

## Literature and medicine: narratives of physical illness

M Faith McLellan

"I have never been anywhere but sick. In a sense sickness is a place, more instructive than a long trip to Europe, and it's always a place where there's no company, where nobody can follow."<sup>1</sup>

They have been called stories of sickness,<sup>2</sup> pathographies,<sup>3</sup> and narratives of illness.<sup>4,5</sup> However they are characterised, patients' stories are an increasingly important contribution to forms of autobiography and to clinical practice. They may also serve as important resources for medical education and medical ethics.<sup>6</sup> These usually autobiographical stories deal with a wide range of illnesses. Obviously, persons with chronic or slowly progressive diseases are more likely to be able to write about their experiences than those in the throes of an acute, life-threatening event; thus, cancer and some neurological conditions are common topics.<sup>3</sup> There are also increasing numbers of narratives devoted to mental illness and to AIDS;<sup>7-9</sup> these are beyond the scope of this discussion.

Exactly when the narrative of illness began to appear as a distinctive phenomenon is unclear. The book-length first-person account may have arisen only after 1900 and was rare before 1950,<sup>3</sup> but clearly there are precursors in earlier, related forms. Letters and diaries bear abundant witness to their suitability for the telling of such personal experiences (panel 1), especially in eras when suffering was understood as a common part of life rather than a singular experience worthy of special examination; stories of sickness were thus encompassed by a larger perspective on one's life, work, family, and day-to-day events. Those who had lingering, chronic illnesses that were once untreatable, such as tuberculosis, could also create full accounts over long periods of time. Effective therapeutics have expanded the possibilities of the illness narrative by creating time for writing and reflection in the cycles of treatment, remission, and recovery that can now characterise some experiences of illness.

Narratives of illness have been grouped thematically on the basis of their authors' intent and on their dominant metaphors and images.<sup>3</sup> The most straightforward type of illness story is a testimonial one—a chronicle of events, thoughts, and feelings by an author often motivated by a desire to help others in similar situations (panel 2). Some narratives are primarily angry, their tone usually a result of misdiagnosis or other bad experiences with medical care. Alternative medicine is the basis for the third type of illness narrative, a prime example of which is Norman Cousins' *Anatomy of an Illness*.<sup>10</sup> Familiar myths and metaphors recur across the range of stories: rebirth and cure, illness as a battle.<sup>3</sup> John Donne's *Devotions upon Emergent Occasions* is

an early account of rebirth that focuses on the spiritual aspects of physical suffering.<sup>11</sup> This 17th-century work, composed of 23 tripartite sections consisting of a meditation, expostulation, and prayer, describes Donne's "acute, febrile, infectious, life-threatening illness".<sup>12</sup> Despite substantial critique of their appropriateness and usefulness,<sup>13</sup> military metaphors are ubiquitous in illness narratives. Disease becomes an invading enemy; drugs are given to combat infections; people win or lose battles with cancer. Martha Weinman Lear's *Heartsounds*, for example, a wrenching description of her husband's heart disease, is deeply marked by battle metaphors.<sup>14</sup>

Stories of sickness have also been described as narratives of restitution, chaos, and quest.<sup>15</sup> The narrator of a restitution story wants her health back; this voice is almost always heard in all types of illness narrative. The chaos story focuses on what is most untellable about sickness: the nearly incomprehensible nature of loss and suffering, sometimes reflected through a haze of perception-altering treatments. The late comedienne Gilda Radner's *It's Always Something*, about her ovarian cancer, tries to sort out this chaos while she contemplates videotaping one of her chemotherapy sessions in an effort to recapture lost time. The quest narrative depicts illness as a mythical journey, in which the hero undergoes a series of trials before being granted upon his return a boon—if not health, perhaps empathy, insight, a special sensitivity, or a deepened awareness of life's transience and value. In *A Whole New Life*, for example, the American novelist Reynolds Price describes his gratitude for the literary productivity he has achieved despite his experience with a crippling spinal cord tumour.<sup>16</sup>

As in Price's exploration of his "unfolding bafflement", the narrator of an illness story may be the patient telling his own story in his own voice, however shaky that voice may sometimes sound. "I had somehow", Price realised, "to build my life on radical uncertainty". Another notable first-person narrative is Lucy Grealy's *Autobiography of a Face*.<sup>17</sup> The memoir details the extensive treatment and multiple, disfiguring surgeries Grealy underwent for Ewing's sarcoma throughout her childhood and adolescence.

When the patient is unable to relate his own story, someone close to him may become the narrator, either in whole or in part. John Gunther, for example, wrote about his son's fatal illness in *Death Be Not Proud*.<sup>18</sup> Sometimes the ill person's story is finished by another person after the patient's death, as when Alexandra Broyard compiled and edited the work of her husband, Anatole Broyard, in *Intoxicated by My Illness*.<sup>19</sup> Likewise, *A Complex Sorrow: Reflections on Cancer and an Abbreviated Life* was written by Marianne A Paget and later edited by a friend and colleague.<sup>20</sup> An example of dual narration, in which the journal structure of the work was designed as a therapeutic tool, is found in the powerful *Cancer in Two Voices*.<sup>21</sup>

Multiple narrators are a hallmark of a new form of illness narrative that is being created on the Internet, in discussion

*Lancet* 1997; **349**: 1618–20

Department of Anesthesiology and the Institute for the Medical Humanities, The University of Texas Medical Branch, Galveston, Texas 77555-0830, USA (M F McLellan BA)

Correspondence to: M Faith McLellan  
(e-mail: faith.mclellan@utmb.edu)

Panel 1: **Illness in letters and diaries**

I am making out fine in spite of any conflicting stories. I have a disease called lupus and I take a medicine called ACTH and I manage well enough to live with both. Lupus is one of those things in the rheumatic department; it comes and goes, when it comes I retire and when it goes, I venture forth. My father had it some twelve or fifteen years ago but at that time there was nothing for it but the undertaker; now it can be controlled with the ACTH. I have enough energy to write with and as that is all I have any business doing anyhow, I can with one eye squinted take it all as a blessing. What you have to measure out, you come to observe closer, or so I tell myself.

From O'Connor F. Letter to Elizabeth and Robert Lowell, 17 March 1953. In: Fitzgerald S, ed. *The Habit of Being: Letters of Flannery O'Connor*. New York: Vintage, 1979: 57.

\* \* \*

This Diary reads for all the world as if I were not living in mighty London. The truth is I live in a bigger, dirtier city—ill-health. Ill-health, when chronic, is like a permanent ligature around one's life. What a fine fellow I'd be if I were perfectly well. My energy for one thing would lift the roof off . . . (Jan 22, 1913)

London certainly lies before me. Certainly I am alive at last. Yet now my energy is gone. It is too late. I am ill and tired. It costs me infinite discomfort to write this entry, all the skin of my right hand is permanently 'pins and needles' and in the finger tips I have lost all sense of touch. The sight of my right eye is also very bad and sometimes I can scarcely read print with it, etc., etc. But why should I go on?

A trance-like condition supervenes in a semi-invalid forced to live in almost complete social isolation in a great whirling city like London. Days of routine follow each other as swiftly as the weaver's shuttle and numb the spirit and turn palpitating life into a silent picture show. Everywhere always in the street people—millions of them—whom I do not know, move swiftly along. I look and look and yawn and then one day as to-day I wake up and race about beside myself—a swollen bag ready to burst with hope, love, misery, joy, desperation. (Oct 25, 1914)

From Barbellion WNP. *The Journal of a Disappointed Man & A Last Diary*. London: Hogarth Press, 1984: 74, 145.

**Biographical notes:** Flannery O'Connor (1925–64) lived in Milledgeville, Georgia, and was a major American short story writer and novelist. Two of her best-known works are *Wise Blood* and *The Violent Bear It Away*.

WNP Barbellion is the pseudonym of Bruce Frederick Cummings (1889–1919), who was severely disabled from multiple sclerosis. For a time he held a post in the Entomology Department of the Natural History Museum in South Kensington, London.

groups or on Web pages.<sup>22</sup> Electronic narratives are often multiauthored; they may have an identifiable primary narrator but are often written collaboratively, as dozens or perhaps hundreds of virtual strangers help create and shape the story through their own postings. Phil Catalfo has been writing an online journal in the health conference on the WELL, a California-based commercial conferencing system (<http://www.well.com>), since the diagnosis of his son Gabe with acute lymphocytic leukaemia. Catalfo began his online journal, "to discuss the chronology of events, emotions and experiences stirred up by this newly central fact of our lives". Having introduced the topic and established himself as the primary storyteller, he then opens the door for exchanges among the readers of this topic. After each posting, whether by Catalfo or someone else, readers are free to respond to the previous entries, thus entering the story as narrators themselves. Or they may choose to communicate with each other privately, or they may elect to simply "lurk" in the narrative, remaining silent readers of the work. The presence of multiple narrators is an important feature of the electronic narrative, because these people have the power to recast the story in ways that may or may not be congruent with the author's intent. The other posters can help or hinder the primary narrator—they may add their personal perspectives, detail additional experiences that may or may not be relevant, provide emotional support for the author, change the subject, and sometimes derail the narrative through a cacophony of voices. More often than not, however, the multiple voices of the electronic narrative add richness and depth to the primary narrator's tale. Some electronic narratives, such as *Leukemia*, consist only of text; others are enlivened by hypertext, containing photographs, graphics, and links to related sites, both technical and personal.<sup>23,24</sup>

Writers' motivations for telling stories of illness have bright and dark features. For many, the writing is cathartic and therefore serves a therapeutic purpose. But catharsis, however helpful it may be to the writer, may be the death knell for the aesthetic qualities of the product, depending on the writer's abilities to rein in the emotional components of the work. Perhaps because they are frequently

undertaken by novice writers, narratives of illness can suffer greatly from stylistic unevenness, but their literary deficiencies are often overcome by the urgency of the messages they have to convey.

This urgency and the need to communicate one's personal experience are powerfully magnified by the extraordinarily adverse circumstances in which some illness narratives are created. The French journalist Jean-Dominique Bauby, who had locked-in syndrome, had motor control only over his left eyelid. He wrote *Le Scaphandre et le Papillon (The Diving Bell and the Butterfly)* through a series of eye blinks, dictating the book letter by letter.<sup>25</sup>

Some writers are motivated by altruism: they want to help people similarly afflicted, warning them against repeating their mistakes, pointing them to sources of help. Online narrators can assemble a support group from which they receive both information and solace nearly instantaneously. Such virtual communities are a positive outgrowth of electronic communication, on the one hand; yet, on the other, they are often testaments to failed relationships, especially those between doctors and patients. Other cultural and social factors may also profoundly influence the illness narrative, with occasionally ominous overtones. One editorialist has declared that the form is created by "ailing baby-boomer[s] . . . displaying their customary self-absorption".<sup>26</sup> Others have criticised the use of such intensely personal experiences as "victim art".<sup>27, 28</sup>

One important value of illness narratives is their capacity to bring about change that improves the lives of patients, families, and caregivers. Some doctors and hospitals have modified their practice and policies on the basis of the experiences patients have detailed in their electronic stories: "By reading what patients say to one another in online forums, doctors say, they learn things about how patients are coping with an illness that would never be disclosed during an office visit".<sup>29</sup> One neurosurgeon, for example, revised a surgical technique after complaints about scarring that patients expressed to each other in an online discussion group.<sup>29</sup> And the Catalfos, bolstered by the

## Panel 2: "I'm Afraid. I'm Afraid. I'm Afraid"

When I was twenty-eight I started to trip and drop things. What at first seemed my natural clumsiness soon became too pronounced to shrug off. I consulted a neurologist, who told me that I had a brain tumor. A battery of tests, increasingly disagreeable, revealed no tumor. About a year and a half later I developed a blurred spot in one eye. I had, at last, the episodes "disseminated in space and time" requisite for a diagnosis: multiple sclerosis. I have never been sorry for the doctor's initial misdiagnosis, however. For almost a week, until the negative results of the tests were in, I thought that I was going to die right away. Every day for the past nearly ten years, then, has been a kind of gift. I accept all gifts.

\* \* \*

Each morning that I wake up, that I get out of bed, is a fresh event, something that I might not have had. Each gesture that I make carries a weight of uncertainty, demands significant attention: buttoning my shirt, changing a light bulb, walking down stairs. I might not be able to do it this time. Inevitably the minutiae of my life had to assume dramatic proportions. If I could not love them, delight in them, they would likely drown me in rage and in self-pity, that tempting, obliterating sea.

\* \* \*

And so I say, *I'm afraid of having MS: of the almost daily deterioration of my strength; of the loss of control over my own body; of my increasing dependence on others to help me with the simplest personal tasks—tying my shoes, getting out of bed. Where will it all end? I'm afraid. I'm afraid. I'm afraid.* But like other MS people (and on the whole we're not very different from people in general, except perhaps that our fears are more focused and therefore easier to get at if we try), I don't give in to my fears. *If I weren't scared of this catastrophic disease, I remind myself, I'd have at least one screw loose somewhere.* So I put my fears to the best use I can, analyzing them to discover how to live carefully and choose my actions wisely. I'm nourished by the encouragement of others, like [my husband], who believe that what's important is not that I'm scared but that I do what I need to do whether I'm scared or not. By speaking my fear aloud, I've reduced it from a giant trampling my interior landscape to an ordinary imp, the kind who dances through everybody's inner house from time to time, curdling the milk and smashing the crockery but leaving the structure basically intact. Surveying the damage, I get out my mop and broom. *This is my life, I say to myself, fear and all. I'm responsible for it. And I'd better get on with it, because it matters.*

From Mairs N, *Plaintext*. Tucson: University of Arizona Press, 1986: 11 (first extract), 6 (second extract), and *Carnal Acts*. New York: HarperCollins, 1990: 145–46 (third extract).



Nancy Mairs

Sean Justice

**Biographical note:** Nancy Mairs lives in Tucson, Arizona, and writes frequently about her illness. Her essay "On Being a Cripple" has been widely anthologised; her most recent book is *Waist-High in the World: A Life among the Nondisabled*. Boston: Beacon Press, 1996.

support of participants in the *Leukemia* narrative, were successful in getting their local hospital to change a policy about sedation for outpatient procedures.

Whether they recount their tales in journals, to friends in letters or e-mail, in a printed book, or in an electronic forum, the authors of illness narratives have common goals: they are all trying to make sense of what is happening to them, to set some boundaries that will confine the experience of illness in their lives, to fend off chaos and the darkness that sometimes threatens to overwhelm. But it isn't just the writers who benefit from these stories: they have power for readers as well. For physicians, caregivers, and ethicists, they are a window on the ways illness can permeate lives and relationships, and on the ways the experience affects thinking and decision making. The texts often reveal truths that sick people and their families cannot or will not otherwise tell. Narratives of illness provide eloquent proof, for patients and practitioners, that "when the lights of health go down", one's own story can be illumination enough.<sup>30</sup>

## References

- O'Connor F, letter to A, 28 June 1956. From *The Habit of Being: Letters of Flannery O'Connor*, ed. Fitzgerald S. New York: Vintage, 1979: 163.
- Brody H. *Stories of sickness*. New Haven, CT: Yale University Press, 1987.
- Hawkins AH. *Reconstructing illness: studies in pathography*. West Lafayette, IN: Purdue University Press, 1993.
- Kleinman A. *The illness narratives: suffering, healing, and the human condition*. New York: Basic Books, 1988.
- Frank AW. *The wounded storyteller: body, illness, and ethics*. Chicago: University of Chicago Press, 1995.
- Jones AH. Literature and medicine: narrative ethics. *Lancet* 1997; **349**: 1243–46.
- Jones AH. Voices from the darkness: narratives of mental illness. *Med Hum Rev* 1995; **9** (1) : 9–24.
- Jones AH. Metaphors, narratives, and images of AIDS. *Med Hum Rev* 1990; **4** (1): 38–42.
- Zuger A. AIDS becomes ordinary. *Med Hum Rev* 1993; **7**(1): 38–42.
- Cousins N. *Anatomy of an illness as perceived by the patient*. New York: Norton, 1979.
- Donne J. *Devotions upon emergent occasions*. Ann Arbor: University of Michigan Press, 1959.
- Ober WB. John Donne as a patient: *Devotions upon Emergent Occasions*. *Lit Med* 1990; **9**: 21–37.
- Sontag S. *Illness as metaphor and AIDS and its metaphors*. New York: Anchor Books, 1978.
- Lear MW. *Heartsounds: the story of a love and loss*. New York: Simon and Schuster, 1980.
- Frank AW. Reclaiming an orphan genre: the first-person narrative of illness. *Lit Med* 1994; **13**: 1–21.
- Price R. *A whole new life*. New York: Atheneum, 1994.
- Grealy L. *Autobiography of a face*. Boston: Houghton Mifflin, 1994.
- Gunther J. *Death be not proud: a memoir*. New York: Modern Library, 1953.
- Broyard A. *Intoxicated by my illness*. New York: Clarkson Potter, 1992.
- Page MA. A complex sorrow: reflections on cancer and an abbreviated life. DeVault ML, ed. Philadelphia: Temple University Press, 1993.
- Butler S, Rosenblum B. *Cancer in two voices*. Minneapolis: Spinners Book Company, 1991.
- McLellan F. "A whole other story": the electronic narrative of illness. *Lit Med* 1997; **16**: 88–107.
- A heart for Susan. <http://www.smartlink.net/~hiller/susan/>. Site accessed on 22 April 1997.
- Murray P. My experience with breast cancer (illustrated). <http://web.mit.edu/pamurray/www/artbc.html> Site accessed on April 22, 1997.
- Bauby J-D. *The diving bell and the Butterfly*. Leggatt J, transl. New York: Knopf, 1997.
- Schwartz AE. Literature of pain. *Washington Post* 23 September 1994: A27.
- Croce A. Discussing the undiscussable. *New Yorker* 26 December 1994/2 January 1995: 54–60.
- Oates JC. Confronting head on the face of the afflicted. *New York Times* 19 February 1995, sec. 2: 1, 22–23.
- Hafner K. The doctor is on. *Newsweek* 27 May 1996: 77–78.
- Woolf V. On being ill. In: *The moment and other essays*. New York: Harcourt Brace Jovanovich, 1948: 9.