Stories from the Infirmary

Edited
By
Carol Wierzbicki
“Stories from the Infirmary is a moving collection of poems and fiction written from a perspective rarely encountered in such variety. These are the angry, passionate, defiant voices of those who live with illness, from multiple sclerosis to post-traumatic stress disorder. They do not permit the reader to turn away, nor does one wish to do so. There is much hard-won wisdom here.”

-Marilyn B. Young, author of The Vietnam Wars and Professor of History, New York University

“These well-told stories hit hard and true, revealing a range of emotions, experiences, and responses to chronic illness with which I identify only too well. Stories is an important work, long overdue, that will help bridge the gap between ignorance and understanding.”

-Michael Gillen, Professor of History, Pace University

“This book is not about illness or disease. It is about real people who are living, struggling, and coping every day with the effects of disease and illness upon their real lives. Stories from the Infirmary is a must for every person working in a helping profession and for everyone in a relationship with a person struggling with an illness. This book has the potential for changing attitudes, lives, and personal and professional relationships.”

-Gordon R. Dragt, Minister, Middle Collegiate Church
New York City

“Nothing so concentrates the mind,” Dr. Johnson famously remarked, “like the prospect of a hanging.” Indeed; and nothing so concentrates the passions, our wild affections, like a serious illness. Stories from the Infirmary offers such passions delineated with care and precision and amplitude. In a culture largely in denial about the rich complexities of illness, this book is a welcome event.”

-Tom Andrews, Author of The Codeine Diaries: A Memoir and The Codeine Diaries: Confessions of a Bleeder
“When I began reading *Stories from the Infirmary*, my first instinct was to run from it. The unheard-of and even painful truths made me wonder if I could stay with it. Then I remembered an experience that I had when working with a man living with AIDS. In expressing his feelings in a group, he reminded me that I could leave AIDS behind after our sessions, but that he and the other group members couldn’t. This book teaches valuable lessons about life and love to all those who have the courage to enter its pages. It is a catalyst to developing skills of listening, empathy and advocacy. It is an invaluable gift to the health care and mental health care practitioner and is at the very core of what has inspired us to enter our professions in the first place.”

-Michele Sarracco, MSW and Social Work Educator
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Carol Wierzbicki
Charlotte Brewster
Front and back cover photos and photos of John Penn and Carol Wierzbicki
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Introduction: Imperfect Understanding

These days, doctors and patients have an uneasy relationship. Managed care, malpractice issues, and confusion over the vast amount of medical information flooding the Internet and other media venues has made being a patient (and a doctor) more complicated than ever.

Many patients believe that they would make better doctors than those who are treating them, if only because they’ve been on the receiving end of the treatment and could empathize more easily with someone going through the same thing. Armed with a broader array of information, be it scientific research or unorthodox healing philosophies, patients have transformed from submissive, trusting subjects into aggressive consumers.

For the doctors’ part, the time they have to spend relating to patients on a personal level is being drastically cut short by heavy caseloads, bureaucratic hospital and insurance policies, and the need to keep up on the latest research in their field. They are confronted by patients who think they are experts after reading something on the Internet.

Those who are responsible for treating patients, and those close to the patients—often called the “caregivers”—can have only an imperfect understanding of what they’re going through. They can feel all the guilt and sympathy they want, but they have not walked in their shoes. Doctors have imperfect understanding because medical school and the research community train them to deal in absolutes; when they find they cannot cure a patient it’s considered a failure. They do not pause to consider that perhaps there is something more they can offer their patients besides traditional treatment: comforting words, reassurances that what remains of their lives can be lived with dignity and grace. Recognition of the patients’ informal support systems—their church, friends, a hobby—can help with this. (Working on this book has, in fact, buoyed up all of us.) Since chronically ill patients’ lives revolve around doctor visits, tests, and procedures, they are not going to want to spend the bulk of their waking hours as passive recipients of cold, impersonal treatment. Nurses can sometimes have better instincts than doctors about a patient’s needs, since they usually spend more time with the patients, monitoring reactions and listening to complaints.

Many kinds of imperfect understanding are expressed in the poetry and short fiction here. In Marc Levy’s trilogy about a Vietnam veteran suffering from PTSD—post traumatic stress disorder—the vet’s
wife only dimly understands the war and its resonance for those who experienced it, yet she never stops trying to draw her husband out, get him to talk about his pain and insecurities. Kristan Ryan struggles with a husband’s seeming impatience with—and her doctors’ reticence about—her Multiple Sclerosis. Ted Blumberg and Tsaurah Litzky explore the ways in which a mother’s illness can change how a grown child relates to someone they are used to thinking of as all-powerful. John Penn’s stories are often pithy, sometimes poignant commentaries on how his illnesses affect the way others—doctors, family, even strangers—relate to him. Hortensia Anderson’s arresting, visceral poetry belies her often vulnerable medical state. And Damien McRae ponders his shattered ankles in a kind of existential delirium.

This book is for those who wish to deepen their understanding—however imperfect—of those whose lives are centered on survival.

Carol Wierzbicki
He could no longer drink from her glass, or eat leftovers from her plate. Her touch bothered him, frightened and disgusted him. “Take me home before they cut me open like a chicken,” she said. “Once the air gets in, you’re finished. Grandma said that, and she was right. As soon as they cut her open she went downhill. The Chinese say metal mustn’t touch the bad cells, metal spreads it.”

“I’ll tell them to use a plastic knife.”

“A picnic knife!”

“And fork.”

They laughed. Her laugh devolved into coughing. He gave her the can of Cel-Ray Soda. She took a swig and handed it back with lipstick marks. Hourly, it seemed, she freshened her lipstick and eyeliner. They stood out against the gaunt, ashy skin. “Hand me my mirror,” she said. Still coughing a bit, she applied the lipstick, set it down, worked on her eyes. “Doctor Monaghan said I should do my whole face, it’s good therapy he said. Foundation, blush, the works. I haven’t the patience. He’s what they call a kidder. Wouldn’t say ‘Shit’ if he had a mouthful. I look like that actress in Betty Jane.”

“Baby Jane.”

“Bette Davis.”

“You look great.”

“Bullshit. I like the feel of doin’ the makeup. Lookwise, it’s like puttin’ Christmas lights around a tombstone.”

“Stop.”

“Stop!” she said, mocking him. She examined her teeth in the mirror. They looked pronounced, horsey, as if the gums had shrunk. She surveyed her face. The flesh hung on her cheekbones like coats on a rack.

“Take me home, let me live on carrot juice and marrow bones. I’ll fight this friggin’ thing. If I die it should be in my own bed, late at night, after Johnny Carson.”

Comfort
“See! You’ll never die,” he said. “Johnny’s been off the show nearly ten years.”
“Too bad you never made it as a comic. Too bad you never made it,” she said.
“There’s still time,” he said.
“Sure, and after I get over this thing I’m going to Radio City to join the Rockettes.” She switched on the television with the remote.
A nurse came with pills. The patient swallowed them with a Cel-Ray chaser. “How are we feeling?” said the nurse.
“Twenty years ago my business went bankrupt. I thought that was the worst thing that could happen. Five years after that my husband dropped dead. I thought that was the worst thing that could happen.”
She turned back to the television and watched.
The nurse nodded and left.
“How am I feeling? she wants to know. Cunt. Let her liver get eaten, let her watch herself shrink and then she’ll know. That’s what this does, it shrinks you. Two months from now I won’t be dead, I’ll be pocket-sized. You can carry me in your knapsack. Why don’t you buy a proper briefcase?”
“This is lighter.”
“Don’t be so fucking lazy. Your father, he did what you want to do, he went in at ten, eleven every day, he carried his ideas in his head, but still he carried a nice brown briefcase, with straps. He looked like a bank manager.”
He looked at his wrist. He’d forgotten to wear a watch. “Well, I have to go,” he said.
“Your exit lines are banal. Where’s your imagination? How about ‘Mom I have to go, they’re taking me to dinner to discuss a job on the new hit series . . . PencilPete.’”
“Sounds like a kid’s show.”
“Make up a title, just tell me somethin’ interesting. You fuckin’ kids are addicted to truth. When you lie you sound like liars. Your father, he knew how to bullshit. Me, I taught him. You should learn it. You, you’ll get married, screw around, run home and confess.”
“Mom, I have to go,” he said. “They’re taking me to dinner to talk about a writing job on the hit series PencilNeck.”
“Better,” she said. She sat forward, took his face in her hands and with surprising strength pulled him close. She gave him a peck on the lips. Her breath smelled of Cel-Ray and rotted meat.
“Come back tomorrow,” she said. “I’m always open.”
He felt the meagerness of the gifts he’d brought, a few magazines, a six-pack of raisins, a pack of Oreos.
She lay back and closed her eyes.

His eyes turned hot. He stood and tried to fight it off. A great sob and moan tore out of him. He let himself fall forward on to her and hugged her close. Through the robe he could feel the slats of her ribs. She put a hand on the back of his head.

He wept. A nurse came and closed the door. After a good long while his mother’s chest fell and rose in the rhythm of sleep.
Ted Blumberg - Comfort
KRISTAN RYAN

RICE DREAMS
Y2K Won’t Be So Bad

In ’96,
I lost my job,
ate rice for six months
while caring for my son
who shattered his heels
and ankles,
who had to have six hours
of surgery,
spent a week on morphine
hallucinating,
then had to learn to walk
all over again.

In ’97,
my cat died,
the only creature to love me
unconditionally.

In ’98
got married,
but then started falling down,
 tripping over my feet,
dropping anything I held
in my hands,
went blind in one eye.

In ’99,
was diagnosed with MS.
My husband says
he won’t find me
attractive if I end up in a
wheelchair.
I tried to throw him out,
but he won’t budge from
his computer chair,
says I’m crazy and sends
me email about
Prozac and Zoloft.
I can’t afford to get rid of him
anyway.

Now,
I give myself shots in the thigh
every Friday, interferon beta-
1a,
designer drug my father calls it.
My neuro tells me,
it’ll keep me walking and
talking
for more of my life,
but I’ve got nowhere to go,
and nothing to say.
I take Neurontin four times a
day
to stabilize my moods,
spend my days sitting on my
bed
counting the specks in the
ceiling.
My neuro says I’m happy,
my husband thinks I’m
agreeable,
the new cat loves me
as long as I feed her,
and I’ve got a grin
on my face that won’t
go away.
Chapter 1

Damaris squats in the corner staring at a row of books by Isaac Babel. Her cold feet feel hard against the carpet and her arms itch. She keeps her back to the onslaught of preseason Christmas shoppers rummaging the shelves, beating the crowds of New Yorkers who will clog the aisles at the last minute.

Not too long ago, Damaris thought she’d grow old, then have a heart attack or die in her sleep, but she never thought she’d be planning to kill herself. Now, she’s planning her own death and the thought is comforting. Suicide is no longer some fucked up thing stupid people do when they don’t have the guts to go on. It’s a logical choice and for her it’s only a matter of when and how.

Damaris imagines all the dramatic ways she could do it; jumping in front of the subway, stepping out in traffic, overdosing on medication, slitting her wrists, but she hates the idea of her guts or blood being cleaned up by some poor slob who has to eke out a living picking up mangled body parts. She’ll wait to kill herself when she can come up with a quiet, inconspicuous way to check out. But in her heart she knows there’s just no good way to do herself in unless, of course, she flies to a country that’s in the middle of a war and throws herself into the melee. Come to think of it, she could go out a hero. She decides to do an Internet search when she gets home to see who’s fighting where. This is what Damaris does two or three times a week; she comes to Barnes and Noble, reads books, then fantasizes about how to end her life dramatically.

Damaris is glad that the literature section is quiet. It’s the one section of Barnes and Noble that never seems to be overrun. She feels safe here. In fact, she thinks she’d like to sleep here among her favorite books. A woman pushes against her. “Excuse me,” she whispers. Damaris ignores her. “Excuse me,” the woman says again, louder. Damaris moves without turning around. She doesn’t want to see this angry shopper. Besides, she can’t bring herself to look directly at people anymore. She imagines their eyesight is as sharp as an eagle’s, that their fingers open and close on cue, and that their steps are unfettered, smooth and light. Even though she knows it’s wrong to feel this way, she
doesn’t care; she hates them all and wishes that, just for one day, they could be her.

Imagining is what Damaris spends most her time doing. She imagines all sorts of things; how proud her family would be if her novels were published, what life would be like if she were suddenly twenty years younger with perky tits, legs that carried her seductively across a room, no cellulite, and what life will be like in ten years when she’s fifty-eight, after her disease has done its dirty work.

Damaris hears her doctor’s voice. It rattles around in her head, follows her to the bookstore, to the grocery store, to bed, and to the movies. She even hears him talking when she and her husband are humping wildly.

Damaris remembers how she felt after the phone call. She can’t stop replaying their conversation, the same way she can’t get rid of the constant buzz she hears in her head.

“Your MRI is consistent with MS,” Dr. Mason is saying. “It’s not so bad.”

“Not so bad for whom,” she thinks. She wishes she had answered, “Easy for you to say. You don’t have it.” But she’s rendered gutless by the diagnosis, stopped in her tracks. It’s her style to catch people in mid-sentence when they say something stupid and call them on it, but not today. Dr. Mason doesn’t have MS and she hopes he never does. She knows he’s trying to be kind, to soften the blow, to keep her from falling apart and she appreciates him for it and hates him, too. Damaris hangs up the phone and slips across the living room and into her bedroom. She’s too shocked to cry. Her left foot catches on the carpet and she almost falls.

“What did he say?” he asks, his mouth drawn tight across his face. She knows he’s expecting something silly, like “nothing” or “it’s all in my head,” but she doesn’t accommodate him.

“It’s consistent with MS.” She drops on the bed, falling flat on her back. “I have multiple sclerosis.” She draws out her words, long and slow while staring at the ceiling. The words knot in her mouth, feel like a wad of cotton stuck to the inside of her cheek that she can’t get rid of. “There’s no cure.” She has no idea why she says this.

She scans the room but can’t concentrate on anything. All she can do is feel the body she’s stuck in. Her arms itch like crazy and the incessant itching makes her want to rip off her skin. Her vagina is dry and tight like a discarded leather glove. Her hands tingle, her fingers burn, and her spine feels as if it’s attached to a live wire. She wiggles her
toes, but they feel hollow and cold, as if she’s had them on ice and worst of all, she can’t stop the constant ringing in her ears.

Richard Pryor flashes though her mind. All she can see is his caregiver pressing his arm down, forcing it to grab on to the handle of his motorized cart. He’s been on TV lately to receive awards for his lifetime of comedy. Nobody will be giving her an award. No one will care when her arms flail about without any prompting or if she routinely pees in her pants. She’s just one of the little people. She can’t decide which is worse, to be Richard or her. She’ll just call him Rich from now on; they’re related by disease. “It must be hard to have the public watch you disintegrate,” she says to him in her head. “At least I can crumble in private.”

Damaris remembers an article she read recently by a woman with MS who’s now quadriplegic.

“I wouldn’t trade my experience with MS for anything,” the woman writes. “I have to thank God for giving the me opportunity to be a better person through my illness.” Damaris sure as shit will never be thanking God for MS or any fucking experiences that go along with it, no matter how much falling on her face enlightens her.

But that day was months ago and remembering only reminds her of what she needs to know. Damaris pulls herself away from Isaac Babel’s books and stumbles over to the section on health. She picks out a book for the newly diagnosed, one on exercise for MSers, one called The MS Diet, and several others containing sections on feeding tubes, wheelchairs, canes, medication to help her control her bowels and bladder, catheters, sections on the new interferons—drugs doctors claim slow the progression of MS. Damaris grabs books containing everything she needs to know about how debilitated she can get if her disease runs wild. When she steps up to the checkout, she’s clutching the eight books to her chest. By the time she’s paid and ready to leave, she’s cradling the bag of books in her arms like it’s a newborn.

Damaris knows her behavior is nuts but she doesn’t care. “Embrace your fear,” is her motto. She hugs the bag of books tight between her breasts. She’s going to read them over and over until she has the chapters memorized, until she can speak to the doctors with authority. She’ll show those MDs she knows what she’s talking about.

Damaris has learned one thing from having lights shined into her eyes, blood drawn, and spinal taps, and from answering questions posed by her optometrist, her primary care physician, her neuro-ophthalmologist, her insurance company representative, and the nurses assigned to her case; the patient had better know her disease like she
knows the inside of her palm and she had better be willing to answer questions about her bowel movements, her sex life, the number of times she urinates per day and any other intimate detail they care to ask and she had better be happy about answering.

“Are you taking care to avoid getting overheated? Can you urinate alright? How about those bowels? Can you still have an orgasm?” Damaris is asked repeatedly.

Most important of all, Damaris has learned that she’d better know what to ask this gaggle of MDs and RNs about her symptoms and care because those guys don’t know shit and what they do know, they won’t tell you. Okay, so she thinks Dr. Barrett, her neurologist, and the nurse that calls her every month know something, and the something they know is this: after all the questions, listen. The art of listening is a secret most doctors keep from each other and their patients, so Damaris will hold on to the nurse and Dr. Barrett because they’re all ears, even though she doesn’t tell them much.

Most of what Damaris feels would probably cause Dr. Barrett to sign her into the mental ward at Bellevue, so she doesn’t tell them about the fifty times a day she considers cutting her wrists and letting the life drip out of her. Quicker than death by nervous system destruction, she thinks, and much more efficient.

Damaris sits on the F train, her bag of books in her lap, snug between her arms. She’s so tired she can barely lift her feet and the thing that bugs her about her exhaustion is that she’s only been away from home for two hours. By the time she gets home, she will have only walked about eight blocks altogether. She remembers when she could walk from home at 34th and 9th Avenue all the way to the Barnes and Noble at 22nd and 6th Avenue with no trouble.

Today she’s taking the subway home, riding from 23rd St. to 34th, but even as short as her trip is, she can’t stay awake. She doesn’t care. Who’s going to steal a bag of books on MS if she falls asleep? A thief sure as hell won’t get any money or ID because she’s out of change and she left her credit cards and identification at home. The only thing she’s got that identifies her is the stainless steel Medic Alert bracelet she wears. Her dog tag, she calls it. Damaris shuts her eyes, dozes, and dreams about her visit back in August to Dr. Regan, the neuro-ophthalmologist.

It’s seven a.m. and Damaris is sitting in a waiting room at Albert Einstein Hospital with her husband and four other patients. She’s
about to meet with one of the world’s top neuro-ophthalmologists. Damaris has optic neuritis, which means that her optic nerve is inflamed. Her optometrist accidentally slipped her the bad news a few days earlier when he ran into her on the street.

“Been to the ophthalmologist I recommended?” he asks.

“Yeah. He had me see some specialist connected with his practice. They still haven’t told me anything. They keep saying nothing’s wrong, but I can’t see and what I can see is faded. Now he’s sending me over to Albert Einstein Hospital, to a neuro-ophthalmologist.”

“Oh,” he says, staring at her right eye, the one that’s giving her trouble.

“It’s a pain in the ass,” Damaris says, juggling some groceries.

“Well, in the worst case scenario,” he says looking away, “you’ve got multiple sclerosis. Optic neuritis is generally a symptom. That’s what you have. An inflamed optic nerve, an MS symptom.”

“God, I hope not,” Damaris gasps, immediately envisioning herself unable to walk, talk, feed herself. Pictures of crutches and wheelchairs flash through her mind. “If I’ve got MS, I’ll kill myself.”

The optometrist walks away as if he hasn’t heard her. “Gotta get to work,” he yells, then waves, his back to her the whole time.

Damaris rushes home to her computer, gets on the Internet, clicks on the Thrive website and looks up the symptoms. Dry, itchy skin, difficulty urinating, dizziness, slurred speech, cold limbs, tingling sensations, optic neuritis. All the early symptoms. She has MS, she tells herself, and boy, does life suck.

Sitting in the waiting room at Albert Einstein, Damaris feels like punching her ophthalmologist and the other specialist in his office for not telling her what they were looking for. She can handle anything as long as she knows what it is. Her husband taps his feet against the carpet and his fingers on his thigh. He should have brought his portable CD player, she thinks, or a book, but now he’ll have to wait, bored out of his mind.

Damaris occupies herself by inventing stories about the people seated around her and the patients who are slowly filtering in. There is a couple, probably in their seventies, puttering across the room, both of them in slippered feet, creeping toward the couch directly across from her. The old man is dressed in a navy blue suit jacket, khaki pants, and a crisp white shirt. His socks are a rich maroon argyle and clash with his bright yellow slippers. His wife is draped in a pale green cotton housedress, the sleeves of which have been trimmed in tiny pink
rosebuds. Her feet slide against the spotty brown carpet in tandem with the walker she pushes ahead of her, its silver aluminum tips lifting from the floor slightly before each step. She steadies herself, then slides reluctantly to the couch, pushes her cheap metal sidekick away and collapses on the cushions.

Damaris imagines that the two of them are longtime lovers, tortured by the fact that they weren’t able to marry until they reached old age. She imagines that the woman is seriously ill and relies on her husband for assurance and care.

The old man hands his wife a magazine. “Here, honey,” he says. “There’s an article on the latest treatment for...” Damaris doesn’t hear the name of the woman’s illness because the old man mumbles, almost in a whisper so only his wife can hear. The woman rips the magazine from his hands and tosses it on the floor.

“I know every damn thing I need to know,” she snaps. “If I wanted to know any more I’d have asked. I just want to get this over with and go home, so if you’ve got any other great ideas, keep them to yourself.” She fiddles with the hem of her dress, then looks over at the nurse’s station where some patients are picking up paperwork and heading one by one to the little rooms where they will meet with their doctors.

Damaris laughs. This woman reminds Damaris of herself. She just wants to get this visit over with and go home. Eamon, Damaris’s husband, reaches over and rubs her back.

“What time is it?” Damaris asks.

“Eleven-thirty,” Eamon answers.

“Christ Almighty,” she says, “we’ve been here since seven. Why the hell did they have me come so early if they weren’t going to see me for five hours?” Damaris doesn’t know who “they” are, but “they” are to blame for having her throw a whole morning away, when she could be making money.

“I don’t know, but I’ve got work to do so I wish they’d hurry up,” Eamon says, then pulls out his cellular phone and punches in some numbers, then slaps the phone to his ear.

“You’re not the only one,” she says, watching him chatter away.

Damaris is a freelance writer and teaches creative writing part-time at a university near her apartment. She has several writing jobs waiting to be finished, that is, if her eyesight will recover enough for her to finish them. She’s almost blind in her right eye and her color vision is shot.