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## Migraine

Foxhall, Katherine

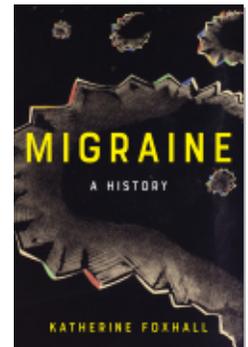
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## Introduction

### *Programmed In?*



#### Nature's Rotten Tricks, 1985

A woman's head with neatly bobbed hair stares out of the picture (fig. 1.1). At least, it would do so if the arcade games machine did not obscure her face. A strange black-and-white crescent shape—a spiky, glowing zigzag—fills the screen of the migraine computer where the woman's eyes should be. The shape emanates outward from a small dot in the jaws of the arc on the right hand side of the screen. The artist has entitled the painting *Programmed In!*, and, in much smaller writing to the side, an easily missed subtitle: (*Unwillingly.*) *Woe Is Me!* The arcade machine—generously supplied by Nature's Rotten Tricks—offers a list of animated games, all for free, that the player can choose. Some of these, such as Rainbow or Expanding Angular, suggest the special effects that might be encountered while playing, while others are more cryptic. Does Mobile Stellate involve intergalactic travel, perhaps, or Fortification some kind of siege? In fact, the game titles on the arcade machine are all types of migraine aura, taken from a lecture given by the renowned Victorian neurologist William Gowers in 1895. The zigzag arc on the screen is a rendering of a well-known diagram of a “scintillating scotoma,” drawn by Dr. Hubert Airy, physician son of the famous astronomer George Biddell Airy, and first published in 1870. In this artist's imagination, Airy's scotoma has been reimagined as Pac-Man, the main character of a coin-operated arcade game released by the Japanese company Namco Ltd. in 1980.<sup>1</sup> In the original game, the yellow Pac-Man gobbled a trail of white dots, all the while being chased by four multicolored ghosts. Here, we might imagine chasing a never-ending supply of little white pills in a constant search for relief from an incurable disorder.

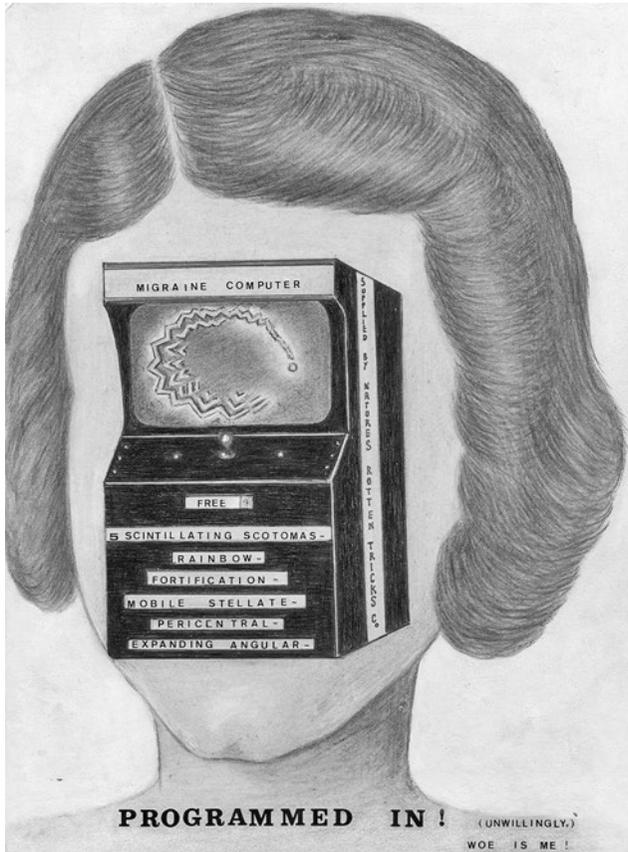


Fig. 1.1. *Programmed In! (Unwillingly.) Woe Is Me!*, submitted to the Third Migraine Art Competition, unnamed artist, 1985, image 449. Courtesy of Migraine Action via the Wellcome Collection, licensed under CC-BY

This revealing image is from 1985, and it was submitted to the third of four Migraine Art competitions held between 1980 and 1987. The electronic machine and the reference to programming illustrate the contemporary emergence of a modern neurological framework for describing migraine, yet the nineteenth-century language and imagery overlaying the face seem to define what migraine is and how it can be talked about. It is not just the illness, but the cultural and historical frames of reference available to speak about it that are programmed into the unwilling woman's head.<sup>2</sup> The machine effaces the woman's identity and prevents her from communicating and experiencing migraine on her own terms. The artist's lament at migraine being programmed

in attests to the significance of heredity in determining who gets migraine. At the same time, we might read this title as a defiant rejection of a modern tendency to attribute migraine to some kind of personal failing or weakness, a disorder primarily associated with women that could be avoided if only they would eat better, sleep more regularly, and avoid stress. While women are overwhelmingly represented in the ranks of those who experience migraine, as *Programmed In!* implies, it is their voices, and their experiences, that are often marginalized.

The blending of modern and historical references in *Programmed In!* neatly illustrates the central argument of this book: a modern neurological framework that defines our current understanding of migraine as a neurobiological disorder located in the brain has determined a narrow set of boundaries with which to understand and talk about migraine. This process, I argue, has had a profound effect not only on our understanding of migraine's history, but also on our ability to account for, and take seriously, the huge range of experiences that people with migraine encounter in the present. In this study, I propose a way to think afresh about migraine's past; to reveal the ways people have described, explained, and treated migraine since the Middle Ages; and to show how and why that long history has shaped our modern knowledge of, and approach to, this extremely common condition and the people who have it. While there are certain continuities in a cluster of symptoms that have been called migraine over hundreds of years, our understanding of migraine's causes and symptoms, the therapeutic practices we use to deal with it, and our cultural and social attitudes toward the people who have migraine all have long histories that warrant investigation. Changing ideas about the role of humors and blood circulation in the body, the physiology and function of the brain, gender, the relationship between various acute and chronic illnesses, national medical cultures, institutional specialization, and the weight we give to particular symptoms have all contributed. We cannot understand modern migraine without a knowledge of its fascinating and varied history.

### What Is Migraine?

For nearly two thousand years, people have known of a disorder called migraine. The origins of our modern term can be traced to the second century, when Roman physician, surgeon, and philosopher Galen coined the term "hemicrania." The essence of Galen's hemicrania was a symptom: a pain that affected half the head. This symptom (and the related disturbance of the stomach that he also identified) has remained important to concepts of migraine

ever since, although migraine is now often, though not always, considered to include such one-sided pain.<sup>3</sup> Through translation and use, Galen's term spread. It became *emigranea* in Latin and Middle English. In medieval Welsh we find *migran*. The fifteenth-century Scots poet William Dunbar used "magryme." The early modern period saw a wide variety of variations on the English vernacular "megrim" or "meagrim." For example, within Jane Jackson's recipe book, we find "migrim," "migrims," "migrime," "mygrime," and "mygrim." In printed works, common since the sixteenth century, the letters *i* and *y* were often considered interchangeable, depending on the typesetter's preference. Examples include "migrim" or "mygryme."<sup>4</sup> Galen's term provides the common root (*m*, *c/g*, and *r*) for the German *migräne*, the Spanish *migraña*, and the French *migraine*. In Swedish, we find *migrän*. Czech and Hungarian have *migréna*; modern Greek, *imikrania*. Today *migréna* would be recognized in Croatia, Azerbaijan, and Poland. And so on.

Over time, other symptoms besides head pain and gastric disturbance have been added, or became important to, developing concepts of migraine. In the early medieval period, sensory symptoms were often included in discussions of migraine, before slipping out of common use until late eighteenth-century European writers incorporated them once more. The significance of gastric disturbances has waxed and waned, depending on the changing medical frameworks that best seem to explain migraine at any particular time. By the turn of the nineteenth century, English-language speakers often used "sick headache" or "bilious headache" to reemphasize the relationship between the key symptoms of head pain and nausea, apparently in response to an evolution of the meaning of megrim toward an association with nervous disorder over the preceding century. Nineteenth-century authors spilt much ink explaining which words denoted particular kinds of headache. In the 1870s, Cambridge physician Edward Liveing used the English term in his influential text *On Megrim*, but by then the majority of his contemporaries preferred the French term *migraine*.<sup>5</sup> Migraine has also been allied with many other disorders, from the humoral concept of rheum in the seventeenth century; to vertigo in the eighteenth; epilepsy and hysteria in the nineteenth; and chronic daily headache, cluster headache, and trigeminal autonomic cephalalgia in our own time.<sup>6</sup> These discussions have all played an important role in shaping migraine's history.

What is migraine in the twenty-first century? For writer and broadcaster AL Kennedy, it's "a ghost, it's a gaoler, it's a thief, a semi-perpetual dark companion."<sup>7</sup> Rudyard Kipling, on the other hand, thought his hemicrania was "a

lovely thing,” though it literally divided him in two: “One half of my head in a mathematical line from the top of my skull to the cleft of my jaw, throbs and hammers and sizzles and bangs and swears while the other half—calm and collected—takes notes of the agonies next door.”<sup>8</sup> Around the world, migraine affects approximately a billion people, or one in seven, of whom two-thirds are women. This means that virtually everyone will live with, work with, be related to, or be friends with someone who has migraine. Globally, it is the most common, and the most economically burdensome, of all the neurological disorders, as well as the third leading cause of disability among the under-fifty age group. It is more prevalent than diabetes, epilepsy, and asthma combined.<sup>9</sup>

Migraine is a spectrum disease, usually manifesting as an episodic or chronic primary headache disorder, characterized by attacks that can last from a few hours to up to three days. It is two to three times more prevalent among women than men, and women experience higher levels of pain, longer lasting attacks, and greater disability than men.<sup>10</sup> For much of the twentieth century, migraine’s causes were considered to be vascular, and the pain a result of dilation of the cranial blood vessels. Since the 1970s, the emphasis has shifted, and it is now defined as a disorder involving nerve pathways and chemicals in the brain, to which people are often genetically predisposed. While migraine is still understood to affect the neurovascular system, it seems likely that the headache pain comes from neurogenic inflammation, rather than vasodilation. This is a problem of brain function, rather than structure. As the website for the National Migraine Centre in London explains, “if the brain is a computer, migraine is a software not a hardware problem.”<sup>11</sup> Nevertheless, a huge amount remains unknown, including the role of the hypothalamus (the part of the brain that controls the endocrine system and has a role in the menstrual cycle, pain modulation, and governance of the body’s circadian rhythms), the cause of premonitory symptoms, the extent to which antimigraine drugs can access the brain, and the role of the blood-brain barrier.<sup>12</sup>

Migraine headaches pulsate, are frequently one sided, can be extremely painful, and often are aggravated by normal physical activity. Other well-known symptoms include nausea and vomiting, as well as visual or sensory disturbances, known as aura, that usually take from five to twenty minutes to develop and can last for up to an hour before resolving completely. Before and during a migraine attack, many people encounter various symptoms, such as tiredness, emotional disturbance, poor concentration, sensitivity to light or sound, blurred vision, nausea, and yawning. On average, migraine sufferers

experience one or two attacks a month. For more than two-thirds of women with migraine, and just under half of men, these attacks last longer than a day. In addition to the pain and discomfort felt during each attack, the cumulative effect of migraine can bear on all aspects of daily life, affecting relationships with family, partners, friends, and work.<sup>13</sup>

There are two major types of migraine. Migraine *without* aura (previously known as common migraine), is experienced most frequently, is usually more disabling, and is often related to the menstrual cycle in women. Migraine *with* aura (known since the late nineteenth century as classic, or classical, migraine), is characterized by recurrent neurological disturbance, particularly of vision, which precedes the onset of headache. The word “aura” comes from the Greek for “breeze,” and visual aura is the most common sensory symptom. A visual aura, usually lasting between five and thirty minutes, is often characterized by zigzag patterns that develop from a central originating point into a C shape that spreads outward across the field of vision, but they can also take the form of a corona, stars, or loss of sight in some of the visual field. Aura can affect any of the human senses, appearing as pins and needles, whistling sounds, numbness, or speech disturbance.<sup>14</sup> In 2011, Serene Branson, a reporter for CBS in Los Angeles, famously was unable to make herself understood when she experienced migraine on air while reporting from the Grammy Awards ceremony, leading many to assume that she was either drunk, on drugs, or having a stroke.<sup>15</sup> Aura can also take the form of vertigo, tinnitus, reduced hearing, difficulties balancing or walking, or even decreased consciousness. For some people, an occasional visual aura may be the only symptom of migraine they ever experience. For others, the aura is a signal, announcing the imminent onset of a debilitating migraine headache, with all its associated symptoms.

As Dawn C. Buse and her colleagues observe, the striking difference in migraine prevalence among women and men in our own time is one of migraine’s hallmarks.<sup>16</sup> Yet, as this book demonstrates, a gendered ratio is not an inherent characteristic of a timeless disorder, but a result of evolving ideas about the kinds of people who are most likely to get migraine, and of key decisions about which symptoms should, and should not, be included in the category of migraine. It is only since the global acceptance of the *International Classification of Headache Disorders (ICHD)* criteria from 1988 that this gender ratio has become widely accepted, a remarkably recent development. We also now know that men and women experience migraine differently. By

comparing women with women, and developing clear criteria for menstrual and menstrual-related migraine, British specialist Anne MacGregor and her colleagues have demonstrated that menstrual attacks (which account for more than half of migraine in women) are “clinically different” from nonmenstrual attacks: they “last longer, are more severe, are more likely to relapse, are less responsive to treatment, and are associated with greater disability.” Significantly, migraine attacks that are directly associated with menstruation tend not to include symptoms of aura, even if those women develop attacks of migraine with aura at other times. Only around one in eight women experience visual aura, compared with around a third of men. In short, for women overall, it seems that migraine is a less visual, but distinctly more painful thing to reckon with.<sup>17</sup>

Other factors beyond gender determine the likelihood of experiencing migraine. Migraine is common in children, affecting between 6 and 8 percent (9.7% for girls and 6.0% for boys). Often, recurrent, severe abdominal pain in childhood can be a precursor for the development of migraine later on. For girls, prevalence increases after puberty, rising from 7 percent under the age of fourteen to nearly 10 percent by the age of twenty.<sup>18</sup> Migraine tends to increase in severity until around age forty before declining, particularly in women.

As socioeconomic status decreases, chronic migraine prevalence seems to increase.<sup>19</sup> The question of whether lower socioeconomic status is a cause of migraine (for example, because of the increased likelihood of factors such as poor nutrition, high stress, and limited healthcare) or whether it is a result of the disease affecting education and employment prospects, is a thorny question. Advocates and headache professionals alike are wary of suggesting that socioeconomic factors can directly cause migraine, emphasizing instead that they most likely trigger or exacerbate an underlying neurological condition.<sup>20</sup> Yet important questions about the extent to which migraine prevalence and experience varies by race and ethnicity, and how this intersects with other social and economic factors remain greatly underexamined, a blind spot reflected in the historical sources on which this study is based. Much more research is needed to understand how the collection of epidemiological data regarding self-reported pain, disparities in access to healthcare, and the quality of healthcare received are factors in differing migraine burdens across social groups. This situation for migraine reflects a broader state of persistent gender, racial, and socioeconomic bias and discrimination when it comes to developing and prescribing treatments for pain in general.<sup>21</sup> Discussions about

the significance of social status, heredity, and gender all have an important part to play in this history and have fundamentally shaped the interpretation of migraine's modern biological reality.

## Themes

The idea to write a history of migraine came from a chance conversation with some medical historian friends in a bar one evening. We were contemplating how strange it was that a pain so intense could appear to be devoid of any real bodily purpose or reason. I began to wonder how people had explained and dealt with such a pain historically. This question remains a central preoccupation of this book. In sources that span hundreds of years, I have been repeatedly struck by how vividly people have found ways to describe the quality and severity of the pain they have associated with a disorder named migraine, and how precisely they have been able to account for migraine's force in the body, using the explanatory frameworks available to them in their era.

Understanding how people in the past have rationalized migraine pain does more than simply bear witness to its existence. Looking at the ways in which the causal frameworks people have used to explain migraine change over time helps us identify how different groups of people, as well as individual lifestyles and choices, come to be associated with migraine, as well as draws our attention to how people rationalize illness within their own life narratives—what we might term the “Why me?” question. This book draws from, and contributes to, a wider body of literature that emphasizes pain as an embodied and highly gendered historical phenomenon.<sup>22</sup> Since the Middle Ages, the consistency of descriptions of migraine pain as arrows and hammers, drilling and boring, or a vise that grips is striking, but it is important for us not to lose sight of how the experience of pain is affected by changing cultural, social, and political contexts. As a methodological approach, *paying attention* to how and when pain is discussed or becomes significant reveals its political as well as its phenomenological role in this history.<sup>23</sup>

Practical attempts to manage, cope with, and relieve pain on a day-to-day basis run through the long social and cultural history of migraine. From classical times, pain was at the heart of humoral ideas about hemicrania and its treatment. Since the late seventeenth century, this book argues, there has been a gradual erosion of the conceptual centrality of pain to medical discussions of migraine. This begins almost imperceptibly with linguistic shifts that saw *megrim* become associated with dizziness, vertigo, and nerves. In the late nineteenth century, the marginalization of pain became explicit, as men of

science denied that subjective experiences of pain had troubled the reliability of their accounts of visual disturbance. Hubert Airy's image, in particular, shaped not only how neurologists understood migraine's biological reality, but also its history. As physicians conferred diagnostic primacy on aura, the field of migraine research fragmented under the weight of competing theories. Most recently, as vascular theories have fallen out of fashion, words that denote sensations—such as pumping, throbbing, and dilating—have given way to an altogether gentler neurological lexicon: pathways, transmission, irritation, and blocking. I am not suggesting that physicians have forgotten, or don't realize, that migraine is painful; of course they do. But even as pain remains the prime target of pharmaceutical developments, a particular framing of migraine as *more than* just a headache has paradoxically served to undervalue the serious pain that does define a migraine experience for the majority of people, particularly women and minorities.

In her memoir about a decade with an “unrelenting, totally unreasonable headache,” Paula Kamen concludes that while she could still find “absolutely no meaning in the pain itself,” pain has been crucial to determining the relationships between female patients and the predominantly male physicians and neurologists she has encountered. Kamen's identification of the continuing influence of historical prejudices about women's pain in particular confirm the necessity for an historical analysis that examines the cultural and social subtexts that underlie our modern-day practices and assumptions.<sup>24</sup> Despite increased understanding of the pathological mechanisms and factors relating to its prevalence, and clear evidence of its substantial global burden, migraine, along with other headache disorders, has a credibility problem. It remains underfunded, underdiagnosed, and undertreated, with an estimated 50 percent of people with the disorder never consulting a doctor about it.<sup>25</sup> A 2007 study of headache research support in Europe found that although migraine attracted relatively strong pharmaceutical investment, it was the least publicly funded of all brain disorders, relative to societal and economic impact.<sup>26</sup> In 2017, America's National Institutes of Health allocated only \$19 million to migraine, compared with \$51 million for smallpox (declared globally eradicated in 1980), and just 11 percent of its total \$161 million budget for epilepsy research.<sup>27</sup>

In *Not Tonight*, an excellent study of the relationship between gender and biomedicine in contemporary knowledge about migraine, sociologist Joanna Kempner describes this situation as migraine's “legitimacy deficit,” a status exacerbated for individuals by many neurologists' lack of interest, as well as

their skepticism and reluctance to persist with patients who are seen as being time consuming, emotionally challenging, and difficult to treat. “Delegitimation,” Kempner explains, is “a fundamental component of the migraine experience.”<sup>28</sup> In researching this book, I have been fascinated by the historical development of this notion of legitimacy. If migraine has existed as a medical diagnosis for hundreds if not thousands of years, Kempner asks, then why have medical advances “so far not been sufficient to validate the experiences of those with migraine, nor to bring resources to [its] study and treatment?” For Kempner, who focuses on the period since the late nineteenth century, the answer lies in the persistence of gendered images, metaphors, and stereotypes that continue to define how migraine is perceived culturally—affecting people who are weak, feminized, oversensitive, and unable to cope—even as medicine, advocacy groups, and patients alike claim migraine for the gender-neutral brain.<sup>29</sup>

In this book, I propose that we need to think slightly differently about this problem of legitimacy, because much evidence suggests migraine had been taken seriously in both medical and lay literature throughout the classical, medieval, and early modern (c. 1500–1800) periods as a serious disorder requiring prompt and sustained treatment. This only began to change in the eighteenth century, as migraine became associated with a range of nervous disorders, and then came to be seen as characteristic of sensitivity, femininity, overwork, and moral and personal failure. While gender plays an important role in this development, other factors are also significant and often intersect with it, including national cultures of medical knowledge, the social status of patients, changes in vernacular terminology, the social and cultural contexts in which people obtained medical advice and treatment, and attitudes toward bodily experiences of pain. While a lack of proof is not confirmation that migraine’s belittlement was absent in earlier centuries, I argue that there is a clear, identifiable point in the eighteenth century when migraine began to attract less than serious attention.

Taking a long historical view suggests that the current state of affairs in which migraine’s legitimacy is diminished is only a relatively recent one. In this light, the wealth of evidence from the medieval and early modern periods that does take migraine seriously provides an exciting opportunity. It allows us to write a rich new history that emphasizes the historical contingency of legitimacy, rather than its permanence, and allows us to bear positive witness to the attempts, over hundreds of years, people have made to care for, treat, and provide explanations for people with migraine. This is a history that val-

idates a wide variety of experiences and explanatory models beyond our own gendered neurological paradigm, at the same time as it situates our current understandings within a much longer trajectory that emphasizes the inevitability of change.

The varied history of attempts to treat migraine is important, because it makes us confront a contemporary situation in which millions of people still do not have access to sufficiently cheap and effective treatments. For centuries, people have attempted to find methods and remedies to manage and treat migraine, including phlebotomy, herbal remedies, surgical procedures, and pharmaceutical preparations. We might be tempted to ridicule seventeenth-century recipes that recommend the application of earthworms, to condemn the extent to which people in the (not so distant) past accepted bloodletting, or to be profoundly unsettled by relatively recent experiments with cranial surgery. We might find it easy to reassure ourselves that such practices have been consigned to the past. Yet there is still no cure for migraine. We have drugs that can abort or reduce the symptoms of individual migraine attacks once they have begun, but these do not work for everyone, and for those who do experience benefits, this relief is by no means total. Beyond the effort it takes to convince physicians, employers, family, and friends of the severity of the disease, managing migraine on a day-to-day basis takes a huge commitment to avoid triggers, juggle medications, negotiate side effects, and regulate stress, sleep, and exertion. In addition, the long-term effects of frequent medication use, and the growing prevalence and burden of chronic migraine—defined as migraine attacks on fifteen or more days per month—are attracting growing concern. We may no longer make use of sedative substances such as valerian, luminal, and hydrocyanic acid, but the prescription of opioid medications remains both a political and a medical problem. Future generations may not be very complimentary about our own distinctly inadequate therapeutic offerings.

A history of therapeutics does more than simply ask whether a medicine worked. As medical historian Jack Pressman has argued in the context of frontal lobotomy: “A therapy’s usefulness is contingent upon a particular historical era. To ignore this is to overlook what was at stake in a given treatment—for the individual patient, the medical profession, or society.”<sup>30</sup> The long history of migraine medicine reveals more than a list of substances people have taken for migraine. Remedies from early modern recipe collections reveal something of the personal, intellectual, and social networks on which people with migraine from across the social spectrum could draw for support,

advice, knowledge, and relief. The stories that people have told illuminate the effects of illness on lives, and methods for mixing recipes suggest something of how migraine was understood both as an acute and a chronic condition. On the other hand, examining the ways in which nineteenth-century physicians developed pharmaceutical products in institutions reminds us that medical power and authority is not achieved without human cost.

Blood has always been a part of the migraine story, whether conceptually or therapeutically. Yet the often explicit rejection of vascular theories since the late 1970s, and a language of reclaiming migraine for the brain and neurology, has had a profound influence on how neurologists have represented migraine and its history. In particular, blood has been noticeably sidelined in this endeavor, a circumstance this book seeks to rectify.<sup>31</sup> Even as scientists have come to regard vasodilation and vasoconstriction as epiphenomenal to migraine's causal mechanisms, blood continues to shape neuroscientific research into migraine, particularly in efforts to understand whether disruption or inflammation of the blood-brain barrier plays a role in migraine, and the extent to which drugs must penetrate it to act centrally in the brain. While it seems likely that existing migraine drugs must be able to cross the blood-brain barrier to enough of an extent to have a therapeutic effect, the quite recent development of anti-CGRP antibodies (very large molecules that would be unable to penetrate the blood-brain barrier) suggests that they are acting peripherally. This has led researchers to focus on the trigeminal ganglion in this hunt for a possible migraine generator.<sup>32</sup> Neither the meaning nor the role of blood in relation to migraine has remained stable or continuous over time, and we should not try to make direct links between the phlebotomy practices of the medieval period and the late twentieth century's fascination with serotonin and blood platelets. But whether the emphasis has been humoral, menstrual, surgical, neurochemical, or genetic, blood's flows, pulses, sensations, and functions have been consistently evoked to describe, observe, conceptualize, and treat migraine since at least the Middle Ages.

Another important theme is the concept of patienthood—who has or has not been a patient—and what it means for people with migraine to become visible as such in particular contexts. In medieval and early modern sources, the experiences of individuals generally remained inferred or abstract. During the seventeenth century, personal correspondence and casebooks began to provide substantial evidence about how people with migraine interacted with physicians.<sup>33</sup> In the nineteenth century, migraine started to appear in institu-

tional settings, a development that had implications not only for those seeking help, but also for clinicians, who used them to advance their own theories, and therapeutic development. In hospitals and asylums, the presence of poor, working-class patients prompted investigation into migraine's causes, as well as experiments with how to treat it. This book continues scholars' efforts to take account of the history of subjectivity, as well as the impact of illness on patients' economic and domestic lives.<sup>34</sup>

Finally, the story of migraine is a very visual history. From diagrams of vein men, which taught medieval physicians the rules of phlebotomy, to twenty-first-century MRI scans showing brain abnormalities in migraine patients, the visual imagery of migraine has been a powerful tool for attempting to communicate migraine's pathological processes in the body. Here, I consider images not just as illustrations, but as meaningful historical evidence in their own right.<sup>35</sup> A significant reason for migraine's visually rich history is the experience of aura, as well as the central role aura has played in modern conceptualizations of migraine. As we have already begun to see in the image that opened this introduction, one of the most important single images in this history has been Hubert Airy's 1870 diagram of his aura (see fig. 6.3), which rapidly became a shorthand for authentic, accurate migraine experience from the late nineteenth century on. Then there is the staggering collection of artwork submitted to the four Migraine Art competitions in Britain in the 1980s, which powerfully attest to the violent disruption of a life lived with migraine. These are the subject of chapter 9. In this book, I argue that visual imagery does much more than illustrate migraine's history. It shows us how a particular way of seeing migraine has come to dominate the neurological framework. This also has shaped medical research and the way in which doctors approach migraine.

In his memoir, Andrew Levy makes an important historical point about the visibility of people with migraine. He notes that in recent times, "we have tended to treat migraine as a private affair, between a migraineur and a migraineur's head in a dark room," that is, as something to be hidden when one is out in public. People in the past, Levy observes, had a different idea: with bands, plasters, and caps, sufferers (including Charles Darwin) literally wore their treatment on their heads.<sup>36</sup> It is also important to think about the moments in which migraine becomes visible on the human body. The signs have often been subtle: the characteristic facial pallor of the migraine attack, or the young servant whose shaking left hand was the only outward hint of the con-

dition she sought help for in 1895. In the Middle Ages, the scars of repeated bloodletting in the temporal veins would have left a distinct corporeal reminder of measures taken to calm humoral turmoil.

Bringing together questions of gender, pain, legitimacy, treatment, patienthood, and visibility requires us to take seriously not just how medical knowledge has changed over time, but how contexts of power and authority have shaped migraine's cultural and social history, as well as its present form. What counts as evidence? Whose voices are amplified when they claim to know migraine either subjectively or objectively? How do ingrained assumptions determine whose words seem to transcend the messy business of pain, fatigue, confusion, and nausea, and whose testimonies are ignored, or considered unreliable? The content of this book is driven by the conviction that while medical practitioners and theorists are an important part of the history of migraine, their ideas are not its *only* history. As well as taking account of changing scientific and medical frameworks, as a social and cultural historian I am interested in a history of migraine from below, that is, one that includes the lives and experiences of men and women with migraine and how they have talked about, understood, and treated this extremely common, but still incurable, disorder.<sup>37</sup>

### Writing a History of a Disease

When I've talked about this project with others, a common response has been to ask how far back people have *known* what a migraine was. This is a difficult question to answer, and it is, in large part, the subject of this book. It depends on what you think these individuals should have known about, and whether we want to understand those ideas in their own terms. The question "Did they know?" gets to the heart of an issue that historians, and clinicians interested in history, have long debated: what is it that we are looking for when we write histories of disease, illness, or medicine?<sup>38</sup> Do works that apply our modern biomedical categories to the past tell us anything about history?<sup>39</sup> If not, then how do we respect and contextualize this knowledge on its own terms, however distant, inaccurate, or strange those contemporaneous disease categories might now seem to our modern gaze?<sup>40</sup>

This volume contributes to an important and growing body of literature addressing the histories of a range of medically elusive, noncommunicable disorders—such as allergy, fibromyalgia, autoimmunity, multiple sclerosis, and some mental disorders—that straddle the boundaries of acute, episodic, and chronic disease. Like many of these afflictions, migraine can often be charac-

terized by periods of disability and pain, followed by remission, a situation that medical historian Catharine Coleborne has aptly termed “unpredictable illness trajectory.”<sup>41</sup> While technological and pharmacological interventions have transformed diseases such as AIDS, diabetes, or kidney failure into manageable chronic disorders, modern migraine drugs that abort acute attacks when used frequently seem increasingly liable to exacerbate a very unwelcome transition to chronicity. Migraine is thus an important case for studying how pharmacological interventions can shape the ongoing character of an illness, rather than effecting its cure.<sup>42</sup>

Even as historians have carefully analyzed social, cultural, and political contexts that have shaped our ideas about individual diseases, they have often assumed the disease entities have an essential transhistorical identity that either has been discovered, or could be.<sup>43</sup> This is not just the case for diseases caused by an infectious pathogen. For instance, one recent history presents depression as a “comparatively consistent disease phenomenon,” and older terms—such as vapors, spleen, and melancholia—as simply different words for the symptoms of “what we would now call depression.”<sup>44</sup> Siddhartha Mukherjee considers cancer to be an “ancient disease,” which has existed with its fundamental feature of “the abnormal growth of cells intact for four thousand years.”<sup>45</sup> In some cases, as for migraine, we can see that a particular word *has* consistently signified one or more symptoms over many centuries. An example is the history of asthma. The word asthma has existed since classical times and has had the idea of “shortness of breath” at its conceptual heart. Nevertheless, medical theories about asthma’s place in the body, as well as social interpretations of it, have changed substantially over that time.<sup>46</sup>

Concepts of disease, as historian Adrian Wilson explains in an influential article in 2000, “are human and social products which have changed and developed historically.” In the case of pleurisy, Wilson shows that while the concept of what pleurisy is has altered over time, it has nevertheless always been seen as “a strictly bodily ailment.”<sup>47</sup> Others have suggested that studying the act of diagnosis itself can illuminate past mentalities in relation to disease at very specific moments.<sup>48</sup> This approach is particularly useful in the case of migraine, because it forces us to consider what significance migraine words themselves held when used either in relation to a particular person or in a more general theoretical sense.

I should stress that while I do not assume that our own neurological basis for migraine is timeless, I certainly do not deny the neurological, biological, and genetic realities of migraine in the twenty-first century. Rather, I work on

the basis that the biological actuality of a disease can only ever be understood (and, to some extent, experienced) in light of the medical, social, and cultural concepts and technologies that are available to any one person at any particular time. Put simply, if your conceptual framework is humoral, your migraine cannot be neurological. Here, I investigate both what people in the past have believed to be the physiological (and at times psychological) reality of their, and their patients', migraine, and the contemporary meaning and effects of that socially and culturally constructed reality.<sup>49</sup> As I have suggested at the beginning of this introduction, I am interested in seeing how supposedly outdated concepts and ideas become layered into new ways of thinking about migraine.

My approach to migraine's history is somewhat different from studies that already exist, of which Mervyn Eadie's *Headache through the Centuries* is the most substantial contribution. Eadie, a professor of clinical neurology and neuropharmacology at the University of Queensland from 1977 to 1997, scrupulously applies modern headache definitions to descriptions of headaches found in historical sources.<sup>50</sup> Individual thinkers—always men—waymark medicine's progress toward modern neurological ideas, breaking the shackles of outdated thought as they go. Eadie is not interested in wider social or historical contexts, despite his comments that lay writers in the sixteenth and seventeenth centuries regarded migraine as an important entity, well before formal medicine did, a tantalizing observation he pursues no further.<sup>51</sup> While Eadie is careful to acknowledge that centuries of thought have yet to produce a satisfactory understanding of migraine and headaches, he nevertheless assumes the historical validity of his own neurological viewpoint.<sup>52</sup> Such an approach marginalizes even quite recent theories that don't accord with a neurological model. Thus endocrine therapies are hardly mentioned, menstruation—so central to how a majority of women experience migraine—receives only one paragraph, and women feature in his history only when they can be retrospectively diagnosed as sufferers. Psychological and allergic theories, so important to discussions between the 1920s and 1950s, are absent.

My approach insists that we must give as much respect to past concepts of, and treatments for, disease as we give to our own. This is particularly important for a disease such as migraine, where so much still remains to be discovered.<sup>53</sup> Recognizing that concepts of migraine have constantly been redefined in dynamic interaction with social, cultural, and medical conditions necessarily makes us accept that this process will continue in the future. Our own ideas, too, will seem painfully out of date sooner than we might care to admit.

## Sources

A wealth of previously unexamined evidence contributes to the history of migraine presented here. Sources include medieval manuscripts, household recipe books, medical journals, printed manuals, physicians' casenotes, newspaper advertisements, pharmaceutical advertising, private diaries and letters, art, poetry, songs, and YouTube videos. My research for this book has been profoundly shaped by an explosion of digitized material available online, the possibilities of which we are only just beginning to appreciate.<sup>54</sup> Digitized searching enables us to explore bodies of material that would previously have been beyond the reasonable scope of a research project. Comparing recipe ingredients in early modern manuscripts with those that appear in printed books, for example, reveals how recipes were adapted to local conditions and then recycled for later generations. Mentions of migraine in nineteenth-century criminal trial transcripts give a sense of how theoretical discussions in medical journals of the time played out in the lives of ordinary people. But we also need to take care. Finding words is not the same as finding history, and, as Lauren Kassell astutely observes, "seeing is not knowing or understanding."<sup>55</sup> It is incumbent on us to continue to pay critical attention to the contexts, narratives, and influences that surround the words we can find and the physical sources in which they exist.

Digitization has changed the way we write history, and it is tempting to believe that any history can be written from the comfort of a good chair, with access to the internet. But this remains far from the case. The vast majority of historical material is still *not* digitized. In general, modern casenotes are one class of material that remains beyond the scope of digitization, not least because of issues of patient confidentiality.<sup>56</sup> Furthermore, as Tim Hitchcock has observed, "the very process of digitization is effectively reproducing a kind of Western cultural hegemony that would not be acceptable if it was a product of self-conscious policy."<sup>57</sup> These circumstances shape which words about illness gain authority, as well as how different kinds of knowledge or valid viewpoints can be rendered invisible by technology.<sup>58</sup> Online content is continually in flux, and the internet is not a democratic space. Socioeconomic status, gender, geographical location, and disability all play major roles in controlling who can find, access, consume, and create online material. In many ways, the limitations of the sources available mirror the blind spots modern medicine has in relation to migraine's global prevalence, an issue to which I return in chapter 10, the conclusion. I acknowledge that limits of time, funding, and

linguistic ability (not to mention space) mean the history I have written here is based primarily on English-language translations and sources. I am also aware that in attempting to chart a course through a thousand years of history, I may tread clumsily at times in historical periods where others are far more expert than I. This book leaves open the very real possibility that a history of migraine might look completely different if written from the perspective of French, Chinese, or Arabic material, and I hope these possibilities will spur further research.

### Chapter Outline

Each chapter in this volume begins with a single source, as a platform from which to examine what people in the past have meant by migraine, and what migraine has meant to them. Chapter 2, on classical and medieval approaches to migraine, begins with Bald's *Leechbook* (c. 950), which contained four remedies for a half head ache, or "healfes heafdes ece" in Old English. The chapter considers how classical ideas about the humoral causes of hemicrania were interpreted, and how knowledge of symptoms, mechanisms, and therapeutics—including herbal remedies and phlebotomy—spread and evolved through learned and vernacular medical cultures in manuscript, print, and imagery up to the fifteenth century. Descriptions of fumes, burning, boiling, and hammering evoked the seriousness of a disorder understood as the result of "evil humours flowing."

Chapter 3, taking Mrs. Corlyon's recipe book from 1606 as its basis, reveals the extent of vernacular knowledge about treating migraine in the early modern period. It traces how individual recipes in manuscript and printed remedy collections from the sixteenth and seventeenth centuries were shared and adapted over time. In addition, it considers the variety of ways in which ordinary people understood and dealt with migraine, including evidence that migraine could be thought of as both an acute and a chronic disorder.

Chapter 4 moves away from domestic medicine and into the medical marketplace, examining the variety of treatment options and professional advice available to the paying public from the sixteenth to the eighteenth centuries. Starting with Francis Thomson's desire to travel to the warm springs bubbling up in the Derbyshire hills, it moves to the chaotic streets and back alleys of eighteenth-century London, and then to the genteel drawing rooms of fashionable Bath, to show how reputable medical practitioners and itinerant gontomorrow salesmen and -women alike dispensed advice, promises, waters, and pills to those in search of relief. By examining the way migraine was dis-

cussed in a variety of contexts—including astrological casebooks, advertisements for cheap preparations, correspondence between physicians and patients, and the reports of charitable establishments for the poor—this chapter demonstrates how the meaning of the vernacular English word *megrim* began to diverge from the classical sense of *hemicrania* by the eighteenth century, particularly under the influence of continental ideas about migraine. It is in this change, I argue, that we can begin to see when migraine started to become something of a joke. The shift matters, because it is in the late eighteenth century's failure to take migraine seriously that we can find the seeds of our own highly gendered way of understanding—and dismissing—this disease.

Chapters 5 and 6 explore two parallel nineteenth-century histories that, together, are crucial to ushering in migraine's modern profile, as well as our assumptions about gender. Chapter 5 examines how nineteenth-century medical writers discussed the relationships between illnesses, including sick headache, *megrim*, and *hemicrania*. As they revised the classical categories of head pain, physicians formulated new theories about head disorders in medical journals, texts, and everyday use. Ideas about nervousness, hysteria, and the sympathetic relationship between head and stomach cemented a tendency to assert particular types of individuals (i.e., young women) tended to suffer from headache disorders, including migraine. In asylums and specialist institutions, such as London's National Hospital for the Paralyzed and Epileptic, people with migraine were transformed into inpatients who would become the ideal subjects for theoretical observation and pharmacological experimentation.

Even as medical writers and researchers firmly began to associate migraine with women, Chapter 6 traces the emergence of a parallel, but very different, cultural profile for migraine. In the 1860s, a group of astronomers, photographers, and physicians began openly talking about their experiences of visual disturbance. At first, these men rarely acknowledged feeling any pain; these were strictly scientific discussions about vision, light, and the brain. It was through these commentaries that visual aura became an important symptom of migraine, and then began to define the modern formulation of migraine we recognize today. The chapter explores how, as a consequence of texts such as Edward Liveing's classic *On Megrim*, a very particular visual representation of migraine—Hubert Airy's diagrams of his migraine aura—came to define authentic, accurate, and, most important, *trustworthy* migraine experiences. This has profound implications for contemporary understandings of how migraine intersected with gender, class, and heredity. Together, chapters 5 and 6 explain how, by the twentieth century, doctors could simultaneously be en-

thrilled by the neurological implications of migraine's visual characteristics (associated with male intellect), while the pain of the patients whom they regularly attended to in their clinics became invisible, hidden behind simple assertions of pharmaceutical efficacy.

Chapter 7 examines three historical stories about migraine that have oft been repeated since their emergence in the first decades of the twentieth century. It first considers the case of the celebrated St. Rupertsberg abbess, Hildegard of Bingen (1098–1179), and how she came to be diagnosed with migraine by a young historian of science, Charles Singer, in 1913. Although Singer's diagnosis took little account of Hildegard's own ideas about illness, his theory became a commonly accepted fact. I suggest it is no coincidence that Hildegard's diagnosis occurred around the same time as two other migraine stories (which would prove to be similarly tenacious) were created: the idea of trepanning as one of migraine's most ancient treatments, and the retrospective diagnosis of seventeenth-century noblewoman Anne Conway. Rather than either accepting or rejecting the truth of these three historical stories, the chapter examines why ideas such as a post facto analysis of Hildegard's migraine have become so attractive both for neurologists, who seized opportunities to anchor neurological ideas in a millennium of history, and the people who have seen their own experiences of migraine reflected in Hildegard's diagnosis.

Despite the emphasis on aura in the early twentieth century, the ascendance of a neurological framework for understanding migraine was by no means assured. Beginning with the case of a young woman treated for allergy in the early 1930s, chapter 8 explores how, in the early twentieth century, competing medical theories from the fields of psychology, allergy, endocrinology, surgery, and neurology reconfigured and fractured medical understanding of migraine. Migraine became, in the words of influential British neurologist Macdonald Critchley, a theoretical "hunting ground," despite pharmaceutical breakthroughs that had begun to promise genuine relief. From the late 1930s, the verifiable and obvious efficacy of ergotamine-based medicines validated the physiological concept of migraine as a vascular disorder, even as ideas about the existence of a "migraine personality" took hold. As this chapter makes clear, none of these competing theories were able to provide an answer to the ongoing fundamental issue of whether migraine was one disorder, or many.

Between 1980 and 1987, in the context of patient advocacy, art therapy, the idea of migraine as an essential part of a migraineur's identity, and the founding of specialist patient clinics, the Boehringer Ingelheim company and the British Migraine Association charity ran four international competitions in

which they invited people with migraine to represent their aura and their experiences of life with migraine. What the organizers did not expect was the deluge of responses that focused on pain. The submissions for the competitions form an extraordinary archive of nearly six hundred images. An analysis of this collection forms the basis for chapter 9, examining how ordinary people found ways to creatively express their daily experience of migraine and its impact on their lives. Most significantly, it argues, the Migraine Art Collection is a profound witness to the realities of poorly treated and inadequately acknowledged pain.

Chapter 10, the conclusion, looks at very recent advances in migraine treatment, which offer hope of a radically improved quality of life. It also describes the acceptance of an internationally recognized classification that has transformed epidemiologists' ability to calculate migraine prevalence on a global scale. Nevertheless, I argue, it is as important as ever that we continue to ask, who speaks for and about migraine and those who live with it? Whose knowledge gets taken seriously, whose experiences are silenced, whose pain is minimized or left untreated, while others are privileged?