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artists' books on wellbeing and medicine

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# PRESCRIPTIONS:

artists' books on wellbeing and medicine

edited by Stella Bolaki and Egidija Čiricaité

*Through certain books, a truth unfolds.  
[...] It was fabulous, what the body told.  
(Rafael Campo)*

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artists' books on wellbeing and medicine

based on the exhibition

Prescriptions: Artists' books on wellbeing and medicine,

with featured artist Martha A. Hall

21 April - 25 September, 2016

The Beaney House of Art & Knowledge, Canterbury,

Edited by Stella Bolaki and Egidija Čiricaite.

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We wish to thank the contributing artists and the authors of the essays who have generously given their time and responded to our requests.

Books donated by the artists are held at the University of Kent's Special Collections, Templeman Library.

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## P R E F A C E :

Waiting rooms, consultations, pills, scans, bandages, surgery, ageing, death, healing, joy, relaxation, distress and pain are ubiquitous experiences, shared around the world. PRESCRIPTIONS is an artist's books collection by 82 artists from 15 countries, which responds to those themes of wellbeing and medicine. First shown at PRESCRIPTIONS exhibition in 2016 at The Beaney House of Art & Knowledge, Canterbury, the artworks are now presented here. Bringing together books on cancer, chronic illness, disability, mental health, surgery, medicine and wellbeing, this volume reveals the empowering role of book art and its potential to become an alternative kind of prescription.

The title PRESCRIPTIONS is taken from one of Martha A. Hall's artist's books. From 1998 until her death in 2003 Hall documented her experience with breast cancer and interactions with the medical community, through intimate, yet complex, handmade books. The physical act of making books was a powerful part of Hall's healing. It allowed her to express emotions that words alone were often inadequate to communicate. Hall wrote that her books are a way to "touch the hearts of other people battling cancer or a life-threatening disease. They are a means to effect change in the way medical professionals interact with their patients. They are a way I can have a voice in the world. They are about living".

*If you have related experiences as a patient or a health professional and are interested in the project, please visit <https://research.kent.ac.uk/artistsbooks/> We would be delighted to hear from you!*

Stella Bolaki and Egidija Čiricaite



## THE MATERIAL POWER OF ARTISTS' BOOKS: HOW BOOKS CAN SPEAK ABOUT ILLNESS AND CARE

Stella Bolaki

The word book usually brings to mind a set of written, printed or illustrated pages or different works by authors, even though nowadays we can't help think of e-books read on Kindles and iPads too. This catalogue of artists' books on wellbeing and medicine presents a body of work created in a medium that is not as well known to the wider public or to the medical humanities community. Artists' books are works of art that are often published in small editions or produced as one-of-a-kind objects. Even though they reference the shape or structure of the traditional book, they adopt a variety of constructions, materials and bindings that challenge conventional book formats. Rather than a mere container for ideas, artists' books integrate their formal means of realisation with their themes, and invite handling, touching and interaction.

In this catalogue you will find books with embossed pages to represent prescription pills (*Prescriptions* by Lizzie Brewer), books made of medical appointment cards (*The Rest of My Life II* by Martha Hall) and books operated upon so that their hidden wounds gradually reveal their layers (*Wound* by Allison Cooke Brown). Origami is used to explore scans before surgery (Bini Atkinson's *Scan Square Book*); an open, yet "frozen," book represents a rare condition of the nervous system (Ashley Fitzgerald's *G. B. S.*); and another book embodies through its multitude of folds, held together by a mesenteric binding, the intestines (*On Innards* by Amanda Couch, Andrew Hladky, Mindy Lee and Richard Nash). An actual prayer book is altered to form the word *PROZAC* as

a way of contrasting approaches to mental distress (*The Book of Common Prayer* by Sophie Adams) while a flag book highlights the changeable nature of our moods drawing on the Buddhist idea of the mind as a cloudy sky (*Like Weather* by Amanda Watson-Will). A set of hand-made booklets of quotations and reflections on objects accompany as a guide three canning jars filled with those very same objects— handling them becomes a wellbeing-enhancing ritual (Janet Marie Bradley's *Madame B's Homemade Existentialist Crisis*). Finally, textile replaces paper in an attempt to remove textual barriers for those with dyslexia (Alison Stewart's *Fabricback Novel*). It is clear from this small sample that despite our daily experience of reading in the digital realm, artists and readers continue to value the physical book which can communicate through myriad forms the essence of its content.

Artists' books are generally understood as a discrete artistic experiment that took place roughly from 1965 to 1980, though with roots in earlier avant-garde movements, and then gradually disappeared. However, as exhibitions like *Prescriptions* demonstrates, the form continues to be potent today. In fact, the multiplicity of art forms and cultural production that constitute the field of artists' books, many of which are represented in this catalogue, is impressive. These include:

fine printing, independent publishing, the craft tradition of book arts, conceptual art, painting and other traditional arts, politically motivated art activity and activist production, performance of both traditional and experimental varieties, concrete poetry, experimental music, computer and electronic arts, and last but not least, the tradition of the illustrated book, the *livre d'artiste* (Drucker, *The Century of Artists' Books 2*).

No matter the activity, artists' books engage their readers intellectually and emotionally, but also physically, and require greater effort than most 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, as if it were a "musical score" (162). Reading an artist's book requires not only interacting with words and images but also paying attention to their shape, size, format, colour, texture, typography and even fragrance and sound. In addition to their aesthetic qualities, artists' books are associated with independent publishing, as the artist remains in control of the different dimensions of production and distribution. Their portability, durability

and inexpensive nature mean that they can circulate more freely and outside the gallery system as well as become available to non-specialist audiences.

The above characteristics of the medium are considered to be some of the reasons why the form has been attractive to female artists in a male-dominated art world. Another reason is its intimacy. As book critic Johanna Drucker writes, book making, in addition to being associated with a range of “feminine” activities (sewing, keeping diaries and decorative tasks), “matches many women’s lived experience” in that it balances “enclosure and exposure”, thus providing a kind of “intimate authority” to women artists (“Intimate Authority” 14). Enclosure and exposure also matches experiences by many people who are facing, or have faced, illness. The book becomes a way of expressing private feelings but also a broader tool of communication. Unlike paintings, sculptures and films, artists’ books are created for one-to-one interactions but can reach many people. Martha Hall’s 2003 artist’s statement—and many of the other artists’ statements in this catalogue—confirm the simultaneous inward and outward-looking character of their books. Hall writes that besides offering her a way “to have a voice in the world”, they allow her to share her experience with other people who are ill and are also “a means to effect change in the way medical professionals interact with their patients” (Artist’s Statement 15).

A variety of art forms are continuing to make contributions to art therapy, medical education and the medical/health humanities. However, artists’ books have been rarely explored in relation to these fields and as distinct types of illness narrative. This is striking as the book as a form and idea has rich cultural, spiritual and metaphorical associations, including with the body. Words like skin, spine and joints may refer to both the body of the book and the human body. Many of the works of this catalogue use the book and its elements as a metaphor for the body (Heather Beardsley’s *Biological Correlations*; George Cullen’s *Point of Contact*; Carolyn Thompson’s *The Eaten Heart*) or as metaphors for particular kinds of illnesses that affect the body in different ways (Lizanne van Essen’s *Osteoporosis*; G. B. S.). Patient narratives often employ embodied imagery such as the surgical scar, but book artists have many more tools and processes at their disposal to explore the scar and stitching in ways that are both literal and metaphorical. The binding of a book, for instance, is similar to the scar as it is the site where the pages of the book stitch together and come apart.

Many of the books in the following pages bear the body’s marks and hold its traces through the inclusion of body scans, pathology lab bags, and even fingerprints and hairs. These objects do not merely function as signs, but have a material presence; they return us to their embodied use by the people

they belonged to and invite us to attend to our own embodied experience when touching and handling them. Scholars of trauma like Laura Tanner have cautioned against “the pressure of immaterialization that would exclude palpable, multisensory experience ... from the realm of knowledge” (209). Many of the contributors to this catalogue have indeed extended the creative nature of academic research by choosing to present it through the artist’s book format (Veronica Adamson’s *Flutterbet of Angst/Joy; On Innards*).

The books of this catalogue transform attitudes to illness, medicine and care through their multidimensional artistic forms and rich metaphors. Whether it is telling a story through the concertina form that allows temporal development (Martha Hall’s *Tattoo*) or capturing the non-linear aspects of illness through folded pages that open out and cascade (Noriko Suzuki-Bosco’s *We Have To...*), these artists find voice and meaning in the shaping of their books and stories. Their work captures lived experiences of illness: for example, what the passing of time feels like during chronic illness in Anne Parfitt’s *Diary of an Illness* which consists of repeated sequential drawings, each drawing “an imitation of the previous, yet never identical”; or how medical events can dominate one’s life in Hall’s *The Rest of My Life II* that consists of an overwhelming amount of medical cards stitched together into a book—as we read in one of the pages, the book becomes a kind of “pulse-taking [...] the present being stitched together—over and over”.

Invisibility and the often depersonalising experience of being a patient are given physical form in books that hide the person behind data and capture the repetitive nature of treatment and tests (*Unknown* by Carole Cluer; *Prescriptions* by Brewer). The books make us feel and sense beyond what we can merely see—their images translate to physical sensations that move our bodies. In other cases the intervention into medical culture is more forceful. Drucker calls transformed books “interventions into the social order” (*The Century of Artists’ Books* 109) and Hall’s *What You Don’t Want to Know about Breast Cancer* functions in this way; it is an altered version of a publication by the National Cancer Institute. Its pages are stitched, stapled, torn, glued, cut, crumpled, marked and resequenced. Moreover, many of the words in the original text, including the title of the book, are erased or highlighted with black ink. In addition to having therapeutic value, through this book/intervention Hall “writes back” to the official medical narrative and reclaims some of her agency as a patient.

Dominant didactic metaphors in medical education, such as “the body as machine,” perpetuate the dehumanising and objectifying aspects of medical care. Many of the books in this catalogue open up the idea of the body as traditionally

understood by medicine: brain lesions on an MRI scan and arthroscopies of knees are re-contextualised through their visual similarity to stars and a lunar landscape (Egidija Čiricaitė's *Innumerable as the Stars of Night*; Véronique Chance's *In the Absence of Running*); an anaesthetic machine is defamiliarised by becoming associated with the story of Sleeping Beauty (Julie Brixey-Williams's *Rosebud*); and bodies are mapped differently to highlight the effect of the environment on them (Lise Melhorn-Boe's *Body Map*) or how illness is "biocultural" (Morris 12). In all these ways, artists "re-enchanted" (Willis et al. 67) illness narratives as they invest in alternative images and encounters for their work that fall outside the strictly clinical framework of patients and doctors.

At the same time, as many patients' accounts show the difficulty of reconciling medical classifications of bodily symptoms with the way they are perceived by individuals, artistic representations of the body like the ones found in this catalogue can be beneficial to both patients and the medical community; in prioritising sensations and feelings, they can lessen patients' alienation that is often exacerbated by impersonal medical imaging technology and help them relate to their bodies better. By encouraging varied interpretations of the body, they can also pave the way for new educational metaphors within medical culture and contribute to an "aesthetic medicine" that is "taught and learned imaginatively" (Bleakley et al. 197).

Like patients, artists' books can be seen from either a clinical distance, when for example they are exhibited behind a glass case and cannot be opened/performed, or close at hand, when they are handled. In the latter case, they require physical intimacy and care. Randi Annie Strand notes about her book *Arabesque 3* that "quick movement is physically impossible" and that "fragility and vulnerability appeal to care and consideration". This slow careful turning of the pages adds "a ritualistic element to the act of reading" and creates "a space for a contemplative experience". Many of the artists in this catalogue show how the process of making books encourages a kind of mindfulness or complete engagement in the present moment (*No Mind* by Gaby Berglund Cardenas; *Like Weather*). While narrative has become synonymous with reflection in "reflective writing" in the health, social care, education and business fields, artists' books can facilitate an alternative kind of reflection that engages both body and mind.

A physician often interacts with the patient's chart as a textual object (for example, before the initial encounter with the patient), but this is to gain clinical knowledge. The demands made by the books of this catalogue on health professionals are of a different nature. Touch constitutes a central element when reading these books. Physical intimacy can be threatening when the object

one comes into contact with explores trauma or serious illness. Hall seems to perceive the threat posed by the viewers' literal contact with her books. As she writes, "People may not want to 'touch' the topics I explore in my books; yet the books invite handling, touching, interaction" (Artist's Statement 14). Touch not only challenges biomedicine's clinical gaze but also becomes associated with an exposure to the other's alterity or difference. In his ethics-centred philosophy Emmanuel Levinas distinguishes the "caress" from "palpation", a word often associated with a medical examination; the difference is that even though it is a kind of search, the caress, unlike palpation, does not seek to disclose something. Levinas describes the caress as a "movement unto the invisible" (257–8). This description fits the endlessly expansive process of reading (each time we read a book, we might discover something new, even though the number of the pages doesn't change). Unlike palpation whose purpose is to disclose something, the caress searches, "seeks the continuation of relationship, the future of relationship, even while it constitutes it" (Oliver 205).

By using her books to communicate with her doctors, as she explains in the documentary *I Make Books*, Hall reconfigures the patient-doctor relationship. The book placed between doctor and patient (in the documentary she tells us how doctor and patient draw their chairs closer to read the book together) transforms the empty space or distance between the two into a space of proximity and touch. Hall's works stage moments of presence, silence and witnessing that call health professionals to be uprooted from their usual routine—for example physical examination (palpation) or verbal interaction—and communicate with their patients in a way that seeks the continuation of the affective and ethical relationship that the books open up in the present.

Even though this catalogue cannot offer readers the pleasure and challenges of handling the books, it will hopefully inspire those who are encountering artists' books for the first time to experiment with this uniquely powerful medium.

#### Acknowledgements:

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- All citations from artists' statements come from this publication.

Stella Bolaki is Senior Lecturer in the School of English at the University of Kent and author of *Illness as Many Narratives: Arts, Medicine and Culture* (Edinburgh University Press, 2016). Her essays on illness and disability have appeared in *Medical Humanities, Literature and Medicine, Journal of Literary & Cultural Disability Studies* and *Mosaic*. She is the Director of Kent's postgraduate programme in Medical Humanities.

## "I MAKE BOOKS SO I WON'T DIE": ARTISTS' BOOKS IN THE ARCHIVES AND CLASSROOM

Cathleen Miller and Jennifer S. Tuttle

What does it mean to make books that are invested in creating a legacy? For Martha A. Hall, whose books explored her experience of living with (and knowing that she would die from) breast cancer, books were "a means to effect change in the way medical professionals interact with their patients" (Artist's Statement 15). Hall made a conscious investment in this dialogue when she chose the Maine Women Writers Collection (MWWC) at the University of New England (UNE), an institution with vibrant programs in the health sciences as well as the liberal arts, as a repository for her books. Hall saw the MWWC as a place that would "make [her] work accessible to the audience [she] most want[ed] to reach" ("Catching Up"). By providing wide access to Hall's artists' books in both the classroom and the archives, the MWWC has answered Hall's call for conversation and consciousness-raising among current and future health care providers.

While graduate students at UNE are engaged in focused professional programs, undergraduates in the pre-health professions have opportunities to elect humanities courses such as Jennifer Tuttle's advanced English course "Writing and Women's Health." Hall's books have been on the syllabus for this course consistently since the MWWC acquired them in 2002, with dialogue a structuring principle of the Hall lesson plan. After perusing the books, students are invited to respond in writing, and many do so in letters. Before Hall's death in 2003, students wrote directly to her; after that time, they have been moved to write to her family. Through this exercise they discern and better understand

Hall's rhetorical choices as well as gain insight into how the books touch them personally and deepen their thinking. One student revealed, "I have now seen and learned something about my future as a medical provider that will change the way I practice medicine". A second student thanked Hall for her "insight. I work in a busy ER where it's easy to forget that bodies are lives. Everyone looks the same when dressed in johnnies and goosebumps".

Bringing the exchange with her readers full circle, Hall responded in 2003 to this first batch of letters with a missive of her own: "I am so grateful to all who wrote letters," she said. "I have such hope that the books will continue to be seen and handled by students, especially those entering the medical professions. . . . I sensed such empathy in the stories some of the students told of their family's experiences in hospitals. These writers will surely work to ensure that their bad experience is not repeated." "The morning I first read the letters," Hall reveals, "I was filled with joy—and moved to tears. . . . They are an affirmation of my work as a writer and an artist" ("Letters from Students"). Hall not only achieved the dialogue for which she had called; she modelled patient-centred health care that is at the heart of the medical humanities. The students, too, attained affirmation that artists' books are a valid means, among many, of getting at the truth of a patient's experience; they learned that while Hall's books might look and feel different from traditional scientific textbooks, they are of equal heft.

Like their letters, students' term papers in this course indicate the power of Hall's books as educational tools and as means of communication with practitioners. Stella Bolaki has written that

the advantage of artists' books. . . is that materiality is foregrounded. . . . Like patients, artists' books have to be examined, touched, unveiled, opened, but require physical intimacy and care. . . . 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. ("What the Book Told" par. 24)

These insights are echoed in one student's analysis of *It's Nothing*. "The form of the book," the student points out, "bound at the top, opening from the bottom, makes it hard to fully read the words handwritten in pencil. The reader must open with care against the resistance of the tight binding. This suggests an ambivalence about sharing, about opening up". In contrast, "one can fully expose the pages that have only images. This points to Hall's desire to show the reader the importance of images and to illustrate the restrictions that written

words may impose". This student also notes that the script resembles that which "one would expect to see in a diary. This very personal way of writing brings the reader into her . . . world and further strengthens her argument that personal interaction is a vital component of her healing process". The book is about Hall's pain being dismissed by practitioners, resulting in a misdiagnosis; "in sharing this book," the student confirms, "Hall finally gets to be heard".

In this analysis of *It's Nothing*, the author illuminates the relationship between form and content. A second student explores similar issues in *Blue Moon*, noting that this book "marries elements of imagery, poetry, texture, myth, [and] science". In doing so, *Blue Moon* is a particularly compelling example of Susan E. Bell's observation that "Martha Hall produced artists' books that often did not make images of her body visible, but [instead] produced textual and symbolic representations of her body" (32). This student author, who has gone on to pursue a career in midwifery, was particularly interested in how Hall critiques the masculinist elements of scientific discourse. Hall writes in *Blue Moon*: "My body is adorned with circles and lines—a lunar landscape designed by surgeons' hands—not God." Considering the "nearly interchangeable visual image of breast and moon," the student traces changing human "perception of the moon in the transition from the sacred to the scientifically deconstructed". Through a combination of symbolism with material choices in representing her sense of objectification and alienation, Hall urged this student reader to ever deeper levels of analysis and understanding.

If *Blue Moon* achieves its critique through representing Martha Hall's body with paint on paper and textual allusion, *Prescriptions* embodies Hall's pharmacological vertigo, pulling the reader into the echo chamber of a pill bottle where the patient's questions are not only unanswered but inaudible. Another student remarks on Hall's use of layered vellum pages that make multiple scrip sheets visible at once:

The effect is dizzying, much like how Hall suggests she often feels. . . . The fact that this small book contains 17 questions with no answers and that each page is surrounded on all sides with pictures of pills, orange bottles and prescriptions establishes Hall's frustration with the over prescribing of medicine and the lack of communication between the doctor and the patient.

While *Prescriptions* conveys an overwhelming experience for the reader in precisely the way this student notes, what is most striking about this book is not the questions themselves but the fact revealed late in the book: "The pharmacist always asks do I have any questions and I always say no". Hundreds of our

students from the UNE College of Pharmacy have encountered *Prescriptions*, in presentations and during a brief tour for first-year students held at the MWWC. One point of the book is to represent the bewildering feeling that a patient has when undergoing cancer treatment. It is hard enough to manage a complex and opaque regimen of medications under relatively normal circumstances, but for someone facing the physical and emotional challenges of cancer treatment, it is well-nigh impossible, and *Prescriptions* puts the reader in a position to glimpse this. Hall's reticence reminds future pharmacists that it is not enough to answer a patient's questions and to listen to the patient. *Prescriptions* is humbling for such readers, demanding that they listen to silences as well as honor questions—that they use their imagination in unexpected ways. *Prescriptions* provides a textual counterpart to Hall's call for conversation as well as her recognition of the deep substance of silence, and it confirms the urgent need to keep her books in our classrooms.

The MWWC provides opportunities each semester for students from UNE and nearby universities to engage in meaningful interaction with Hall's books, with audiences ranging from book arts seminars to introductory art classes. Artists may find themselves drawn to the form of a book, examining the folds and choices of paper; likewise, they may be interested in the affective nature of the application of colour or a particular style of drawing. These students look to the books for inspiration—to imagine new methods of storytelling or to delve into ways to create their own intimate narratives in visual language.

Book artist Rebecca Goodale, who was one of Hall's teachers, regularly brings her classes from the University of Southern Maine to examine the artists' books in the MWWC. During these visits, Goodale emphasizes Hall's work and asks that her students watch the film *I Make Books* to acquaint them with Hall's voice and story. Students are visibly moved by the film, feeling the poignancy of Hall's death as they see her legacy before their eyes. Goodale counters the heaviness that inevitably develops with a human portrait of Martha Hall as a determined, strong, business-savvy artist who marketed her books to archival institutions with which she wanted to be tied. Goodale's remarks provide a more complete picture of Hall's life, one that Hall created for herself despite adversity, illness, and extreme pain. Students are offered a lesson in marketing through this story and are introduced to the idea that they might begin to imagine their work being held in a special collection or archive in the future. Unlike Goodale's, our own art students at UNE have limited knowledge of artists' books; many plan careers in health care or research. Exposure to Hall's books in an art elective course as they begin to envision their future careers plants the seeds of curiosity about,

and empathy for, the patient experience, which was one of Martha Hall's primary goals when she chose the MWWC as a repository.

Situated on UNE's Portland campus, home of the university's graduate programs in the health sciences, the MWWC has participated in numerous inter-professional education events using Martha Hall's books to interact outside the traditional classroom with students who have few hours to devote to the study of the medical humanities. In a 2015 "lunch and learn" event with over eighty students, for example, we opened a conversation about the power of story and listening when students interact with patients. We presented the case of Martha Hall in a way that mimicked the medical model. The students were given a case history, based on information documented in Hall's books and associated biographical material. They also viewed some footage from *I Make Books* along with copies of pages from Hall's books that illustrated her frustrations with her medical conditions and, sometimes, with her health care providers. After this presentation of the case, the students, seated in inter-professional practice groups, were asked to discuss it—specifically to explore how they felt about Martha, what they thought they could do to help her, and whether the case brought up any of their own personal experience or emotions. In a conversational analogue to the "parallel chart" developed by Rita Charon, students spoke with one another about how Hall's narratives might impact their care of her or their feelings about her. As a large group, people then shared highlights from their conversations.

What emerged was a dialogue about how a patient's anger, fear, and other negative emotion affect the health care provider. When we designed the discussion, we expected that students might identify with Martha's personal experience and better understand how difficult it is to have so many tests performed and to know that you are simply a medical record number in the majority of cases. Students, of course, did feel empathy for Martha's experience and acknowledged the challenges she faced as a patient, but they also wanted the patient to understand just how difficult it was for them to offer the necessary care and empathy most beneficial for the patient in the span of time allotted by our health care system. How, they asked, would they be able to offer the kind of care that Martha wanted within these systemic constraints? This conversation enhanced students' understanding of both the patient's perspective and their own predicament, encouraging just the kind of dialogue that Martha Hall hoped her books would evoke.

Hall wrote: "I make books so I won't die" (*I Make Books*); our experiences reading and teaching her books after her death confirm that she was right. In

depositing her books in the MWWC, Hall ensured that her work would provoke conversation long after her death and remain a vital part of health sciences education. Even so, she may not have imagined the number and variety of students whose lives and work would be altered through exposure to her texts. The form of the artist's book, conveying profound content and raw emotion, provides non-artists a comprehensible structure in which to place Hall's non-linear narratives of health and illness; it also models for other artists how one might use this protean form to considerable effect. Because Martha Hall's books will be available to students, scholars, and researchers in the archives at UNE, she will remain a living voice and will continue to challenge and enrich the lives of her readers.

#### *Acknowledgments*

We are grateful to Stella Bolaki and the University of Kent for envisioning and bringing about the "Artists' Books and the Medical Humanities" symposium, which the Maine Women Writers Collection was honoured to cosponsor. We would also like to thank Alan Hall for permission to quote from the letters students sent to Martha.

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## INTER-FACE: ARTISTS' BOOKS AS MUTUAL INQUIRY

Caroline Wellbery

What does a patient want? A patient, according to Richard McCann, wants to be seen. And yet, so often, patients feel their doctor is not paying attention, not in that close, attentive way we all wish to be noticed, particularly when we are vulnerable. But the problem of attunement between doctor and patient isn't so simple. If doctors merely needed to be better observers, or better listeners, perhaps remedial efforts, such as those outlined in an article describing an intervention to make medical trainees more aware of their communication skills (Smith et al.), a few careful training manuals and practice sessions would soon satisfy patients' needs. But the fact that the medical humanities and medical professionalism literature clutter our virtual libraries with advice and research on improving the doctor-patient relationship suggests that we haven't made much progress in nurturing one of the most powerful and meaningful professional relationships our society has to offer. One of the difficulties for physicians, who tend to follow a script carefully groomed over the years, is that it is not always easy to know what patients want. Patients want many, and mostly different things.

A hospitalized patient may, for example, find a cheerful nurse poorly in tune with his miserable psychological state. Another patient in the very next room may be put off by a sympathetic social worker who is perceived as overly somber or seemingly herself in need of reassurance. Or: a patient who smokes cigarettes might respond well to the question: "Have you ever thought about quitting?" whereas another might vow to quit only the moment he's told: "Smoking will kill you". Indeed, a fascinating study on physician self-disclosure found that patients also wanted different things from different doctors, depending on

whether that doctor was a generalist or a surgeon (Beach et al.). Patients were less satisfied when their family physicians disclosed personal information than when a surgeon disclosed such information to patients preparing for surgery. Here, context is everything: we can surmise that in the outpatient setting where less is at stake, patients aren't that interested in the lives of their doctors; however, in the context of greater anxiety, as in the example of an upcoming surgery, it's possible that a few personal remarks humanize the surgeon and lessen their patients' fears.

Artists' books model intriguing answers to this contextual instability. For one thing, they suggest that in many cases, patients don't look to their doctors for the type of deep, inner healing their illness demands. Rather, they seek remedies for their despair through self-exploration. As the example of Melanie Mowinski's *Waxing My Third Eye* in this catalogue illustrates, artists' books offer a way through and out of physical and psychic pain. Many of the books in this exhibit literally process the artist's illness experience, an introspective exercise made visible through stitches, glue and tears. Further, as communications, these books often reach out to peers, whether these are fellow patients or just ordinary witnesses. As shared experience, the expectation is simply to connect with others, as Carole Cluer's *Unknown* metaphorically does through its gold-threaded grid of blue dots, each representing an individual cancer patient. Connection occurs by instilling understanding, recognition and even solace in those who engage with the individual artist's work.

In other words, much of what patients want takes place outside the physician's office. But occasionally the books in this exhibit reveal themselves as potential communication tools through which the patient can let her caregivers know enough about her needs to engage in authentic conversation. These books intriguingly contain indirect messages in the form of visual and verbal fragments, while having a materiality that requires handling, a particularly delicate, gentle and attentive handling that becomes a metaphor for the kind of care a patient might want.

First, then, the books' artistic form has a particularly provocative role. The books rely heavily on visual images, many of which aren't even representational, but rather vivid collages of colour or abstract forms. Verbal elements tantalizingly accompany or augment these images, or are themselves compositions first and meaningful missives second. A physician with whom such a book is shared will need to be receptive to indirect messages, to the patient's version of "telling it slant". That is because these books are not narratives per se. They do not call upon the doctor's "narrative competence," as Rita Charon describes it, where "he or she can quickly and accurately hear and interpret what a patient tries to say"

(“Narrative and Medicine” 862). Instead, these fragments, these multidirectional and multi-formatted objects, demand from the doctor a conversational competence, the ability to open, and open up to the book, and let its mysteries or provocations generate inquiry.

“I see your version of a doctor’s note...you write ‘Prescription: Vigilance’” (see Sue Hague’s *What Lies Within + Vigilance* in this catalogue). “What might I do so you won’t feel so alone as you monitor your breast cancer?” or: “Here you are naked and vulnerable, but I’m instructing you to ‘not cross your legs’ after hip surgery” (see Mary Rouncefield’s *Mr Darcy’s Advice to the Hip Patient*). “I think you’re experiencing our protocols and your sense of exposure as contradictory. Maybe I should revise these medical instructions to help address your emotional needs. What do you suggest?” or: “It says here, ‘I’m sorry,’ over and over again” (see Martha Hall’s *Voices: Five Doctors Speak*)—“I suppose we do say that a lot. Should we be saying something different? Or is this an inevitable part of a patient’s experience?” An engaged physician would be able to glean insight into the patient’s concerns by interrogating this shared object, which the patient presents for mutual interpretation.

Second, the materiality of the book introduces in the encounter a unique and even confrontational challenge. This is perhaps what is meant when George Marshall and Claire Hooker write: “[T]he reality of singular empathy events... would affect bodies, inserting itself into consultations when bodies come together in a given context” (133). Unlike the now virtual electronic medical record, the artist’s book is a physical representation of the artist’s body. Unlike the official record, each artist’s book, each page or panel is unique, as is the patient, rather than constituting a series of preformatted boxes to check. And unlike the electronic chart, which forces the physician into her silo of record-keeping clicks, the book opens up, often in different directions, or unfolds, or unwraps, physically interactive and bridging the space between patient and physician as they sit, perhaps joined where parts of the book touch each of them as the book is spread across their laps.

In insisting that it serves as an alternative or that it contributes to the patient’s medical record, the artist’s book helps equalize the doctor-patient relationship. A doctor who lets go of those tools that support his or her superiority in the encounter—for example the superiority of medical knowledge—becomes more of a partner than a doctor. But unlike in a narrative medicine approach, where the engaged doctor writes a story on behalf of the patient, and then allows the patient to review and revisit the encounter through a sharing of that narrative, in bringing and sharing an artist’s book, it is the patient who generates the

material for discussion. A simple example can be found in *What Lies Within + Vigilance* which contains an alternative doctor’s note, which intercalates the physician’s with the patient’s vocabulary: “Symptoms: Tenderness/Referral: Scan, Consultation/Diagnosis: Breast cancer, texture, form, invasion”. This patient-generated approach is a more radical stance than what Charon writes about when discussing the “intersubjective processes of therapeutic engagement”. “Such engagement,” she writes, “allows doctors to travel alongside their patients, neither lost in space nor pulled in too dangerously close but poised in responsive and reciprocal alignment” (“Two Hemispheres” 148). No, the artist’s book a patient brings to the physician to peruse together forces the physician to let go of his or her agenda and plunge headfirst into uncertainty. What does the patient want from me? The physician might ask. How will I respond? What about the medical information I need to impart? What billing code can I use to get reimbursed for this visit?

How difficult it is for the physician to change gears is demonstrated by one of Martha Hall’s physicians who, according to her telling in the documentary *I Make Books*, refused many times to look through her book in spite of repeated requests, until at last she was able to persuade him. Physicians are pressed for time. The patient opposite them is only one patient of many. For the physician to relinquish her agenda, she must for those moments she and her patient are together, at the very least, be fully receptive to the patient’s needs. Having a discussion about the artist’s book is, in a way, so far outside of the formalities and protocols of the office encounter that it makes possible some knowledge or insight or connection that might never have emerged in the conventional setting. However, it is crucial that this stepping down comes at the patient’s request. Not all patients will want to have such conversations with their physicians. The artist’s book is for those who want their doctors to become vulnerable to them. Ironically, this takes a certain fortitude, which the artists in the exhibition seem to have in abundance.

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## "WE MAKE BOOKS": REFLECTIONS ON ARTISTS' BOOKS AND THE MEDICAL HUMANITIES WORKSHOPS

Emma Isworth

One of the many and various ways in which medicine intersects with the humanities is through the medium of art. To complement the Prescriptions exhibition, the School of English at the University of Kent organised a series of practical workshops to offer participants from diverse backgrounds the opportunity to make their own artist's book. A pleasing cross section of disciplines including doctors, nurses, psychologists, counsellors, occupational therapists, art therapists, artists, writers and academics were represented. Several amongst them had also been cancer patients. As a practising physiotherapist with over thirty years of NHS experience and then also a student of the Medical Humanities, I was invited to observe these workshops and talk to the participants.



At the beginning of each workshop the participants were invited to introduce themselves and say a few words about their reasons for attending. This was a useful way to gauge the broad mix of disciplines and the multifarious motivations for exploring the uses and benefits of artists' books within the context of illness. An excerpt from Martha A. Hall's *I Make Books* documentary film (available from <http://www.une.edu/mwwc>) was shown to demonstrate that far from being the traditional linear, numerical pages between two covers, artists' books are multidimensional. They make use of a wide variety of materials which are stitched, torn, sewn, painted, printed and folded. Hall's books contain poetry, prose, images, quotations by health practitioners as well as autobiographical objects such as x-rays, medical appointment cards and original prescription bottles. They demand to be touched, uncovered, explored, and in them can be found the artist's fears, anger, frustration, depression and her humanity. The workshop participants had the opportunity to visit the Prescriptions exhibition and handle a selection of other artists' books which had been made available for this purpose. These activities allowed them to reflect on certain aesthetic choices artists had made and glean ideas for their own works.

A practical demonstration of some of the techniques, tools and media that can be used to make artists' books was then given. Some of the techniques



included cutting, folding, dissecting, stitching, collaging, creasing, hiding, excavating, combining and adding. Observing and listening to these

descriptions, it occurred to me that any one of those techniques could equally be used to describe many medical or surgical interventions. Each participant was given a length of concertina folded paper from which to begin to construct their book. In advance of the workshops, the participants had been invited to bring along a personal item connected to the theme of well-being which would be used in the making of their book. I saw appointment cards, prescriptions, sutures, x-rays, lab reports, wrist bands, medication wrappings and instruction leaflets, photographs and even a bar code. In addition, laid out around the room were large open boxes of materials the participants were encouraged to pick over and select for their artworks. There was an eclectic mix of coloured and textured papers, yarns, stamps, buttons, pins, maps, old books and magazines, felts and fabrics, inks and paints.

Work tables for four people were arranged around the studio and to start with, there was a hushed air of concentration with each person keeping to their defined quarters. Chewed lips, furrowed brows and furtive looks at what everyone else was doing gradually gave way to discussion and exchanges of



materials, and the neat, defined work spaces became a chaotic jumble with some people choosing to move onto the floor and spread out further. As the atmosphere relaxed a little, I was able to circulate and talk to the participants as they worked. There were some definite themes emerging as the workshops progressed. Illnesses and treatments were strongly represented as journeys with a defined origin and a less defined destination. Some destinations were depicted

as death either of the disease or of the person; some as resolution, either cure or acceptance.

There appeared also to be a subtle difference between the ways in which this workshop was approached by the different groups. People who had suffered or were still under treatment for cancer appeared to readily embrace many of the themes and ideas demonstrated by Martha Hall with representations of pain, fear, anger, isolation and confusion. One patient, nearing the end of her treatment for breast cancer, told me that she felt an overwhelming sense of urgency, a feeling of having to rush to “get it done” because she has no idea how long she has left. This sensation was present in everything she did, from making a cup of coffee to returning to her job. She had had this feeling at the beginning of the workshop and told me she felt apprehensive about it and having to think back at her experiences of her breast cancer: “I don’t know if this is too soon or if I will be able to do it”. I caught up with her at the end of the session and she told me she was amazed at how absorbing it had been and that she felt she had slowed down for the first time. She said she felt exhausted both emotionally and physically but had had a huge feeling of achievement and that she felt happy and remarkably calm.

One notable exception to the generally difficult issues that cancer patients had highlighted was a remarkably ebullient woman who said that she found all the



negative talk about breast cancer very hard. She felt that modern medicine and experiences of breast cancer had given her a new life that she wanted to

celebrate. She had met a new circle of health professionals, counsellors, other patients and their families who had provided inspiration, given her hope and confidence and ultimately a new career direction. She is now a trained volunteer mentor with a cancer charity. She described her treatments in the same gruelling terms of sickness, pain, sores and hair loss but, rather than this being the focus of her artwork, hers was a riot of colour with a feeling of optimism, celebration and even humour.

Participants who came from a healthcare background seemed to approach the workshop in a more investigative way. That is to say, they were trying to draw on ideas to use when treating their own patients. One of the most frequently recurring themes was that of communication especially when therapists were talking about patients who have learning or cognitive difficulties. The making of artists’ books seemed to offer access to bilateral communication that other art forms do not. One therapist told me that she found that the use of lots of different materials gave multiple sensory experiences and an opportunity to experiment with what these materials can do and what they cannot do—what works and what doesn’t. She felt that this was a metaphor for life experiences.

One doctor told me that she worked in a busy general practice and she was interested in exploring ways of improving her patients’ sense of well-being, as well as her own. She had gathered a huge, random pile of materials which included lots of brightly coloured pens, buttons, sparkly papers and stickers and printing stamps. With a wide grin, she told me it felt like being a child again and how she had loved painting and sticking and cutting out when she had been at primary school. When I asked her what she had brought as her “medical” artefact, she showed me an NHS identity label. These labels appear on a large adhesive sheet in the front of hospital notes and they are peeled off by clinicians and used to identify blood samples, appointment cards and investigations requests for example. At this point, she said she had no idea what her book would consist of and she did not elaborate about the ID label. When I went to see her near the end of the session, she had made a poignant biography of her daughter who was diagnosed at a young age with autism and her son who was in good health. Their stories were mapped out along the folds of a concertinaed page, one child on either side of the page and about half way along, a cut-out window where they could climb through to each other’s worlds. Chatting openly, and a little emotionally, she told me that this had been the first time she had really stood back and considered the very different worlds her children inhabited and what that might actually mean to each of them.

Thinking in particular of the healthcare professionals in these workshops, I felt

an undertow of frustration with the way in which they are required to practise. They are constrained not only by time but also by rigid pre-printed care plans and protocols, prescribed teaching modules and examination papers; they are boxed in, forced into uniformity and reductive expression. This model of practice affords no space for these clinicians to extend their communication skills. Introducing clinical staff to workshops such as these would be inexpensive and not particularly time-consuming. As was clearly demonstrated during the bookmaking workshops, clinical staff were able to engage in valuable and meaningful reflective practice both about their own well-being and that of their patients.

Two of the workshop participants were writers; one academic and the other a poet. The academic told me she had found the whole experience “quite stressful” because, as an academic, her way of working was methodically one-dimensional and linear with constant revision and editing. Making the artist’s book presented a challenge to this ordered way of working and she surprised herself in discovering how inflexible her thinking had become. The pages in her artist’s book were predominately text with very minimal pictorial or symbolic content. In contrast, the poet had really embraced a new way to express her poetry – her book was dense with multimedia and text and she had created folds and pleats, flaps and cut-outs to keep her readers interested in discovering what had been hidden. Although the subject matter was illness, there was a sense of fun or mischief about her work where she seemed to be poking fun at some of her clinicians.

An artist and teacher attending one of the workshops had been a life-long



sufferer of migraine and used this as the theme for her artist’s book. Working in monochrome with a very fine nib pen, her drawings consisted of thousands of tightly packed lines in waves and swirls punctuated with sharp points and the whole design perforated with tiny, precisely lined up pin holes. She described the feeling of her migraines as a combination of sharp, intense pain and a trance-like state and her drawing perfectly reflected both those states as my eyes were almost hypnotised by the swirls and then sharply interrupted by the jagged points and pin-holes, rather in the way that Edvard Munch’s famous painting *The Scream* has the ability to evoke a visceral, physical and emotional response in the viewer.

A senior lecturer in Nursing had constructed a book of pages each with an outline of an identical human hand. These were cut from many different materials including sandpaper, fabrics, newsprint and embossed and glossy papers. The final few pages were stamped with progressively fading ink prints of her own hand. “Hands,” she told me, “are such an important part of nursing care”. The final pages seemed to be emblematic of current nursing trends which



put technology between carer and patient thus reducing physical contact to a bare minimum. This lecturer also argued that to become a nurse, students were required to be proficient essay-writers and that many capable and potentially outstanding practitioners were lost to the profession because of a fear of or inability to write academic essays. In making her book, a seed had been sown to think about other ways in which students may be able to articulate or communicate their learning and caring experiences.

Given the wide variations of participants' responses to the workshops, it would be interesting to know whether medical and humanities communities experience the same or different physiological and neurological effects when engaged in creative activities like those undertaken in the workshop or when taught new skills. This may possibly inform how artistic workshops such as this one could be used and developed further in healthcare and wellbeing.

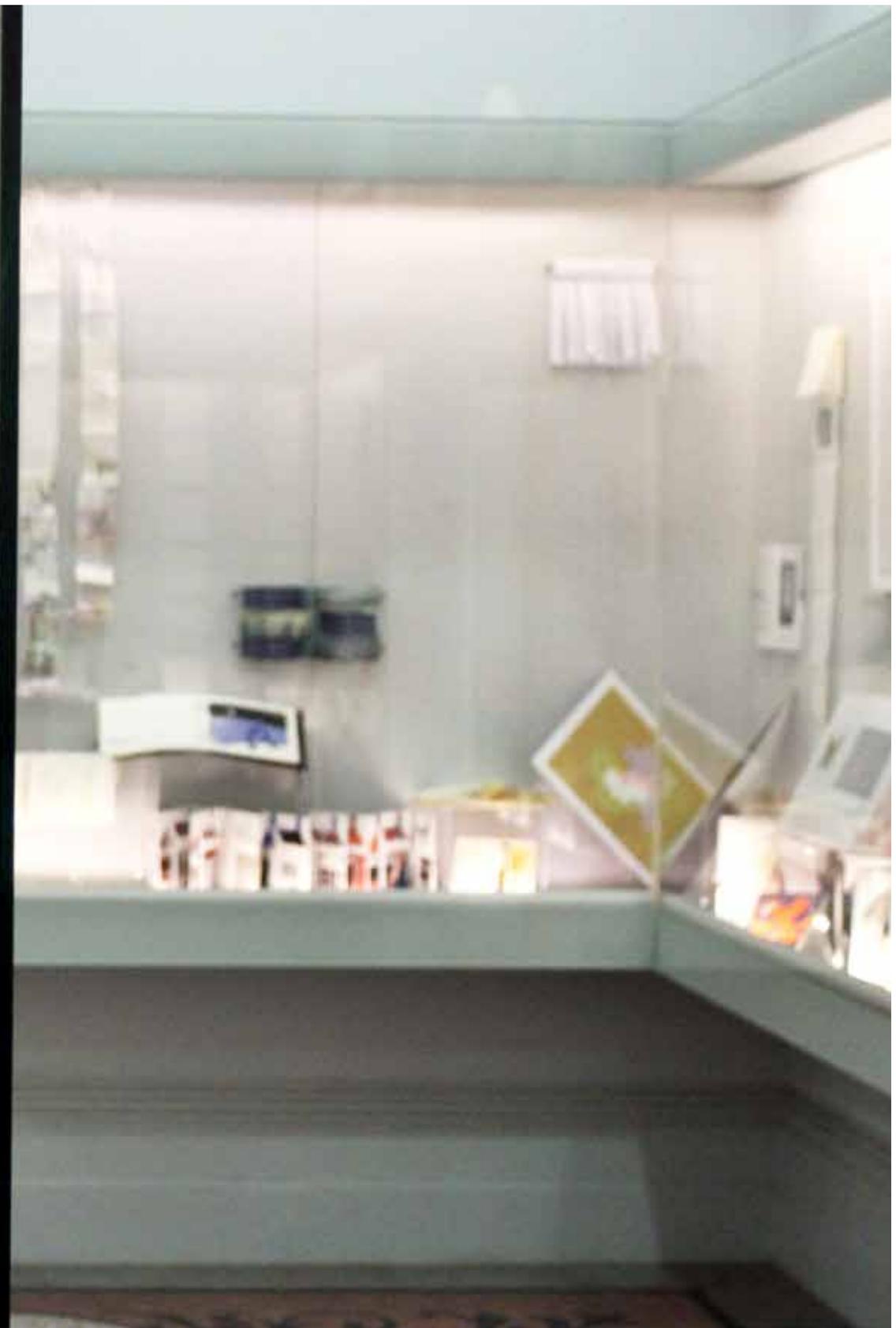
Martha Hall desperately wanted to share her books with her doctors and nurses and most had complied with her wishes. Sadly, in her documentary, we were given no feedback from her clinicians so the effect on them of looking at her books is not known. This led me to wonder what might happen if another workshop were to be planned where patients and one or more of their own clinicians were to take part together. Reflecting on the day, I was struck by how easily artistic and scientific communities can communicate when put into a collaborative situation such as this workshop. At the end of the sessions, when all the books were put on display, I heard comments from those in the medical and allied health professions which expressed surprise at the knowledge and depth of some patients' understanding and experiences of their illnesses and treatments. The details of these are rarely exposed in patient-doctor consultations. Comments from the patients and artists revealed some surprise at the impact that treating illnesses had on the health professionals and at the fact that they, too, suffered illness in similar, often isolating ways.

Two of the most commonly cited causes for dissatisfaction in the health service are poor communication and lack of time. Both service providers and service users complain about these issues in equal measure. It seemed to me, as an observer of the workshops, that by bringing the two communities together and engaging them in this expressive and collaborative exercise, a space was created to foster mutual understanding and empathy. Clinicians and patients have a joint goal in the pursuit of health and well-being but their paths run in parallel and are deeply divided by lack of communication. I saw, in this series of workshops, a real possibility for improvement in effective and meaningful communication which has the potential to benefit all who provide healthcare and those who need to access it. The wider implications might be discussed at commissioning level when it comes to setting policies and designing health services in the future.

#### Acknowledgements

Workshop photos were taken by Dr Emma Bainbridge, School of English, University of Kent.

Emma Isworth is a practising NHS Physiotherapist. Qualifying in 1978, most of her professional life has been in Paediatrics where she developed a special interest in young people with unexplained pain and fatigue symptoms which did not respond to conventional therapeutic techniques. In 2016 she graduated from the University of Kent with an MA in Medical Humanities.



1 .

## 'THE GHOST PROJECT' PUBLISHED

Mara Acoma

*A perfect bound photo book*

2015

The terminal illness of a loved one requires a coping mechanism. *The Ghost Project* was made during my mother's fight against breast cancer, allowing me to confront mortality through my own "ghost", who in turn became my therapist, my guide; allowing me to remain strong and function during her illness. Subsequent analysis of the images created led to a greater understanding of my own mental state, demystifying my own emotional journey. I was able to explore questions of family bonds through life, death and afterwards, exploring both my own personal thoughts and universal themes raised around loss and transitions.

[www.maraacoma.com](http://www.maraacoma.com)



2 .

## THE BOOK OF COMMON PRAYER

Sophie Adams

*Altered book*

2016

I strongly identify as a book artist; it is through this medium that I'm best able to express myself. This work takes a significant source volume and alters it, reflecting on approaches – ancient and modern – to mental illness, loss and grief. I'm drawn to repetitive, meditative processes, and the laborious folding (never cutting) of the pages has its own rhythm, its own cadence. Making the work is much easier for me than explaining it.

[www.sophieadams.com](http://www.sophieadams.com)



## FLUTTERBET OF ANGST/JOY

Veronica Adamson

*Folded, bound and digitally printed artist's book*

2015

*Flutterbet of Angst/Joy* uses words and text from my doctoral dissertation *The Dance to Death: The Aesthetic Experience of Dying* (University of Edinburgh, 2015). The portfolio contains the nine stories of an illness narrative – the shared experience of living with, and dying from, ovarian cancer. The stories are excerpts from blog posts, email and medical records as used in the thesis. The alphabets are words of pleasurable and difficult experiences from the illness narrative. The two works provide alternative forms of representation that extends the creative nature of original academic research.





## MIND MAPS

Penny Alexander

*Typewriter on watercolour paper with Japanese paper overlay*

2016

After postnatal depression, I recovered therapeutically via the medium of typewriter art. Having previously worked with typography and artists' books, I put together a conceptual book to document transitional moments in my life. Twelve hand typed maps of my home addresses to date sit alongside duplicate "keys" which have varying responses as a result of the particular surroundings in question: my private life, experiences there and my general well-being. Mapping my life, albeit subjective, is comparative to everyday experiences many people can relate to; birth, death or mice infestations are telling indicators of a person's overall contentedness.

[www.pennyalexander.wix.com/artist](http://www.pennyalexander.wix.com/artist)



6 .

## LOSING TOUCH

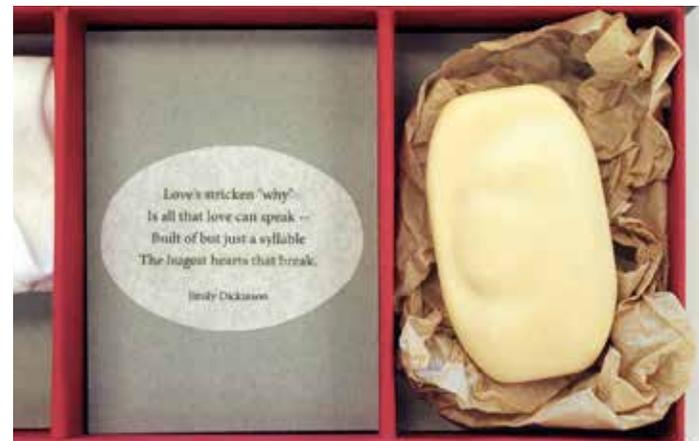
Karen Apps

*Paper, board, book cloth, soap, gloves*

2016

*Losing Touch*  documents the separation of a mother and child, and erosion of their bond, through the loss of physical and emotional contact. The book is inspired by an account from a former resident of the Foundling Hospital in London who recalled “the functional but loveless care received and the longing to be hugged or comforted”. On admission to the hospital, children were first washed and baptised, and for me the soap symbolises a loss of identity and of physical contact. I imagined that for them being bathed was the nearest they came to receiving a comforting hug.

[www.karenapps.com](http://www.karenapps.com)



## PROTECTING MY MIND

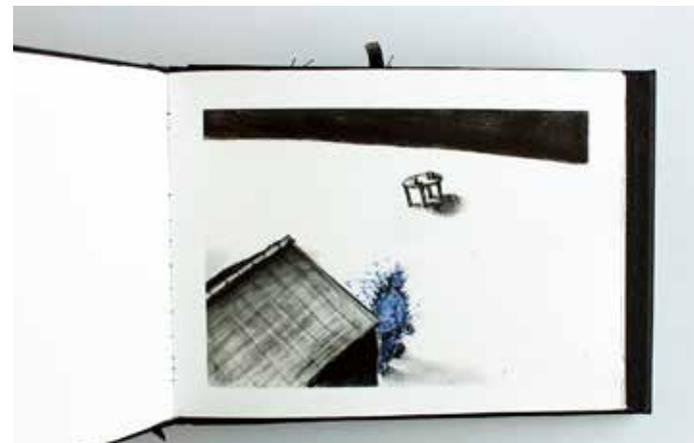
Gunilla Åsberg

*Covered in painted cloth with cuts and seams on all three covers. Ink-jet printed drawings and text on Hahnemule paper. Ink jet printed text on Ingres paper on the inside of the right board.*

2015

For many years I have worked with creative activities for long-term ill women. Together with a psychologist, I met groups of women who all suffered from stress-related illnesses. During six months participants formulated thoughts concerning their situation. It is from their stories, that this book has received its form and content. The text on the right side of the book is made of excerpts from the regulations in Sweden regarding protective equipment (helmets, safety shoes, earplugs, goggles and respiratory equipment). Category 4 in the book is my own text about protection against mental overload, which is not included in such regulations. In contrast to the equipment and regulations that exist to protect us from physical injury, there is no protection today against the stress that actually causes the majority of work-related illnesses.

[gunillaasberg.se](http://gunillaasberg.se)



## SCAN SQUARE BOOK

Bini Atkinson

*Dry point etching, dye, stitch, foil*

2010

Having considered myself an active, healthy individual, it came as a total surprise to find myself with multiple, life changing health issues. In order to come to terms with surgery and its outcomes, I used the process of making art to interpret my progress through the health service as a form of therapeutic activity. These three small books are a response to scans made before surgery (the books were executed when in recovery). From the patient's perspective these scans appear technical, beautifully complex and reveal much about my health. The folded nature of the books reflects that revelation.

(photograph by Bini Atkinson)



## HALLUX VALGUS

Bini Atkinson

*Dry point etching, ink and pastels*

2009

The folded concertina book records the healing and recovery period after my first experience of surgery. Being very squeamish, making a record through drawing, photographs and print helped me stay focused. My surgeon has used an edition of this book as a teaching aid – an example of how practical creative activity can play a part in managing pain and recovery for patients. Following that, I was asked to present my work to the medical team. This in turn led me to be offered an art residency workshop, working with chronic pain patients.  
(photograph by Bini Atkinson)

[www.biniatkinson.wix.com/bini](http://www.biniatkinson.wix.com/bini)



## BIOLOGICAL CORRELATIONS

Heather Beardsley

*Altered book*

2013

I use books as a material because they function so well as a metaphor for the body. The parts of a book build on each other to create larger systems, which together form the whole: letters create words, strung together to make sentences, arranged into paragraphs to be formed into chapters that make up a book. When I cut into the pages of these books the sentences become mangled as words and letters are dissected. By reducing the book to its most basic elements I am reiterating its connection to the imagery I am carving into it.

[www.heatherbeardsley.com](http://www.heatherbeardsley.com)



## NO MIND

Gaby Berglund Cardenas

*Spool book. 1.65-meter-long ink calligraphy script on Nepal paper mounted on antique wood sewing spool. 3/3 each handwritten and unique.*

2014

For centuries Buddhist monks have used meditation to obtain enlightenment. In the early 17th century Zen monks drew Ensō circles with brush and ink as a form of meditation. More recently, physicians have employed meditation to successfully help treat certain disorders. I studied Buddhism and meditation in S. Korea. Sitting daily for long periods, handwriting repeatedly the words “no mind” allowed me to quiet my mind and body and empty my mind. “No mind” is a Zen expression equivalent to being mindful, present. The script became 1.6 metre long and it evolved into a series.

[www.gabyberglundcardenas.wordpress.com](http://www.gabyberglundcardenas.wordpress.com)



## PARENTESI SETTEMBRINA (SEPTEMBER PARENTHESIS)

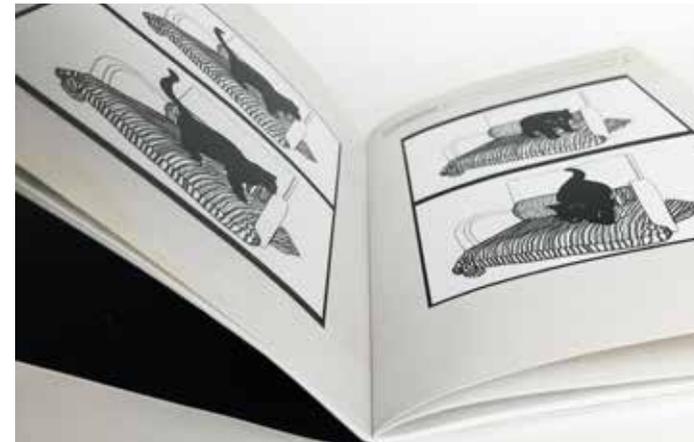
Marina Biagini

*Ink and oil illustrations, photographs*

2014

*September Parenthesis* is a diary written during the three months I spent in bed due to a slipped disk (L5-S1). I spent the majority of this long period in bed, then in a chair and then I was slowly able to stand again. The diary is designed, written, printed and illustrated in bed and chair. There are illustrations in ink, oil paintings and photographs – each day for 82 days I photographed the window of my room. When I recovered I bound the diary and made it into a small book.

[duo09.wordpress.com](http://duo09.wordpress.com)



## MADÂME B'S HOMEMADE EXISTENTIALIST CRISIS

Janet Marie Bradley

*Jars and found objects. Digitally printed pamphlets.*

2014

The English word “mad” is combined with the French word for soul “âme” has a bit of humour stirred in with the deeper questions surrounding existence and the meaning of life. Canning jars are symbolic of menial tasks and domestic expectations. Perhaps opening the jar is like finally lifting Sylvia Plath’s bell jar, releasing the grip of depression and oppression. Each jar contains items that can be used for ritual, reflection or simply a good laugh at oneself. The small hand-made book of quotes can be used as a guide or for inspiration.



## PRESCRIPTIONS

Lizzie Brewer

*Fabriano Rosaspina paper embossed and printed, linen thread, laser beam*

2015/16

The book was made as a physical recognition of the amount of pills taken over a period of five years and the radiotherapy which was required during my treatment of breast cancer. I documented the event by choosing particular symbols. Embossing and text become a metaphor for vulnerability – delicate and just visible. I chose white to reflect the clinical medical world. The laser beam represents the sophisticated nature of modern cancer therapies. The book captures the exactness of the treatment and the scientific world. It is an acknowledgement of the countless numbers of people who have suffered.

[lizziebrewer.com](http://lizziebrewer.com)



## ROSEBUD

Julie Brixey-Williams

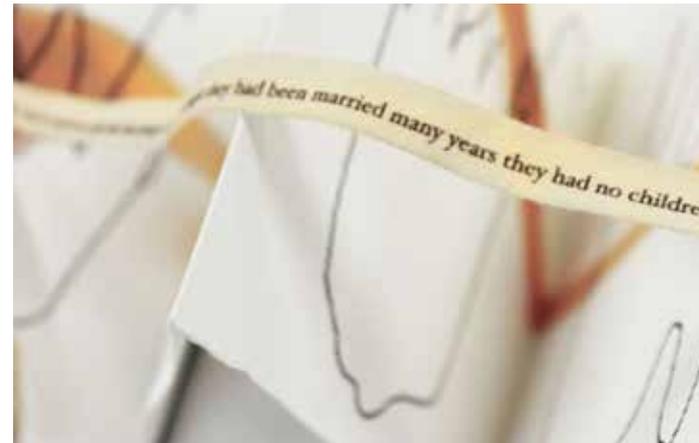
*Digital inks & shellac on watercolour paper with printed ribbon*

2004

An original bookwork, *Rosebud*, was made as part of a ten-month residency for The Association of Anaesthetists of Great Britain and Ireland. I read the story of Sleeping Beauty into an anaesthetic machine, which drew the breathing patterns as a series of flow loop waveforms. These calligraphic translations were then combined with photographs of a red-haired "Sleeping Beauty" to highlight Edwin Liem's research that red haired women require up to 20% more anaesthetic to dull pain and obtain satisfactory sedation.

B. Edwin et al., "Anesthetic Requirement Is Increased in Redheads." *Anesthesiology* 101.2 (Aug 2004): 279-283.

[www.juliebrixey-williams.co.uk](http://www.juliebrixey-williams.co.uk)



## IN THE ABSENCE OF RUNNING

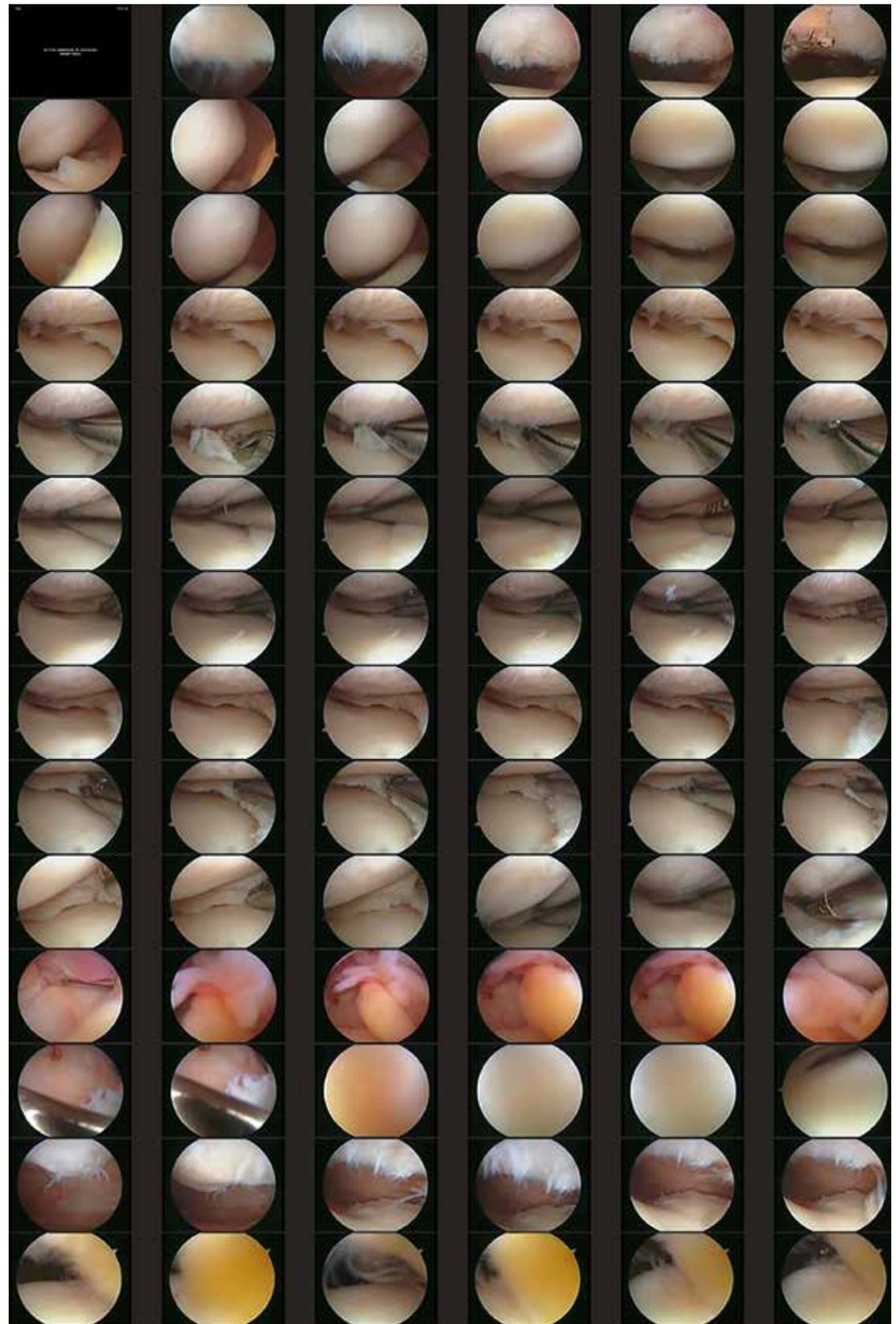
Véronique Chance

*Inkjet on Japanese paper*

2015

*In the Absence of Running* was made with photographic material from recent arthroscopies of my knees, following cartilage injury. Formerly a keen long distance runner, with running a significant part of my practice, the injury forced me to put planned work on hold and to re-think my practice. The material was reworked into a stop-frame animation/e-book, emphasising the electronic body captured as data. The panels here show a section of the layout for two physical flick books, also being produced. Removed from their original context, the circular images are reminiscent of view through a camera lens onto a strange lunar landscape beyond. (photograph by Véronique Chance)

[www.veroniquechance.com](http://www.veroniquechance.com)



## WHAT DO I DO NOW YOU'R GONE

Sally Chinaea

*Voile, thread, artist's photos, image transfer, mirror, vinyl, wooden box*

2015/16

A tribute to Cindy March.

Cindy was diagnosed with breast cancer aged only 28, with an 18-month-old son; she was determined to go on. Twelve years later, after completing a fine art degree and teacher training, Cindy received the devastating news; the cancer was back ... it was terminal.

The work is a reflection of our story, one of friendship, courage and the fragility of life; the constant balancing act of work, family and illness, whilst struggling to hold it all together.

Sadly, Cindy lost her battle in December 2015. She was a talented artist, inspirational teacher and my best friend.



## INNUMERABLE AS THE STARS OF NIGHT

Egidija Čiricaite

*Brown and semi-translucent unbranded papers printed in black and white and luminous gold*

2016

A set of folios in a slip-case draws parallels between macro- and micro- universe in attempts to explain the results of an MRI scan. The book structure mirrors the aesthetics of a filing system while the content transforms specks of light into isolated and enchanting spots of gold. On an MRI scan brain lesions appear as light spots – luminous patches, scattered in the dark image of brain tissue. While their cause is often unknown, they could be a sign of many serious conditions, including multiple sclerosis (MS). *Innumerable as the Stars of Night* makes sense of brain lesions by re-contextualising them with other enchanting and mysterious spectacles of light.



## [METAPHORICALLY LOOKING] [ANGER]

Egidija Čiricaite

Digitally printed newsprint

2016

An ongoing set of works which explores representations of conceptual metaphors and metonymies in visual language as used in artists' books, especially in relation to subjective bodily experiences, such as illness and emotions.

The book is informed by experience and knowledge gained from curating Prescriptions exhibition. *[metaphorically looking][anger]* considers the process of anger as a transitive emotion from rise to explosion to calmness: its visual translation in the book parallels the conceptualisation of the process, as it is described in cognitive metaphor theory.



## UNKNOWN

Carole Cluer

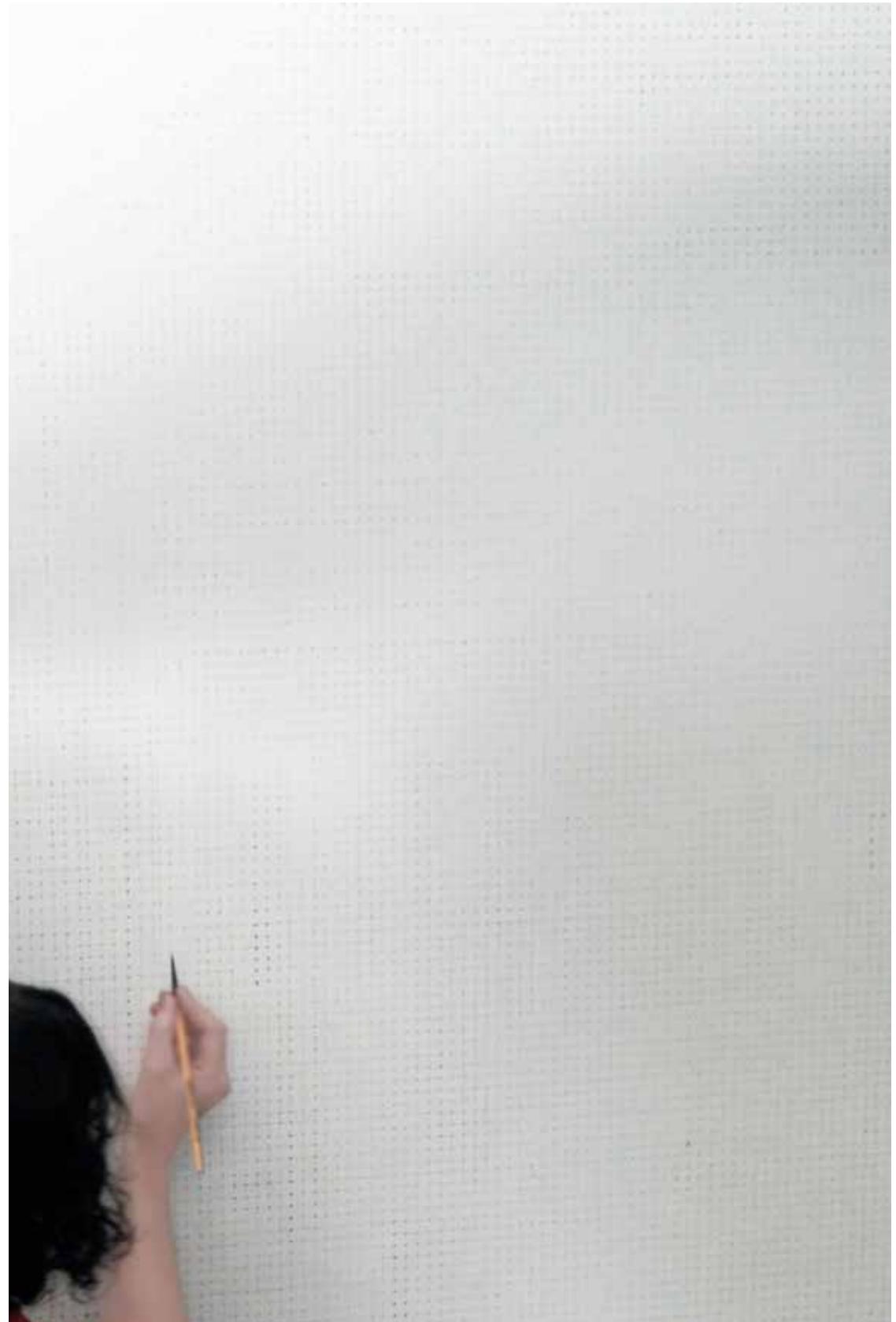
*Ink and 9ct gold on prepared paper.*

2012

While reading an article about the numbers of people diagnosed with cancer in 2004, I realised that somewhere there were statistics that contained me. In 2004, the year I was diagnosed, 45,704 people were diagnosed with breast cancer, including nine men. Based on the measurement grids and tattoos used when you have radiotherapy, each blue dot represents one person. The grid is goldpoint, made by dragging a fine gold wire across the paper to deposit a tiny amount of gold. The line looks very ordinary, a bit like graphite pencil.

Like life, its preciousness is easy to overlook.  
(photograph by Carole Cluer)

[www.carolecluer.com](http://www.carolecluer.com)



## BOOK OF SCARS

Allison Cooke Brown

*Silk thread, fabric and gauze*

2001

I think of all the women who have had mastectomies, including me, and how they have each had different experiences and scars. This is a book of scar “samples” made with silky pages suggesting sexy lingerie for women, and gauze representing their breast surgery. Its structure also reminds me of the process of ordering fabric for decorating one’s house by leafing through a book of fabric samples. (photograph by Allison Cooke Brown)



## CORE SAMPLE

Allison Cooke Brown

*Paper, ink, paint, punched label, book board.*

2003

Some scars are deeply embedded inside us. The pages of this book take you on a journey through a woman's body, from clothing to scar to cell structure and back. The book is structured in such a way that one page moves you to the next, somewhat like a diagnostic scanning of the human body in a hospital setting. It will detect cancer cells which need immediate removal resulting in a scar.

[www.allisoncookebrown.com](http://www.allisoncookebrown.com)



## WOUND

Allison Cooke Brown

*Vellum, milk, thread, fabric, clamp*

2001

I dipped the pages in milk (suggesting breast milk), slightly scorched them, and then machine sewed the word “remember” on the stack of them. I made the hidden “scar” by angrily ripping the pages all off one by one until the word is totally revealed. Our wounds can sometimes be that hidden and that layered.  
(photograph by Allison Cooke Brown)



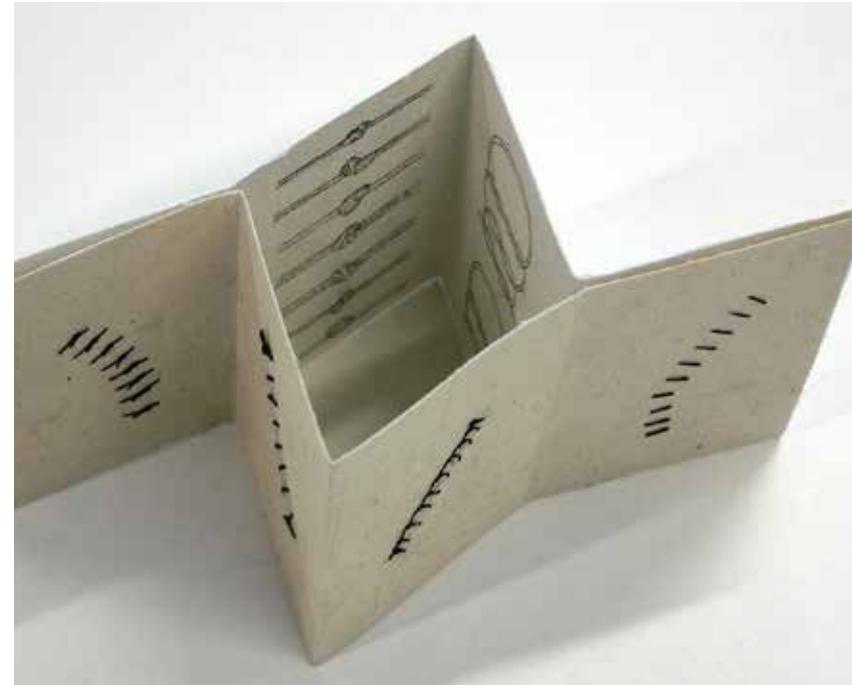
## SUTURING

Margaret Cooter

*Stitching and drawing on cloth laminated to paper*

2016

“Closing up” marks the end of a surgery, and the start of the patient’s recovery. Seeing the mending stitches on their skin is a visible cue (and reminder) to the patient that they are “on the mend”, that recovery is happening from within. Something almost magical has been done to the patient – yet to the surgeon, the procedure is hardly magic; it is just some of the knowledge gained during intense training. The process of stitching, and the use of the most appropriate needle and thread for the suture, is a very small part of surgical technique.



## ON INNARDS | PUBLICATION

Amanda Couch, Andrew Hladky, Mindy Lee, and Richard Nash

*Textblock digitally printed by Riverprint on Colorplan 135 and 270gsm stock by G. F. Smith. Manilla folder printed on an Epson R2000. Cut, folded, bound and finished by hand. Individually numbered and signed. Produced at the bookRoom Press by Lee, Couch, Hladky and Nash. Published by bookRoom Press, Farnham. 200 pages of various intersecting formats and custom binding.*

2015

*On Innards | Publication* is the record of the two-year *On Innards* project. Dissected, reinterpreted, and reconnected in the form of an artist's book, it is a collaboration between the artists, as well as contributors to the *On Innards | Event* from the fields of gastroenterology, virology, the medical humanities, cultural theory, poetic practice, yoga, and performance, exploring multi-disciplinary perspectives on digestion and the interior body. The form of the book is an embodiment of digestion, a multitude of folds, held together by a mesenteric binding, which when unwound, allows the book to be fully experienced.

[oninnards.wordpress.com](http://oninnards.wordpress.com)



## HUWAWA IN THE EVERYDAY: AN ALMANAC

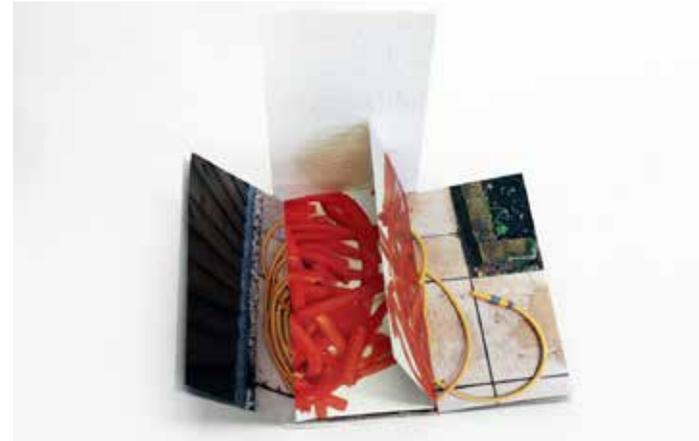
Amanda Couch

*Six double-page folded leaves, laser printed on 120gsm Munken Lynx paper, sewn at tab, with 410gsm Somerset satin collograph and embossed print cover, brass eyelet and mix-media cord.*

2016

This is a photobook in the form of a medieval medical folding almanac. Folding almanacs were worn from the belt, containing astrological, medical and calendrical information, and employed by physicians to prognosticate and diagnose. This book contains twelve images, one for each month, of coiled materials encountered in my artwork and the everyday, which might resemble the demon Huwawa/Humbaba's face. It makes reference to the Mesopotamian divination model housed in the British Museum, which portrays Huwawa's face as coiled intestines. The inscription on the reverse reveals an omen that if entrails were encountered that look like this model, it would mean "revolution".

[www.amandacouch.co.uk](http://www.amandacouch.co.uk)



## ENTRAIL TROYEN

Amanda Couch

*Double-sided inkjet print on variety of Japanese papers and weights, with salami skin collage and threads, bound in 300gsm Waterford folio with wax seal.*

2016

A leporello depicting the life-size scan, 152cm, of a sculpture of the same name: a tube of French knitting made from salami skins. As various sections of the sculpture are stitched from material collected from the casings of charcuterie, saucisson, chorizo, bresaola, with their diverse colours, transparencies, weights and strengths, so the pages of the book are printed on different types of Japanese papers, Kozo, Mitsumata, Inbe, Okawara. At the bottom of the book, image returns to material with collaged salami skin continuing the line, threaded through the folio cover, and held with a wax seal depicting an anus.

[www.amandacouch.co.uk](http://www.amandacouch.co.uk)



## REFLECTION ON DIGESTION

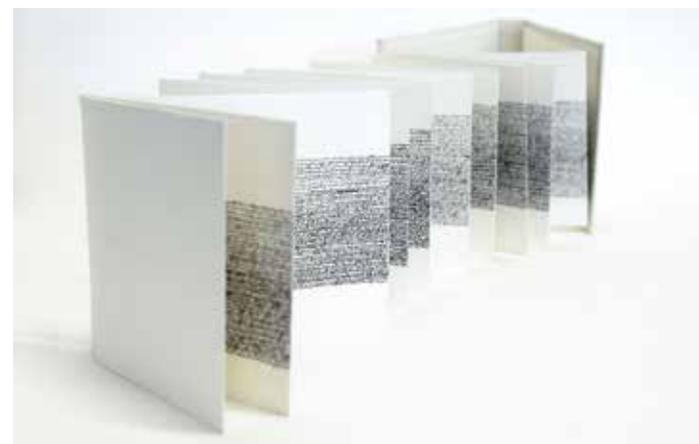
Amanda Couch

*Photo polymer relief printed on 410gsm Somerset satin paper with calf skin and gold hotfoil. Published by bookRoom press.*

2016

*Reflection on Digestion* brings together research, writing, performance and bookmaking: A fair calfskin leather-bound tome with nine metres of concertina pages. The scribed text stems from a body of knowledge encountered whilst on a postgraduate course in education. Writing, knowledge and the body are explored, and the metaphors of reflection and digestion consider process, processing, and ways of knowing and becoming. "Digestion" stems from the word "digest", which can both refer to an arrangement of written work; and to the processing or making sense of knowledge and experience, as well as to break down and absorb food.

[www.amandacouch.co.uk](http://www.amandacouch.co.uk)



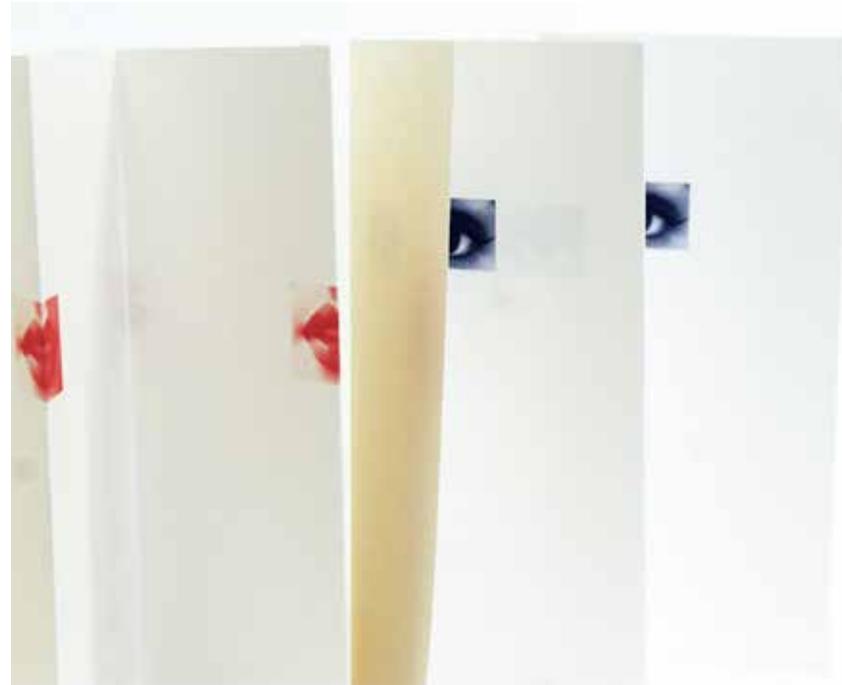
## POINT OF CONTACT

George Cullen

*Two digitally printed concertina sheets, held together with a belly band.*

2014

The book is given anthropomorphic qualities. The point when you come into contact with the book is expressed through a gaze and a kiss; the centre spread which looks out upon you; the edge of the page that touches you. As you turn the page, the edge of the book kisses your finger and reiterates the intimate act of reading. It reiterates the role of your body.



## BLEEDING OUT ( INTERNALLY) PARTS A AND B

Fiona Davies

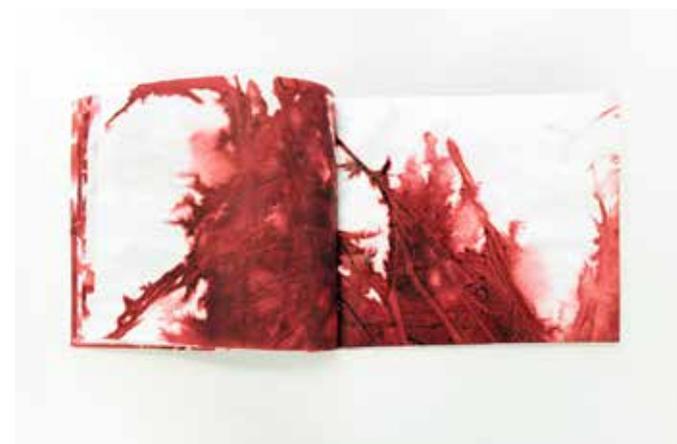
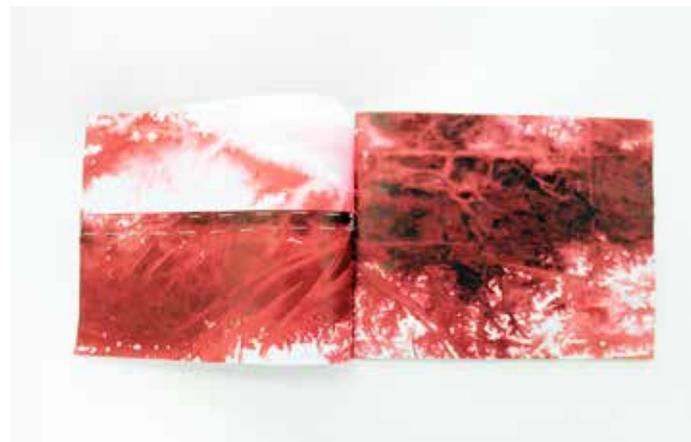
*Rice and archival papers, ink, thread and wallpaper paste*

2015/16

*Bleeding Out (Internally)* consists of two parts, A and B. The sizes of the two parts are slightly different so it is not immediately obvious that they belong together. Part A is a picture book intended to be touched, pages turned and held close by the reader. The images are representations of the sublime in the materiality of blood or bleeding out (internally).

Part B is an instructional manual trying to make sense of a short, traumatic, catastrophic event such as uncontrollable internal bleeding. The patient and the witness experience this event simultaneously but not together.

[www.fionadavies.com.au](http://www.fionadavies.com.au)



## THE OLFACTORY ARCHIVE VOLUME 1 & VOLUME 2

Emma Dolphin

*Volume 1. Archival inkjet print, glass phials, pigment, print*  
*Volume 2. Test tubes, print, pigment, wood*

2015

This work explores how the olfactory system acts as a powerful trigger for memories of people, places and events. It is in the form of an artist's book in two volumes. The first volume simulates an old leather-bound book. Inside are glass phials and pipettes and printed "negatives" of the images which the particular aroma within the phials evokes. Volume Two is in the form of laboratory test tubes and rack – as though the memories have been extracted from the printed "negatives" within. Although historically perceived as a lower sense because of its associations with the corporeal and the primal, the olfactory system is the first of the senses engaged by the new-born baby. Its loss is an early indication of the onset of dementia and other such conditions.



## PHARMACOPOETICS

Stephen Emerson

*Glass vials, paper, stickers, cellulose capsules, gelatine capsule, and rice paper*

2013

These pills were made to be swallowed. I am interested in the placebo effect and how it can be interpreted as art/poetry. I am not interested in the healing properties of art, rather in exploring how language is refined and used as a mechanism of control by particular regimes.

Ideally I want to present a blank canvas in which participants have almost total freedom. But writing is also about control. A reader who has total freedom is a writer. I like to think that my work explores the areas in between writing and reading, and how language (all language) is inherently about control.

[stephenemerson.wordpress.com](http://stephenemerson.wordpress.com)



## THE GERM THEORY VOLUME 1: MODERNHYGIENIC DRESS MODES

Beth Evans

*Bound concertina with intaglio prints and hand colouring*

2012

By the last decade of the nineteenth century, the germ theory of disease was widely recognised. There was a profusion of home texts applying scientific principles to domestic labour and to teaching women mastery over the invisible microbe. The link between dirt and disease had begun a war between humans and bacteria. My artist's book looks at how the germ theory gave rise to some extraordinary methods of evading disease; men shaved their beards and women shortened their skirts to eliminate germ-catching appendages.

[www.bethevans.com.au](http://www.bethevans.com.au)



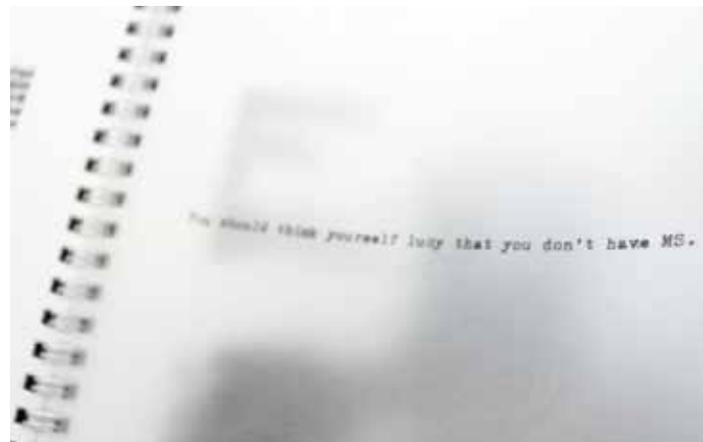
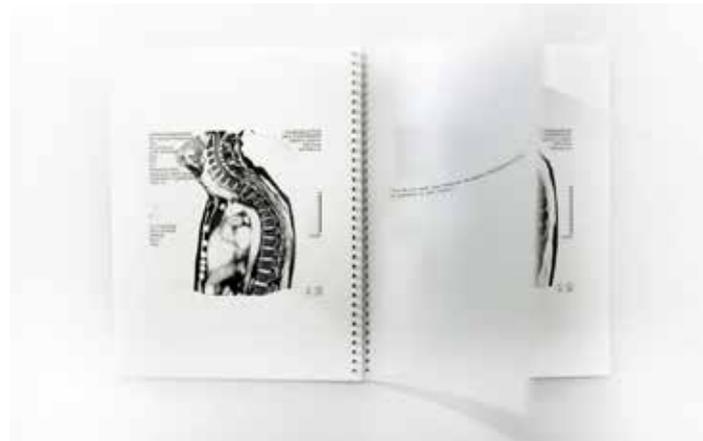
## HUMPTY DUMPTY'S BONES

**Bernard Fairhurst**

*Ring binding, digital images interleaved with typewritten text on tracing paper.*

2014

MRI images record 38 years of spinal problems, interleaved with the “traces” of comments from health professionals. The use of nondescript ring binding and text from a typewriter represent an anonymous bureaucratic report. The work is an auto-ethnographic account of chronic illness and the necessity for resilience and a sense of humour. The “bones” are both bones-of-contention and the damaged skeleton of Humpty Dumpty. I became Humpty Dumpty when told I had to “accept that Humpty Dumpty could not always be put together again,” but ultimately we are all Humpty Dumpty.



## G.B.S.

Ashley Fitzgerald

*Altered book*

2015

This piece is about my experience with a viral infection called Guillain-Barré Syndrome, also known as the creeping virus. The book itself is open yet frozen as if shut itself down, relying on the inner organs to keep working. This is similar to my experience. The piece *G.B.S* changed my method of working since I came from an abstract painting background with also the influence of having dyslexia and colitis.



Facebook (Ashley Scott Fitzgerald)  
Twitter (@golemash).

## INSIDE

Yvonne J. Foster

Digitally printed pamphlet

2013

*Inside* is a direct and unapologetic visual account of my experiences, thoughts and emotions following a breakdown. I used altered photographs and scribbled images to describe my feelings and observations of living with mental health issues. The subject of mental health is challenging, hard to talk about openly and can be harder still when faced with images. By its nature the work challenges opinion, stigma and discrimination, stimulates conversation and attempts to bridge the gap between “them and us”.



## ALL WITHIN A BINDING

Dylan Fox

*Cartridge paper, ink, thread and tape.*

2016

By investigating my own human condition in relation to time and place, I am able to address aspects of my gender transition from assigned female at birth to male. Within my practice I utilise elements of archival, social and text-based works to examine the physical, medical and social elements of this process. *All Within a Binding* acts as a comparative metaphor of the daily routine of chest binding and as such this book details the wear and tear that prolonged use of specific chest binding garments has on the garments themselves.



## THIS, IS MY CRISIS

Elizabeth Fraser

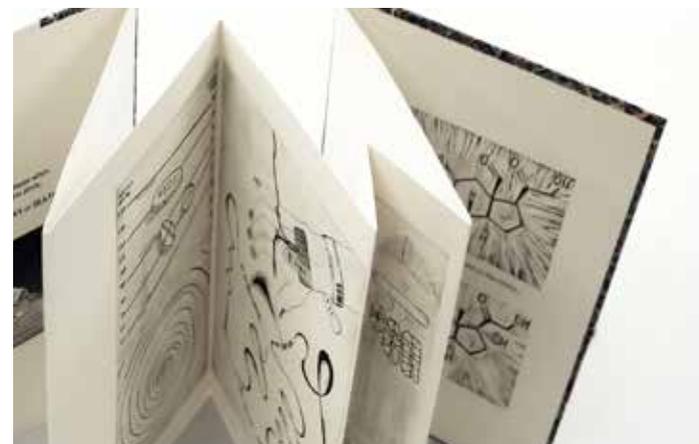
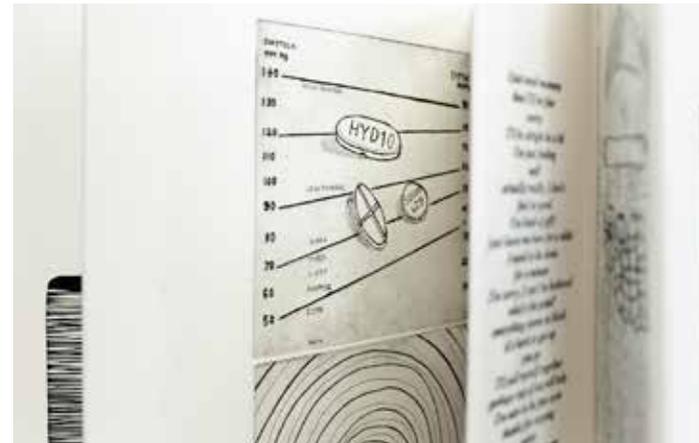
*Hard ground etching, hand set letterpress, and further additions on 300gsm Somerset Soft White paper.*

2016

*This, is my Crisis* is a reflection, representation and explanation of my experiences of suffering from Addison's Disease, its ongoing symptoms and sudden dangerous acute incidences which are called a "crisis".

Hand-drawn, etched images and text lead the audience towards a position of new understanding. Voice is given to the imagery with a first person account of this rare medical emergency. The book consists of four hard ground etchings from zinc plates presented with hand set letterpressed italic text, and further additions on 300gsm Somerset Soft White paper. The zig-zag construction is contained within hard covers.

[www.behance.net/ElizabethFraser](http://www.behance.net/ElizabethFraser)  
Twitter (@frauhaus)



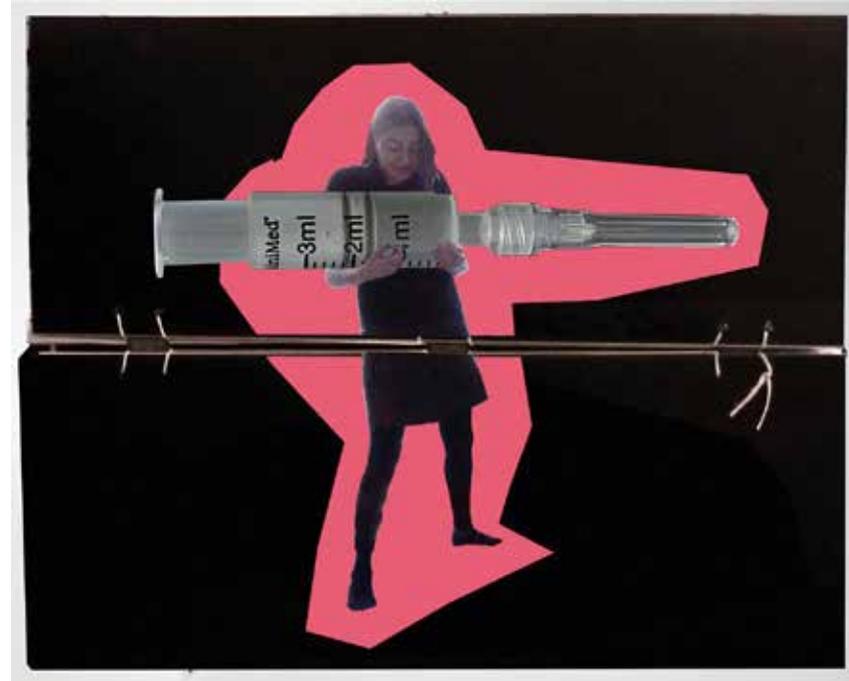
## CAN YOU HEAR ME?

Paula Garcia Stone

*Digital imaging & collage bound into a book*

2008-16

The subject of my art has always been the human body. I express our experience of living with it in this world, and within particular spaces and situations. From an ongoing concern with conveying my 41 years of living with Type 1 Diabetes and its complications (affecting blood vessels and the nervous system of other organ function), the book *Can you hear me?* gives the disturbing experiences a tangible form. I lighten the burden by turning my insides outwards. The surreal imagery is intended as both metaphorical and humorous. Through such images I release hauntings and demons. They are aesthetic interpretations of viscera and an approach to the materials involved in my daily treatment. (photograph by Paula Garcia Stone)



## WHAT LIES WITHIN + VIGILANCE

Sue Hague

*Wire: crochet, stitch, wrapping*

2015

What Lies Within

Symptoms: Tenderness

Referral: Scan, consultation

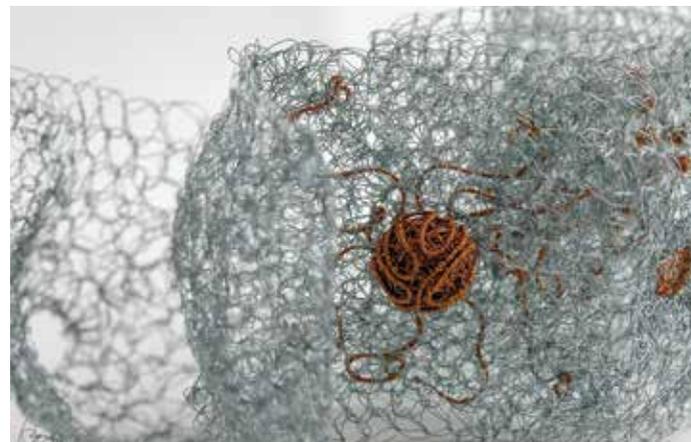
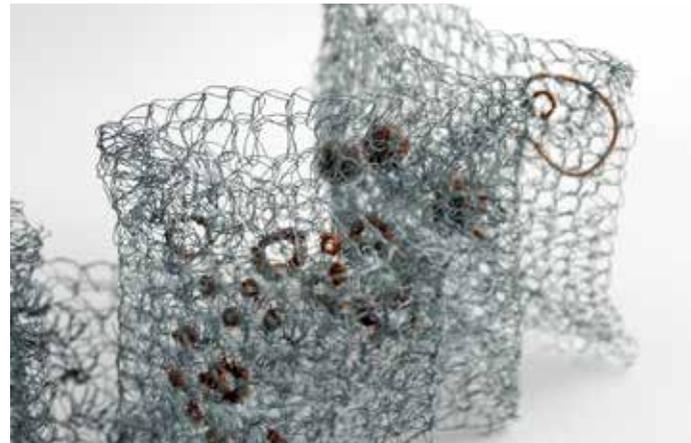
Diagnosis: Breast cancer, texture, form, invasion

Course of Action: Surgery

Prescription: Vigilance

Note: Invert, rash, dimple, pucker, lump, denial,  
delay, consequence

Repeat vigilance regularly. Notify GP of change to  
current status.



## BLUE MOON

Martha A. Hall

[44] leaves; ill. ; 23 x 37 cm. in box 25 x 38 x 3 cm. Japanese stab-sewn binding; clear acrylic sheets as covers; lokta paper wrapper with mica disc for clasp. Layered acrylic ink paintings on sheer coloured papers and clear acrylic sheets; handwritten in pencil.

2000

The text relates to the artist's sadness about losing natural patterns in her life and the discovery of new ones. Hall writes about the relationship between the moon and women's bodies and rhythms.



## DARK ROOM DAYS

Martha A. Hall

*[12] p.: ill. ; 9 cm. (opens to 9 x 101 cm.) in box 10 x 8 x 1 cm. Accordion on black Lokta paper.*

1999

The book consists of artist's black and white photo fragments and original handwritten text about Hall's depression. The book is in black Lokta paper slip case, tied with black linen thread. Twelve panels are folded accordion-style. Hall's original photographs and text in white ink on one side of accordion only. Text reflects a dark mood and thoughts of death; the book's text finishes with the words, "Where are life's colors?"



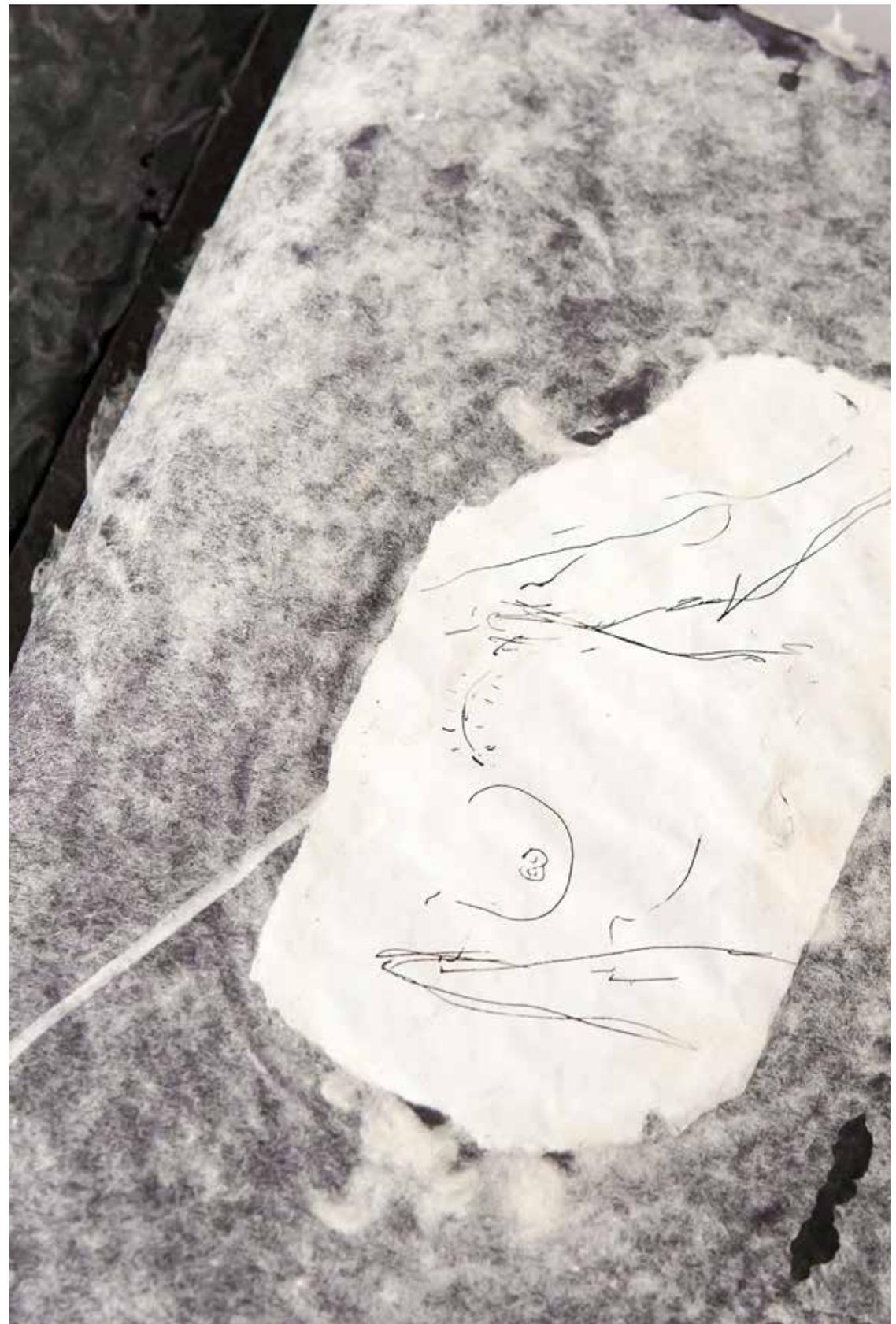
## DIAGNOSIS

Martha A. Hall

*[8] leaves: ill. ; 30 cm. Concertina binding with hand-made wrappers. Hand-made paper, drawings in black and white from the artist's sketchbook.*

2000

The pages have design elements both front and back, referring to the lines of pain, charts, medical monitors, and changes in the artist's emotional state during diagnosis for breast cancer.



## I MAKE BOOKS

Martha A. Hall

[10] p. : chiefly col. ill. ; 30 x 58 cm., opens to 30 x 116 cm. Artist's book, consisting of paste papers attached to accordion hinges with text handwritten on the hinges; accordion-bound in red handmade paper, title handwritten on grey paste paper on front cover.

2001

Artist's book, consisting of paste papers attached to accordion hinges with text handwritten on the hinges; accordion-bound in red handmade paper, title handwritten on grey paste paper on front cover. The text on the hinges includes "I write what I cannot say," "I paint in colors fearsome and strange" and "I make books so I won't die."



## IT'S NOTHING

Martha A. Hall

[18] leaves; ill. ; 16 x 22 cm. Concertina binding. Handwritten original text on transparent pages, alternated with acrylic painting on heavy pages.

1999

Text describes doctors' responses to the artist's reports of pain, which turned out to be indications of spreading cancer. Hall also describes her return to art class, drawing her body to help heal it.

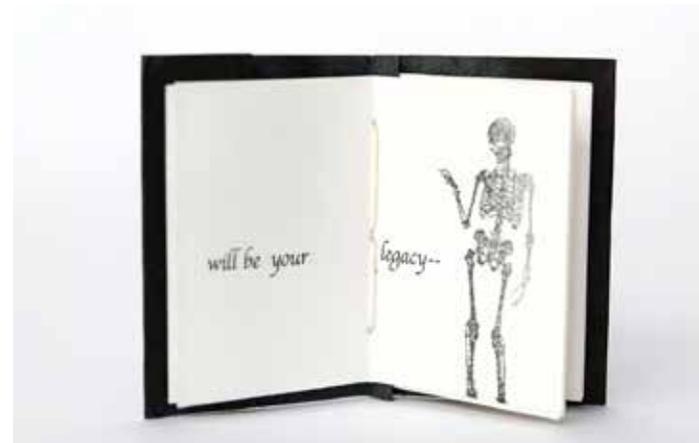


## LEGACY

Martha A. Hall

[16] p. : ill. ; 7 cm. Two signatures stitched into paper wrapper. Rubber stamping and inkjet  
2001

*Legacy* reflects a lighter mood and explores the value of making books as a legacy. This book is also included as part of *Voices: Five Doctors Speak* (see 53) as it represents what one of her doctors (Letha Mills) told Hall about the value of her art.



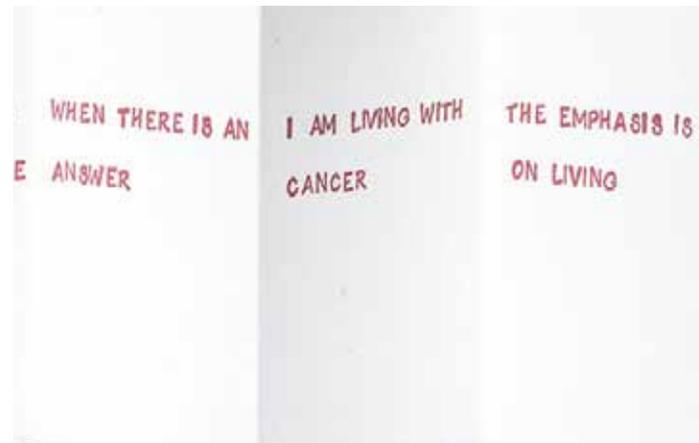
## LIVING (II)

Martha A. Hall

1 vol. ; 17 x 87 cm. folded to 17 x 12 cm. Book made with accordion fold, self-cover.  
Dieu Donne hand-made flax paper.

2002

The book was made in multiples for distribution at the Cancer Community Center where Martha Hall served as a board member. The text questions the term “cancer survivor” because it “implies some people win” and others “lose”. The final lines read: “I am living with cancer. The emphasis is on living”.



**PAPER PASSAGES: JULY 2001  
THROUGH JANUARY 2002:  
A DUOLOGUE BETWEEN FRIENDS**

Allison Cooke Brown and Martha A. Hall

*3 cases (30, 21, 21 pieces): col. ill. ; in boxes 17 x 24 x 16 cm.*

2002

Epistolary artist's book, composed of three groupings of bound pieces, each piece bearing a postal cancel; each grouping housed in a clamshell box with cross-stitched cover labelled "Summer," "Fall," and "Winter." Brown and Hall were treated for cancer at the same time during Hall's first occurrence, when they developed a friendship that would last through Hall's life.



## PRESCRIPTIONS

Martha A. Hall

[43] leaves : ill. ; 20 x 26 cm. in box 22 x 27 cm. Japanese stab-sewn binding; modified clamshell box is covered in silk book cloth.

2003

Coloured and patterned transparent leaves with Xerox copies of prescriptions and medicine containers. The artist expresses her anxiety and fears around illness and medication. The book expresses her frustrations with the number of pills she needs to take for her cancer.



## TATTOO

Martha A. Hall

*1 v. (unpaged); col. ill. ; 12 x 12 cm. Complex binding composed of 8 gatherings, each with its own decorative paper wrapper. Accordion base with linen-stitched signatures on both sides of book.*

2001

The original text deals with the artist's changing attitudes and experiences with tattoos, including her own tattoos from cancer treatment. Rubber stamped images, computer printed text and paste paper. "Tattoo" title pierced with a needle inserted into title block.



## THE REST OF MY LIFE (II)

Martha A. Hall

*1 v. ; 5 x 9 cm. (opens to 5 x 408 cm.) in box 11 x 7 x 6 cm. Handmade box covered in colour copies of the artist's planning calendar holds a long accordion with hand stitching and original paste covers.*

2003

The accordion segments are the doctor's appointment cards for one year of cancer treatments, October 30, 2000-October 2001. Also included are brown envelopes that contained medication, which were given to the artist before chemotherapy treatments. There are two simultaneous texts in addition to the appointment dates and calendar pages: notes on everyday events made during treatment and a history of the past ten years of the artist's life with cancer in red pen. The book can be opened from either end.



## TEST DAY II

Martha A. Hall

[8] p. : ill. ; 19 cm. Eight panels folded accordion-style. Signed, dated and numbered by artist.

1999

The poem "Tests" is printed on first two pages. "Tests" explores the dehumanization that Hall feels during medical tests where she is an object viewed through a screen and the only words addressed to her are: "Take a deep breath," "Hold it," "You can breathe". The other pages have shadow painting in black and white.



## VOICES: FIVE DOCTORS SPEAK, JULY 7-16, 1998

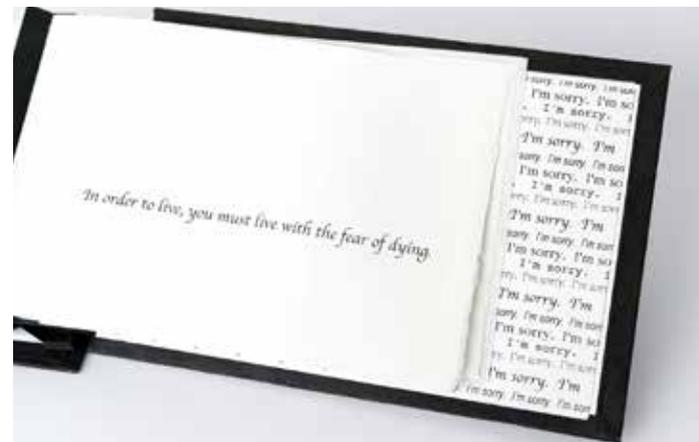
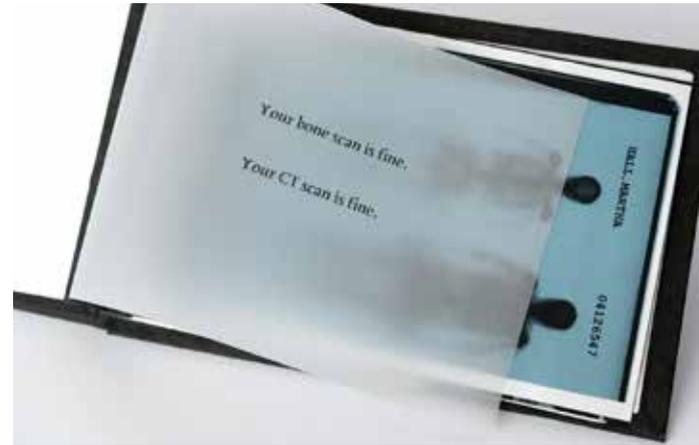
Martha A. Hall

1 v. (unpaged): ill.; 16 x 24 cm. Compound binding on concertina spine with tipped-in single pages, pockets, stitched-in signature, and folded pages. Lokta paper boards. Black rubber stamp images. Inkjet.

2001

The original text, printed on a variety of papers, documents what five doctors each said to the artist when telling her about her second recurrence of breast cancer over a nine-day period. The text explores how what is said in a medical setting can change the patient experience dramatically. Skull, eye, and skeleton stamped images. A different font and paper are used to differentiate each doctor. Miniature book *Legacy* attached to one page.

Voices of doctors: Tom Ervin, William Herbert, Hector Tarraza, Letha Mills, Rodger Pryzant.



## WHAT YOU DON'T WANT TO KNOW ABOUT BREAST CANCER

Martha A. Hall

[20] leaves : ill. : 22 cm. Altered book with sections sewn onto accordion base. The pages are stitched, stapled, torn, glued, cut, crumpled, marked and resequenced.

2003

Text by National Cancer Institute, highlighted with black ink. The text describes breast cancer and what the patient can expect. The artist expresses anger and frustration in her alterations of the text.



## THE SEARCH FOR YOUR SPARK

Sarah Harley

*Glass jar, water, porcelain, nylon thread, gold leaf*

2015

This work is part of “Threads of Thought”, an ongoing collaborative project with scientists Professor Murray Shanahan of Imperial College London and Dr Srivas Chennu of Cambridge University exploring consciousness and the complexity of the brain. It was made in response to Dr Chennu’s research at Addenbrooke’s Hospital which uses EEG to record the brain activity of patients in a vegetative state; a significant number of patients show signs of “covert” consciousness, and sometimes this has led to the possibility of communication.

Although brain injury has a tragic impact, I wanted to make something beautiful to portray the desire and determination to communicate with our loved ones which lies behind this research.

(photograph by Sarah Harley)

[www.axisweb.org/artist/sarahharley](http://www.axisweb.org/artist/sarahharley)



## FLORASCRIPT: WILD GARLIC, YARROW, FOXGLOVE

Cas Holmes

*Textiles, paper and mixed media: found materials associated with the healthcare.*

2015

These pieces remind us of the “roots” of our relationship with medicine; a time when prescriptions or “script” were written up for treatment of a patient using ingredients collected and sourced from the natural world around us. During the “Great War” children and adults grew and collected medicinal plants and herbs from the wild (to compensate for the loss of German pharmacological products on which Britain was heavily dependent).

[casholmestextiles.co.uk](http://casholmestextiles.co.uk)



## THE VARIANCE, VAGARIES AND EXTREME RANDOMNESS OF MS

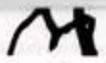
Deborah Humm

*Digitally printed and cut book, perfect bound.*

2015

Having multiple sclerosis I experience lost, broken and misarticulated nervous signals first hand. Everybody has these moments, these nervous system glitches. *The Variance, Vagaries and Extreme Randomness of MS* is written with mathematical constraints: 10 pages of 14 lines; each line has 10 syllables and the last phoneme/sound on each line is the same. These constraints allow the lines to be completely interchangeable giving the book almost limitless possibilities. The form highlights broken signals and bodily malfunction experienced on a daily basis. It is hard to communicate the random nonsensical symptom – even the patient cannot find the words. These lines may help...

[www.deborahhumm.co.uk](http://www.deborahhumm.co.uk)

Sitting in quiet still tranquillity  
 Sit in peaceful silence contemplating  
 Drawing that black line, sketching that same piece  
  
 Space opening black foggy scary voids  
 Wonder enters space and walks through my Mind  
 Over my body and down my spine  
 Stretching fingers and toes  
 Off with the fairies high in the atmosphere  
 So vociferous it became odour  
 And whatever is that delicious smell  
 So substantially strong it can taste itself  
 ...my range the steep spiral stairwell  
  
 Yes lavender, French purple lavender  
 A purple haze seductive in ones sight  
 But I cannot feel my hands or my feet

## TOUCHE NOT WITH YRON

Dávid Katona

Watercolour, ink, pencil, paper

2015

*Touche not with Yron* draws upon medieval medical manuscripts, which, if regarded with 21st-century eyes, would easily pass as artists' books, and fuses them with contemporary modes of textual arrangement. Medieval medicine regarded the human body as a microcosm, corresponding to the world, the macrocosm – while the macrocosm itself was conceptualized as the Book of Nature. The linking between the body parts and the signs of the zodiac evokes the hyperlinks of digital texts, which is manifested in the non-linear structure of the artwork, creating an anachronistic “analogue hypertext system”. (photographs by Dávid Katona)

[www.facebook.com/david.katona.14](http://www.facebook.com/david.katona.14)



## INSIDE OF ME

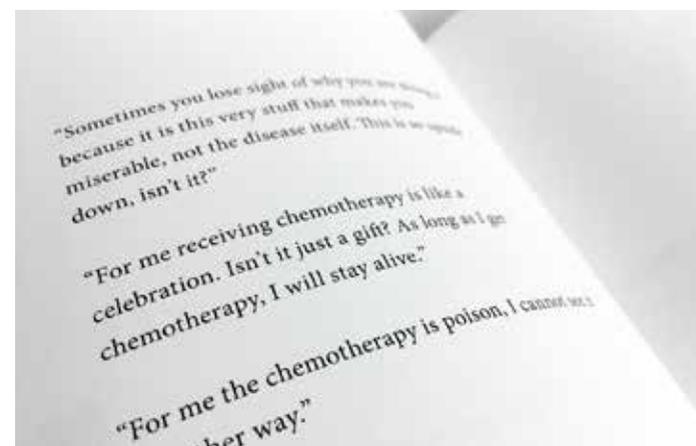
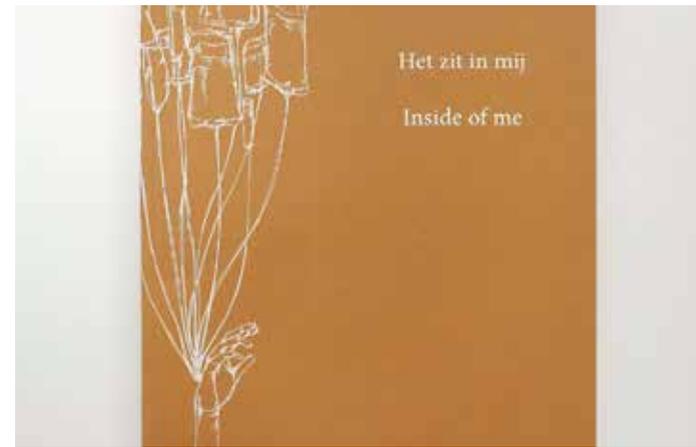
Sonia Kneepkens

*Digitally printed book.*

2015

*Inside of Me* illustrates the experiences of people with cancer. The name of the disease may not change but patients' experiences differ. Cancer patients have trouble expressing their feelings to family, friends and care-givers. That's what I found after interviewing patients undergoing chemotherapy at a local hospital. I noted down their most poignant expressions and translated these into a series of expressive drawings bound together in a book. Drawings form a universal, wordless language that makes complex, painful emotions visible and therefore easier to understand. This book is a tool for people with cancer aimed at helping them recognise the emotions evoked by the disease and its treatment and enabling them to express such experiences to their loved ones as well as to health professionals.

[www.soniakneepkens.com](http://www.soniakneepkens.com)



## HOME

Gemma Lacey

*Screen print, rubber stamp and inkjet text*

2010

The photos were taken at the home of my Nan just after she went to live in a care home. The question formed by the text on the flash cards (“Why won’t you let me go home?”) was asked many times over the years that dementia took hold and the question and subject itself changed meaning over this time. The work was made to help me come to terms with the change and subsequent loss of my Nan and mark a place we both considered home. I also intended to share this particular experience of dementia with others.

[gemmalacey.co.uk](http://gemmalacey.co.uk)



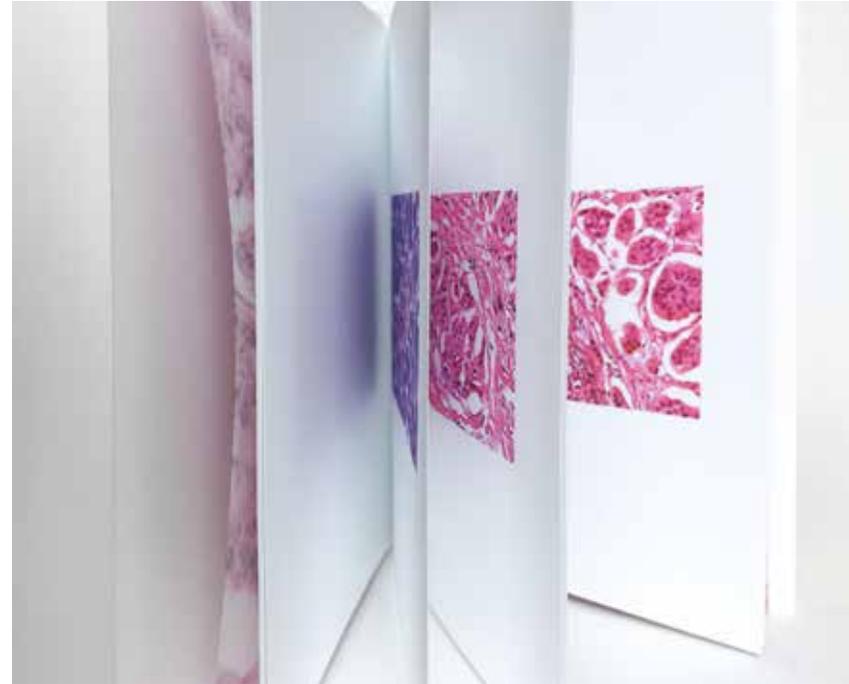
## DANGEROUS BEAUTY

Pauline Lamont-Fisher

*Paper, waxed linen, inkjet printing*

2016

*Dangerous Beauty* was inspired by the death of a dear friend from breast cancer. Since childhood, I have been fascinated by the view in a microscope. The female pathology digital images in this work are beautiful to look at, but they are all of dangerous and sometimes fatal conditions, predominantly unique to women. They were found on the web, which nowadays we all use to diagnose our own conditions.



## DEPENDENCY

Pauline Lamont-Fisher

*Paper, cotton thread, waxed linen, inkjet printing*

2016

This book represents a life journey, which ended suffering from Alzheimer's disease. It charts the progress, from the perspective of the observer, from cared for to carer as the photographer became the photographed. On one side, things start to go array, subtly at first, and then chaotically. On the reverse side, the telltale plaques and tangles form, and function is lost.



## AGAINST ALL ODDS

Melisa López

*Mixed media on cardboard and paper.*

2015

*Against All Odds* is an artist's book project that explores the human body's fragility through poetic symbols and materials that capture the difference between the appearance and reality of the human body. I decided to create a poetic work that represents all the parts of the body through the process of drawing. Each part of the drawing expresses the body's fragility, focusing on the female body and exploring the perception of time through the body. The text emphasises these themes: "Against all odds", years after years, "your body is fragile".



## GRAB LIFE

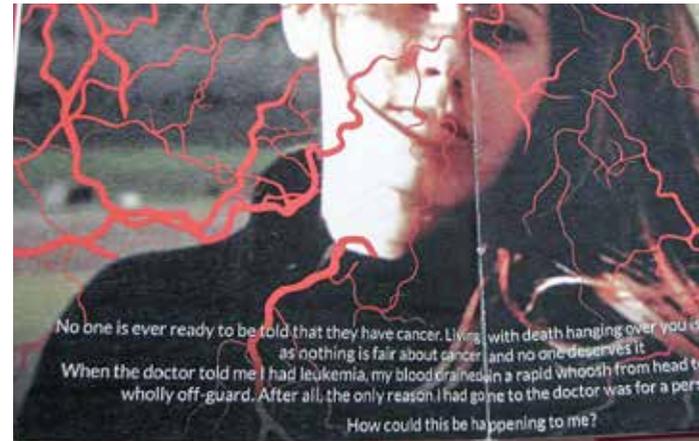
Celeste Maia

Case: Lotka handmade paper, letterpress. Book: inkpress on recycled paper with cloth covers and velum spine. Antique glass, calligraphy, laboratory tubes, sculpted head. Hand cut and embroidered doll

2015

*Grab Life* is my reaction to living with leukaemia for several years. I can never again be the person I was before diagnosis, for now I live with periodic blood tests, CAT scans, scary treatments, and transfusions. Anger and fear are also permanently coiled inside me. But *Grab Life* is about living, doing, enjoying, fighting. *Grab Life* translates a condition and a state of mind; my physical interaction with leukaemia expressed graphically. Injections, pills, anatomy, the geometry of human's veins, the colour red, all convey a life that has its own identity.  
(photographs by Celeste Maia)

[www.celestemaia.com](http://www.celestemaia.com)



## THE NURSE

Andrew Malone

*Hand-cut Ladybird book*

2015

*The Nurse* is a hand-cut book, one of a series made for “Ladybird, Ladybird”, a commission in 2014 to celebrate 100 years of Ladybird books in Sheffield. The book comes from a more innocent age and paints a cosy but unreal picture of the hospital. My books are made by cutting away sections of the pages to expose the illustrations making them more sculptural. The act of cutting turns a series of two-dimensional images into freestanding entities that can be read as flip-books or static objects and where the contents of the book can be seen at one glance.



## CHOICES and NARCOTICS ANONYMOUS

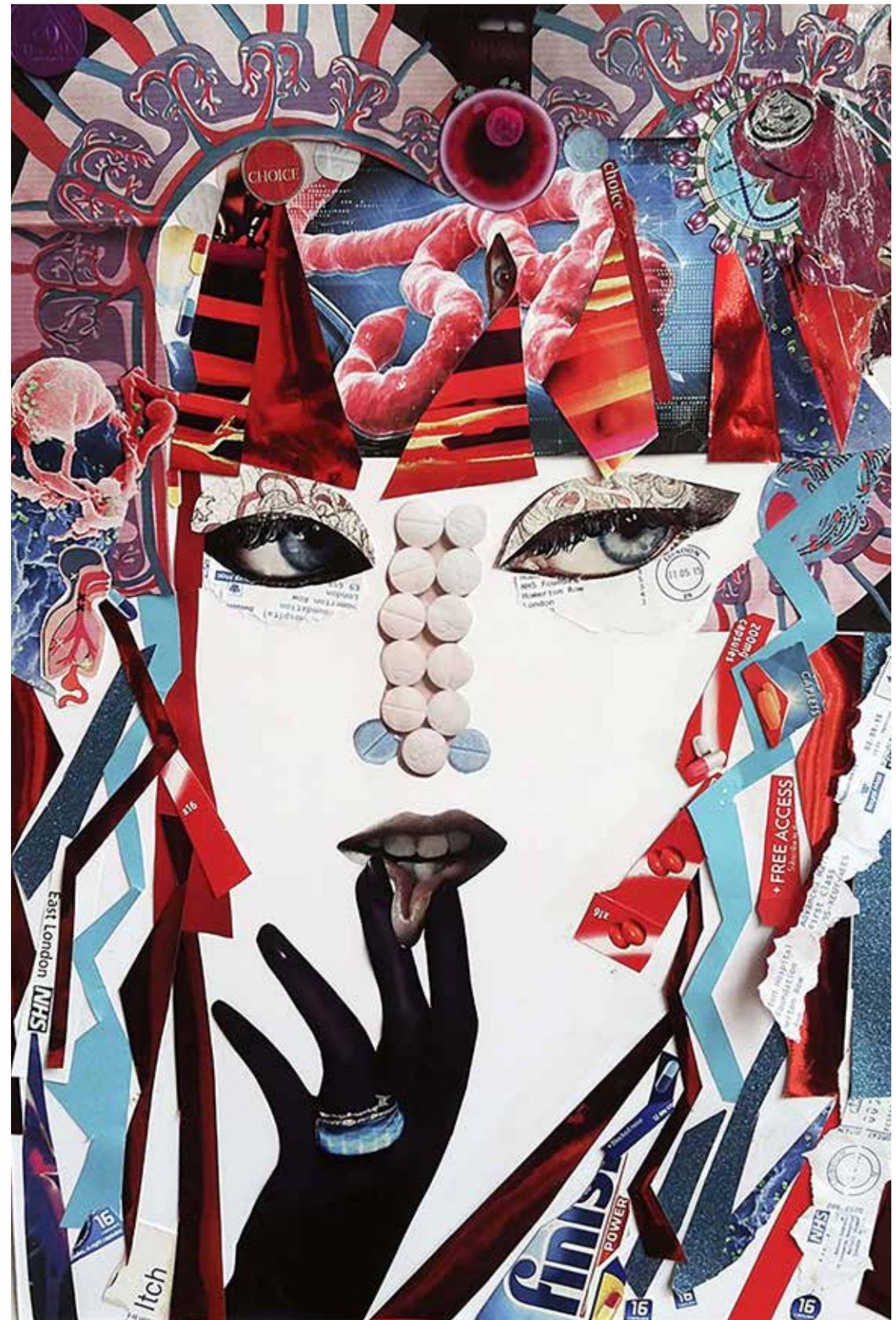
Kirsty McKenzie

Mixed media collage on paper

2015

These mixed media collages from my *Addiction* series deal with my psycho-stimulant addiction, recovery and co-occurring bipolar disorder. The series focuses on the anxiety, paranoia, frenzied obsession, greed and mood swings that come with the detrimental relationship of chemical dependency. These surreal collages are dark yet whimsical; some depicting the 6th chakra or “third eye”, and how that is often blocked or cloudy whilst in addiction. The works incorporate many elements such as prescription pill packets, NHS letters, diagrams of the HIV virus, the chemical compounds of drugs like Clonazepam and MDMA, and explore how they affect the brain. (photograph by Kirsty McKenzie)

[www.kirstymckenzie.com](http://www.kirstymckenzie.com)



## CURIOUS APOTHECARY

Nicki McNaney

*Screenprinted concertina book*

2015

The work began with an investigation into historical apothecary at the Thackray Medical Museum in Leeds. It draws on medical ephemera of the eighteenth century, exploring the curious nature of ledgers, quacks, recipes, prescriptions, weights and measurements. A number of illustrations were created initially based around pharmacy ceramics, old prescriptions, objects and medicine recipes found in the Thackray museum archives. A fascination for recording the collection at the museum led to a screen-printed accordion artist's book created through a combination of mono-print, collage and drawing.

[www.woodendogpress.co.uk](http://www.woodendogpress.co.uk)



## BODY MAP

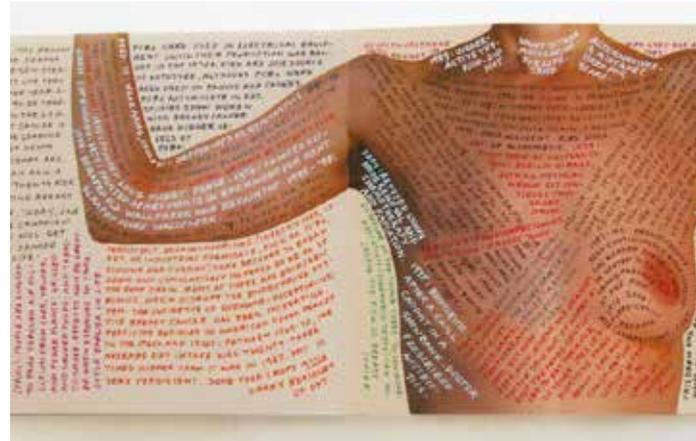
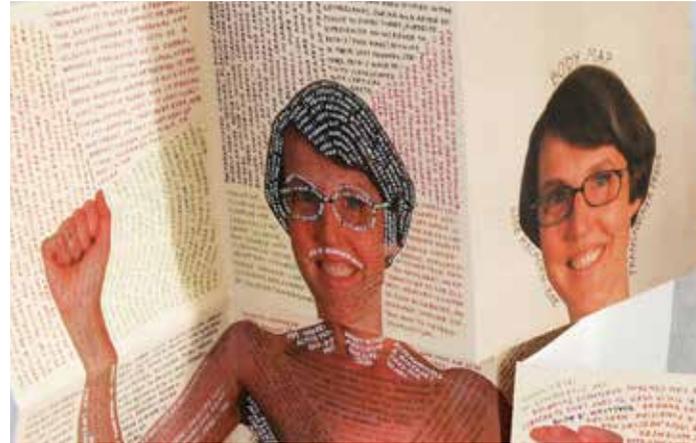
Lise Melhorn-Boe

*Meander book, digitally printed (Epson Pro 9600 with the Untrachrome Inkset)*

2009

*Body Map* is one of a series of books about the relationship between our bodies and our environment. Inspired by the “body maps” created by persons with AIDS/HIV, I asked my husband to photograph me nude and then created square pages, each with a section of my body. I printed those and then hand-printed text on top of the photos – the text written directly on my body contains personal references, while the text around my body is researched information about environmental hazards and toxins, which might have impacted my body. These pages were scanned and beautifully printed by Nick Dubecki, in Sudbury, Ontario, Canada, in an edition of 50.

(photograph by Lise Melhorn-Boe)



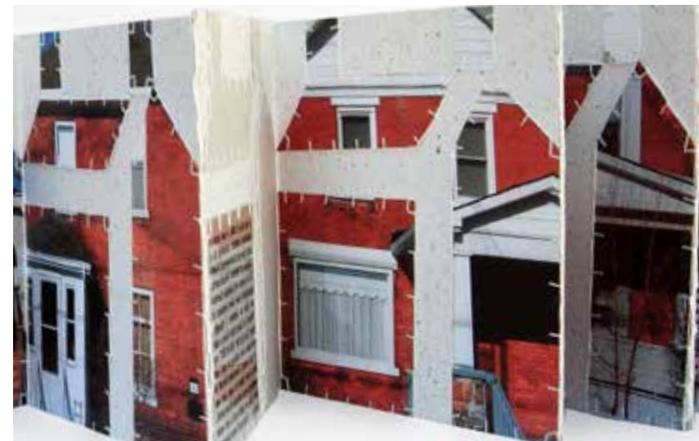
## HOMELESS

Lise Melhorn-Boe

*Accordion, hand-stitched handmade paper*

2008

For the environment/health series, I was consciously using left-over materials from other projects, whenever I could, and also recycled ideas and techniques from previous books. This book was modelled on an earlier book of mine entitled *Little House/Happy Home?* about abuse of women in their own homes. "Little House" is a traditional quilt pattern. The grey handmade paper is my own; the flecked white paper was made by La Papeterie St Armand in Montréal, Quebec, Canada. The photographed houses are those of my neighbours on my block in North Bay, where I lived at the time; the house with text only was mine. This edition of seven was hand-stitched in a Rehabilitation Hospital while I watched over my son's recovery from a brain injury. (photograph by Lise Melhorn-Boe)



## WOMEN AND CANCER

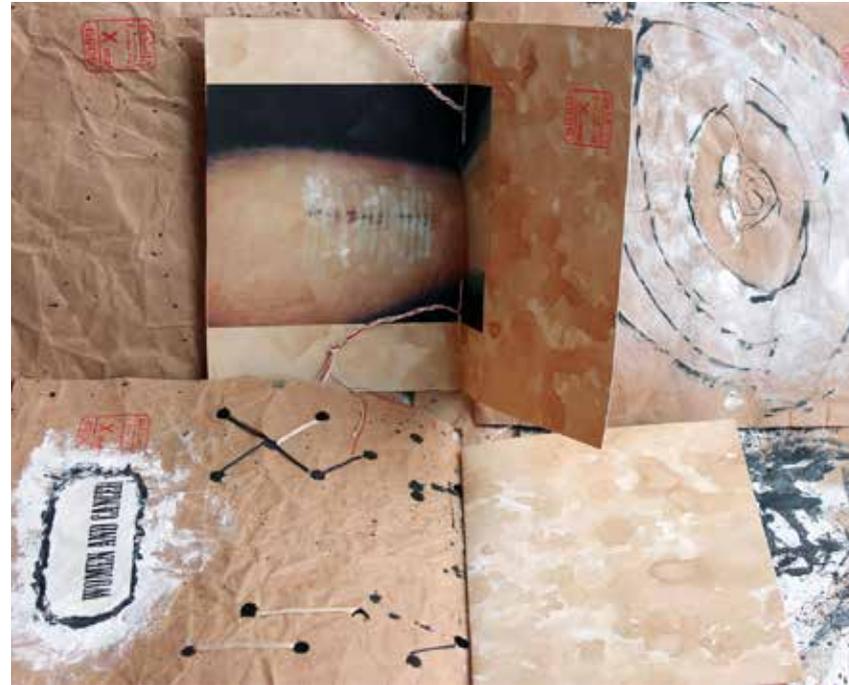
Virginia Milici

*Mixed medium, collage, recycled paper, ink, acrylic, wires*

2015

Is skin melanoma a hereditary condition? Is it in the DNA passed from mother to daughter? Up to which generation? My mother, my sister, my niece: three lives, one story. The book as an intimate object represents our reality. At the centre of the work is the human figure, love, suffering, but also hope. The thread is the union and the history that link the three women.

Documentation leaves no doubt; the female cancer, in this specific case the melanoma, is genetically transmitted from mother to daughter ... I wait answers from research.



## WAXING MY THIRD EYE

Melanie Mowinski

*Letterpress pressure print, letterpress, cuts and collage*

2015

*Waxing My Third Eye* was the first work I created after having a mastectomy on June 1, 2015. This series addresses processing cutting off my breast. I struggled to accept the surgery. Terror wrapped itself around and through me. I often pass out when poked with a needle and the sight of blood makes me sick. I couldn't imagine what this surgery would do to me. While I know art can heal, I could not go to my studio. These pieces helped me begin to find myself again, allowed me to feel empathy for myself, and understand my vulnerability. The title evolved from a conversation around how much I enjoy getting the space between my eyes waxed. I love how it feels and this became a metaphor for the whole year of the breast, a time where removal of something can actually eventually feel good and spark a new beginning.  
(photograph by Melanie Mowinski)

[www.melaniemowinski.com](http://www.melaniemowinski.com)



## S:ST298.402

Emma O'Connor

Book, accompanying poster, and experimental film

2015

*S:ST298.402* explores the fragmentary nature of experience, the drive to find order and build a coherent patient narrative. *S:ST298.402* accompanies *ST298:402* – a 14 minute 37 second experimental film with sound. Over a year I had filmed daily, documenting aspects of my life including the journey of my Ph.D. research. In both works, I search for a meaningful way to communicate my experience of genetic diagnosis and preventative surgery. *S:ST298.402* is part of a wider project, The Editions, a twenty-two book series with accompanying posters, led by Dr Sharon Kivland at Sheffield Hallam University.



## WIDE LOCAL EXCISION

Carol Pairaudeau

*Digital print*

2016

*Wide Local Excision* looks back at my own experience of breast cancer surgery, which took place on 13 March 2013. The book, which is intimate in scale, is presented in a pathology sample bag. When a tumour is removed it is then sent to the pathology lab for testing. The book reveals both the physical effects on my body whilst also attempting to convey some of my emotions associated with the procedure.



## DIARY OF AN ILLNESS

Anne Parfitt

*Ink on paper (single edition prints of original drawings)*

2000-01

*Diary of an Illness* is a visual narrative analogy of the passing of time during a chronic illness. This was a period dominated by waiting (for diagnosis and treatment), which transformed time through its deceleration, making me acutely sensitive to each minute, hour and day. The bookwork consists of repeated sequential drawings of a black ornamental bottle, significant in its response to the changing light, and which became a personal metaphor for time itself. Each image is an imitation of the previous, yet never identical – mirroring the indistinguishable yet unique nature of each moment.

[www.anneparfitt.com](http://www.anneparfitt.com)



**SPEAKING IN TONGUES:  
SPEAKING DIGITALLY /  
DIGITALLY SPEAKING**

David Paton

*Digital print on Innova Smooth High White 220gms;  
Hand Letterpress and video on flash drive*

2015

In this artist's book I explore the passing of time, aging and the complexities of communication through the depiction of, on one side of the leporello format, my young son's subtly moving hands whilst playing an online game (*Digitally Speaking*) and, on the other side, my aged mother's remarkably expressive hands whilst recounting stories from her youth (*Speaking Digitally*). The book (with accompanying video) explores the temporal and spatial gap between youth and old age, the stories which exist in between and the skin as an index of the passing of time, aging and of memory.

[www.theartistsbook.org.za](http://www.theartistsbook.org.za)



## SYMBIOTIC/PARASITIC

Christine Pereira-Adams

*Pergamena paper (laser and hand cut), linen and nylon thread*

2015

The creative narrative and canon I refer to, and engage with, are strongly informed by gender and motherhood. Working with the concept of the book as the medium reflects my impulse to reconsider conventional structures and methodologies. Historical materials, models and narratives are redefined from familiar structures to more organic forms. Contemporary technologies and thought have transformed medical environments and relationships. The patient's body, all that is personal and intimate, becomes part of a clinical and increasingly abstract process. Supporting the individual's evolving sense of identity, self and autonomy is crucial. *Symbiotic/Parasitic* is a portrait of the nature of these developments. The reading is unpredictable and requires unexpected considerations.



## DELIRIUM

Corinne Perry

*Concertina photographic diary*

2012

*Delirium* is comprised of traditionally hand-printed and coloured self-portraits. Produced as part of my *Delirium Series* of 2012, the work intimately depicts my fragile emotional state. To bury this mind-set deep within would allow it to thrive, but through the diary's production I am offered a cathartic release. Though the work is deeply personal, I relate the emotions explored to Victorian author Charlotte Perkins Gilman's novella *The Yellow Wallpaper*. The underlying vulnerability, explored within the imagery, is further emphasised by the small and intimate scale of the diary.



## RECONSTRUCTION SERIES

Clare Petherick

*Graphite on Shodo Daigaku paper*

2015

I was diagnosed with breast cancer in December 2014. My treatment started with chemotherapy and a week before my operation I decided to make some drawings of myself. Post-surgery I used the original drawings as a template for subsequent drawings cataloguing the effects of my mastectomy, DIEP flap reconstruction and lymph node removal. I noted everything from the swelling under my arm to the tiny radiotherapy tattoos and shadow. I am keen to show these works as a way of demystifying the subject of breast cancer treatments. It is an ongoing project.



## A BOOK HAND

Marta Pieregoczek

Mixed media

2016

*A Book Hand* challenges the conventional book format and becomes a sculptural object in a box display. It is a sophisticated way to freeze a moment of great intimacy between two people when one of them is dying. Those often very quiet moments contain entire conversations; thoughts, fears, hopes and hesitations which are never vocalised. *A Book Hand* is an attempt to analyse these moments and visualise them. The text is from Emily Dickinson's poem "If I Should Die", fragments from the book *Staring at the Sun: Overcoming the Terror of Death* by American psychiatrist Irvin D. Yalom and from my personal diary.



## THE CANCER OF THE WEATHER

Stevie Ronnie

*Weather balloon circuit board, paper, wire, ink, map, unique book*

2013

*The Cancer of the Weather* was made using a circuit board from a weather balloon that I found during a residency in the High Arctic. I attached several paper signatures to the circuit board using wire and they contain words related to prostate cancer beginning with the letter P. During my time on the residency my father was undergoing treatment for an aggressive form of prostate cancer and this was on my mind throughout the trip. I was thinking about how accepting the severity of my father's illness was a similar process to accepting the current predicament of our planet.

tevieronnie.com



## BOOKS AS MEDICINE

Susannah Ronnie

*Paper, transparent paper and card with topstitch thread, leather case*

2014

*Books as Medicine* is a piece created for people to interact with. The small stitched handmade books are intended to be picked up and handled. Inside them is a series of layered short poems that are contemplations on the word “medicine”. Each word in the layered poems is made up of letters from the word “medicine” itself. For example: M / i / in / Mind and Me / Men / end / Mend in the “M” book. The collection of eight books is housed in a leather Gladstone bag, which is mentioned in numerous works of literature. (photograph by Colin Davison)

[susannahpickering.com](http://susannahpickering.com)



## LINES, WEAR AND TEAR

Anne Rook

*Concertina book: archival inkjet print on fine art paper*

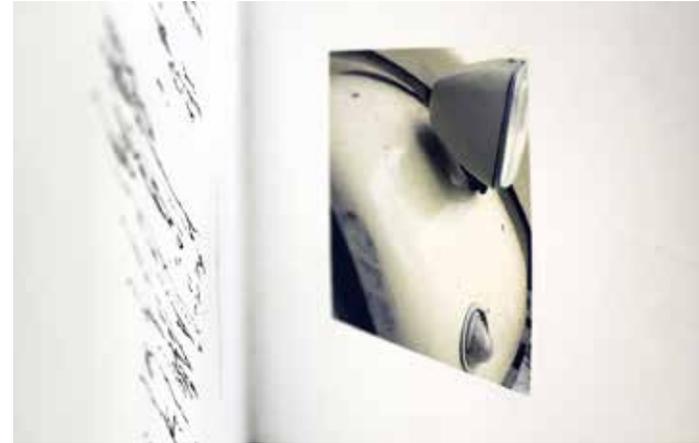
2013

Lines of wear on objects I look at every day and yet rarely see.

Lines I don't want to see.

Looking at the overlooked.

A book of drawings and photographs of lines on objects around my house. The drawings of wear lines as a "mise en abyme" of these objects.



## MR DARCY'S ADVICE TO THE HIP PATIENT

Mary Rouncefield

*Watercolour and ink*

2013

This book was written and illustrated while I was recovering from a hip operation. Even though I received excellent care, I did feel I was on a very efficient "production line". I was given a series of "rules" designed to help patients avoid dislocating their replacement hips. These rules form the basis of this book, along with Jane Austen's Mr. Darcy (who fortuitously appeared on television, to provide me with a much needed diversion!) The illustrations show the female patient quite naked, emphasising her complete vulnerability and status as "patient" and "victim".

[www.maryrouncefield.co.uk](http://www.maryrouncefield.co.uk)



## UNDERSTANDING MYSELF BETTER

Angel Sameth

*Artist's book made of paper, card, cloth*

2013-16

My mother, at 27, had breast cancer and a mastectomy. I was 28 when I experienced her secondary cancer; she was bitter and angry and died aged 52. I had spent my adult life petrified of having this disease. In 2013, aged 54, I was diagnosed with Ductal carcinoma in situ (DCIS) in one breast – a type of breast cancer I had never heard of. My DCIS resulted in two lumpectomies, a mastectomy, reconstruction and a nipple tattoo, but fortunately no radiotherapy, chemotherapy or drugs. I was determined to grow from this experience, to be stronger and positive. This book shows in a chronological order the paperwork I received over my two and half years of treatment.



## THE UNFINISHED BLANKET

Erin K. Schmidt

Crocheted book - cotton yarn, inkjet printed ribbon, inkjet printed silk  
2016

*The Unfinished Blanket* is a book about my much anticipated pregnancy which ended abruptly. It was a rare and complicated twin molar pregnancy resulting in miscarriage, two very thorough dilation and curettage procedures, and months of bloodwork to ensure that the affected cells did not continue to grow into a deadly cancer. This book takes the form of a baby's blanket, a blanket begun with hope, but no longer needed. Text on ribbon closures describes joy turning into sadness. A book wrapped within the blanket contains words taken directly from pathology reports of the procedures I had to endure.

[www.erinkschmidt.tumblr.com](http://www.erinkschmidt.tumblr.com)



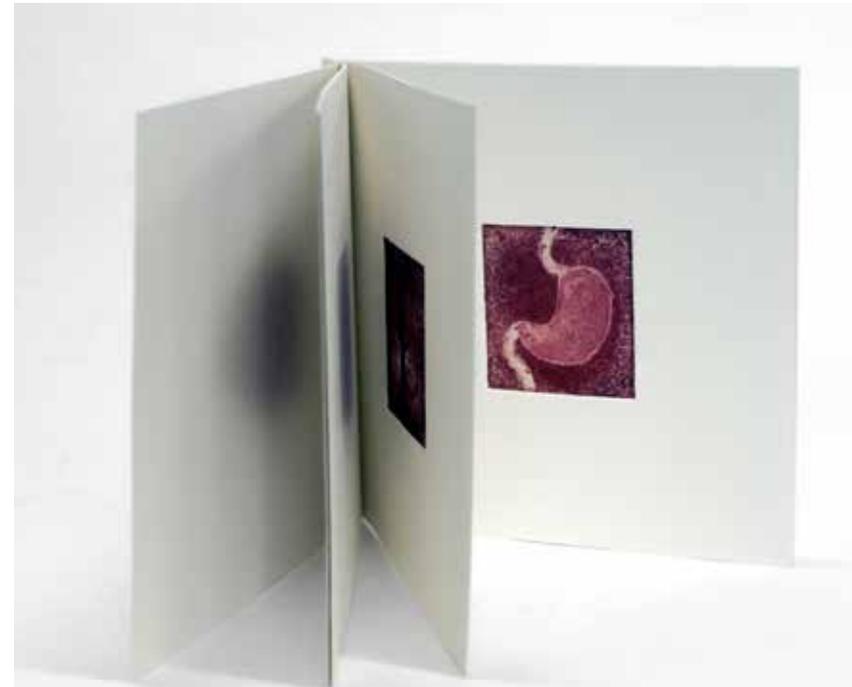
## -ECTOMY

Maya U. Schueller-Elmes

*Collagraph prints on Somerset paper*

2016

The inspiration for this book came from reflecting on my father's experience of kidney disease. For me, this experience highlighted the simultaneous fragility and resilience of the human body. I chose to make visual representations of organs which could be wholly or partially removed, or altered, without the need for a replacement or replica part – focusing on the strength of the human body. The scale helps to emphasise the preciousness of each organ. The use of collagraph echoes the cutting involved in surgical procedures.



## WOUNDS

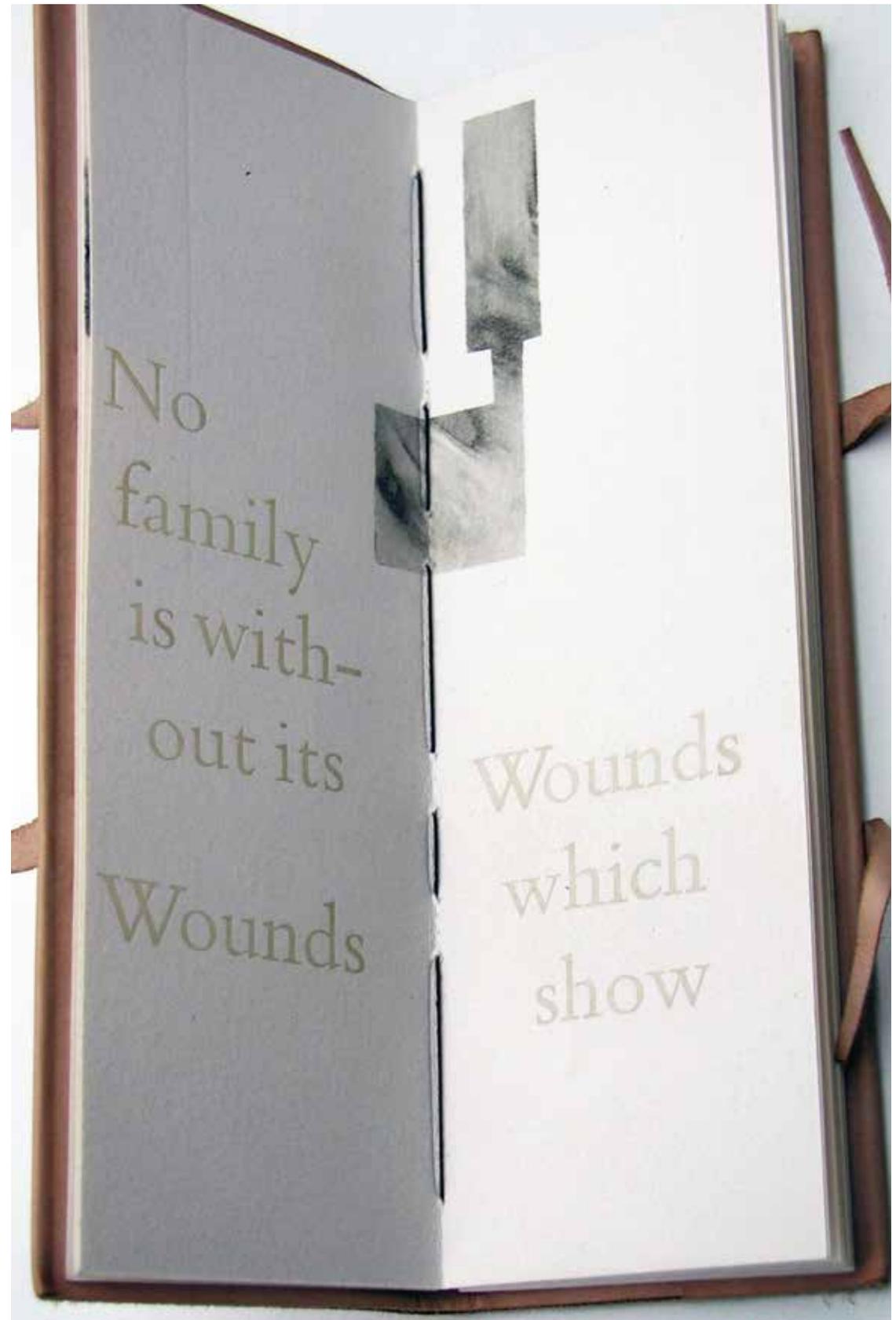
Ruth Shaw-Williams

*Bookbinding calfskin, letterpress and photo-etching on Arches 250 gsm, bound with linen thread.*

2004

This piece chronicles my family history. Wounds which show and wounds which don't. No family is without wounds. The most damaging wounds are the least visible, those denied. I asked my mother's permission to photograph some of her many scars left by surgery. She was hospitalised from birth until she was eight, with vivid childhood memories of life in hospital. Chronic ongoing illness not only impacts upon the life of the sufferer, but also upon the whole family. Marks are etched like scars onto the paper surface. Stitching, integral to surgery, and a calfskin cover were used to record traces of previous handling.  
(photograph by Ruth Shaw-Williams)

[ruthswrenhill.com](http://ruthswrenhill.com)



## THE CANCER DIARY - I

Ruchika Wason Singh

*Banana paper, cartridge paper, collage, cotton thread, surgical suture thread, sumi-e ink, gouache and pencil on indian handmade paper.*

2015

As an artist-patient, I reflect upon mastectomy beyond a surgical scar on my body. As a part of my work methodology, I paint breasts and tear them into pieces, which are then restored by painting onto them. This process almost marks a visual resurrection of the breast. By working with fragments, rupturing, tearing, losing and resurrecting, I express the loss of the breast and my acceptance of the same. I then paste the pieces onto sheets of deckled edge paper into a format of a book. This further contributes to the idea of archiving the experience between illness and art.

[du-in.academia.edu/RuchikaWasonSingh](http://du-in.academia.edu/RuchikaWasonSingh)



## FABRICBACK NOVEL

Alison Stewart

Textiles

2010

My personal journey maps out my understanding and comprehension, developed through my struggle with dyslexia. I find it difficult to access books through the language of text and generally give up reading when 3 or 4 words don't make sense. I explored paperbacks in an investigation of text in textiles and produced *Fabricback Novel*. I created a visual system of communication to investigate the structure of textiles as a means of removing textual barriers. The fabrics were constructed using a grid pattern like a matrix for text – a parallel representation of the printed word within the book.



## ARABESQUE 3

Randi Annie Strand

*Book, relief print / stencils*

2014

The book is a medium of intimacy, presence and touch. In my *Arabesque* books, the 12 gram paper is translucent. This causes overlaps that create new shapes and colours. The paper is airy and completely silent. Quick movement is physically impossible. Fragility and vulnerability appeal to care and consideration. Touch and treatment interrelate. The actions necessary may add a ritualistic element to the act of reading. I have tried to create a space for a contemplative experience, displaying the ever changing character and relativity of existence, where different elements are always coloured by their surroundings.

[www.randistrand.no](http://www.randistrand.no)



## WE HAVE TO...

Noriko Suzuki-Bosco

*Monoprint pages, cotton thread, glue*

*We Have To...* attempts to depict illness as a non-linear process. This is expressed through the folded monoprint pages, which have been put together to open out and cascade. Each page/ section of the book is unique and the overlapping images and stitched marks create a layer of complexity that invites the viewer to take time to engage. The process encourages the viewer to look and sense beyond what they can physically see, metaphorically aligning them to the patient whose internal vision has been sharpened through the experience of illness.

[norikosuzukibosco.com](http://norikosuzukibosco.com)



## THE EATEN HEART

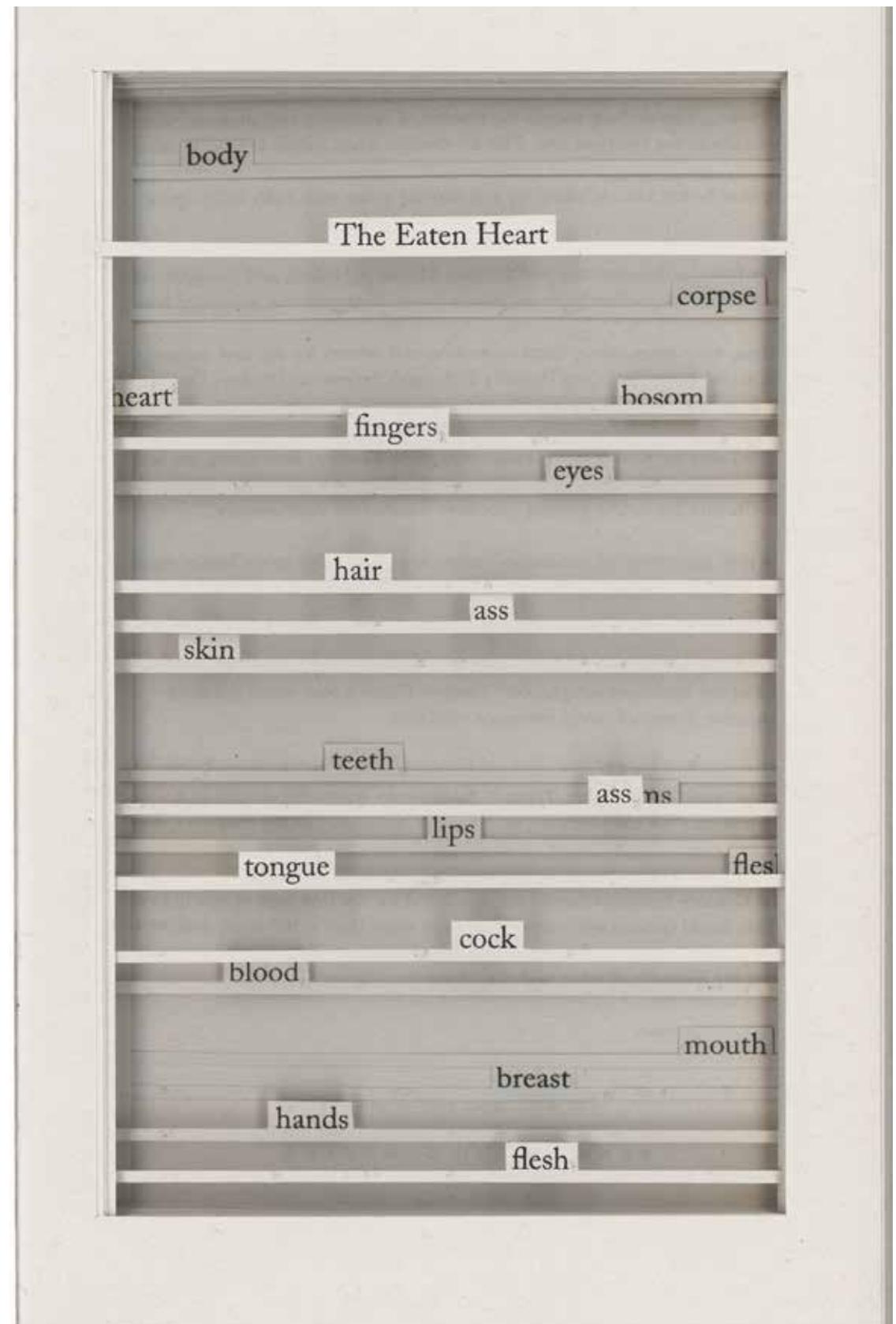
Carolyn Thompson

Found book

2013

*The Eaten Heart* is an adaptation of Giovanni Boccaccio's *The Eaten Heart: Unlikely Tales of Love*. Text has been removed from every page with the use of a scalpel, leaving only words that pertain to the body and the bare skeletal bones of the book. By grouping these remaining words together, their significance changes dramatically and highlights the abundant innuendo in Boccaccio's original text. (photograph by Carolyn Thompson)

[www.carolynthompson.co.uk](http://www.carolynthompson.co.uk)



## THE SILENT FLUTTER OF THE BUTTERFLY

Wendy Ann Titmus

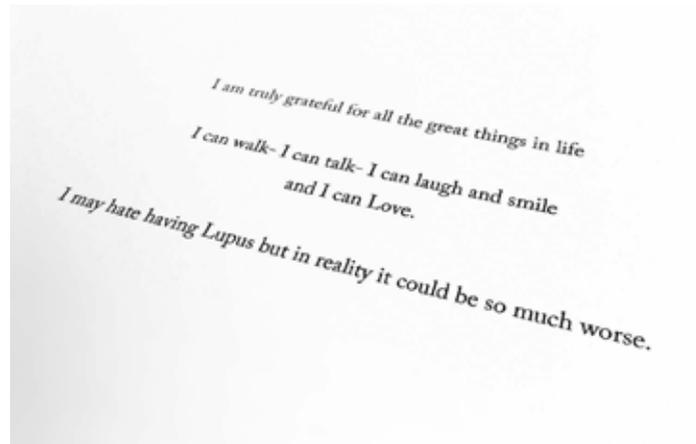
Hardback book: photography, text & poetry

2012

*The Silent Flutter of the Butterfly* was intimately configured through the participation and collaboration with patients and medical professionals, during an artist residence at the Wellcome Trust Clinical Research Facility. The book explores the inner feelings and emotions of individuals diagnosed and living with Lupus. Through the personal interpretation of patients the book aims to allow the reader to experience how their psychological strength, faith and belief in medical science form an extraordinary coping mechanism that defines positivity, at a time when one can only imagine the psychological strain and physical deterioration that such a medical condition can evoke.

(The Wellcome Trust Clinical Research Facility Lupus Art Project)

[www.wendyantitmus.co.uk](http://www.wendyantitmus.co.uk)



## COPD: DEREK'S STORY

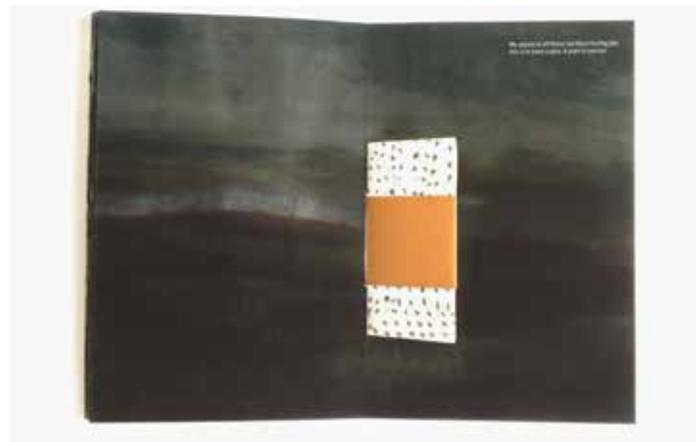
Josie Vallely

*Digital print and folded paper*

2014

My practice centres around collaborative social documentary, focusing on the arts and health. I am particularly interested in the psychological impact of long-term conditions. I work with individual narratives to create artists' books. Their size, structure and handmade quality communicate to the viewer a sense of personal experience and quietness, which suits messages of personal journey, discovery and resolution. This book focuses on narratives of chronic obstructive pulmonary disease. Based on a narrative provided by Derek Cummings, I employ landscape to create a visual response to his expressions of the multimodal experience of chronic illness in contemporary society. (photograph by Josie Vallely)

[www.josievallely.com](http://www.josievallely.com)



## OSTEOPOROSIS

Lizanne van Essen

*Artist's book: hand cut and folded paper and card.*

2008

I wondered what it would be like if, instead of informing the reader about human medical conditions, the books themselves displayed these actual conditions. Paper cannot become flesh but the book form can display a variety of human symptoms and I was fascinated by how this could be achieved. Osteoporosis is a bone disease with an increased risk of fracture, where the density of the bone is reduced and the connecting structures within the bone are severely reduced. This book exhibits the characteristic holey appearance of osteoporotic bone.  
(photograph by Lizanne van Essen)



## GERMS

Lizanne van Essen

*Artist's book: hand cut and folded paper and card.*

2016

Bodies are not unique in suffering decay and coming under attack by outside forces, and books and paper are equally vulnerable. Injuries such as breaks, cuts, brittleness, and infestations can happen to both bodies and books. I was interested to see if I could make books that did not inform about, but displayed, human illnesses. Germs are micro-organisms (bacteria, viruses, fungi and protozoa) that can cause disease, attacking the body so that the body's defences can give rise to inflammation. This book is my interpretation of germs' dangerous growth attacking a human body and of its inflamed reaction.

(photograph by Lizanne van Essen)



## HOW TO SURVIVE A SHORT COURSE OF CHEMOTHERAPY

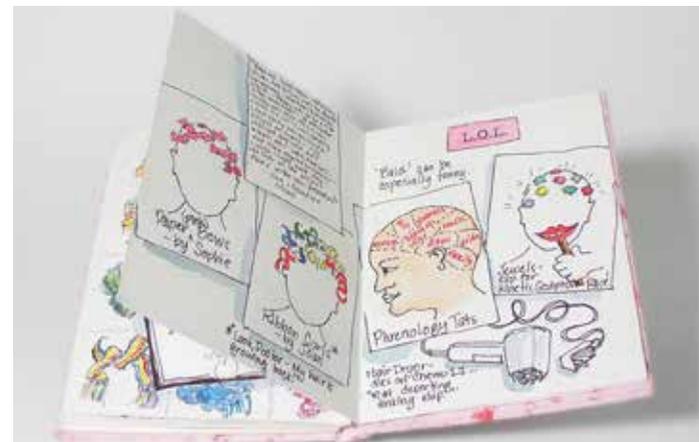
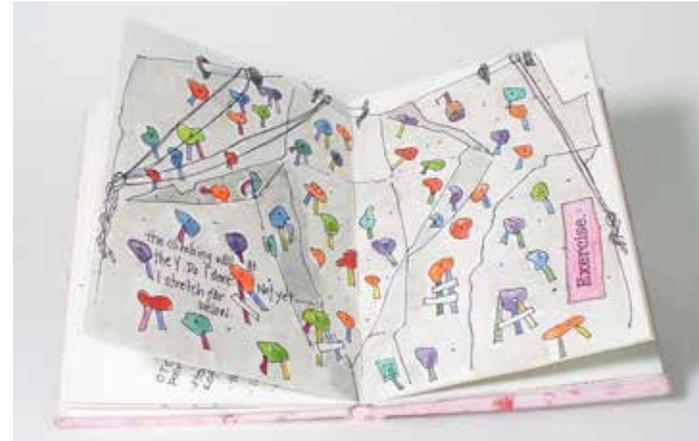
Susan Walther

*Watercolor and felt-pen illustrations on 140# watercolor paper, with hand-made and ink-jet papers, book board, matte medium, wheat paste, linen thread.*

2013

My art practice – to chronicle, collect, and then arrange scraps and images into coherent paintings, collages, and small books – gave me the focus I needed during chemo. Determined to be pro-active in my return to health, I drew and painted and bound together 14 prescriptives (for example, “Read/Research/ Ask!” “Pray/Meditate/Dream/Imagine!” “Believe in your treatment!” “Get a short haircut!” “LOL!”), and now, when I share the book with someone newly diagnosed, it insists: I survived, and so will you. (photographs by Susan Walther)

bmoreathome@hotmail.com  
Facebook (B-More Artist Books)



## LIKE WEATHER

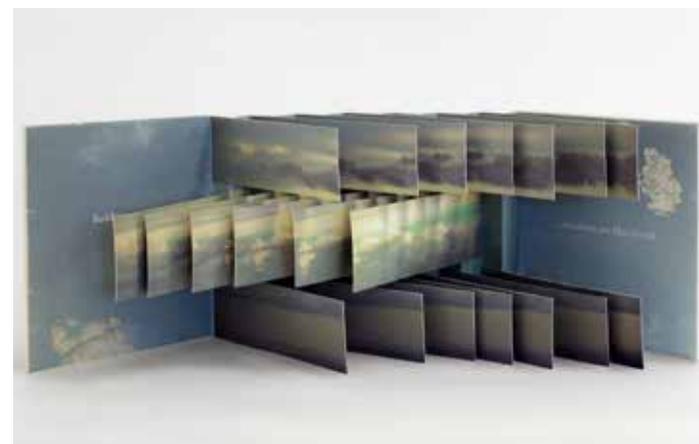
Amanda Watson-Will

Digital pigment print

2007

In my work, I use psychological and spiritual frameworks, particularly Buddhism, to try to integrate the big picture with the small detail of the everyday. This book developed from the use of mindfulness as a technique to manage fluctuating emotions and mood. *Like Weather* can be viewed as a snapshot of my mental status at the time. Its creation both reinforced the practice of mindfulness and facilitated processing of the emotions I experienced. The flag book structure highlights the changeable nature of our feelings.

<http://amandawatson-will.weebly.com>



## CELL

Susie Wilson

*Mixed media tunnel book*

2014

My work looks at the fragility and strength of the human body, things hidden and revealed with traces left behind. This small scale tunnel book is made from layers of tracing paper printed and cut into. When held up to the light, the cell-like imagery is both revealed and obscured by partial shadows. The intimacy of holding the book – each layer hiding then revealing the next – creates an atmosphere that is deeply personal.



## A VIEW FROM INSIDE

Alexa Wright

Artist's book

2012

With *A View from Inside* I am challenging our preconceptions of what constitutes reality. The ten portrait photographs in the book draw on the principles of eighteenth-century portrait painting to give form to the unique realities encountered by different people during psychotic episodes. The accompanying narratives offer a vivid first-hand insight into the experiences of the people portrayed. Two essays, by a psychiatrist and a cultural theorist, give the portraits a wider theoretical and social context. The book is published to accompany a series of larger, framed photographic portraits designed for gallery exhibition.



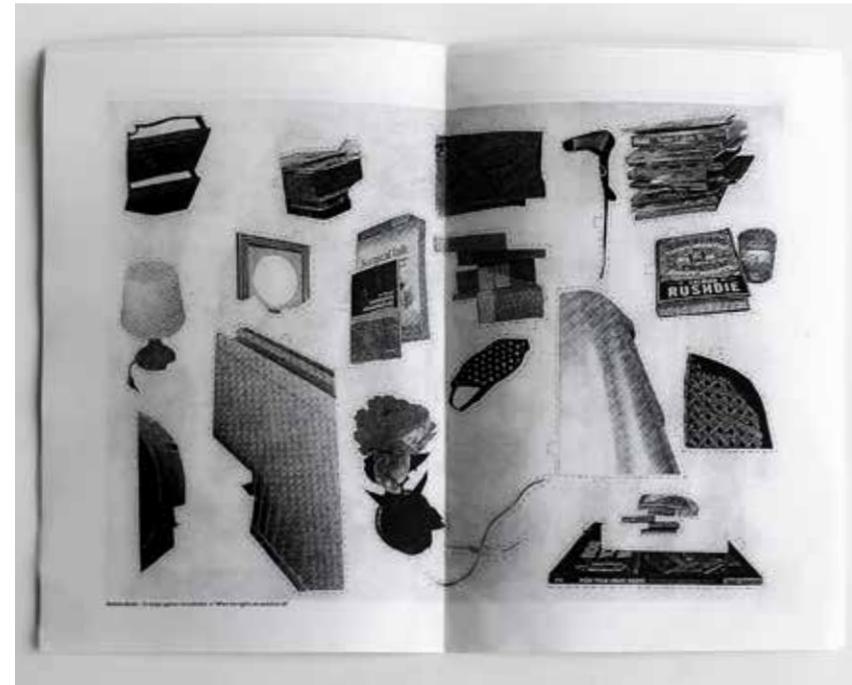
## INBEDSIDEBOOKS

Lena Wurz

*Plexiglas, letterpress, collected photos, copied and scanned on 80 gsm paper*

2014-15

This movable is part of the project *inbedsidebooks* about nictophobia, the fear of darkness, and the mental and architectural space around oneself when falling asleep. The included QR code in the book serves as a possibility of (self-) therapy giving access to a Pop-up-PDF to download and print anywhere. The folded A4 format of the printed movable connects to this idea of approachability. The magazine is accompanied by perforated cards that can be divided into bookmarks suggesting having pages of a book rather than a screen between one's fingers before switching off the bedside lamp.



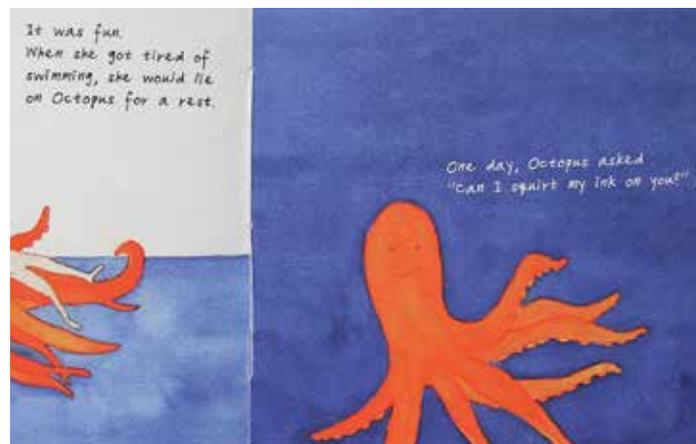
## BECAUSE IT ALSO HAPPENED

Winnie Yoe

Watercolor on Paper

*Because It Also Happened* is a response to a series of traumatic events I experienced at Dartmouth College in the US when I was 22. Struggling to find closure, I decided to build my own narrative and define my own experience. The book opens with the protagonist Winnie befriending Octopus. One day, Octopus asks if he could squirt his ink on Winnie, to which Winnie agrees. Buried everyday under layers of ink, she no longer recognises her own skin. She eventually leaves. However, memories still loom, leaving her confused about how to gain strength and like herself without Octopus.

(photograph by Winnie Yoe)





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