, there is a quiet center where objective evidence, if analyzed impersonally, can guide a true understanding of the historical position and sequence of events, and the author has admirably proceeded on this basis.

The first aim of the book is to be a chronicle but its secondary focus is at least of equal importance, and potentially of more interest to many readers: explanations from various perspectives for the directions taken, not only describing what happened but also why it happened. The scientist, the physician, the everyman, and the patient each interpret the story from their own vantage point, and their

interpretations, their emphases, and meanings strikingly differ one from the other. In this book, the broad nature of history is presented and represented by the inclusion of four particular perspectives: (1) Science: scientific thought and theory has infiltrated not only medicine, but also personal and social life in a bidirectional way. Political and economic issues are powerful drivers of the scientific agenda, as are social influences on the direction of science. Science is frequently driven by the strong tides of the contemporary «Zeitgeist». (2) Medicine: 'the burning problems are etiology, pathogenesis, and treatment'. In the context of epilepsy, medicine is essentially applied science, dependent on technological advances e.g., in neuroimaging, clinical chemistry and genetics, but also on cultural fashion and societal trends. Many medical theories and practices, once hegemonic, are now viewed as bizarre aberrations. Some, once enthusiastically adopted, were later rejected. The same fate will await many of our contemporary practices. (3) Society: contemporary culture and societal beliefs are of fundamental importance in setting the medical agenda. Cultural attitudes define how universities and the industry prosecute science, and how doctors practice medicine. Capitalism dominated the century discussed, and the impact of political and economic policy on medicine has been notable in the fields of pharmaceuticals, legislation, and healthcare. Funding and societal norms dictate how science and medicine are progressing. Pharmaceutical money, through sponsorship of professional organizations, determines much of the medical agenda. Social forces also exert their influence through legislation. Laws and rules are put in place in relation to consent, employment, education, driving institutionalization and civil rights. Centralized, state-controlled healthcare systems are in place as part of the 'welfare state' and in this setting, healthcare is perceived as a right not as a privilege, with both positive and negative consequences. All these factors have a large impact, not only on science and medicine, but also on the person with epilepsy and their caregivers. (4) The person with epilepsy: the insider's view, obviously vital to the history of epilepsy, is the most difficult to unravel, but Simon Shorvon also impressively succeeds in this difficult topic. No single answer exists to the question 'How does epilepsy feel?'. Individual reactions differ and any attempt to provide definitive descriptions of a multilayered and com-

plex human experience is doomed to futility. A surrogate source of information about how epilepsy 'feels' and what it means is the depiction of epilepsy in biography, autobiography, literature, and film – a mixture of first- and third-person accounts, fiction, and fantasy. The book provides a treasure trove of striking and touching examples on many levels, open to different interpretations and sometimes deliberately ambiguous. However, the feelings, emotions, and thoughts of those with epilepsy can be explored with depth and subtlety through the unique mediation of the creative arts. Graphic art can also assist to indicate the emotional effects of epilepsy and its treatment in various guises and the illustrations in this book designed as they are by David Copley are examples thereof.

In this extensive and deep text, the word 'epilepsy' is essentially used as a reflection of contemporary convention in its historical context. It is a term of convenience and sort of a shorthand, especially in the societal and personal context grating against linguistic precision. In the arena of science, language is commonly mangled between the Scylla of unintelligibility and the Charybdis of blur. The term 'epilepsy' is a label not an entity and could possibly be dropped, not only in the interests of linguistic accuracy but for the benefit of medicine and its patients. This last quotation demonstrates how carefully Simon Shorvon uses his language in guiding us through the various and different, truly anthropological perspectives on epilepsy by laying out his vast knowledge and deep wisdom related to the topic before us readers. All is so well organized, referenced and formulated in particularly clear and beautiful English. We can only be grateful for this great work and congratulate the author and the publishing house Cambridge University Press on a masterpiece!



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