

INTRODUCTION

EPILEPSY OCCUPIES A UNIQUE POSITION AMONGST HUMAN AILMENTS. In medicine, it is now, as it has always been, the unparalleled hierophant of neurological disease. But at the same time, the notion of epilepsy extends beyond that of a medical disorder. With its complex scientific, societal and personal significations and meanings, it has attained a symbolism (an ‘idea’) which has become deeply embedded in the culture of mankind. In consequence, although primarily a medical history, the topic of this book, the story of *Epilepsy’s* voyage through the long twentieth century (1860–2020), has a wider brief, to incorporate other themes in addition to those of medicine. To ignore these would be to isolate epilepsy and deprive it of its deeper meanings. Although similar considerations apply in many diseases, this is probably truer of epilepsy than of most others. To Oswei Temkin, epilepsy was a ‘paradigm of the suffering of both body and soul in disease’,¹ and with its broad and deep connections, who can disagree?

Medicine occupies much of this book, but of the non-medical themes that I have attempted to grapple with, three in particular stand out: the involvement of science, the impact of societal trends on epilepsy and, not least, the often harrowing personal experiences of individual sufferers. These themes are entangled one with another, but each 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. The first theme is that of science – and this grows in importance. Medicine could be defined as the art of transforming

¹ Oswei Temkin (1902–2002) was the leading historian of epilepsy. His book *The Falling Sickness: A History of Epilepsy from the Greeks to the Beginning of Modern Neurology*, first published 1945, is a brilliant and scholarly account of the history of epilepsy up to the end of the nineteenth century. This notable expression appears in the last sentence of the book (2nd ed., p. 388).

natural science into human experience; in making this transition, science becomes entwined in social, political, economic and psychological issues, and the result is an often messy business. As the extent of this interaction is at the heart of any epilepsy history, the second prominent non-medical theme is the exploration of the societal currents as they washed over *Epilepsy's* decks. The most notable of these have been the impacts of capitalism, social democracy, legislation, public attitude, and, last but certainly not least, the social concepts of heredity. The third theme, the impact of epilepsy on the individual, is manifest most notably in prejudice and restriction of rights, on the individual's sense of identity, on stigma and on affect and confidence, which influence many facets of personal and public existence. Underpinning all this is the weight of the past. There is history in all men's endeavours; and it is the past which provides the context for the present. To ignore the past history of epilepsy is a form of illiteracy that condemns us not only to misunderstanding the present but also to bungling the future.

Why the long twentieth century? The year 1860 was chosen as the departure point for this journey as it was around then that the first modern conceptions of epilepsy appeared. It had been my initial intention to start the history in 1900, but the prior forty years proved so directly important for epilepsy that elongating the century made irrefragable historical, medical and scientific sense.

On launching into the process of writing, it also became immediately obvious that complexities had to be faced which were the consequences of the broad nature of epilepsy; some were unexpected and some indeed counter-intuitive – not least the proposition that epilepsy should perhaps not now even exist. I therefore decided – at a late stage – to include the following introductory section, outlining the aims and purposes of the book and surveying the complexities and the approaches taken to navigate around them. I was reminded of the words of Blaise Pascal, who himself died in status epilepticus, that 'The last thing we discover in writing a book is what to put in first',² and I found myself agreeing with him.

THE PURPOSE OF THE BOOK

Aims and Perspectives

As has been the case in medical histories of many conditions, the first aim of the book is to lay out a chronological story: to provide a ship's log of *Epilepsy's* voyage, a gazetteer and a Pevsner's guide to her ports of call. In this sense, its primary purpose is to provide a straightforward narrative history. However, even this relatively modest goal is not without complications. Many 'facts' are far from absolute and, like the ocean wave, the appearance of a fact can change

² Translated from Pascal, *Pensées*, p. 265.

depending on scale, time and perspective; in a very real sense, many facts are thus at some level fake news – relative, subjective and dependent on context.³ Nor, as sometimes assumed, are the facts of medical science immune to truth's elasticity – these too need to be viewed in a matrix that includes the influences of societal, economic and political trends, personal circumstance and contemporary intellectual fashion. In other words, medical facts, like all others, have meanings which are to a degree dependent on the cultural trends of the time.⁴ Furthermore, not all is necessarily what it seems⁵ in a world of spin and exaggeration, and neither truthfulness nor honesty in contemporary medicine and science can be taken for granted.⁶ Despite such blurred edges, there is a still centre where objective evidence, if analysed impersonally, can guide a true understanding of the historical position and sequence of events, and I have proceeded on this basis

The level of detail is another consideration. I have put into this history considerable detail on the medical aspects with a medical readership in mind. Lay persons can skip the detail if they wish, and to facilitate this where possible I have endeavoured to bring out the salient points in summary. There is then the question of what items to include. In mapping the century-long journey, a navigator inevitably steers an arbitrary and intuitive course in choosing which tide to be swept along on and upon which star to point his sextant, as Temkin similarly noted.⁷ It is also clear that the direction of travel is not one of seriate or uninterrupted social or scientific progress, as of an ocean liner moving on the shortest trajectory between two points. Rather, it is a journey in which *Epilepsy* not infrequently travelled down blind fjords or tacked in aimless circles, routes which yet consumed much energy and time. This complicates the story, but to ignore the meanderings would be to sanitise the narrative.

If the first aim of the book is to be a chronicle of *Epilepsy's* voyage, its second is of more than equal importance, and, one may feel, of more interest. This is to offer an explanation for the directions taken: to explain not only *what happened* but also *why it happened*. Exploring the 'why' of the story is a task more hazardous than defining the 'what', largely because of the fundamental problem

³ As Orwell noted in 1943, 'The very concept of objective truth is fading out of the world' (*Looking Back at the Spanish War*, p.198). In 2022 it is difficult to disagree.

⁴ See, for instance, the works of Roy Porter, Michel Foucault, Thomas Kuhn and Paul Feyerabend.

⁵ As Sherlock Holmes observed, there is nothing more deceptive than an obvious fact (Doyle, *Adventures of Sherlock Holmes*, p. 91).

⁶ A theme interestingly explored in a fictional way by Lauren Slater in her epilepsy biography (autobiography?) *Lying: A Metaphorical Memoir*, described in Chapter 5.

⁷ 'But I have nowhere aimed at completeness; rather I have tried to obtain a picture of the thought of the different periods. That such a procedure is not without danger I am fully aware. The material used is only a fraction of the tremendous literature written on the subject and I may easily have overlooked material which would give a quite different aspect.' (Temkin, *Falling Sickness*, p. xi).

of perspective. The scientist, the physician, the everyman and the patient will each interpret the story of *Epilepsy's* journey from their own vantage point, and their interpretations – their emphases and meaning – do strikingly differ one from the other. In this book, I have tried to represent the broad nature of the history by the inclusion of four particular perspectives:

The perspectives of science: As Peter Watson⁸ has correctly pointed out, the influence of science on the history of the twentieth century is one often overlooked by historians. Indeed, science and its armies, officers and foot soldiers have played an overwhelming role in the history of modern epilepsy, both directly, and also indirectly by their impact on society and culture. Increasingly through this period, scientific thought and theory has infiltrated not only medicine, but also personal and social life. The influences, though, have been bidirectional. Political and economic issues have been powerful drivers of much of the scientific agenda, as have social influences on the direction of science. Science, at least as applied to epilepsy, has been frequently driven by the strong tides of the contemporary zeitgeist.

The perspectives of medicine: The primary concerns of medicine were (and are), as Francis Walshe – whose perspective was quintessentially that of the clinical neurologist – famously put it, ‘the burning problems of . . . etiology, pathogenesis, and treatment’;⁹ and these have indeed remained at the centre of epilepsy medicine throughout the long twentieth century. The medicine of epilepsy is essentially an applied science, dependant on technological advances, for instance in neuroimaging, clinical chemistry and clinical genetics, and also on cultural fashion and societal trends. Because of their multiple and sometimes contradictory influences, many medical theories and practices, once hegemonic, are now viewed as bizarre aberrations, and once enthusiastically adopted were later completely rejected. No doubt the same fate will await many of our contemporary practices (and this is a point taken further in the Epilogue, and see also Appendix 2). The predominant attitude of doctors to epilepsy, and the style of medicine, have also varied greatly as have the medical facilities provided for epilepsy and these also have greatly influenced the social and personal course of epilepsy.

The perspectives of society: Often downplayed in scientific and medical treatises is the fundamental importance of contemporary culture and societal beliefs in setting the medical agenda. Throughout the long twentieth century, cultural attitudes defined how university and industry prosecuted science, and how doctors practised medicine. Capitalism dominated the century, and the impact of political and economic policy on epilepsy has been notably in the fields of pharmaceuticals,

⁸ Watson, *A Terrible Beauty*. ⁹ Walshe, ‘The present and future of neurology’.

legislation and healthcare. Funding and societal norms to a large extent dictated how science and medicine were to progress. Pharmaceutical money, through sponsorship of professional organisations, bankrolled much of the epilepsy agenda. Social forces also exerted their influence through legislation, and laws and rules in relation to epilepsy were put in place in relation to consent, employment, education, driving institutionalisation and civil rights. Following the Second World War, centralised state-controlled healthcare systems were then put in place as part of the 'welfare state' and in this setting, healthcare for epilepsy (and most other conditions) has become to be perceived as a right not a privilege, with both positive and negative consequences. All these factors had a large impact not only on science and medicine but also the person with epilepsy.

The perspectives of the person with epilepsy: The final perspective is that of the sufferer – the insider's view of epilepsy. Although obviously vital to the history of epilepsy, this area has been the most difficult to unravel. No single answer exists to the question 'How does epilepsy feel?' as, of course, there are all sorts and conditions of man. Individual reactions differ and any attempt to provide definitive descriptions about what is a multi-layered and complex human experience is doomed to futility. Nevertheless, general statements are possible, and have some validity. 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. These of course work on many levels, are open to different interpretations, and are sometimes deliberately ambiguous. However, within this corpus of work, the feelings, emotion and thoughts of those with epilepsy can be explored with the depth and subtlety that only the creative arts can convey. Graphic art can also assist – and the illustrations in this book by David Cobley are an example, designed as they are to indicate the emotional effects of epilepsy and its treatment in various guises.

Does Epilepsy Really Exist?

Epileptic seizures certainly do. But is epilepsy really a disease entity or a term worth preserving? It is argued in this book that by 2020 the condition may no longer exist, in part the result of the advances in epilepsy medicine which have brought into sharp focus the inherent vagaries of the concept of disease and the confusion between disease and symptom (this is a point expanded upon in the prologue and epilogue of this book). Throughout this text, I have used the word 'epilepsy' essentially as a reflection of contemporary convention. Often it would have been better and more precise to have rejected the word 'epilepsy' as a meaningful entity, but I have tried to maintain its historical context. At another level,

epilepsy is a term of convenience and to some extent a *shorthand*, especially in the societal and personal context. Its existence is an issue which grates against linguistic precision – another under-rated virtue in the arena of science, wherein language is commonly mangled between the Scylla of unintelligibility and the Charybdis of blur. Perhaps now we have come to a point where the term ‘epilepsy’ should be recognised for what it is – a label, not an entity – and be dropped, not only in the interests of linguistic accuracy but for the benefit of medicine and its patients. This is an issue debated at the end of this book.

Complexities

Other difficulties and complexities have compounded the problems of writing this history and are briefly articulated here.

First, the story is divided, in the main, into chronological periods despite the obvious fact that the division is artificial. Currents ignore the boundaries of time and, for reasons of clarity in the telling of the narrative, chronology has been not infrequently breached; it is hoped this does not disrupt too much the tempo of the voyage.

Second is the bias of language. The choice of material has been made with a preference for documents written in English, a problem more troublesome at the beginning of this history than at the end, when much is published in English regardless of source. I also have tended to cite well- or interestingly-written works, a strong personal preference but one which does not necessarily have much relevance to historical importance.

Linked to language is geography, and the emphasis on the anglophone carries with it an inevitable tendency to overstate the Anglo-Saxon perspective. I have tried to avoid this as far as is possible, but realise that, particularly in relation to the social and personal aspects of this history, there is bias towards British and American material. It is these cultures and their history that I know best. In my defence is the fact that many trends in anglophone culture were shared in other countries, and the political and economic descriptions of such aspects as drug regulation and finances are to be read as *examples* of very similar trends elsewhere. Similarly, when referring to Europe, the text not infrequently confines its discussion to Western European countries, including Britain, at the expense of those of Eastern Europe. Where I have been able to, I have tried to temper this bias and maintain a broader perspective; and, at least in the second half of this history, the globalisation of epilepsy and its cultures has anyway diminished regional differences.

Third, in describing the progress of *Epilepsy*, the greatest emphasis has in general been placed on origins and foundations of trends and events, rather than on their

subsequent course, and on the originators, not subsequent epigones. Elephants and butterflies are described, but not the worker ant. This emphasis seems justified but again leads to a bias of material with which all would not agree.

Fourth is the conundrum of where to include detail and where not to. Too much and the wood is obscured by the trees; too little and there is no wood at all. There is also a tension between providing a synoptical yet explanatory view of *Epilepsy's* voyage, and so I decided to include great detail on those points in the journey in which the direction changed (examples are, for instance, the rise and fall of eugenics, the discovery of EEG and the changing funding structures of research in the post-war years) and to take a more abbreviated approach where progress was incremental and the trajectory more straightforward – indeed, to the extent that mention of whole areas of work are severely truncated. Another bias is the fact that the developments in medicine are discussed in most detail, and science in the least, reflecting my own interests but also to rein in the length of the book. The last quarter-century provided particular problems in this regard, both because the amount of activity in all fields of epilepsy has massively increased, and also because the waters of history have hardly receded, leaving the ground too wet to know exactly what shape its landscape will take. The story of the last quarter-century is therefore described deliberately in a much more brevilouquent and provisional form – particularly in relation to the science and clinical medicine of epilepsy.

Then there are the hurdles of intelligibility and jargon. The book is written in the hope that it will interest the informed public at large. But the language of science and medicine are inevitably technical, and the narration has not been dumbed down. A balance has to be drawn. Too technical and the conversation becomes closed to all but specialists; too loose and the science is rendered banal and tiresomely infantile. In this book, technical description is included, albeit modified with the intention where possible of making it comprehensible to the informed lay reader. A glossary of some of the technical terms is included to help bridge the gap of readability.

Another apology is needed regarding terminology. In parts of the text I have used terms which today are rightly considered prejudicial. For example, in the earlier chapters the word 'epileptic' is used in place of a 'person with epilepsy' and 'mental defective' in place of a 'person with learning disability'. Prejudicial wording has been retained where these were terms in contemporary usage, as in narrating the history it seemed to me more truthful to reflect the tone and nature of the historical voice as well as its content. I diverge from a 'cancelling' tendency, and believe that history should not be sanitised or rewritten by prohibiting terms which today are not appropriate. Similarly, I have in general described the science and medicine of epilepsy using contemporaneous

terminologies, and not changes subsequently made (for instance, when referring to seizure types or treatments).

A final issue to be grappled with is determining the extent to which the course of *Epilepsy* has been due to the genius of individuals, as Thomas Carlyle put it to ‘Great Men’ (or, as Heinrich von Sybel pronounced, ‘[t]he masses do nothing’) or conversely to the milieu in which they lived, the fertile soil in which genius could flourish.¹⁰ There have been great men and women whose contribution to epilepsy has been epochal but whose work is embedded in a pre-existing clinical, scientific or societal framework, and on the shoulders of more minor work of others, and untangling how much this framework facilitated their contribution is not possible. In general, my preference has been to avoid hagiography (a constant danger in any medical history), and so the book is based more on factual action than on biography or people. But I have diverged from this rule for a small number of truly exceptional individuals whose accomplishments transcended the conventional to such an extent, and were so personal, that exemption seems justified; for those with more modest but nevertheless important contributions, a short biographical footnote is added.

An assessment of the value of any individual’s contribution to any field can be made sensibly only after the passage of time, and indeed in some cases only over generations. It is for this reason that I have taken the decision *to avoid describing in any detail at all the personal contribution of any living individual*. This, I realise, is likely to be most contentious, and is bound to cause displeasure to the many still alive who are well worthy of inclusion. It is also a decision made in the full recognition that it weakens the focus of the most recent history, which, as mentioned, is abbreviated and more provisional. I hope those searching the index for the names of the living will understand the reasons for, and the logic of, this injunction and pardon the author for their omission.

This book was written by a clinician, one entranced by history but not a historian by trade or training. Incorporating the broader political, economic and historical trends, and their antecedents, has been the most difficult task – not least because, in describing the course of *Epilepsy*, efforts have been made to avoid value judgement, unifying theory or overarching political philosophy, or taking strong historiographical positions such as are often at the centre of other historical narration. In my view, key to describing history is the need to guard against one’s own sympathies, but, however much one tries, an act of interpretation will always be a personal matter. The story thus has the inevitable biases of a Cambridge-educated, Caucasian, male, British, clinical neurologist, of the baby-boomer generation, and a university academic, with all the cultural baggage that this entails.

¹⁰ Carlyle, *On Heroes*; H. von Sybel, cited in Thompson, *History of Historical Writing*, vol. 2, p. 214.

Whether the book succeeds in either satisfactorily documenting the narrative history or providing convincing explanations of it is for the reader to decide. For the author at any rate, its writing has been both a cathartic and an exciting voyage of discovery, as few subjects are as interesting or as complex as the story of this ancient disease.

THE STRUCTURE OF THE BOOK

One of the supreme works of medical history is Robert Burton's *Anatomy of Melancholy*.¹¹ The title of the current work is a deliberate homage to Burton's book in recognition of the many ways that it has set the standard against which all other disease histories should be matched.¹² Burton liked to paint a sprawling canvas, mixing up different themes and perspectives: as he put it, 'An Anatomy . . . philosophically, medicinally and historically opened and cut up'; this I find attractive and have also attempted. For epilepsy (in Temkin's words, 'a paradigm of the suffering of both body and soul in disease', p.388) and melancholia (in Burton's words, 'this being a common infirmity of body and soul, and such a one that hath as much need of spiritual as a corporal cure', p. 27) share enough similarities to justify this approach.

He liked to draw in facts from many fields, in recognition of the fact that the effects on a disease are not limited 'to the confines of physic', and issued this warning: 'If any physician in the mean time shall infer, *ne sutor ultra crepidam*, and find himself grieved that I have intruded into his profession, I will tell him in brief, I do not otherwise by them, than they do by us' (p. 26). This is a sentiment shared in this book. Epilepsy, like melancholia, has both involvement in and implications for many areas of human endeavour.

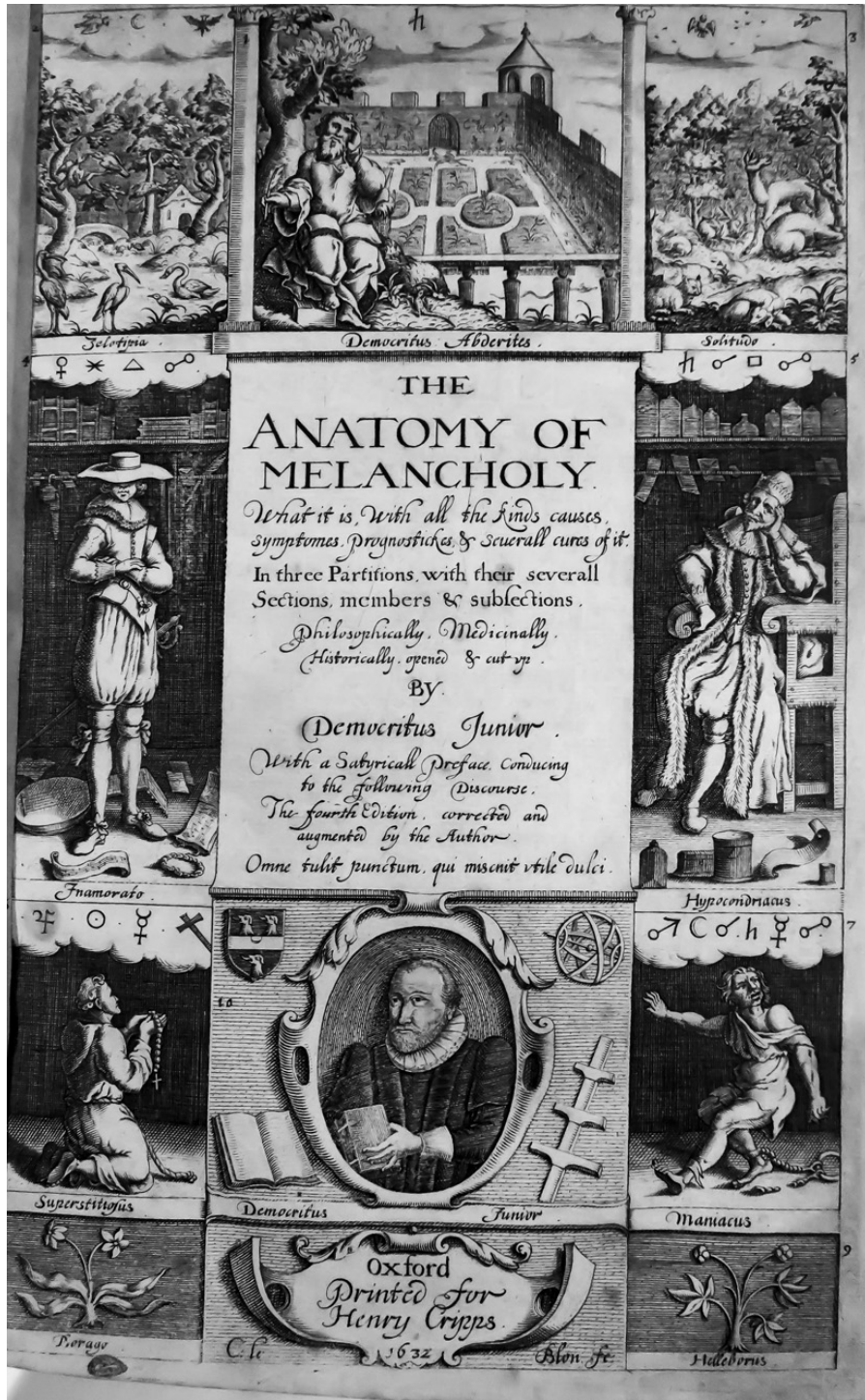
The book is divided into three sections (similar to the 'partitions' in Burton's work), each of which has a specific purpose.

Section 1: The introduction and prologue adopt one of the purposes of Burton's *preface*, to briefly outline the aims of the book, its scope, structure and perspectives, and some of the complexities encountered in its writing. The prologue briefly reviews the changing concepts of epilepsy. Burton's preface was in part satirical, but here this story of epilepsy diverges and, in the wkish style of today, the condition is treated with more decorum.

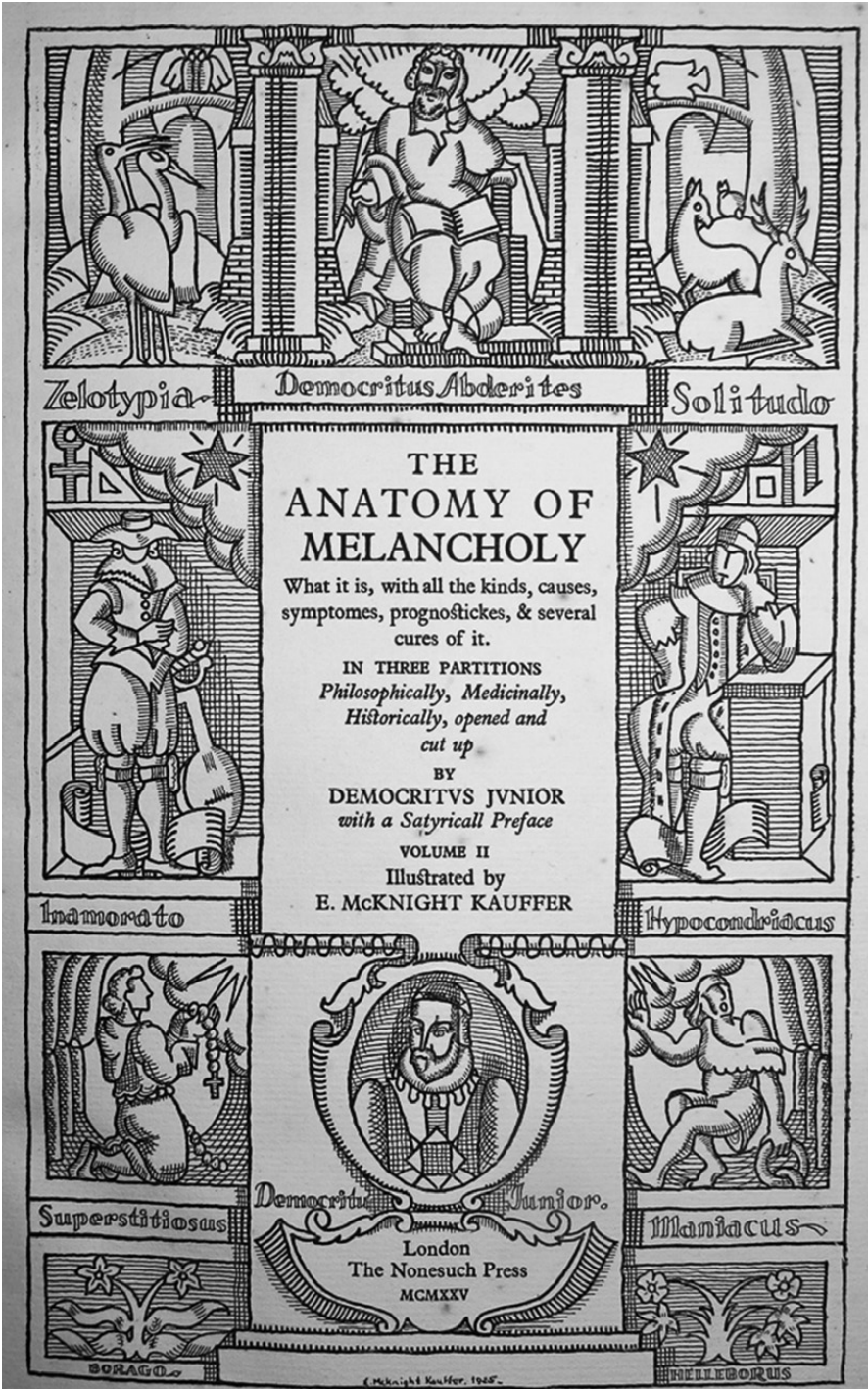
Section 2: This is the heart of the book (and its fat) – a chronological narrative history (a log book) of the journey of *Epilepsy*. The five chapters cover

¹¹ The full title of the book is *The anatomy of melancholy, what it is, with all the kinds, causes, symptoms, prognostics, and several cures of it. In three partitions. With their several sections, members, and subsections, philosophically, medicinally, historically, opened and cut up. By Democritus Minor. With a satirical preface, conducing to the following discourse* (Oxford: printed by Henry Cripps, 1626 (second edition). Quotations are from the Preface.

¹² 'Idea' is substituted for 'Anatomy', as the latter word and page numbers from the Nonesuch edition now carries too strongly the imprimatur of science.



2. The frontispiece to the 1632 edition of Burton R., *Anatomy of Melancholy*, and Edward McKnight Kauffer's reinterpretation for the Nonesuch Press's edition in 1925.



2. (cont.)

the years 1860–1914, 1914–45, 1945–70, 1970–95 and 1995–2020. This chronological narrative is detailed and divided into topics roughly mapped across the four perspectives outlined previously. As mentioned earlier, the last chapter, covering the period 1995–2020, is dealt with less comprehensively as the recency of events precludes a detailed historical assessment. It is in this and the preceding chapter that the linked decision not to describe in any detail the achievements of *living persons* has its most obvious impact.

Section 3: A single chapter, the *Epilogue*, with its appendices, is written with two purposes. The first is to assess the progress *Epilepsy* has made since 1860, and to identify which of the many ideas and discoveries that bubbled up during its long journey *have endured* and why. I have attempted very briefly to summarise this progress from the four perspectives outlined above. The second aim is to articulate those ideas and concepts of contemporary epilepsy which in my view might be misconceived, heading in the wrong direction or frankly incorrect. It is in this section that my personal views are expressed and where my own prejudices and preferences trump the neutrality I have tried to ensure in the earlier text. And then, in the last pages, and briefly, I also address the ambiguities of the concept of disease and question the very existence of epilepsy – suggesting that it is an *idea* and a *term* which now holds up progress and has had its day.

Finally, and for all mistakes and distortions in any part of the book, I offer my apology – which I borrow verbatim from Burton, for no one can have expressed this better:

GENTLE reader . . . [If] I have overshot myself, have spoken foolishly, rashly, unadvisedly, absurdly, I have anatomized mine own folly. . . . [If] I have had a raving fit, a phantastical fit . . . If through weaknesses, folly, passion, discontent, ignorance, I have said amisse, let it be forgotten and forgiven . . . I hope there will no such cause of offence be given; if there be, *Nemo aliquid recognoscat, nos mentimur omnia*.¹³ I'll deny all (my last refuge), recant all, renounce all I have said, if any man except, and with as much facility excuse, as he can accuse; but I presume of thy good favour, and gracious acceptance (gentle reader). Out of an assured hope and confidence thereof, I will begin.

¹³ Burton translates this in a footnote as: 'let not anyone take these things to himself, they are all but fictions'. (Burton, *Anatomy of Melancholy*, Nonesuch edition p. 78).

