

Introduction

‘Men have had every advantage of us in telling their own story . . . the pen has been in their hands.’ In no field have Anne Elliot’s famous words from *Persuasion* been more true than in medicine. Physicians and surgeons have for centuries been men, and the narratives of medicine and of medical history have been in their hands. Patients, male as well as female, have been feminised, in the possibly tendentious sense of subordinated, voiceless. In effect patients were for long the passive and unspeaking subjects on which medicine was practised and through whom discoveries and progress were made. After the introduction of teaching hospitals in the nineteenth century, attending to the patient’s voice by consultants around the bed became more usual and often provided important and fruitful information, but this was the literal speaking voice, responding to questioning, not an independent testimony. Patients may have written accounts of their experiences of illness and their medical treatment, but these were fragmentary, informal or, at best, parts of works devoted to quite different ends. In the past half-century this has changed dramatically, and now patient narratives, and narratives by those who have cared for them, have been published in such great numbers so as to constitute more than a supplement to medical history, but indeed to form a new literary genre, sometimes called the ‘pathography’.

This development might be compared to the direct revelation of the inner workings of the human body that Vesalius inaugurated with the first dissection of a human corpse in public in 1543. The publication of Vesalius’s *De humani corporis fabrica*, with its many illustrations, brought about a break with more than 1,500 years of Galenic medical theory, education and practice.¹ Like Vesalius’s opening of the previously sacrosanct space, the pathography, or patient narrative, discloses the formerly unknown, ignored or perhaps misunderstood: the inner and personal experience of patienthood. Paradoxically, though, it was Vesalius’s procedure that inaugurated the view of the body as ‘a carnal machine’, the

scientific, ‘objective’ medicine which for the next centuries can be said to have depersonalised illness.² It is this very depersonalisation that the project of the patient narrative seeks now to remedy and to restore. Or, to put it another way, it again marshals the authority of experience against the authority of medical tradition. This has taken a gradual evolution over the past century and a half, but as Thomas Laqueur has put it, the present time is probably ‘the golden age of pathography’.³

This book enlists Frances Burney’s records of illness into this genre and argues that her letters and journals, which describe in detail and with a skilled novelist’s intense focus several distinct medical crises, are not only substantive contributions to this history but also anticipate many of the features – and especially the powerful ethical and emotional issues – that circulate within modern illness narratives. She was a pioneer recorder of medical dramas from the patient’s point of view. She was resident at the royal court in 1788–1789 when the most eminent doctors of the age struggled to understand and to treat those disturbing symptoms of King George III that were eventually called madness. Burney observed his behaviour and recorded his speeches with extraordinarily persuasive detail. The king’s illness precipitated events within the court that led to the onset of Burney’s own illness not long after. Seven years later she held her small son in her arms when an apothecary performed the risky procedure of inoculation against smallpox, and left the only detailed account of an operation which must have been performed thousands of times. Trapped in France during the Napoleonic wars, she wrote with similar attentiveness in 1811 a now famous account of her own mastectomy before anaesthesia, at a critical moment in the history of medicine, and in which conflicts with her doctors (as well as conflicts between her doctors) are recorded and her own physical sufferings are written up in almost unbearable detail. The tensions between patient and physicians that play such a significant role in these earlier accounts are present in heightened form in her self-titled ‘Narrative of the Last Illness and Death of General d’Arblay’ written in 1819, an extended account of her husband’s last months, which presages many of the issues now current in contemporary carers’ accounts of fatal illness.

Some outstanding modern books about illness experience are discussed in the book’s final two chapters. They belong, however, to a very different medical world from the one in which Burney wrote her narratives. Though she lived at a time when public hospitals had already been instituted in London, these were charitable endeavours established to provide medical care for those who could not afford doctors’ fees. If you could pay for it,

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your doctor or apothecary attended you in your home. The medical occasions that Burney describes all took place in private rooms, with doctors who were often known to the patient. These circumstances are very important because they fostered a key aspect of her accounts – that they describe not just a single patient's own experience, but that experience in and played out within a group. The home, family, intimacy, interplay between doctors and the patient, often with a third person or persons present, the medical occasion as an ensemble: these are the given, the natural circumstances of the occasions she wrote about.

This feature – broadly speaking, interplay between patient and doctor within a closed and private setting – carries over into the modern pathography, even though so much of contemporary medical and surgical experience takes place within the large public domain of the hospital. The familial setting, and Burney's practice as a novelist, led Burney to report her experience in detail and to evoke as part of that experience its accompanying psychological and emotional effects. Nervous tensions, fear, anger and hostility then came into play as frequent aspects of patienthood, as well as gratitude and respect. Thus the modern genre, which almost always presents the patient as a person within a family, has crucial affinities with Burney's. This is the case even though the representation of patienthood often carries an undercurrent of protest against the very circumstances (such as hospital bureaucracy) that divide the modern scene from hers. In this book I have extended the term 'patienthood' to encompass the carers of the nominated patient.

'Pathography', however, is a contested term, since its analogy with 'pathology' seems to suggest that the patient's narrative may be a record merely of disease and its treatment. Disease, as understood from the medical viewpoint, it is argued, is quite other than 'illness', the condition experienced by the sufferer or patient. This distinction was established by Arthur Kleinman MD in his book *The Illness Narratives* (1988), which opens with the declaration that illness is 'something fundamentally different from disease'. 'By invoking the term illness', he writes, 'I mean to conjure up the innately human experience of symptoms and suffering. Illness refers to how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability.'⁴ The distinction was maintained by Arthur W. Frank, himself the author of an important pathography, *At the Will of the Body: Reflections on Illness* (1991) in *The Wounded Storyteller* (1995), and has been developed and amplified more recently by the phenomenologist Havi Carel in her *Illness: The Cry of the Flesh* (2008): she too writes as a patient. Both

‘pathography’ and sometimes ‘autopathography’ are used, along with ‘illness narrative’ to distinguish these books from more mainstream memoirs and biographies.⁵

Disease is identifiable, a containable concept: illness is diffuse and pervasive and may seep into every aspect of the life of the sick person and their family or partners as well. Disease is usually thought of as transcultural. Illness is embedded within a particular culture and social world. The illness narrative, then, broadly speaking, as Carel shows, explores the phenomenon of illness as it is lived within that particular and distinctive setting. It must therefore dovetail with, and to a lesser or greater extent contest, the medical culture that is a crucial part of that setting. In fact some illness narratives have an adversarial relationship to medicine – medical practice, institutions, and medical discourse.

In this book the term ‘pathography’ is reserved for works that are wholly devoted to the course of a medical experience, such as Frances Burney’s self-contained journal records of her mastectomy and of the months of her husband’s final illness. The pathography, in this usage, is a genre of writing in which an illness (or sometimes an accident) is the instigating or key event: it is the matrix from which the narrative gets its organisation and purpose. The ‘illness narrative’ belongs in a broader field, where the boundary between memory and reflection, a specific case and general concerns, can be unclear. It may include pathographical material. The chapters in this book that deal with Burney’s journals during the king’s illness or ‘madness’ of 1788–1789 with its physical and psychological aftermath for Burney, and the chapter about her son’s inoculation for smallpox are best considered under this more general and elastic rubric of the illness narrative. It must, however, be admitted that both ‘pathography’ and ‘illness narrative’ are flexible and imprecise terms, sometimes overlapping with each other. I have called Burney’s account of inoculation an illness narrative because, existing merely as letters, it is not formally presented or shaped: but it could just as well be called a pathography since the letters focus, almost exclusively, on that experience.

Kate Chisholm, whose excellent biography *Fanny Burney: Her Life* came out in 1998, published four years later a short book called *Hungry Hell*, subtitled ‘What It’s Really Like to Be Anorexic: A Personal Story’.⁶ This brief work nevertheless demonstrates the modern illness narrative’s hetero-generic qualities. Its purpose is to give guidance and encouragement to others suffering the same condition (which links it with the self-help or advice manual); it includes research – references to and quotations from medical and psychiatric experts on anorexia – which gives it affinities with

formal studies of the condition – and invented dialogues, aligning it with fiction. Fundamentally, though, it is an autobiography, but with personal testimony brought into a critical relationship with the subject's treatment by doctors and hospitals. Most, but not all, illness narratives share these elements. The 'personal story', whether by the patient or by their carer (most usually mother or child, close friend or partner) is certainly the key element, but with lots of other material brought in too.

Frances Burney was not, of course, the only author of her era to write about medicine, doctors, or being a patient. Her friend Samuel Johnson published in 1783 a poem on the death of his own friend and housemate Robert Levet that commemorates a man working as a doctor among the poor of London's slums, managing to imply at the same time the author's old age and his own fear of death.⁷ Johnson also included passages in his *Lives of the Poets* (1779) which might be considered pre-pathographic, such as the page or so in his *Life of Pope* describing the poet's painful physical disabilities. When James Boswell in his turn came to write his first memoir of Johnson, *Journal of a Tour to the Hebrides*, in 1785, he included a similar 'character' of Johnson, uneasily mentioning his 'constitutional melancholy, the clouds of which darkened the brightness of his fancy'. More controversially he said that Johnson's body 'shook with a kind of motion like the effect of a palsy', which he diagnosed as 'that distemper called St Vitus's dance'.⁸ An even earlier work, Robert Burton's *Anatomy of Melancholy* (1641), which is clearly prompted by its author's own propensity to depressive illness and was much valued by Johnson, might also be considered as an ur-illness narrative, especially as it is offered as a resource to fellow sufferers.

But these references are incidental; these texts have none of the impetus of a narrative, and none of them shares the dynamic charge of Burney's representations of medical occasions and conflicts. A text that is often cited as a pioneering illness narrative, the chapter in George Cheyne's *The English Malady* of 1733 entitled 'The Case of the Author', simply recites the story of his own 'nervous disorder', his melancholy symptoms, his own diagnosis of their cause, his diet, and his own eventual recovery. Cheyne finds it necessary to defend his 'Egotism' in writing so much about himself. He thought 'thus much was due to Truth, and necessary for my own Vindication; and perhaps it may not be quite useless to some low, desponding, valetudinary, over-grown Person, whose Case may have some resemblance to mine.'⁹ Many fragmentary autobiographical records of suffering and medications exist, but there is a world of difference between a person's solipsistic account of their illness experience and the

encounters between actors in a medical drama that constitute the pathography's important contribution to modern culture.

Certainly, other writings by Frances Burney's contemporaries contain elements of the illness narrative. William Godwin's *Memoir of the Author of A Vindication of the Rights of Woman* (1798) for example, includes a detailed and dreadful account of Mary Wollstonecraft's death following childbirth in its last chapter. William Cowper wrote a *Memoir* of his early life, which included an account of his suicide attempts and what he called his alienation from God: 'Satan plied me with horrible visions, and more horrible voices,' he wrote. 'My ears rang with the sound of torments, that seemed to await me. Then did the pains of hell get hold of me, and, before daybreak, the very sorrows of death encompassed me. A numbness seized the extremities of my body . . . My hands and feet became cold and stiff.' This led to his being taken to St Albans, where the 'mad doctor' Nathaniel Cotton took him in. Though Cowper writes of Cotton's 'well-known humanity and sweetness of temper', he also writes that '[i]t will be proper to draw a veil over the secrets of my prison-house,' so nothing can be known of his treatment.¹⁰ Some striking passages were cut from this edition of 1816: they related occurrences which 'befell [him] indeed while in a state of insanity' in 1763. They describe the 'horrible visions' as well as hallucinatory states which convince Cowper that God is sending him personal messages (one of them is a thunderstorm in which a storm cloud appears to take the shape of a hand reaching out to him).¹¹ Cowper also wrote a memoir of his brother, known as *Adelphi*, which originally included 'An Account of his Last Illness' describing his own mental illness that led him to attempt suicide on at least three occasions. Neither of these memoirs was published until after Cowper's death in 1800. Both his seemingly psychotic symptoms and the 'veil' thrown over his treatment might be contrasted with George III's 'madness' twenty-five years later, over which a veil has certainly not been thrown.

Thomas De Quincey's *Confessions of an English Opium Eater*, first published in 1822, is much closer to an illness narrative of the modern type than these documents. 'I speak', he wrote, 'from the ground of a large and profound personal experience: whereas . . . even of those who have written expressly on the *materia medica*, make it evident, from the horror they express of it, that their experimental knowledge of [opium's] action is none at all.'¹² De Quincey seems to have been initially prompted to use the drug for pain relief by 'Dr Buchan'. William Buchan's *Domestic Medicine* (1769) was a highly successful handbook for the layperson and went into editions well into the nineteenth century. Buchan recommended 'not to

take above five-and-twenty ounces of laudanum', and De Quincey managed to avoid addiction for eight years.¹³ His book is written with a dual purpose: to advocate for the medicinal value of opium when taken moderately, but also to describe the horrors, both physical and mental, that beset him when he succumbed and became an addict. Like many a modern illness narrative author, he seeks to contribute to the understanding of illness (broadly described) 'illustratively', or from the alternative perspective of the patient, as well as to help to prevent others from succumbing to the addiction. He also includes a great deal of fascinating but not strictly relevant autobiographical detail.

Later in the nineteenth century Harriet Martineau published *Life in the Sickroom* in 1844, Bulwer Lytton's *Confessions of a Water Patient* went into four editions in the mid-century, and W. E. Henley's series of poems 'In Hospital', written about 1875, gave a vivid account of the grim conditions in a Victorian public hospital – 'half workhouse and half jail' – when he endured the amputation of his lower leg and of the nauseating effects of chloroform, by then introduced as an anaesthetic.¹⁴ Earlier an anonymous patient had given James Young Simpson, the pioneer of anaesthesia, a description of his amputation without chloroform to publicise the virtues of the gas. 'Suffering so great as I underwent cannot be expressed in words', this man wrote, adding 'only the wish to save others makes me deliberately recall and confess the anguish and humiliation of such a personal experience.'¹⁵ Fragments like this prompt us to read Burney's exquisitely exact and graphic account of her own amputation as a revelatory development in the pathographic form.

This document and the 'Narrative' written later were composed for Burney's family: addressed to her sisters, in one case, to her son in the other. It is interesting that the mastectomy account, which was written in the form of a letter, and presumably smuggled across the Channel, was copied out in full by her son and her husband. On the cover of a folder that contained this copy, Burney wrote, 'Respect this & beware not to injure it!!!'¹⁶ Though these documents would certainly have been intended for posterity, the fact that they were written initially as private records as part of the family archive is important. The question of propriety, of what is allowable in public discourse (which De Quincey for instance had to negotiate in a preliminary note 'To the Reader' before he gave his personal account of addiction), would have entirely forbade a woman as conscious of propriety and reputation as Burney from publishing such works. Their candour, then, is a product of their privacy.

One facilitating condition for the appearance of illness narratives in the mid-twentieth century must certainly have been the lowering of these barriers of politeness: it was now becoming possible to reveal and to detail intense personal suffering without shaming oneself. Richard Hillary's *The Last Enemy*, the story of his being shot down in his plane during the Second World War and his subsequent plastic surgery and disfigurement, was published a year before his author's death in 1943. Betty Macdonald's *The Plague and I* was published in 1948; Denton Walsh's account of an accident, hospitalisation and subsequent disability, *A Voice through a Cloud*, came out in 1950. Grace Stuart's little-known but compelling account of her life with rheumatoid arthritis, *A Private World of Pain*, was published in 1953. These are only some examples. To them must be added Simone de Beauvoir's *Une Mort Très Douce*, translated into English as *A Very Easy Death* and published in 1966. This tells of her mother's last weeks in hospital, a work of extraordinary honesty and self-revelation which is discussed and compared with Burney's record of her husband's final illness in Chapter 7 of this book. If there is a classic of modern pathography, this is it.

What seems also to have happened is that gradually in the middle years of the twentieth century writers began to realise that illness – the experience of illness – was dramatic, meaning that like theatre or the novel the presence and actions, as well as the words, of other figures than the protagonist played a part, and could be represented in dialogues.¹⁷ It also might be made into a compelling narrative because, like all dramas, it involved conflict. And the obvious site of conflict was between medicine and the patient. In a reversal of the classic stereotype of illness, incarcerated in the very term 'patient', in which a suffering, passive, certainly not responsible, figure is acted upon by an agent (patient and agent being antitheses), in the person of surgeon or doctor, writers began to see themselves as actively engaged, sometimes through the very act of composition itself, in an interaction with and intervention into the previously sacrosanct or sequestered medical domain. Drama involves conflict, but also heroes and villains, or at least figures representing some version of those attributes. A common feature of the illness narrative then became a contrast between the advice and often the personal style of one medical figure with another – 'the cool clipped manner and an air of restrained authority' of one physician as opposed to the 'vivid' personality, the 'optimism and enthusiasm' of his colleague, though in this example, from Sandra M. Gilbert's *Wrongful Death* (1997), the choice of consultant was probably mistaken.¹⁸ Given the stress and fear in which patients and

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their relatives so often continuously live, it is not surprising that recalling narrators often slip into atavistic emotional states, dividing the world into good and bad, like the Kleinian child: the lovely caring nurse and the casual, careless witch.¹⁹

Death or mortality is a dark, hovering presence in many illness narratives. This confers on the genre another dramatic quality – suspense. More significantly, the apprehension of death is the occasion, the stimulus or condition for another pervasive feature of any drama – the ethical or moral issues that are inseparable from the course of a serious illness and medical practice. In a work that is referred to several times in this book, Robert A. Aronowitz, a physician, writes of the precarious balance that a consultant of a seriously or mortally ill person must somehow maintain between ‘hope, trust, and truth’;²⁰ a challenge that Paul Komesaroff, an ethicist as well as a physician, describes compellingly as ‘riding a crocodile’ – the everyday danger of making mistakes, being kind and attentive to one patient while at the same time being harassed by the needs of many others, the need to make quick decisions that one can rarely be sure are absolutely right.²¹ Medical figures who act carelessly or unconscionably, accidental errors and unhelpful remarks are recorded relentlessly in some illness narratives. No one can blame their authors, though they sometimes reflect an unrealistic conception of medical institutional life.

But the moral issues presented by the imminence of death confront the patient, and especially perhaps their carers, more urgently and potently than their physicians. Is it right to soothe your dying mother with comforting lies? What is the cost of this to the carer’s own integrity, their own sense of right? If a doctor takes the avenue of telling the blunt truth, because the patient asks to be told it or because he or she believes that preparing their patient for death is their duty, how does the patient or his wife manage this – especially if they or their husband refuses to believe it? What if a doctor’s tones and gestures seem to the patient to intimate a more ominous future than her cheerful words imply? These are fundamental questions of right or wrong, dramatic aspects of the illness narrative that must be located within the consciousness of the narrating patient or their narrating carer. They are sometimes explored with great subtlety and harrowing honesty in modern pathographies. In the many lesser crises that a typical illness narrative confronts and navigates, the need to make possibly momentous decisions – such as the choice of doctor – is a recurrent theme. What also has to be stressed, though, is that excruciatingly difficult decisions regarding the choice of treatments – whether to order or to perform an operation or to prescribe a drug that may save the

patient but that also might kill them, for example, have to be made by physicians riding the crocodile every day.

All of these dramatic aspects of the illness narrative are anticipated in Burney's work, as in none of her contemporaries, because they stage (and in this book, I also stage) each illness experience as an interplay, sometimes a confrontation, between two agencies – patienthood and medicine, the patient and the doctors. One feature is more transparently present in Burney's stories than in most modern narratives, and this is clashes between doctors themselves, their personalities, opinions and possible treatments. The doctors brought in to deal with George III's endless wild delirious speech, among other symptoms, could not agree either on treatment or on the likely prognosis. (Burney herself sided with the one doctor among them who believed that the king would neither die nor be condemned to permanent insanity, and later became friends with Dr Francis Willis, the 'mad doctor' brought in as a last resort to handle the patient.) Another intense conflict of medical opinion is revealed through Burney's acute observation of the faces and gestures, even the tones of voice, of the surgeons who arrived at her home in Paris to perform her mastectomy twenty-five years later. In this situation another conflict becomes very clear: Madame d'Arblay is engaged, as George III most certainly was, in a struggle to make her own authority felt, but like the king she does not succeed. Then six momentous years later when her husband was dying, Burney again found herself fighting against the treating medical men, in this case not eminent surgeons, but lower on the medical ladder, apothecaries in Bath, a provincial city. It seems that then she allowed her own fear of losing her husband to overwhelm any recognition of their honest concern and accurate opinions of his prognosis. If this is a judgement a reader might make, they would be themselves drawn into a dissenting ethical response to the fraught circumstances Burney relates.

Despite these uniquely dynamic tensions in Burney's reports of medical experience and the dearth of analogous or comparable accounts from her contemporaries, it has been possible to find interesting material to set alongside them in this book. In Chapter 2 her journal's accounts of the king's medical condition, and especially of its fallout on his family and the court, which she had to infer from conversations with other courtiers, with one of his doctors, or confidential sessions with the queen's vice-chancellor, are read alongside the diary kept by Robert Fulke Greville. Greville, one of the king's equerries, a reliable and devoted attendant upon His Majesty, kept a detailed daily record of the extraordinary events in the king's apartments, to which access was strictly controlled. Several courtiers