Why doctors’ stories matter

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For me, the invitation to participate in honouring doctors’ stories* completes a circle that has been going around for 20 years. In 1989 I wrote what became my first book, At the Will of the Body,¹ which tells the story of my own illness experiences during the mid-1980s. I had a virally induced heart attack—which I was disappointed to hear has now been downgraded to a “cardiac incident”—and just when I felt recovered from that, I began to have symptoms of what was diagnosed after some delay as testicular cancer. Soon after I finished treatment for that, my mother-in-law died of cancer.

At the Will of the Body offers the story of those years as a companion to others who are going through illness. When I found out I had had the heart attack, I was suddenly forced to think about my life and body in a new way. That undertaking requires companions, so I looked for a book—somebody else’s story—to be a companion to me. There was not much available 20 years ago, and ultimately I had to write that book for myself. I believe that we’re always telling stories first for ourselves and then, although then can be a very short time, for other people.

It might be slightly inappropriate, but only honest, to tell you that I wrote At the Will of the Body with a sense of considerable alienation from medicine. I mean this in the literal sense of the German word from which English usage derives: doctors seemed strange to me, and being with doctors made me feel strange to myself. As some part of myself watched me interacting with doctors, I didn’t quite recognize the person who was me; he wasn’t expressing what I was feeling. But I realized that version of me was acting in response to how he was being treated by individual physicians and by the institutional context from which those physicians were inseparable. I kept asking myself: Are doctors acting that way because it’s how they choose to act, or because of how they feel they have to act? Shane Neilson’s story (page 55) raises that issue when he observes: “I am locked into the sentences I have spoken before, many times.” Dr Neilson then questions the advice given by a mentor to “Say the same things in the same way.” That advice seems hollow when faced with patients who are “breaking down in individual ways.”²

Several years after I’d written my book, my alienation was articulated in a posthumous illness narrative by the prominent critic Anatole Broyard, who died of prostate cancer.³ Broyard wrote, or more accurately he said in a grand-rounds lecture that he was invited to give at the University of Chicago’s medical school, “doctors discourage our stories.”³ That was my experience exactly: I felt my stories were discouraged. This celebration of stories changes that discouragement and thus closes the circle that opened 20 years ago. Or, if not exactly closes it, at least starts a new loop.

The mutuality of respecting stories

What is honoured by the AMS-Mimi Divinsky Awards, and what the award winners represent, is doctors taking seriously their own stories, which is the absolutely necessary prerequisite to doctors encouraging their patients’ stories. Because I believe it’s a simple principle of mutuality: You cannot respect others’ stories unless you respect your own stories. That, for me, is the point of the History and Narrative in Family Medicine competition: making a professional statement that these stories matter. Medicine is far more than what goes into the chart.

Anatole Broyard also recognizes how doctors bear the “emotional burden of avoiding the patient,”³ which means avoiding the full, extensive story of illness that the patient is living. The scheduling and floor plan of clinical spaces choreographs the avoidance that Broyard evokes. The emotional burden that results is really a double burden, because to avoid someone else is to avoid some part of yourself. Sharing stories is an essential step toward laying down that burden of avoidance. By valuing not only the content of what these stories tell, but also by valuing the act of writing about medical experience, doctors move past the avoidance that Broyard spoke of and that I have heard many ill people note with regret, both for ourselves as patients and for our physicians.

Narrative and suffering

I wrote At the Will of the Body as a means of survival, because I needed to tell that story so that my life could regain a coherence that illness had disrupted. To narrate is, first and foremost, to order events in time, so

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that each part of the narrative gains significance with reference to the other parts. Narration is essential to being human, because the world in itself is not ordered. The world in itself is what William James famously called a “blooming, buzzing confusion.” Whatever order and coherence exist in life have been created by humans.

Learning to create order begins with hearing and telling stories, because to narrate is inherently an act of ordering. Stories order things in time and space, in priority, and in relations between actions and outcomes. A world that we can tell stories about becomes a meaningful place, insofar as outcomes not only have a certain predictability, but also because stories convey a sense that what happened was good or bad. Stories evaluate. When terrible things happen in stories, those terrible things at least have a place. They are meaningful in the sense of fitting a pattern. As we humans discern that pattern, we are better able to live with those terrible things.

Illness is an occasion for stories—it calls for stories—because illness disorders. Illness fractures the patterns that hold lives together. Telling stories is essential to creating new patterns, in which illness now has a place.

Filling the incomplete narrative

Over the years that are now decades, my work on illness experience has given me the opportunity to get to know many doctors, and I’ve learned that doctors have the same problem that their patients have, which is how to live with the persistence of suffering. In one way doctors’ version of this problem is easier, because their bodies are not yet sick. But in another way their version of the problem is more difficult, and here’s my way doctors’ version of this problem is easier, because doctors too rarely allow themselves to tell their own stories. As I have also learned over the years, storytelling only happens in relationships. To tell a story establishes a relationship, and unless we humans trust that a relationship can be established, we can’t tell stories—it’s like trying to breathe under water. To press that metaphor, where once I saw patients drowning, now I see all kinds of medical workers drowning.

For storytelling to be a relationship, the stories have to get around. Telling these stories at society meetings or in journals read by peers can be only a first step in that process. As I read the winning stories, I had a fantasy, which is probably not a good idea to apply literally, but it’s useful as what philosophers would call a thought experiment. My fantasy was that in a doctor’s waiting room, instead of old magazines and public health brochures, patients might pick up stories that the doctor had written—stories not unlike these winning stories. And maybe patients would then bring in their stories and leave copies of those on the rack next to the doctor’s stories. That would open the silent world on both sides. It is a fantasy, and there are multiple good reasons not to go that far, but we should imagine going that far, because my fantasy represents the ideal of doctors and patients knowing one another as having lives that go beyond the clinic doors. My story exchange would show people how doctors are deeply affected by the strange and often terrible things they are called to participate in. Until stories like those we honour with these awards are heard by patients, and until ill people can get their stories heard by their doctors, there are still two silences. This contest is a crucial beginning. Because here we have doctors taking their own stories seriously, and as I said earlier, people cannot respect other people’s stories until they respect their own stories.

Stories and mourning

I want, now, to say something about these three particular stories, how they affect me, and what they lead me to hope for.

In my current writing about storytelling, my argument is that stories work for us humans. Stories are more than equipment that we require in order to live, although they are that. Stories are active companions. They go places with us. Depending on which stories accompany us, we see places differently. Living with these narrative companions is a different life than we would lead without them. What, then, do these stories do for the storytellers who tell them, and what do they do for those who hear them?
These three stories are companions in the work of mourning. Societies have funerals and other grief rituals because mourning needs companionship. Among these stories, two storytellers write about bodily death and go to funerals. But at some point a mourner gets home from a funeral and finds him or herself alone. One thing to do at that point is to write a story much like any of these three.

Shane Neilson’s story about diagnosing Alzheimer disease is not about bodily death; but the repetition of the husband’s line, I’m dying inside, makes it a story about how the end of this man’s wife as a fully communicative, fully social being is more than an occasion for her husband’s grief. His wife’s passing into dementia is a kind of death for him, his own death conflated with hers. Neilson’s story may be the most deeply mournful story of all three, because there is not even the companionship of the funeral.

As I read these stories, I thought to myself: This is the work of mourning. Writing these stories is how you grieve after the funeral, for Drs Lodge and Motheron (page 58), or when there is no funeral to go to, as for Dr Neilson. Writing a story such as any of these is, first, an act of witness. Unlike the observer, the witness declares her or his stake in what is seen. The witness is not detached but engaged, and that engagement generates a duty to tell others what the witness saw. In that telling, the witness calls upon the listener to join the expanding circle of those who have seen and declared that what they saw matters. Christine Motheron writes, addressing the baby who has died, “Your life was not just another case in my day-to-day work.” All three writers say that, in one way or another. A medical chart would be sufficient to observe a death. But to memorialize a life, a story must be told.

Even while the story is being told, something happens that, as often as I think about it, I always consider magical. The story takes on a life of its own. These three stories stand apart from their authors, even while they remain representations of what their authors lived through. The salient issue is how these three storytellers—physicians might live differently, having told these stories so that they are no longer inside but out there, as vital presences in the world. Here I project onto these writers my own experience of having written a story that contained a great deal of my own sadness and loss. The key word in that last sentence is contained. When we tell a story, we build a kind of container for experience, and when we can put experiences in that container, we have a better chance of having them as useful companions instead of feeling unpredictably flooded by the experience. We no longer relive the experience in the sense of being at its will. What has happened loses none of its sadness, but, as contained in the story, it has a time and place to be sad.

To communalize and memorialize
Putting stories into containers does hold them, and holding them is necessary for sharing them. Or I would prefer to say, stories communalize experience. The Greeks knew about the ability of stories to communalize grief, and they staged their tragedies as civic rituals of collective mourning. I have heard from someone who should know, but I have not yet been able to confirm, that when the Athenians staged tragedies, veterans sat together with their military units. If that is not historically true, it is in the spirit of communal, ritualized grieving that scholars agree pervaded the staging of the tragedies in ancient Greece. We today suffer for the lack of such collective rituals, although not always. I remember once attending a meeting of the National Coalition for Cancer Survivorship in Albuquerque, New Mexico. At the start of the closing dinner, we had a ritual of remembrance in which the names of cancer activists who had died that year were read, with each name followed by a bell ringing. Too often I find cancer groups taken over by what a friend beautifully called “enforced hilarity.” But on this occasion, we mourned together.

Physicians need to mourn not only colleagues who have died, but even more, the patients whose deaths you have witnessed. Christine Motheron writes: “You don’t learn how to deal with such emotions until they become brutally apparent,” which is the complementary line to Andrew Lodge writing that he must have missed class the day they learned how to deal with such situations. “[H]ow to deal” is Dr Lodge's phrase, and it’s the unfortunate limit of what classes can teach. These three stories are about what cannot be dealt with, in the sense of doing something professional that counts as an adequate response. Alzheimer dementia that ends life as it has been known, or perinatal death that ends a life that has not yet begun, are not matters to be dealt with. Such experiences need to be memorialized.

Being a good enough physician
The death in Andrew Lodge’s story is different. For all the absurdity of how Dr Lodge’s patient is forced to die, at least that death has been accepted and even welcomed, and it happens more or less at its appointed time and place, with some ingenuity from Dr Lodge. Dr Lodge takes a situation he has the misfortune to inherit and makes it good enough, and sometimes doing well enough is the best to hope for. His story is written after ritualized work mourning has taken place, and so the story is free to do different work—it can be a companion. The story can accompany the physician on his medical journeys, assuring him that however strange things get—and they will—he has the capacity to find a way to make them right enough.

Finally, let me say that what I appreciated most about these stories is their humility. All three stories depict events outside the physician’s control, and at best—in
Andrew Lodge’s story—a makeshift solution is found more by luck than skill. The great pediatrician and psychoanalyst Donald Winnicott praised what he called the “good enough mother,” who knows when to stand back enough to allow her child to play, develop, and grow. These three stories all praise being good enough as a physician. Crucial to the moral stance of being good enough is the clear recognition that there are forces far more powerful than you, your profession, or your institutions. Much of the time in this life, we humans simply hold on. Holding on is not how mid–20th century physicians imagined themselves, and humility was not the usual characterization of that generation’s stories. With the stories being honoured with these awards, we see times changing. That humility can only be good for patients, and it can only be good for physicians both individually and as a profession. Medicine, I believe, has something to answer for when people end up feeling either that they have failed or have been betrayed because they have a disease that cannot be cured. Too many physicians are embarrassed by such diseases and act out their embarrassment by turning away from their patients. This still happens. But it does not happen in these stories, and that’s all to the good.

A dialogue of stories
I began by saying that this celebration closes a circle for me. With these physician stories, the first-person narrative of illness finally finds a partner in dialogue. That dialogue is about vulnerability, about loss, and about helplessness. The dialogue is about whether it is possible to find some kind of redemption in life’s worst moments. Christine Motheron works hard to believe that the short life of her infant patient might make a difference. Andrew Lodge seems certain that his patient does go to the spirit world. Shane Neilson notices that his patient can still sing, despite her dementia. None of the authors makes too much of these slight openings; none suggests any kind of balance sheet. In that modesty, these become stories that ill people can fully appreciate. They represent a practice of medicine to be hoped for.

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References
5. Lodge A. Into the spirit world. Can Fam Physician 2010;56:56-7 (Eng), e45-6 (Fr).
6. Shakespeare W. Hamlet. Act 1, scene 2, line 133.