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HOLDING THE WHOLE:
VIEW FROM THE BED & VIEW FROM THE BEDSIDE

I think my own interest in the different and often dissonant views from bed and bedside is over-determined. It's hard to select the most potent contributors. They derive from various personal experiences in the bed and at the bedside, often as a loving observer. What concerns me most is the experience of lost opportunity, cross-purposes, needless pain.

Much of my professional life I worked with physicians and scientists, first as a writer helping them express their thoughts clearly, then as an editor of science journals moderating their conversations with each other, and finally as a communications specialist developing training courses and doing research on professional identity formation and the role of narrative in building social trust between professionals and the public. As an editor and publisher that interest in how people explore meaning in the face of illness has continued, beginning with our first Wising Up Anthology, *Illness & Meaning; Terror & Transformation*, and now with this anthology that combines the perspectives of doctors, nurses, therapists and patients.

But my own interest has very personal roots as well and, when I think about it, may have preceded me into this world. I was born, somewhat inconveniently, in the middle of my mother's second year at Columbia University College of Physicians and Surgeons. Born on Election Day, I interfered with my mother's ability to vote—something she wrote the election board to protest when they said that childbirth did not make her eligible for an absentee ballot. My actual birth may also, from hints she later gave me, have been a source of greater personal challenge because members of her predominantly male class felt they could come and observe the birth of a vigorous and unplanned child that she was desperately searching for the energy to absorb into her life plans. I think sadly now of that combination of emotional ambivalence and physical exposure, how trapped she was then between bed and bedside.

My sisters, as children, had serious illnesses—congenital heart defect and septic kidney—but in general the attitude toward our health was dispassionate and robust. My mother didn't pander to hypochondria, brusquely offering to write a parental excuse from school if we would just stop our hypocritical coughing. She was very kind to us when we were truly felled by cold or flu, bringing us soup and sympathy. On the other hand, when in genuine duress my body tried to communicate with her through illness, it went deafeningly unheard. Instead of my mother seeing my skin disease as a sign of unusual stress, she (a dermatology resident at the time) saw its unilateral distribution as a medical oddity and proudly took me to various medical meetings as a live dermatological specimen. She was oblivious to the discomfort I felt when strange men pulled my skirt up higher and higher to see more of my lesion, which I later came to understand as an expression of my existential rebellion against earlier molestation.

For years, every time I saw a physician, I would leave, condition identified, prescription in hand, with the most profound and seemingly unmotivated feelings of despair—as if the real source of my dis-ease were, forever, undiagnosed. It's a look that I've seen on the faces of patients when busy physicians race briskly from their hospital beds leaving them to puzzle through the world-reversing implications of their diagnosis.

Like anyone, when I start thinking about my own experiences with doctors and the healthcare system, I experience a meteor shower of associations: How the nurses in the pediatric ICU watched, mesmerized, as my brother-in-law spoke to his three-year-old son in a language they didn't understand but whose tone soothed them as deeply as it did my nephew. "What is he saying?" they asked. "He's just telling him exactly what happened today, what is going to happen tomorrow," I answered. I can remember a few years later, after a less successful operation that left the surgeons sullen, reluctant to visit, telling my sister and brother-in-law, "Take your son home. They can't teach you how to live well with this." And, some years after that, parsing responsibilities with my sister so that I could question a cardiologist eager to catheterize my nephew about the risks of the procedure, that meager 60% success rate, while she listened and wept and understood exactly what it might mean for her child and herself if she made the wrong choice. I can remember my aging, Parkinson's-bent father, also a physician by training, also weeping as he pointed to a rough hand-drawn diagram of his grandson's heart, its lethally narrowing valves: "It's just a pump, a goddamn pump."

I see the expression on my husband's face when a urologist, staring at my MRI scan, casually mentioned that 90% of tumors found in kidneys are cancerous. We were meeting with him at my husband's insistence to review the results of the tests before the doctor went on a two-week white-water rafting vacation in Colorado. "No, this can't wait," my usually mild-mannered husband had told the nurse, using his own full title. "Tell him I am sure he will be able to find ten minutes in his very busy day *because it is the right thing to do.*" It had been a question of civic responsibility. "It is bad *practice*," my husband had said. And it was up to us, as enlightened consumers, to create a world we wanted to be part of.

"I insisted he fit us in because he was so inconsiderate," my husband said in the car. "I had no idea what he was sitting on. How would he feel if another doctor did that to his wife." He fumed all the way home. I was the one who, bemused, was treating this as a communications case study, noting how my facile use of medical language (and familiarity with the ominous literature) had calmed the doctor who steadfastly refused to meet my husband's gaze or shake his hand. It was easier for me to be detached—for I had already managed to receive duplicates of my scans and the radiologist's report (which was reassuring, I had a benign angiomyolipoma, not cancer) before the urologist had himself and without his knowledge. His callous behavior, predicated on a belief he was our sole source of information, may have had reasons, but really no excuse.

The list goes on, of course. The hospital clerk and gastroenterologist who before giving me a complete GI series asked me to fill out a questionnaire on sexual assault, but when queried about what use they intended to make of this information, shrugged. Standard procedure. "You ask for that information before a surgical procedure, arbitrarily activating those memories, without any plan to address them?" I asked a member of the hospital's ethics board amazed. Their intentions, of course, I never questioned—just the consequences of their social tone-deafness.

And there are, of course, powerful images on the other side: The chief resident who held my hand during childbirth. The tall white-haired patrician surgeon who visited regularly with my nephew and his family whatever the outcome. The oncologist at the University of Pennsylvania I once shadowed

through a typical day who said quietly, "I like this specialty. There is always something, however small, I can do to make my patient more comfortable." The wonderful family medicine practitioner I have now who, when I asked about nutrition and inflammation said that her own knowledge was limited and then pulled out her phone and dialed her mother, who had thoroughly researched alternative treatments for her fibromyalgia, and handed the phone to me so we could consult directly.

But this question of missed opportunities, of cross-purposes, has a keen and present edge to it too, one that brings us directly to the purpose of this anthology.

In my early fifties I went through several years of profound depression. I understood it to be a response to life pressures, ones that felt close to insuperable, and also the answer to a prayer—a profound need to know myself fully before I died. I was clear that I wanted to get through this anguishing time without drugs. I had seen my own mother hospitalized, given electric shock, drugged stuporous with Miltown, which she replaced soon enough with equally sedating doses of gin. As a young feminist, I felt actions, decisive actions like divorce, would have served her better. But I also knew that wasn't the answer to the challenges I faced. I needed to see my own depression as a faith journey, one that had inner coherence, a gracious purpose, if, as yet, no clear path. My husband and spiritual director were both brave enough to keep faith with me, but there was a moment early on when, with a caution I agreed with, I went at my spiritual director's suggestion to see a psychiatrist about whether drugs might be advisable.

I can remember where I was sitting—on a couch slightly lower than his office chair that he had pulled around from his desk. There was dark leather everywhere, tall bookcases, a few token pieces of art. I looked over his shoulder at his desk, his computer. I knew my spiritual director thought highly of him, but I can still remember how I understood almost immediately that it wasn't just a mistake, it was a near disaster to come and see him. It had to do with the structure of the interview itself. From his point of view it made perfect sense. He wanted to sound the depths of my despair. He wanted to know if I was a danger to myself or to others. He didn't want to know the light in me, only the dark. He wanted to know about every trauma in my life. He didn't want to know how I had resolved them, grown from them, integrated them. He *didn't* want to know my strengths, the powerful mystery of my resilience. Every time I tried to include this, he shook his head, rattled his paper impatiently. That box was already checked.

In my memory there was a point in the interview when something in me went mute in self-defense. I stopped trying to explain myself, share my story. When he looked up from his checklist, I just shrugged, rose, thanked him for his time, paid him on the spot. All I wanted to do was get out of that room, get away from someone who intended no harm but whose gaze was annihilating.

I haven't thought of that moment in many years, but it comes back to me as I read, cover to cover and back to back, various memoirs of illness. I remember how time slowed, how some part of me just stepped back refusing to help this thin, humorless, well-intentioned, unimaginative man rip away one more scab on my psyche. And all the time I was keenly aware he meant no harm—*and* that he was truly dangerous to me and my fraying life wish. In his urge to treat, he was gutting my life of meaning, stripping me of all agency. *Innocently*.

Reviewing Rita Charon's *Narrative in Medicine* yesterday in preparation for writing this introduction, I came to a shocked standstill before the word *pathographies*, which she used a little hesitantly as a description of memoirs of illness. When I read it, I had a similar sensation to what I had a little later when I recalled this episode with the psychiatrist. *Pathography,* I thought, sounding the word out. *Pathological. Pathetic.* My life as a disease. That poor man who didn't know me from Eve was listening loyally for my *pathography* while I was, in one of the darkest periods of my life, living the namelessness that was mine alone to live as a blessing story, one that was, it was true, leading me deep into a dark and seemingly endless wood.

There is a movement now to study the role of narrative in medicine, to apply the techniques of literary analysis to the stories patients tell, to train physicians to listen for story, which I too think is crucial. But even more crucial is what kind of story we are listening for—and whether it bears any relation at all to the one that, whatever the encroaching circumstances, blesses our continuous dying into life and living into death. *That* one, the one we can't imagine ourselves without, the one we can't imagine for ourselves at all unless we are securely held in someone's imagination, some one person more than ourselves. That story does not know itself as a *pathography* or its protagonist as *pathographer* even if its catalyst is illness.

I think of the memoir *Sick Girl* and Amy Silverstein's inner response when her doctor, seventeen years into her heart transplant, asks in response to her despair and expressed doubts about the value of going on, "What gives your life meaning?" She realizes that her focus has simply been on survival, and knows that is not enough. She turns to writing and discovers there that more spacious story inside which she is truly free to share her reality, eloquent, biting, undistorted, with those whose lives, too, have been consumed by their desire for her survival. For to know ourselves to be held whole in someone else's imagination is to begin to hold their reality as tenderly and faithfully in our own. The slightest glimpse, actually, will do. That's really all we are asking of each other—the awed recognition that we are, each one of us, a universe.

I am sure that every one of us has a similar shower of associations, for there is no way to live to sixty, or even twenty-eight, without some meaningful and meaning-challenging exposure to our medical system, to generous and competent and harried and mediocre physicians, nurses wise and blasé, plodding and inspired counselors and therapists. But why bother to make a combined anthology, especially when these stories fly right past one another in real life? Maybe because there are so very many stories. For this painful mismatch of expectations and needs drives us all to speech—and there is a lot of that speech. Listen in as patients compare notes on the internet or in support groups. The social implications of that mismatch are an amplification of personal anguish, a precipitous rise in litigation and a paralyzing level of chronic mistrust.

The difficult question is how much if any of this chronic friction can be changed? How much is structural, the result of our crazy quilt healthcare system? Social—the result of professional training and incommensurate social expectations? Psychological? Whatever the cause, how much is intransigent? Intractable?

Why is it so difficult for patients to listen to their doctors' stories, to accept the walk-on parts they are given in the doctor's heroic battle against

DISEASE? Why is it so hard for physicians to spend even five minutes in the absolutely unique reality of any given patient's experience of sickness?

Thomas Graboys in his book *Life in the Balance,* which describes his own experience of Parkinson's disease and Lewy body dementia, quotes Anatole Broyard's desire that his doctor "would *brood* on my situation for perhaps five minutes, that he would give me his whole mind just once . . . ." Graboys, himself a physician, and one noted for his own holistic approach and attention to patients, recognizes the enormous burden this expectation places on physicians: "How do you give yourself over to hundreds and still function as a physician, a spouse, and a parent?" But as a patient, he also says, "That is why, as Broyard says, we cannot expect our physicians to suffer with us. But we can expect them to move out from behind the technology and pharmacology to connect with us briefly, to genuinely share, for a moment, our pain and anguish."

In her memoir, Amy Silverstein describes how she decided never to confuse long-term camaraderie between her and her physicians with friendship. She didn't want to be on a first name basis with the person who might in time tell her that she was dying and that there was nothing he could do to stop it. Underneath that resistance, there is of course a pervasive need—and a genuine and humane reality—in these decades-long relationships that is life-giving. Part of the process she goes through in this memoir is to claim it, to release herself from the ways she diminishes her own world.

For when we talk about doctor-patient or nurse-patient realities, we often don't discuss as well the powerful centripetal pull of illness, how it can absorb not only the self of the person experiencing it but also the selves of those around her. If we read patients' memoirs, doctors and nurses appear, often at life-defining times. Opening one door, shutting another, they march through unscathed. The drama is essentially solitary and metaphysical. It is about what happens when we find ourselves alone in a dramatically transformed world where nothing means what it once did, where simple words like 'body,' 'tomorrow,' 'normal' are filled with spaces we tumble through again and again without warning.

And yet that word *pathography* shocks me in this context. Who is defining here? And why? For I do hear in most memoirs of illness a profound blessing story, a rising to the enormity and magnanimity of mortality. But it is an intense journey to enter even for the time it takes to read a book (just trying reading a few back to back). Who among us could do it twenty times a day, even for five minutes at a time? Especially if we were trained to see it as the abnormal, the pathological, the contradiction of our own *raison d'être*.

Why *is* it so important that we can hear the stories of people with different roles, different social locations as taking place in the same reality?

This is actually a very tricky question in medicine and healthcare. Professionalization is usually defined by having a specialized body of knowledge, a systemic way of looking at the world that is different from 'common' knowledge, 'common' sense. This different way of looking at the world, however, derives its value from the *social* function that profession plays—and that social function must, by definition, have a common denominator. Within a profession, the intrinsic value of the knowledge system itself is usually used as the proof of the profession's social standing. However, in the world at large, it is the importance of the general human condition it addresses (illness, death) and its success at meeting its *social* function (to relieve us in some way of this fear and suffering) that provides the status of the profession. Medicine and healthcare are important because they help us as a society live longer and less painfully with illness. They are measured by how successfully they address our social fear of our inescapable mortality and vulnerability to disease. No other profession comes so close to what it means to be human, to be ourselves. The stories we hear here, the stories we find in ourselves, tell us something, often more than we might like to know, about the essential meaning of life. No wonder a careless word by a busy and abstracted physician can turn a world topsy-turvy. The worst part of it often is that the other person didn't even notice.

Professions define themselves to some extent by talking about people in different terms, a different language, within their system of knowledge and action than they do outside it. We have the patient (bearer of suffering) and the doctor (wielder of knowledge) not Herb and Jessie. And the way Jessie describes Herb when in his hearing and when alone with her colleagues may not only be quite different but irreconcilable with the way Herb understands himself. The stories he tells, at home, away from the smells of the clinic or hospital, may be equally incomprehensible to *Dr.* Jessie. This distance, this disjuncture, is a good measure of the level of social distrust and chronic discord. In some areas of our life, this disjuncture is not crucial, but it is in healthcare because we are, finally, dealing with care, with our society's response to core human vulnerability, core social contracts. It is, always, ultimately, about *us*.

In this anthology, we are suggesting by our use of categories that cut across professional divides, that associate patients' realities and doctors' realities around common themes, that the more the way we talk *to* each other and the way we talk *about* each other are congruent, the more we begin to heal our system, hold our whole. This suggestion goes for everyone. If we want our doctor or nurse to share our reality, even for five minutes, we must be willing to share theirs too. The categories that we use in this anthology—immediate experience, boundaries, long-term relationships, defining experience: the power of words, errors, growing in our roles, and changing places—apply to all of us.

The authors who have sent their work to us are also interested in addressing this divide, or they wouldn't have submitted. On both sides, they had important experiences they wanted to share. In "The Gift," Matthew Smith writes forthrightly about what it felt like as a physician to accept valid criticism from a patient, while David Page in "Burr Holes in the Heart" writes as a surgeon and a brother about the devastating impact of negative outcomes on all involved. In "My Doctor and I," Nancy Brandwein explores the complexity of a relationship that has lasted as long as her marriage. Nina Gaby writes personally about her own experience of commitment and burn-out in "The Inventories We Keep" and serves as scribe for a group of residents at Second Spring, a transitional facility for people transitioning from the state psychiatric hospital to the community, who were inspired by the web publication of her essay to write their own. Gerri Luce's powerful memoir "The Fine Line Between Love and Insanity" describes inhabiting both sides of the experience of mental illness, as patient and as therapist, and the role of writing in helping her bridge these two roles, claim this one reality.

We do note that almost all the work submitted, poetry or prose, was memoir. That makes sense since people have very personal bones to pick, thanks to give, and unique existential sense to make. However, one very practical suggestion we make here is that we all use some of the crucial assumptions of fiction rather than memoir, in real life and in reading—and take on the role of the omniscient narrator, graced listener, the one who can bear to enter into other realms of experience, can bear to hold all those points of view in a single story that is more than the story of any one of the people in it.

Who has the time? the tired suffering patient might ask. Or the harried nurse. Or the over-scheduled doctor. Who *doesn't?* If we cannot entertain, even for five minutes, the reality of another, can we ever, truly, do them justice? It takes very little time—but it does require a liberating moment of full, free attention. It does release us into a healing, humane and ultimately mysterious *more*. Try it as you read here. Try it the next time you are in an examining room.

This anthology is the result of two disparate calls for submissions. One was directed to nurses, physicians, therapists and other healthcare professionals: *The Patient Who Changed My Life*, and was first published as a web anthology. A subsequent call was directed toward patients and their responses and was originally titled, "The Doctor or Nurse Who for Better (or Worse) I Can't Forget." It is important that we didn't ask for expository essays, for people's responses to the health system as a whole, to doctors or nurses (or patients) as categories, but for a personal experience that had a direct, lasting impact on one's own life. We were interested in reflection on that experience.

As could be expected, we received substantially more submissions for the second call. It took awhile to decide on a title for the combined collection, but when *View from the Bed ⁂ View from the Bedside* came to us, it felt right since it did seem that these disparate points of view had a common meeting point—the sick bed (or examining table or imaging machine). I had a strong desire, and still do, to call it *Under One Roof* because our focus is on what holds these disparate, often achingly, frighteningly, sometimes humorously—and always stubbornly—different points of view together is the irreducible reality of illness and death. Sooner or later, every one of us will find ourselves on a sick bed and, if we love, at its side as well. Death, illness, essential vulnerability *and its care* is there, always the real heart of healthcare, whether its pulse is steady, erratic, slow.

Pauline Chen writes fascinatingly in her memoir *Final Exam* about how doctors' attitudes toward mortality are shaped by their temperaments, their training and their practice—and how these attitudes both help in the provision of care and also increasingly isolate physicians from their own inner life and from their patients when disease can't be vanquished.

Stories of medical success fit, quite comfortably, with a little carping here, a little quipping and clipping there, under one roof. It is the other stories, the ones we really need to hear and to tell that interest us here. The ones either the doctor or nurse doesn't have time to hear or the patient doesn't have the heart or stomach for, the ones that let us know what we look like to each other when we don't feel we're on the same team or even in the same game. And not only the BIG ones, but also the little, damaging interchanges that take place a hundred times a day.

If we're interested in what people find difficult to say, or to hear, in each other's presence—where does that leaves us as publishers committed to finding the We in Them, the Us in You? This was my first uncomfortable insight when, after having collected and ordered these interesting selections, I tried to imagine what groups of people could read this book together and join in conversation through it. Doctors, and often nurses, really don't want to spend extended time in their patients' often narcissistic worlds. The same is true for patients. They don't want to wander through their doctors' minds in which they play, at best, a walk-on part. The point seems obvious—and as understandable as the daughter or son of any age putting their hands over their ears when a parent decides to share his or her sexual quandaries, peccadilloes, however ancient. *Too much information!* So much desire to be heard.

For we also note that the people who wrote here all hungered, for a variety of reasons, to be in conversation with a world that had not fully understood them. And it is people like that we wish to reach with this anthology, who can then quietly, one by one, share it with someone else whose story could fit in here, who would welcome a common roof.

We want to reach the physician or nurse who can feel that an important opportunity to create a more caring and trusting connection, to participate in a healing story, was lost and they don't know exactly what went wrong but they know it matters. We want to reach physicians who are tired of dreading their time with their patients because they always feel they are walking on eggshells, that their words are misunderstood, that the expectations of them are unrealistic or completely off-base and so are the interpretations. And the ones who get it, whose relations with their patients are good, but are tired of seeing these failed opportunities all around them.

We want to reach the nurse and therapist who know they have something important to add to this conversation about care—and some of it involves speaking truth to a resistant structure, and some of it involves opening their hearts, and some of it involves holding people accountable too.

And we want to reach the patients who may be getting tired of feeling let down or dismissed—who know that the stories they find themselves telling about their doctors or nurses are too stylized, too predictable and that some part of them wants a completely different tone, a different dialogue, doesn't know how to get it started, but does know it is never too soon to start. And that it begins right here.

For this anthology we did not go out and seek the very best, the last word, in previously published medical writing. We have some beautiful writing here by some very accomplished writers; most of it hasn't been published before. Indeed, with many of the pieces, I'm not sure they were written originally with publication in mind, rather from a strong drive to understand, to absorb, to in some way right a vision of the world. We put out two calls, one to professionals and another to that group that excludes none of us, those who know the sickbed. We looked at what we received over the transom, selecting good, solid, heartfelt writing from writers who are not that different from you or me, who face similar events, are driven to speech by similar frustrations and joys. This is a roof that has room for you too. This is a conversation that has room for your voice, your insights, your truth. *And more.*

For when we reach people through this anthology, we want to get them, whether from the bed or from the bedside, to start imagining a story that can hold, generously, the subjective realities of everyone in the room—the patient, the nurse, the doctor, the grieving mother, the bewildered daughter—can see them as part of a complex whole, can feel all these multiple interpretations adding up compassionately, at times comically, at times profoundly, to something larger and richer than any one of their separate stories and feel they themselves are an essential part of that more.