If we are to avoid undermining, belittling, or stigmatizing migraine and the people affected by it, then the words we choose matter. Throughout this book, many of the words I use reflect historical ideas about migraine, but, as accepted conventions for the appropriate terms are constantly in flux, it is important to be clear about the rationale I have followed when selecting my terminology. Since 2016, the American Headache Society has accepted and described migraine as a “neurological disease.” In Britain, the website of the National Migraine Centre also uses “disease,” while the main advocacy charity Migraine Trust describes migraine as a “complex neurological condition.” In this book I use the terms “disease,” “condition,” and “disorder.” The authors of historical sources often talked of migraine as a disease, while I use the terms “syndrome” and “illness” when historically appropriate. In particular, I understand illness as denoting the presence of a subjective sense of unwellness, to differentiate it from the notion of disease as an underlying condition that may not manifest in tangible symptoms. I use “migraine” to refer to the underlying condition and “attack” to describe individual episodes.

It is also important to consider how we speak about people. Unless used by my sources, I refer to a “person with migraine” or a “person who experiences migraine,” rather than “migraineur.” Although many people with migraine, including migraine scholars, have actively adopted the term migraineur to describe themselves and their identity (as well as using migraine as a verb, as in “I’m migraining”), others find the label unhelpful. To talk of someone as a migraineur implies that they are defined by their migraine. As Joanna Kempner has suggested, these kinds of words can imply that migraine is something that people do, and, therefore, have control over—so their use (or not) should be a personal choice. I try to avoid words related to “suffer,” “sufferer,” or “complaint” altogether, except when necessary in quotes or when paraphrasing historical material. In so doing, I follow the lead of neurologist William B. Young, who has done a great deal to raise awareness of the effect of terminology in migraine and who has provided clear guidance for talking about migraine.1

As published work becomes ever more visible online, we must consider carefully how we reproduce the details of personal medical records. For this reason, in chapter 5 the patients from London’s National Hospital for the Paralysed and Epileptic are referred to only by their first name and the initial
of their surname, as requested by the archivists at the University College London Institute of Neurology, Queen Square Library.

The artists who submitted their work to the Migraine Art competitions in the 1980s have not been named, either on the website that now makes the entire collection available or in the discussion in this book. While, at the moment of submitting their pieces, entrants freely gave their names and agreed that their artwork could be used, this was in a period before the internet. Particularly because many of the artists were children at that time, it would have been wrong for us to have a person’s name digitally available in a way that would make elements of their medical history visible without their knowledge.
Migraine
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