# "What the Books Told": Illness, Witnessing, and Patient-Doctor Encounters in Martha Hall's Artists' Books

By Stella Bolaki, University of Edinburgh, UK

### **Abstract:**

The essay explores the specific insights artists' books offer to contemporary feminist understandings of breast cancer, questions of representation and embodiment, discourses of 'witnessing,' and to doctor-patient relationships, using the work of American book artist Martha A. Hall as a case study. Hall's artists' books, created in response to her initial diagnosis of breast cancer in 1989 and the effects of later recurrences until her death in 2004, consist of poems, prose passages, ironic quotations by health practitioners, and images such as x-rays, bone scans, and pictures of prescription bottles. Artists' books create a different kind of 'reading experience' compared to most ordinary books. While this is often described in terms of a powerful 'aesthetic' experience, in the essay I am more concerned with illustrating how artists' books engage and complicate discourses of witnessing, which have recently become foregrounded in the fields of trauma, disability, and illness studies. I also discuss the potential the artist's book holds as a medium for sharing experiences of critical illness and for effecting change in the ways medical professionals interact with their patients, thus commenting on both its personal and political value. The essay concludes with a series of reflections triggered by my own particular encounter with Hall's work.

Through certain books, a truth unfolds. Anatomy and physiology, The tiny sensing organs of the tongue— Each nameless cell contributing its needs. It was fabulous, what the body told. (Rafael Campo)

Martha A. Hall created around a hundred artists' books in response to her initial diagnosis of breast cancer in 1989 and the effects of later recurrences until her death in 2004. Leaving a new career in New York City as a business executive after being diagnosed with a recurrence of breast cancer in 1993, and returning to art, which she had studied as an undergraduate in Smith College in 1971, Hall took a series of art courses and workshops in book making, and familiarised herself with several printing and binding techniques. Her books vary in size, are made of diverse materials, and are either hand-bound or of folded or accordion construction. Most of them are in limited editions while a few exist only in the original. The books do not only combine words and images, including stamped designs, ink drawings, and acrylic paintings, thus embodying a new form of "visual literature" (Rice 59); they also contain medical artifacts such as X-rays, pill containers, prescribed medications in original envelopes and appointment cards, as well as black and white photographic prints,

hairs, and other memorabilia. Some of the books are housed within handmade boxes of different shapes and sizes.<sup>1</sup>

- Artists' books, as most art historians agree, "mark a genuine historical moment of dissatisfaction with art's outreach, a declaration of independence by artists who speak, publish, and at least try to distribute themselves, bypassing the system" (Lippard 50). These developments are more typical of the second half of the twentieth century. Hall does not specifically allude to such literary/political origins of the artist's book as independent publishing or activist art. However, in her artist's statement included in *Holding In, Holding On* (2003), a catalogue accompanying a travelling exhibition of her books in several US colleges and libraries, Hall writes that besides offering her a way "to have a voice in the world," her books are "a means to effect change in the way medical professionals interact with their patients" (15).<sup>2</sup> A series of artists' books have been used for the benefit of public causes,<sup>3</sup> and in "The Artist's Book as Idea and Form," book artist Johanna Drucker writes that the question as to "whether such work can result in a change of political structure and policy opens the door to another set of debates about the role and function of art in the 20th century."
- Two critics who have contributed to this discussion specifically addressing the theme of illness, as well as Hall's work from a sociological perspective, are Alan Radley and Susan Bell. In a recent article, which examines Hall's work together with that of British photographer Jo Spence, they convincingly argue that visual images are important for "their anchoring potential in social practices surrounding breast cancer" while they also function as survival strategies and a source of social support for individual women who cope with lifethreatening illness (369). While Spence's work has been the object of much critical discussion, to my knowledge there is hardly any work focusing on Hall's artists' books other than the article mentioned and an earlier one by Bell, which equally revolves around the "benefits of a *visual sociological* imagination" (37, emphasis added). At the same time, while there are many studies on the personal, cultural, and political work illness narratives do and, more specifically, on the interventions of various genres of breast cancer literature, there has not been an explicit focus on the kind of insights artists' books, in particular, can offer to

<sup>&</sup>lt;sup>1</sup> Images of Hall's books can be seen at http://www.smith.edu/news/2004-05/MarthaHall.html.

<sup>&</sup>lt;sup>2</sup> All pages of quoted excerpts from Hall's books, Hall's artist's statement, and Letha E. Mills' foreword refer to the exhibition catalogue Holding In, Holding On (2003).

<sup>&</sup>lt;sup>3</sup> See Hubert and Hubert for examples of artists' books that have been used in this way, particularly pages 123-

<sup>&</sup>lt;sup>4</sup> A recent book on five genres of cancer literature by women is Deshazer's *Fractured Borders*.

contemporary feminist understandings of breast cancer, questions of representation and embodiment, or to discourses of "witnessing" and to doctor-patient relationships.

- 4 Certainly, there are a number of better-known artists' books which deal with experiences of illness, but they are often discussed in a different context or with different aims in mind. This results in marginalising the topic of illness, even though the technical excellence of the books is directly relevant to the demands posed by precisely such a topic. To mention a few examples, Scott L. McCarney's *Memory Loss* is about his brother who had an automobile accident in 1985 that left him with traumatic brain injury. The book, which uses an accordion binding, is, in the artist's words, "meant to be experiential, putting the viewer in the space of having only sporatic access to a lifetime of memories." Similarly, Susan King uses the maze at Chartres Cathedral in France as the structure of Treading the Maze: An Artist's Journey through Breast Cancer (1993). The book places the reader/viewer in the role of a pilgrim, walking into the maze of illness and back out again. In a chapter on artists' books as "visual literature," Shelley Rice briefly mentions three books which are of interest: Matthew Geller's *Difficulty Swallowing*, which provides a medical case history of the artist's partner who eventually dies of leukemia; Thirty Five Years/One Week, which is Linn Underhill's memorial to her sister's illness—there is a clear division of labour as the photographs included in the book document the sister's normal life while the excerpts from the diary deal with her illness; and, finally, Nancy Holt's Ransacked, which also consists of photographs and text, and which tells the simultaneous story of the gradual decline of Holt's dying aunt and the falling apart of her house as it becomes invaded by a manipulative nurse (62-64).
- It becomes obvious from this short overview of artists' books with illness as their theme that, like other illness narratives, the authors/artists need to make certain choices when it comes to their narrative strategies, such as, for instance, create a balance between the clinical and the metaphorical, adopt a personal or distanced tone, or use a structuring motif to provide coherence and draw in readers. However, the specific characteristics of the artist's book medium, such as its "complexity, density, and intimacy" (Drucker, "Cultural Status" 41), means that artists' books create a different kind of "reading experience" compared to most ordinary books. While this is often described in terms of a powerful "aesthetic" experience, I am interested in exploring how artists' books engage and complicate discourses of witnessing, which have become foregrounded in the fields of trauma, disability, and illness studies. In the epigraph that opens this essay, poet and physician Rafael Campo writes that "through certain books a truth unfolds" (What the Body Told 122). Another topic I address in

the essay is what kind of truths artists' books can communicate to medical practitioners, and what kind of changes they can initiate or facilitate in perspectives and attitudes towards illness and patients. Hall served for years on the Board of Cancer Community Centre, in South Portland, Maine, and received invitations to speak to medical professionals in hospitals and colleges. She decided she would like her work to be in public, rather than private, collections, particularly college libraries. Her books are currently used in Medical Humanities units, and the Maine Women Writers Collection, which owns twelve of her books, regularly receives requests to have the books used in medical schools across the United States.<sup>5</sup> If the book as a cheap, portable, and accessible object has the capacity (at least in theory) to enter numerous locales, and to transform the viewers' expectations, what impact could artists' books have on future physicians and the medical community in general if they were to be used in this way?

Ι

In the old art the writer writes texts. In the new art the writer makes books. (Ulises Carrión)

Artists' books challenge reading conventions associated with ordinary books. Breon Mitchell characterises the reading of an artist's book as "a performance"; the "ideal" reader is someone who "plays" the book, "actualising" the various elements the artist has built into it, such as its shape, size, format, colour, texture, typography, and, possibly, sound (162). While Mitchell emphasises the unique aesthetic experience artists' books offer, and argues that very few people have *really* "read" artists' books, in turning to Hall's books I wish in this section to consider how the central question of how one reads artists' books becomes modulated when the topic is life-threatening illness.

There are many ways in which the formal means of realisation and production are integrated with the thematic or aesthetic issues in Hall's books. Breast cancer writing has focused on embodied imagery such as the surgical scar, but, through the process of making books, Hall seems to perform her own version of surgery in ways that are not merely symbolic or metaphorical. The binding of a book is similar to the scar as it is the site where the pages of the book stitch together and come apart. Campo suggests that "writing good iambic pentameter feels like putting stitches into the anonymous, eternally gaping wound of being human, and [that] rhymes can be intertwined like surgical knots" (*Desire to Heal* 116); Hall's stitches are clearly more tangible. In 1999, Eve Kosofsky Sedgwick, who had become

\_

<sup>&</sup>lt;sup>5</sup> Information on the "Martha A. Hall Collection, 1998-2003" at the University of New England can be found at http://www.une.edu/mwwc/research/hallm.asp. I am grateful to Cully Gurley, curator of Maine Women Writers Collection, for her help and for giving me permission to use the film *I Make Books* in my research.

more and more interested in art and weaving after her cancer diagnosis, exhibited a series of cloth figures she had made—"stuffed forms dressed in blue leggings and tunics, draped with woven cloth"—and hung from the ceiling as part of an installation that temporarily filled the lounge of the City University of New York Graduate Center (Miller 221). As Sedgwick explains, "[t]he figures' strongest representation ties were to the disorienting and radically denuding bodily sense generated by medical imaging and illness itself on the one hand; and on the other, to material urges to dress, ornament, to mend, to recover, and heal" (qtd. in Miller 221-22). While most of Hall's books are the result of an urge to mend or ornament (Hall was a former professional weaver), in other cases the process of creation is driven by a desire to destroy. A good example is the book What You Don't Want to Know which functions like a palimpsest. Hall created this sculptured book by pulling apart and reassembling a publication of the National Cancer Institute entitled What You Need to Know about Breast Cancer. In her artist's statement, she writes that "the process of stitching, crumpling, tearing, cutting, and stapling the pages helped [her] express and release anger" (13). But this book does not only have the apeutic value. Erasing parts of the original text, altering the title and substituting new words and images, Hall "writes back" to the official medical narrative and reclaims part of her agency. Given that the new book is composite as it is held together by different voices, it becomes a site of struggle over the meanings ascribed to breast cancer.

The binding of a book is not only the site of trauma and healing. Canadian book artist Lucie Lambert suggests that the binding "is a container, a wrapping, a *skin*, a meeting point *between the content and the potential reader*" (qtd. in Plesch 221, emphasis added). Artists' books, like other physical objects, do not exist primarily as vehicles through which ideas are accessed "but as objects that mark and incite bodily contact, exerting the force of the tangible upon the touching body" (Tanner 202). Hall's books also bear the body's marks and hold its traces through the inclusion of hairs as well as autobiographical objects, such as used medical appointment cards and original prescription bottles. Writing about objects of grief, such as the AIDS memorial quilt, Laura Tanner argues that "thinking about the way we know objects [...] in and through the body allows us to resist the pressure of immaterialization that would exclude palpable, multisensory experience not only from the realm of knowledge in general but from our understanding of grief in particular" (209). Still, Hall seems to perceive the threat posed by the viewer's literal contact with her books: "People may not want to

-

<sup>&</sup>lt;sup>6</sup> Other artists' books by women explore bodily emissions and traces left by the body. The most well known, perhaps, is *Emissions* (1992), a collaboration between Susan Johanknecht and Katharine Meynell.

'touch' the topics I explore in my books; yet the books invite handling, touching, interaction" (14).

Touch constitutes a central element in the reading process of artists' books. The choice of paper conditions and enhances the viewer's tactile experience of a book and of its contents. In the book *Shell Bones*, for instance, thick and strong heavyweight wrapper is used. This conveys through touch what the story of the book is about: finding thick and strong shells on the beach, which remind Hall of bones, and taking them home. In the case of other books, their construction requires a specific way of interacting with them. A good example is *Jane*, with Wings, which uses a multi-layered folding structure. A polished stone serves as a knob for lifting the red cover of the black box that houses this book; it is an invitation as much as it attests to the need of secrecy. Radley and Bell are right to note that "to read this book is perhaps above all to learn to handle it":

To read the words one has to handle the book very carefully, going deeper into the 'origami' folds so as not to tear the paper; unwrapping (not turning) the pages so as to read the words. [...] The power of the book is in the physical unfolding, in the contiguous relation of revealed pages of text that speak of closing, hiding, and ultimately of difference. (381-82)

While the construction of *Jane*, *with Wings* invites opening, the text advises the reader to "close it away," creating, I would argue, a productive tension:

Close it away.
The fear ...
Close this page.
You are not
The one
Who is dying.
You do not
Need to see
Beneath the surface
The skin,
The scars. (56)

The delicate boundary between concealing and revealing that this book negotiates seems apt when it comes to thinking about narratives that explore illness as well as other traumatic experiences. An appeal for recognition and empathy is made more difficult when the narrative addresses people who do not suffer from the same condition as in the case of *Jane*, with Wings; through the pronoun you, this book does not only relate the reader to the author but also the healthy to the sick. Shlomith Rimmon-Kenan examines the narrative strategy employed in Gillian Rose's memoir Love's Work, whose first part does not read as an illness narrative at all. Rose, who recounts her experience with ovarian cancer, confronts the

anxiety of losing the (presumably disease-free) reader in a self-reflexive moment in the middle of the narrative, but through her deferred account effectively "manipulates the reader into continuing to read in spite of the emotional difficulty" (Rimmon-Kenan 248). Hall's books present a similar challenge to both "our conventions of reading as well as to our attitude toward illness" (Rimmon-Kenan 248), but utilise strategies specific to the genre of the artist's book: At first glance, the reader/viewer is faced with the creativity and uniqueness of the books as works of art, as well as with their inaccessibility, and is therefore lured into opening them (or the boxes in which they are housed) without, in most cases, knowing what to expect. Given that the books are handmade, and, in many cases, handwritten, there is a much more immediate sense of exploring privacy; the reader, inevitably, takes the role of *voyeur* but soon realises that the book makes different demands on him or her. By that time, however, it is difficult to withdraw, not only because this goes against reading conventions (namely, against the desire to reach the end), but also, because, not unlike Rose's memoir, it is as if the text says: "You can't leave me now that you know my condition" (Rimmon-Kenan 248).

- It is clear then that reading *Jane*, *with Wings* does not only entail handling it with care so as not to tear the pages. It also demands taking up the interactive/ethical challenges the book presents. Radley and Bell, drawing on Bruno Latour, write that the work of representation in artworks is "aimed at engaging the viewer in order to bring before her the ideas and values that are mediated by the signs" (385). As they are right to point out, "[t]heir message is about *the viewers/readers currently engaging the work*, and what these individual might do *now*. It is not just about the disease in general, or the fate of individuals who once shared their diagnosis" (Radley and Bell 385, emphasis in the original). Coming back to Mitchell's idea of performance, *Jane*, *with Wings* can be thought of as a kind of *interactive* art which constructs the reader as responsible, in Kelly Oliver's sense of "response-able" (7), and therefore engages him or her as witness: Whether one chooses to advance in the reading of the book or not, there is no way not to interact; the piece already through its form and text establishes a relation between writer and reader/viewer.
- While *Jane*, *with Wings* seems to compel a specifically ethical form of engagement, the reader (even the "ideal" one who reaches the book's centre) is paradoxically told that he or she is to close the book without knowing, without seeing. The book demands *and* exceeds a response at the same time. However, what may initially seem like a performance of failed interaction can in fact transform us as readers in that it compels us to bear witness to what is, in Oliver's phrase, "beyond recognition", namely the process of witnessing itself. Oliver

writes that "we must be vigilant in our attempts to continually open and reopen the possibility of response" (19), and *Jane, with Wings* does precisely that by drawing attention to both the necessity and the impossibility of fully witnessing another's experience. In my conclusion I return to this idea and consider the significance of my own particular mode of encountering Hall's work "in the here and how", which, through its mediated proximity to the other, keeps open the possibility of future witnessing.

## II

I would like a doctor who *enjoyed* me. I want to be a good story for him, to give some of my art in exchange for his. [...] Just as he orders blood tests and bone scans of my body, I'd like my doctor to scan *me*, to grope for my spirit. [...] Without some such recognition, I am nothing but my illness. [...] [The doctor] has to dissect the cadaver of his professional persona; he must see that his silence and neutrality are unnatural. It may be necessary to give up some of his authority in exchange for his humanity. [...] He has little to lose and everything to gain by letting the sick man into his heart. (Anatole Broyard)

Hall's books critique medicalisation and objectification, namely how bodies of cancer patients are handled during surgery, radiation, and chemotherapy, in various ways. Several of Hall's books were inspired by specific interactions with her physicians and nurses. As in Anatole Broyard's essay "The Patient Examines the Doctor," from which the epigraph of this section is taken, through her books Hall shows what kind of qualities she would like her doctors to have. In her book *Just to Know*, she literally examines the female technician who administers radiation therapy:

"Take in a deep breath. Hold it." The test. The technician's voice sounds eerie, comes from a speaker in the machine. She is in the other room, eyes on the computer, not me. The machine whirls softly as if something is spinning around and around at high speed inside. "Breathe." The machine moves forward a fraction of an inch. "Take in a deep breath. Hold it." Then the muted whirling sound. "Breathe." Again and again. Perhaps a hundred times. She must be tired of repeating the same phrase. (20)

In his memoir *The Desire to Heal*, Campo draws a compelling comparison between "withholding words" through the conscious process of "forbidding [him]self the application of heartfelt, meaningful language" and that of commanding his patients "to hold their breath" (114). Hall seems to suggest something similar about the technician in the above excerpt. In *Test Day*, like Broyard, Hall distinguishes between scanning the body and scanning the self, expressing her anger at her doctors' unwillingness to see her as anything more than her illness:

I will light up their screens, My insides black and white. Circles, shadows, lines. But the watchers will not see me; Will not see my self, my soul; (38)

- Broyard writes: "To the typical physician, my illness is a routine incident in his rounds, while for me it's the crisis of my life. I would feel better if I had a doctor who at least perceived this incongruity" (43). *Small Rooms*, a book which is made to look as a series of examination rooms, dramatises this incongruity: "The nurse asks [Hall], 'And how are you today?' I answer, 'I'm in terrible pain.' And she responds, 'Oh. I like the color of your sweater.' She doesn't look at me" (70). The text evokes a never-ending cycle of superficial interaction rather than meaningful communication between patients and doctors: "I leave the long corridors, the waiting women, the nurses and doctors asking someone else, 'And how are you today?'" (72). Another book in which repetition is central is *Prescriptions*. Hall expresses her agony with the number of pills she needs to take and with her doctors who are quick to prescribe them. The pages of this book, which consist of transparent leaves with photocopies of prescriptions and pill containers, and the refrain in the text "I have too many prescriptions" foreground her feelings of frustration.
- In his study *The Renewal of Generosity*, Arthur Frank argues that "the physician dreams the monological authority of being the single unquestioned voice. The patient dreams the monological passivity of having this other pronounce their truth" (103). Letha E. Mills, one of Hall's physicians, who opens *Holding In, Holding On* with a statement on Hall's books, notes that because "medical evaluation of disease has become highly technical" there is so much waiting that a patient's "future hangs in the balance, determined by 'how well they did' on the test" (8-9). In the book *Test Day*, already mentioned, the condition of passive waiting is communicated by bringing together the idea of women's infantilisation with the kind of infantilisation inflicted upon patients by the medical community, which has been heavily criticised in illness narratives of the eighties and early nineties. The silent patient is also compared to an obedient pupil who needs to do as told in order to earn a passing mark:

I will be obedient,
As if my desire to please
Will earn me good grades,
A passing mark.
Small child thoughts
In my woman head.
[...]
I will do as I am told. (38)

In her book *Anxiety (to Martin Antonetti)*, Hall emphasises waiting by alluding to her double identity as artist and cancer patient. The book starts with Hall waiting for Martin (curator of

rare books in Smith's Mortimer Rare Book Room) to call in order to let her know whether he will buy her book entitled "The Rest of My Life," but her anxiety quickly shifts; the book closes with Hall waiting for her doctor, this time, who will call her "about *The Rest of My Life*" (59, emphasis in the original), not a book with this title, but literally the rest of her life. *Anxiety* emphasises feelings of dependence by evoking Hall's insecurity about the future of her art *and* of her life, which remain inextricably connected. The book is an atlas foldout, and symmetry is created as the top part concerns the curator and the bottom the doctor. Since its form does not dictate a single way of reading it—as it does not involve turning pages, the book can be read either horizontally or vertically—the conflation of identities and positions intended by Hall is foregrounded.

Voices: Five Doctors Speak, which was made into an edition of twelve, emphasises the interpersonal dimension of medicine in an intriguing way. The book reads like a theatrical play or script—if one is accessing this book through the exhibition catalogue Holding In, Holding On, there is a section at the end which provides information on the "cast" by giving the full names corresponding to the five voices, distinguished in the text through the use of their surname initials. However, this is not how the original book sorts out the various voices. There, a different font and paper are used by Hall to differentiate each doctor. Voices also consists of skull, eye, and skeleton stamped images and of a miniature book entitled Legacy attached to one page inside an envelope. This idiosyncratic script can be better described as a series of monologues since the voice of the patient is not audible. The choice not to turn the sections of which this "performance" consists into dialogues is perhaps a statement in itself: Medicine takes away the voice of the patient, which returns us to Frank's idea of the doctor's "monological authority."

Voices documents what five doctors each said to Hall when telling her about her second recurrence of breast cancer over a six-day period (July 7-16, 1998), and they can be read comparatively to emphasise different approaches and patterns of interaction between doctors and patients. Some of the voices are more generous, and though they communicate the same bad news, do so with more empathy and caring, while others consist of thoughtless comments ("Four and a half-years is not bad"; "We are buying time") or superficial interactions and uncaring comments ("Do you want to speak to me on the phone or in person?"). A few of the voices contain condescending or patronising comments ("You are my poster child. You've done so well") or, on the contrary, blame the patient for failing to do well ("You've failed"), sustaining the ideals of female infantilisation and dutiful compliance already mentioned. In *I Make Books*, a documentary created by the University of New

England Media Services Department in 2003, Hall explains that the doctor who said that she had "failed" used the term merely "in a medical-terminology sense," but it was only after she confronted that doctor that the burden she had to carry for a long time softened. In the same film, Hall explains how she uses the books to communicate with her physicians, doctors, and the medical community in general. She did show *Voices* to all of her physicians, including the one she was most angry at, who delayed seeing it providing various excuses. As she writes in her artist's statement, the book "elicited various responses including denial, disbelief, and discomfort, but overall using the book to communicate with physicians and nurses has a positive impact on her interactions with the medical community" (13).

- 18 In his chapter "Physicians' Generosity," which draws on Bakhtin's work, Frank argues that identification with others requires giving up the monologue; dialogue is achieved when a "physician reconstitutes him- or herself in the voices of his or her patients" (101, emphasis in the original). In Hall's case, we also notice a reverse process taking place, which confirms the mutual positive impact meaningful communication between doctors and patients can have. One of the voices, belonging to her female doctor Mills, already mentioned, tells Hall the following: "In order to live you must live with the fear of dying. Your books will be your legacy, for family and for friends. And if you live to be an old lady you'll reminisce" (26). As Broyard writes, "Whether he wants to be or not, the doctor is a storyteller, and he can turn our lives into good or bad stories, regardless of the diagnosis" (53). Mills' statement encouraged Hall to continue to make books, and inspired the miniature book Legacy, made in March 2001, which she decided to include in *Voices* as a separate book, using the image of a dancing skeleton to dramatise her doctor's story. It serves as an example of the patient, this time, reconstituting herself in the voice of her practitioner. Hall of course shows the finished book to all her physicians, which means that now that Mills' words have been transmuted into her patient's book, the doctor can also reconstitute herself in the voice of her patient in future the circle is complete but can open again. In her foreword to the catalogue, this becomes evident as Mills constantly returns to Hall's work, speaking in her voice, in order to show the impact Hall's art has had on her own practice and life: "Martha's stories will speak to each of us differently and their meaning will change as we change and grow" (7).
- The last page of *Voices* is a haunting page which is filled with a single phrase repeated on every line in all the different fonts of the doctors: "I am sorry." The use of different fonts suggests that all of the five doctors have said that to Hall at some point. The litany of "I'm sorry" leaves barely any white space on the page creating the effect of concrete poetry or of a painting made of words rather than images. Besides causing a visceral response, it raises

questions concerning the frequency with which "I'm sorry" is being uttered by physicians and its implications: Is "I'm sorry" meaningful in any way or simply a distancing technique from an emotionally difficult situation as in the example of the voice by a doctor already discussed—"Let's take this one step at a time. I am sorry. Do you want to speak to me on the phone or in person?" (25, emphasis added)? Does it evoke, instead, the difficult issue of failure (for either the patient or the doctor) to which I have already alluded? Medicine and science are resistant to the idea of failure: The modern medical narrative can only be sustained if progress and efficacy are confirmed through good survival rates for patients and expensive treatments that work rather than through the acknowledgement of victims, which belie the triumphant discourse of science. If through "I am sorry" a doctor relinquishes his or her authority, does this signal a shift from an emphasis on cure to care, which has been in recent memoirs by doctors? Lisa Diedrich foregrounded study Treatments with a chapter entitled "Towards an Ethics of Failure." In it, drawing on Lyotard's idea of the "différend," which he defines as "an unstable state and instant of language wherein something which must be able to be put into phrases cannot yet be" (qtd. in Diedrich 149), Diedrich asks whether the process of truly addressing uncertainty, errors, failure, and suffering by the medical community, might be the beginning for a search to find "new rules for forming and linking phrases" between the subject positions of doctor and patient (150). For Diedrich, an ethics of failure "takes failure not as an ending" (as, for instance, in Hall's doctor's statement "We failed. You failed" in Voices) but "as a beginning" (166), and I suggest that illness narratives, like Hall's books, which explore despair, frustration, and pain, can help the medical community take the risk of opening up to failure. 20 This possibility is not explored in the book It's Nothing, an ironic title for a story of misdiagnosis. Hall insists that she is in pain, but since the tests do not show anything her judgement is disregarded. The new tests, however, reveal multiple lesions "there where I had shown you [to the doctor] I had pain. There where I had told you" (45). The medical notes mute this incident and present "aches which [the patient] has minimized and really brought out fully today" while they describe Hall as "slightly more depressed than she has been in the past" (45). Hall's determination to "keep listening—to hear what her bones are saying" (45), at the end of the book, challenges the knowledge monopoly of doctors as well as the patients' supposed ignorance. This book is interesting, in that like others in which Hall shifts between the positions of breast cancer patient and artist, it compares and contrasts the consulting room and the art classroom as spaces of body examination. The suggestion is that the latter can become a model for a more holistic approach to health and healing. The book starts with Hall

drawing the skull in art class while holding it cupped in her hands and proceeds to trace the rest of the body: "We gently moved our fingers down our vertebrae, felt for our first rib. [...] The next week we traced our sternum, pushed on our ribs" (44). While this exercise is painful (Hall hates "knowing where the jabs of pain would be—long ago memorized"), it is also a healing experience. The book concludes with Hall asserting the need to draw her body and pain: "So in art class I draw my ribs, my vertebrae, my skull. I draw my pain. I draw delicacy that hides anger, fragility that holds strength. These are my bones. I need to draw them to heal" (45). The lines she draws are not the same as the lines revealed by the bone scan. The emphasis on touching the body (feeling the different parts), which takes place in art class, complements the medical gaze, or "the machine vision" of "the watchers," as Hall calls it, in *Test Day*. In turn, listening to hear what the bones are saying is a corrective to the doctors' only and distant words: "Take a deep breath.' 'Hold it.' 'You can breathe'" (38).

21 In "Welcome to Cancerland," Barbara Ehrenreich writes that "in the overwhelmingly Darwinian culture that has grown up around breast cancer, martyrs count for little; it is the 'survivors' who merit constant honor and acclaim" (48). The "mindless triumphalism of 'survivohood,'" in Ehrenreich's phrase, is perpetuated not only by science but also by the mainstream breast cancer culture, which "denigrates the dead and the dying" (53). Hall's Ghost Friends, the last book I would like to mention in this section, is a moving card catalogue compilation of remembrances of similarly afflicted acquaintances, most of whom do not survive. It consists of sixteen books, each one of them sitting in an expendable file format. The bookcloth covered clamshell box in which they are housed creates a realistic filing cabinet expected to be found in a hospital or clinic. Hall supplements impersonal biomedical patient files, which document symptoms and treatment, and have statistical value through the particular stories of people she narrates. These stories fight facelessness, in that the individuals involved are named, and document both haunting and more optimistic moments by providing snapshots of encounters without passing judgement. For instance, one of them tells the story of Joyce who "walked into the treatment room and told us, the regulars, she had decided not to have chemo, not to fight anymore. She would not be coming back." The story concludes with the comment "Her husband was crying" (66). Ghost Friends consists of lyrical elegies but also functions as a form of public memorialising that recalls the AIDS Memorial Quilt Project and other remembrance rituals. Several doctors, particularly those working with AIDS patients, have also attempted to do something similar. For example, in his poetry collection What the Body Told Campo includes a long sequence of deconstructed sonnets called "Ten Patients and Another," through which he attempts to speak

for his patients in a literary rather than scientific language, thus humanising medicine. Likewise, Kate Scannell has a five-page list of names enumerating her dead patients in her memoir Death of the Good Doctor.

### Ш

I make books. I write what I cannot say. I make marks with meaning only in their making. I paint in colors fearsome and strange. I make books so I won't die.

The dialogue is something I am going to miss in letting my books go to an institution [University of New England] and I would hope that—I am carrying out half of the conversation—from time to time somebody would carry on another piece of the

conversation. That would be a real gift. (Martha Hall)

22 If the artist's book as a medium can bring into being a different set of strategies for "doing illness," in Diedrich's term (25), how political are these strategies? In the "Martha Hall Collection" at the University of New England, together with twelve of Hall's books, there is a small amount of foldered material which belonged to the artist, including a copy of Ehrenreich's article "Welcome to Cancerland," to which I have briefly alluded. This article, which was published in *Harper's Magazine* in November 2001, diagnoses the circumstances behind the shift from the politicisation to the depoliticisation of patienthood, which occurred at the turn of the twenty-first century (Diedrich 48-49); its thesis is that there is "nothing very feminist—in an ideological or activist sense—about the mainstream of breast-cancer culture today" (Ehrenreich 47).

23 Hall's books do not establish links to radical activist agendas such as environmental or gay/lesbian movements and do not explicitly grapple with questions of difference, such as class and racial disparities, which often determine who is more likely to have access to health care and, possibly, better survival chances. However, as we have seen, they address discourses of victimhood/survival and infantilisation, which Ehrenreich takes issue with in her article, and express anger and frustration, thus questioning the "universally upbeat" stance that Ehrenreich finds disturbing in breast cancer patients (48). These are some of the threads of Ehrenreich's argument to which Hall seems to respond directly, but, by way of conclusion, I want to draw attention to a little detail in the article which I would like to imagine "spoke"

<sup>&</sup>lt;sup>7</sup> The fact that Hall does not deal with the invisibilities which, for instance, Audre Lorde, a black, lesbian woman with breast cancer addresses in The Cancer Journals (1980), is inevitable given the position from which she speaks: that of a middle-class white heterosexual woman, who has better access to health care and treatment than, for example, women from poor backgrounds.

to Hall in a certain way, though of course this is speculation. While commenting on the ultra feminine and infantilising theme in breast-cancer discourse, represented by the teddy bears and the prevailing "pinkness," Ehrenreich specifically refers to the contents of a bag distributed to breast cancer patients, which, besides cosmetics, includes, to her amazement, "a small box of crayons" (46). The founder of the Foundation who distributes these bags, explains what the crayons are for—they go with a journal and sketch book also contained in the bag "for people to express different moods, different thoughts"—but admits to Ehrenreich that she has never tried to write with crayons herself (46). Now, thinking of Hall's artists' books discussed in the previous sections, I would like to suggest that, rather than negating writing, and its power, crayons can, in Drucker's phrase, "extend its communicative potential" (Figuring 18). "Painting in fierce colors" and "making marks," which is how Hall describes the process of making books in her book I Make Books from which the first epigraph of this concluding section is taken, is not a solipsistic or merely ornamental activity that promotes infantilisation. It is neither dictated by the parameters of American consumer culture, which is what Ehrenreich finds troubling about mainstream breast cancer culture. While surveying the pink-ribbon-themed breast cancer products, Ehrenreich notes that "I can't help noticing that the existential space in which a friend has earnestly advised me to 'confront my mortality' bears a striking resemblance to the mall' (46). I am not suggesting, of course, that all women with breast cancer should become book artists so that the mall can give its place to what is often perceived as a more elitist space, namely the art gallery, even though, as already mentioned, artists' books often operate outside the constraints of the art market and gallery system.<sup>8</sup> Even so, creating a book and sending it out to the world is different from putting down thoughts in a diary that will not be read by others. As Drucker writes about printing, an important component of book making:

It provides a fundamental means of transforming personal expression into an authoritative form within the social order and the public sphere. The physicality of printing makes that transformation a somatic experience, an act of the body, which moves the interior voice, the personal word, into the cultural domain. (*Figuring* 4)

The implication is that not all women who write about their illness or create artifacts can reclaim discursive authority, but my point is that writing and drawing do not only serve to communicate personal experiences. Artists' books are a means through which some women can have a voice; they are therapeutic, but also political insofar as the books are shareable, can provide insights to the process of witnessing and enlarge its circle, and, finally, as we

-

<sup>&</sup>lt;sup>8</sup> Stephen Bury suggests that one of the reasons why artists' books are particularly attractive to women is because these systems are still male-dominated (22).

have seen in Hall's case, can be used to effect change in the ways medical professionals interact with their patients.

- Artists' books together with ordinary books exploring illness can become part of a doctor's training in the context of the ongoing development of medical humanities curriculum units. Like a literary scholar, the doctor is faced with a text, a narrative voiced by the patient, which has to be interpreted. The advantage of artists' books over ordinary ones is that materiality is foregrounded so that, rather than merely having symbolic status, artists' books constantly return us to the body. Like patients, artists' books have to be examined, touched, unveiled, opened, but require physical intimacy and care. They also exemplify different ways of approaching the process of examination itself: Artists' books can be seen from either a clinical distance or close at hand where turning or unwrapping the pages uncovers more personal feelings and struggles, just as "reading" a patient involves more than anatomy and physiology or conducting a set of bodily scans.
- Ultimately, the books can open up a new space of communication between patients and doctors that can renew intimacy and generosity, and even reclaim an alternative form of silence:

I am afraid
To speak my fears aloud,
[...]
to hear your answers,
to know what you know,
so do not tell me.
Just turn the page
And close the book.
Do not tell me
now. (86)

The above excerpt is taken from Hall's book *Tell Me*. The book stages a silent but meaningful interaction between herself and her doctor; involving a form of communication beyond words, mediated by the book that connects the doctor and the patient as if it were a skin. The doctor is asked to simply turn the pages of the book, as if partaking in a silent ritual, and delay telling the patient what she fears to hear. Considering the importance of "an ethics of touch," Sara Ahmed writes that "thinking of speaking and hearing in terms of touch might allow us to challenge the very assumption that communication is about expression, or about the transparency of meaning" (155). Transparency is what is aimed for in patient-doctor exchanges (in most contexts), even though the emotional difficulty entailed makes communication difficult. This is why neutrality and silence, in the form of withholding words that can touch another person's heart, are opted for by the doctor, and sometimes by the

patient too. However, as Ahmed adds, "[c]ommunication involves working with that which fails to get across or that which is necessarily secret" (155).

- Turning to my own *particular* encounter with Hall's books, I would like to finish with a few brief reflections on the responsibility that is opened by that which fails to get across or cannot be grasped in the present. "What am I experiencing when I turn these pages? This is what the critic of an artist's book must ask," and, as Dick Higgins adds, "for most critics it is an uncomfortable question" (12). As he clarifies: "The language of normative criticism is not geared towards the discussion of an experience, which is the main focus of most artists' books" (12). I would like to further complicate this statement. If, as suggested, artists' books invite touching and handling, that is, they compel not only involvement with the ideas expressed in the text and the images, but also *physical* engagement, how is it possible for me to respond to Hall's books "in a way which is generous, in a way which gives" (Ahmed 149), when proximity is mediated and thus one cannot get close enough to the other?
- 27 In a chapter on ethical encounters, which draws on Levinas' work and Derrida's ethics of hospitality, Ahmed stresses the need for a more proper and rigorous thinking of what it means to encounter an other by shifting our attention to the question of particular modes of encounter through which others are faced. Reading Ahmed's lyrical and moving description of her encounter with Indian writer Mahasweta Devi and her fictional character Douloti, I am tempted to draw parallels and comparisons. Although my encounter with Hall's books does not raise the kind of questions Ahmed considers in the context of post-coloniality, it is, like Ahmed's mediated. I come to Hall's books through a kind of translation not very dissimilar to the one that allows Ahmed to encounter Devi's text in English (Spivak's translation). This is not a translation into another language, but one, nevertheless, which makes Hall's work accessible to a wider audience, including myself working in Britain: I am referring to the award-winning exhibition catalogue Holding In, Holding On, and to the film I Make Books, from which the second epigraph of this section is taken. The former reproduces excerpts taken from Hall's books (though unmarked, as the same font is used throughout), together with photographs; the latter allows a more faithful, three-dimensional view of the books, but can only simulate the process of turning their pages:

And so I face this text in writing about it here. I must respond to it. But in responding to this text, already mediated by the failed proximity of translation, I cannot fully face this text, I cannot transform the text into a face. I miss it. But my missing of it, my failure to face up to it, is also an encounter with it, and engagement with it, and a responsibility for it. (Ahmed 148)

As Ahmed is right to suggest, "[o]ne's infinite responsibility begins with the particular demands that an other might make," but cannot stop there (147). If the particularity of my response to Hall, mediated by the catalogue and the film, cannot fulfill my responsibility, rather than seeing this as a form of failed witnessing, I prefer to approach it as "a call, a demand, for a future response to an other *whom I may yet approach*" (Ahmed 146, emphasis in the original). I hope this essay performs a particular and finite engagement with Hall's artists' books while also gesturing towards an approach that is "yet to be taken."

## **Works Cited**

Ahmed, Sara. Strange Encounters: Embodied Others in Post-Coloniality. London: Routledge, 2000.

Bell, Susan E. "Living with Breast Cancer in Text and Image: Making Art to Make Sense." *Qualitative Research in Psychology* 3 (2006): 31-44.

Broyard, Anatole. *Intoxicated by My Illness and Other Writings on Life and Death*. New York: Fawcett Columbine, 1992.

Bury, Stephen. Artists' Books: The Book as a Work of Art, 1963-1995. Aldershot: Scolar Press, 1995.

Campo, Rafael. *The Desire to Heal: A Doctor's Education in Empathy, Identity, and Poetry*. New York: Norton, 1997.

---. What the Body Told. Durham: Duke UP, 1996.

Carrión, Ulises. "The New Art of Making Books." *Artists' Books: A Critical Anthology and Sourcebook*. Ed. Joan Lyons. Rochester, NY: Visual Studies Workshop Press Layton, 1985. 31-43.

Deshazer, Mary K. Fractured Borders: Reading Women's Cancer Literature. Ann Arbor: U of Michigan P, 2005.

Diedrich, Lisa. *Treatments: Language, Politics, and the Culture of Illness*. Minneapolis: U of Minnesota P, 2007.

Drucker, Johanna. Figuring the Word: Essays on Books, Writing, and Visual Poetics. New York: Granary Books, 1998.

- ---. "The Artist's Book as Idea and Form." *The Century of Artist's Books*. 1995. Granary Books. 15 May 2009 <a href="http://www.granarybooks.com/books/drucker2/drucker2.html">http://www.granarybooks.com/books/drucker2/drucker2.html</a>.
- ---. "Artists' Books and the Cultural Status of the Book." *Journal of Communication* 44. 1 (Winter 1994): 12-42.

Ehrenreich, Barbara. "Welcome to Cancerland." *Harper's* (Nov. 2001): 43–53.

Frank, W. Arthur. *The Renewal of Generosity: Illness, Medicine, and How to Live*. Chicago: U of Chicago P, 2004.

Hall, Martha A. *Holding In, Holding On.* Catalogue to accompany exhibition, Mortimer Rare Book Room, Smith College, Herlin Press, 2003.

---. *I Make Books*. Dir. Hollis Haywood and Kari Wagner. University of New England Media Services Department, 2003.

Higgins, Dick. "A Preface." *Artists' Books: A Critical Anthology and Sourcebook.* Ed. Joan Lyons. Rochester, NY: Visual Studies Workshop Press Layton, 1985. 11-12.

Hubert, Renée Riese, and Judd D. Hubert. *The Cutting Edge of Reading: Artists' Books*. New York: Granary Books, 1999.

Lippard, Lucy R. "Conspicuous Consumption: New Artists' Books." *Artists' Books: A Critical Anthology and Sourcebook*. Ed. Joan Lyons. Rochester, NY: Visual Studies Workshop Press Layton, 1985. 49-57.

McCarney, Scott L. "Artist's Statement." *Memory Loss*. Queensland Digital Library, 15 May 2009 <a href="http://www.slq.qld.gov.au/coll/austart/ab">http://www.slq.qld.gov.au/coll/austart/ab</a>.

Miller, Nancy K. "Reviewing Eve." *Regarding Sedgwick: Essays on Queer Culture and Critical Theory*. Ed. Stephen M. Barber and David L. Clark. New York: Routledge, 2002. 217-25.

Mitchell, Breon. "The Secret Life of the Book: The Livre d'artiste and the Act of Reading." *Conjunctions: Verbal-Visual Relations. Ed. Laurie Edson.* San Diego: San Diego UP, 1996. 161-67.

Oliver, Kelly. Witnessing: Beyond Recognition. Minneapolis: University of Minnesota Press, 2001.

Plesch, Véronique. "From Image to Word: The Books of Lucie Lambert." *Orientations: Space/Time/Image/Word*. Word & Image Interactions 5. Ed. Claus Clüver, Véronique Plesch, and Leo Hoek. Amsterdam: Rodopi, 2005. 215-28.

Radley, Alan, and Susan E. Bell. "Artworks, Collective Experience and Claims for Social Justice: The Case of Women Living with Breast Cancer." *Sociology of Health & Illness* 29.3 (2007): 366-90.

Rice, Shelley. "Artists' Books as Visual Literature." *Artists' Books: A Critical Anthology and Sourcebook*. Ed. Joan Lyons. Rochester, NY: Visual Studies Workshop Press Layton, 1985. 59-85.

Rimmon-Kenan, Shlomith. "What Can Narrative Theory Learn from Illness Narratives?" *Literature and Medicine* 25.2 (Fall 2006): 241-54.

Scannell, Kate. *Death of the Good Doctor: Lessons from the Heart of the AIDS Epidemic*. San Francisco, CA: Cleis Press, 1999.

Tanner, Laura E. Lost Bodies: Inhabiting the Borders of Life and Death. Ithaca and London: Cornell UP, 2006.