# Ars Medica A Journal of Medicine, The Arts, and Humanities

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# Redemption

C. Michael Gibson, M.S., M.A. (Hon.), M.D., FRCP, FAHA, FSCAI, FACC

"Redemption" by C. Michael Gibson, is a 5' x 5' in house paint and oil on canvas. Some bodily diseases are rooted in biologic determinism. Suffering, though, often arises from afflictions of the soul. These afflictions require more than medicine and surgery, they



require healing. The hopes and capacity for self-healing on the part of the patient, and the compassion and "placebo effect" offered by the shaman have now been replaced by the indifferent potent drugs of the physician scientist.

When modern medicine fails, sometimes a long arm, either your own, that of a loved one, that of a healer or love and forgiveness themselves reach down and pull you out of the dust bin of the void; and a soul is redeemed and healed.

C. Michael Gibson's hope is that his art is experiential, not intellectual: "I hope to convey not a representation of the experience but the experience itself and move beyond words to the universal language of feelings."





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# **Editorial**

The submissions we receive at *Ars Medica* always impress us, and we take seriously the job of presenting the works we publish to their best advantage. As part of our responsibility, we think not just about the individual pieces, but also about the conversations we provoke by bringing them together in one issue of the journal and by uniting them under the headings in the table of contents.

Over the past eleven years, *Ars Medica* has used no fewer than twenty-seven categories to group its contributions. In some cases, these categories have been purely functional. How else, for example, would we designate the writing competition winners other than by the heading *Writing Competition Winners*? Many of the other categories we have used, however, have been less straightforward: they may be vague, overlapping, or sometimes both at once. Are all *Narratives of Illness* also *Personal Narratives*? Can *Narratives*?

The truth is that many of the texts we publish defy categorization, and the ones that appear in this issue are no exception. Dan Campion's poems ("Palliatives," "The Readers," and "Sinew") consider illness from the point of view of both doctor and carer. Ruth Deming's poem, "This is the night of your 302," describes mental illness from the perspectives of nurse, carer, and patient. In weighing up the experience of death and dying, Dale Guenter's

"Nearing the Shore," Kaja Weeks' "The Silver Swan and her Stroke," and Karen L. Armstrong's "Once upon a Time" all consider not only what it must be like to die, but also what the implications of a death are for those who continue to live—be they family members or medical practitioners.

With an eye to the complexity of categorization, this issue takes a new approach. Aside from our feature piece, the contributions have been grouped under two simple headings: prose and poetry. This is the result of the editorial board's grappling with the tension between truth and fiction, and with the problems (and opportunities) inherent in the blurry boundary between the two. Some of our previous categories have distinguished between truth and fiction, but not all of our contributors are at liberty to write non-fiction. Doctors cannot write about their patients—or at least they cannot do so in a way that would render their patients recognizable and their confidentiality betrayed. Should the same rule apply to patients who write about their interactions with their doctors? How about people who write about the experiences of loved ones? What about pieces featuring those who cannot give their consent, such as those who suffer from severe mental health problems, or those who have died?

While we demand that medical practitioners protect their patients' confidentiality, we yearn for stories that give us access to private worlds and personal experiences. We seek out stories of places that are culturally or socially distinct, like Maureen Hirthler's descriptions of the borderlands of Indigenous and Western medicine in "Navajoland."

Sometimes, we read to prepare ourselves for things we may experience one day, as with Minter Krotzer's account of Parkinson's in "Electric Husband" or Darian Goldin Stahl's depiction of multiple sclerosis in her work of art, "Numb Body." Deirdre Hennings' "Because I Did Not See" offers the perspective of caring for someone with cancer, while Barbara Lydecker Crane's "The Invaders" and "Dancing in the Dark" describe the experience from the perspective of the patient. We readers are likely to some day fill the shoes of the carer—and, unfortunately, many of us will also share in the suffering of the patient.

Stories can also open the door to things we may never experience in our own lives, such as the first-person accounts of the practitioner's journey that is described by Nicole Leigh Aaronson in "Call Night" and by Clara Lu in "Speaking Medicine." Even the most fanciful tales—such as Adrian Chapman's fable, "Like a New Snake," which imagines psychiatry's place in the animal kingdom—can offer surprising reflections of and insights about reality.

In future issues, we may yet return to categories such as *Personal Narrative* and *Creative Non-Fiction*—categories where the tension between truth and fiction is laid bare right from the start. For now, however, instead of distinguishing between factual and fictional texts, we have chosen to group the contributions in such a way that will allow our readers to focus on the truths contained within.



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# Electric Husband

Minter Krotzer

The neurosurgeon holds a crown of metal above my husband's head. It is slick and gleaming like a futuristic headpiece or medieval torture instrument. It cost us \$200,000 he says, with pride, smiling. The hospital owns only two of them. I watch as he lowers the frame on to my husband's shaved head. Hal looks only at me. A visiting doctor is in the corner, watching, having come all the way from Iran to observe my husband's surgery. We are in the basement of the Jefferson Hospital of Neuroscience, in downtown Philadelphia. In less than an hour Hal will be in the operating room, having a 14 millimeter hole drilled into his skull, and electrodes the size of Tic-Tacs placed into each side of his brain. The electrodes will eventually be hooked up to a neurotransmitter, which will send electrical impulses to the brain and help decrease the symptoms of his advanced Parkinson's disease.

Hal has waited months for this day, with the excitement of beginning a new life in mind, free of the involuntary, spasmodic movements of dyskinesia, and relief from the immobility of his legs and

the clubbing up of his feet. The crown, known as a "stereotactic frame," is a navigational tool, used by the surgeon to help locate the correct place in the brain to plant the electrodes. "Deep Brain Stimulation," or "DBS" as it is called, is a long procedure, taking up to three hours for each side of the brain. Approved by the FDA in 2002, DBS is the latest surgery for Parkinson's patients, invented in France by two professors at the University of Grenoble. We are told that Hal will be able to decrease his medications by 80 percent, the dyskinesia will be eradicated, and he will no longer freeze when walking.

A month before the scheduled surgery date, I looked up DBS on the internet, opening the Wikipedia entry, the first hit. There was a photograph of a man lying on the operating table with the frame around his head and a surgical instrument above him in the glare of bright operating room lights. I clicked out, not able to look at the photograph too closely: I didn't want to see this man's brain or to see the details of what will happen to Hal. Perhaps Hal's *Parkinson's for Dummies* would be more palatable, less real life. I skimmed through his dog-eared copy. It warned against the possible consequences of DBS: brain hemorrhaging and bleeding, coma, severe depression, and worsened symptoms.

Hal's neurosurgeon, Dr. Paval, extended a special invitation for me to come early to the hospital on the day of the procedure, to witness the installation of the stereotactic frame. Hal had discouraged me, thinking I should stay home and get sleep, but

I knew I had to be there. It would be a chance to give him a kiss before going into surgery, to fare him well. And it was the only part of the day, of all that would happen to him, where I could be there too, cheering him on.

On the morning of the surgery, I am led through the maze-like corridors of the hospital's basement, to a closed off section with a comfortable lounge, and then to a room where Hal sits on an elevated throne of a hospital chair. An entourage surrounds him. Dr. Paval greets me, excited to have me there to witness this moment. I walk up to Hal, who is wearing a pale blue gown with vellow hospital socks on his feet. He extends his arm out to me and I take his hand and hold it. I watch as two nurses and the doctor lower the frame down to Hal's head. It is lightweight (we are told) but Hal will say later it must have weighed thirty-five pounds. Hal's hand begins to tighten as it is screwed on. We have been warned that this can be even worse than the operation. Some patients don't make it past the installation of the frame, thinking if the measurement tool for surgery is this bad, what will the surgery be like?

Once the frame is screwed into his head, I reach down to his face and he gives me a kiss. I tell him that I love him and he grins painfully back. He is wearing the frame like a king, a huge hat of metal. They raise him up from his seat and move his unmedicated, stiff body to a wheelchair. It takes two male nurses to lift him. Then they wheel him down the corridor, away from the lounge and its smell of burnt coffee, and away from me. A parade of atten-

dants follows: nurses, Dr. Paval, the visiting doctor from Iran, and two residents. I observe the back of Hal's bare, brave, crowned head, as they take him through the double doors to the operating room.

I go to the lobby downstairs and find an empty corner to sit in next to a wall of glass. Hospital employees smoke in the designated smoking area outside. This is ironic to me, seeing them dressed in their green garb, chain-smoking away. The lobby is drafty and I can feel the cold air from outdoors coming in from the huge panes of windows. I pull out the New York Times, today's, and the days I'm behind on for that week. I try to start reading but I keep thinking of Hal in the operating room with all of the people surrounding him. They will be listening to music, I am told. They listen to CDs throughout DBS surgery (Dr. Paval's preference, we are told, is country music). They had even invited Hal to bring his own CDs, but he hadn't. It was a funny request to both of us, as if he were choosing music for an aerobics class or a party. What kind of music does one choose for brain surgery?

At 9 a.m., just when surgery is scheduled to start, my father arrives with cups of coffee nestled in a cardboard tray. He hands me a bag. Sweet rolls, he says, nothing beats a sweet roll at a time like this. The sugar helps. I pull the big whopper of a sweet roll out of the bag. I cannot remember the last time I had a sweet roll. There are swirls of cinnamon and it is covered in white icing. I take a bite, and it is delicious; then I take a swig of coffee to chase the bite down.

And we sit there, reading the *New York Times* together, eating our sweet rolls, drinking our coffee, waiting for the phone calls from the operating room, from a male nurse named Karl, who calls every two hours to give us updates.

First call from Nurse Karl: Is this Mrs. S? He asks. This is Karl. I'm a nurse working with Dr. Paval's team, calling from the operating room. I'll be calling you every two hours to give you an update on your husband. We are just about to start. We're going to begin with the left side of the brain, and then, if all goes well, we'll continue to the right.

If all goes well, I think to myself, already beginning to worry. I know from the pre-op discussions that they will start by giving Hal local anesthesia, carving through his skull so that they can enter and begin the journey to place the electrodes. Once they have found the right location for the first electrode, in the left side, they will use that information to place the second electrode in the right side. If the first electrode takes longer than anticipated, or if Hal gets tired and unable to cooperate, they will have to end at the left and continue with the right at another time. They will be in conversation with Hal, to keep him awake and to track his responses. They will listen to the sounds of his brain. Dr. Paval had explained that the Parkinson's brain makes a different sound than a healthy brain. What is it like to listen to a brain? I imagine it is like being underwater—the muted beats, echoes, and vast silences.

I try reading the paper but it is hard to pay attention. I flip through the pages, finding it easier to

focus on advertisements than news. An Easter sale at Tiffany's, caravan tours to the Costa del Sol, Sherry-Lehmann's spring wine selections.

I don't want to think about how my husband is having his skull cut through at this very moment and how dangerous this could possibly be. What if he turns out different? Becomes brain damaged? Loses his sense of humor? Will he be a different Hal? I have to think about how much better his life will be, how he will not waste away from dyskinesia and how he will be able to decrease his meds and have more stamina. This is for Hal to have a new life, I keep telling myself. But what really gives me courage, keeps me from losing it, is Hal. I know from our support groups that many people who have Parkinson's don't have the courage to go through with this operation. He is being brave and I must be brave too.

Second call from Nurse Karl: We have found the correct place for the electrode on the left side and now we are starting on the right side.

How's Hal doing? I ask.

He's great. He's entertaining us, making us laugh.

I smile. Only Hal, Hal the performance poet, would be entertaining the operating room team while undergoing brain surgery.

Six months before, on a quarterly visit to Hal's neurologist in the fall, we were told that it was time for Hal to consider DBS. He was getting thin from the dyskinesia—so thin that the shoemaker was no longer able to add new holes to his belts. His pants started hanging on his hips. I'd joke that

he looked like a white rapper. The neurologist told us that he would only get thinner, that he was wasting away.

In the beginning he wouldn't tell anyone about his Parkinson's. He was in the closet about it as many people are with Parkinson's. Of all the people I've met who have PD, about half are in the closet. Not even their close family members know. We are a culture that has become open about coming out of the closet sexually, about personal lives and addictions, but we are still not open about disease. There is shame and fear of judgment. Hal would perform his poetry all over New York City, most people not noticing anything different, but in the years before the DBS, the dyskinesia would give him away: he'd have to hold his hands in his pockets to keep them still. Hal learned, over time, to tell everyone he had Parkinson's before he started reading his poetry. He wrote poems about his illness too, holding a crowd like he never had before. Here was a man with a disease reading a poem about the disease. The audience could see how it had taken him over, how he struggled to express the words that once came so easily.

Third call from Nurse Karl: We have finished with the right side and your husband was just amazing. He's heading to recovery. Go have some lunch and call Dr. Paval in a couple of hours.

I thank him and get off the phone. I feel so appreciative of Nurse Karl, my lifeline to the OR, whom I have never met and will never meet. His confident voice helped get me through the six

hours of waiting. The structure of his appointed calls gave me something to hold on to, broke up the waiting period into manageable segments.

Where are you? It is 6:30 a.m. the next day and Hal is on the phone, calling from the hospital. Come get me out! I am ecstatic to hear his voice, the Hal voice with the Long Island Jewish accent. He sounds the same! I jump out of bed and run to catch the train downtown.

When I arrive at the hospital, he is in recovery, barely sitting up on the hospital bed. He grins at me from across the room. I am shocked when I see him. He looks like he has been through hell: his head is covered in dry blood and there are big Frankenstein-like stitches across the top of his skull with thin butterfly bandages set across them. He is holding a cup of ice and is hooked up to a beeping machine. He is groggy, drugged-acting, and tries to climb out of the bed.

The nurse explains how to take care of the incisions, giving us gauze and antibacterial cleanser to take home. I help Hal get dressed. I take off the yellow socks and start to throw them away. No, I want them! he says. They will be a souvenir. I throw them into his suitcase.

My aunt and father wait outside of the hospital to drive us home. In the sunlight Hal looks like he just came out of battle. The sun shines on his bloody head. People walking by stare at him. Did he just get back from Iraq? My aunt acts nervous, no doubt in shock seeing Hal. We carefully load him into the car. I tell her to watch the bumps as we drive up the winding road along the Schuylkill

River, past the boat houses and the Lipchitz sculpture, back up the hill, to our house.

When we arrive home, we are in for a surprise. The dog walker has taken our standard poodle, Bijou, to be washed at Doggie Wash 'n Go. Bijou tries to jump on Hal to greet him but I put her in the crate. Hal is glad to see her but knows that he can't lean over to pet her—for at least a month. We go into the bathroom, where Hal sits on the closed toilet and I begin to clean him up. It takes a full hour to get the blood off of his head. Some of it is dried, hard to remove. I am careful so that I don't accidentally rub off one of the butterfly bandages. I'm glad to have a task, some way to help care for him.

As I clean off the blood, Hal tells me that the worst part of the operation was going off the meds. He says he was in so much pain the night before surgery that he couldn't sleep. Hal had been on those meds for sixteen years, ever since his diagnosis at the age of forty-four. He went cold turkey off of them so that his body wouldn't have dyskinesia for the surgery, so that he would become unmovable. He experienced aches and pains unlike he ever had before. It made the brain surgery seem like nothing, he tells me. I almost walked out of the hospital in the middle of the night. The only thing holding me back was that I wasn't able to walk. I tell him I wish I could have been there, massaging his cramps and unfolding the bent up feet—as I've done for years in the middle of the night.

Three months later we meet at the neurologist's office with representatives from the neurotransmit-

ter company so they could turn the voltage on, starting at the lowest amount and then working their way up over a period of a few months. We crammed into a small examination room: Hal and I, the neurologist, a nurse, two residents, and the two reps from the transmitter company. After the rep turned it on, using a remote control that he held up to the box in Hal's chest, they asked Hal to get up and walk down the hallway. Hal then walked down the hallway with all of us at the end, watching. There were no signs of PD at all—no shuffling or freezing. We stare in amazement. Hal grins from the end of the hallway, yells out: I can walk better! He practically runs back to us. Don't get too excited yet, his neurologist warns us. Sometimes the effects are amazing that first time, when the voltage is first turned on. We have to see over time. It's a long process. But still, Hal and I have hope. This is our new beginning.

Before we leave they hand me a small box with the remote control in it, to adjust the voltage levels if need be. I joke now that I can control my husband with this remote control—pointing it at him and telling him to wash dishes or give me a kiss.

Having the DBS surgery has given Hal a new life to look forward to. He writes poetry all day now, not just in the mornings, as he did before, when he had more energy. He loves the idea of having the electricity in his brain. He brags about it, opens his shirt and shows off the transmitter box. He claims to feel its buzz. He tells people, *I* am the body electric, just like in the Walt Whitman poem. I am the living body electric.

For me, even though I now have an "electric husband" and more hope, I still worry. Worry hovers over me all the time, like a grey rain cloud floating in a blue sky. I worry more about Hal than he does about himself, and perhaps that's my role, since he's the one living with this disease, trying to get through the day. I am there on the sidelines, the cheerer-on, silently thinking about all that could or will go wrong, but also learning to get past my worry and to enjoy my husband as he is now. After all, I still do have Hal and that is what matters most.

# blogs about Parkinson's and writing on www .minterkrotzer.com. She is working on a collection of essays about Parkinson's

Minter Krotzer

Disease.



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# This is the Night of Your 3 0 2

Ruth Z. Deming

In Pennsylvania, the Mental Health Act No. "302" means involuntary hospitalization" for mental illness.

I watched through the glass doors of our mental health clinic for the person to be 302'ed, he would walk through the outer doors, a man who'd lost the finer workings of his mind, and would be delivered up for safekeeping by the cops, escorted into a tiny room that locked and was filled with windows that can't be broken.

They were wild sometimes, flailing, crying out in broken words, fighting to escape their captors, believing until the end deliverance was at hand.

From my perch at the door the doctor joins me. She is eating an apple and talking about going out for Chinese food after. 302-ing makes you hungry.

I tell her that once
I had ridden
in the back of a police car.
My senses gone,
alert,
radiating to the
staccato points of night
and the babble of the police radio,
I leaned forward in my backseat nest
like caged Hansel in the gingerbread forest
and stuck my little finger
through the iron grates that contained me.
It was all I had of freedom.

"Were you scared?" the doctor asked.
"Why, not at all," I said.
"I thought they were taking me to a live performance of the Nutcracker Suite."

Thinking I was kidding she crumpled up with merriment.

We watched as a police car pulled in sideways with a flourish. Black letters like ribbons scrolled across the door. I watched as a man stepped from the car, steady, unafraid, handsome as a game show host striding on stage to marvelous applause. Barefoot, his hair uncombed with great prodigal waves falling upon his brow, his face had a pulled-down look I hadn't expected to see. He'd played his chips and lost.

Chin up, I whispered.
This is your hour,
for now —
and for all time.
Use it well.
Don't get hurt,
run a comb through your hair,
And, for God's sakes, pay attention
for this is the night of your 302.

Ruth Z. Deming has had her poetry published in literature magazines, including River Poets, Hektoen International, Mad Swirl, and Blue Lyra Review. She runs New **Directions Support** Group, www.new directionssupport .org. Sometimes, later in life, bipolar disorder vanishes. Ruth is among these lucky people. She hasn't experienced a high or a low in 33 years and takes no medication for bipolar disorder.



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# The Silver Swan and Her Stroke: First Songs as Last Songs

Kaja Weeks

The silver swan, who living had no note,

When death approached, unlocked her silent throat;

Leaning her breast against the reedy shore,

Thus sung her first and last, and sung no more.

Farewell, all joys; O Death, come close mine eyes;

More geese than swans now live, more fools than wise.

-Orlando Gibbons, 1612

She had a life-long embodied elegance of a swan, having been a rhythmic gymnast trained by those who learned directly from the Hungarian choreographer Laban. Mother's movements, honed in the

1930s on the white sands of Pärnu, Estonia, her hometown on the sea, were exquisitely attuned to music. Yet likely she never had an inkling that she'd become like a silver swan, who waits a lifetime to unlock her musical notes.

One night, cousin Adele, with growing nervousness, drove to the small New Jersey Cape Cod where my mother had been living alone and—mostly—self-sufficiently. At 92, she still paid her own bills, cooked, and in summer grew lettuce, dill, and mini-cucumbers side by side with flowers in the crumbly, dark soil she had cultivated. Cosmos were her favorites, along with the double-blossom orange tiger lilies that my brother had brought home from the railroad tracks nearly six decades ago. Though devoted to each—her son and those special wild, old lilies—bitter sweetly, she outlived both.

In winter, despite our protests, she swept snow off the brick steps and walkway. Likely it was only pain from the hip operations she'd had in the last decade that persuaded her that the driveway could be cleared by someone else. For this, one of her better solutions last winter had been to barter for services with the young fellow she saw shoveling snow across the street. From the doorway she called out in her accented high voice, "Halloohh stheere!" For years, she had been an avid and creative knitter who made up intricate, colorful patterns in her mind's eye as she clicked the needles. Promptly, a freshly-knit ski hat perched on the fellow's head. Mother had drawn it right over his hair as he got to the door, eyeing with tilts of her

head, tugging right and left, straightening and then nodding with approval over how it looked on him, and then thanking him for having cleared space for her visitors. Like many who came into contact with her, he was surprised and charmed.

Reluctantly, mother had given up driving; now, her primary need was to be driven out for grocery shopping and occasional appointments. One week in early March, when she hadn't picked up the phone for two days, it was not unreasonable at first to think she might have happened to be outside completing some chore, or that she might be on one of her accompanied weekly outings. These could easily last three to five hours. She loved the Korean market most, inspecting every tomato and bin of green beans in the produce aisle; at the local A & P grocery she captivated (or pestered) the man behind the deli counter with all the reasons why she was choosing a particular liverwurst or potato salad, never deterred by the line behind her. In fact, she sometimes turned and engaged them in the conversation as well, with "Don't you sthink so, too? Sthe little bit of egg and pickle make sthis one more..." She would search carefully for just the right English words. "... Hear-tee." Hearty.

But now, after the third day with no answer by telephone, cousin Adele arrived at nightfall to a locked, pitch dark house. Mother lay crumpled in a room of carnage. The bedside phone and its unplugged cord lay on the floor, surrounded by objects strewn helter-skelter or pulled in desperation—a trove of coins scattered over clothing and photos of grandchildren from an over-

turned shelf; mementos, the contents of her purse and colored yarns; one of the Styrofoam heads meant for her knitted hats lay bare. Mother was motionless on a damp, cold bed covered only by a pillow over her face. She had suffered a major stroke. The infarct may well have struck three full days earlier, and we can only imagine her hellish survival.

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Mother had never been an openly defiant person in public. In fact, she was deferential by nature or upbringing. For example, there was always that northern European reserve in play, the kind that produces sentences like, "One wonders what one is doing tonight," which is actually meant as a question to the other person.

In the midst of tragic circumstances, those of the stroke and the ones that were re-triggered from a lifetime of excruciating events, I finally understood that her defiance was internal, rooted determination. Simply put, it was her will to survive overwhelming destructive forces, something she had begun as a refugee with three young children during World War II.

Consider here what I witnessed after her stroke. It was, once again, an adaptive life force formed under the direst circumstances, but this time it was so rare in its distinctive characteristics. One day I walked in on my mother singing with full power and nuance, like a glorious Wagnerian soprano. Truly, imagine the soaring, high phrases

of Birgit Nilssen, the legendary Swedish singer, backed by full orchestra. That was the tonal quality. Mother's lyrics, however, were spontaneously invented Swedish-sounding phrases, though Swedish is not her native language nor has she ever spoken it. She had facial expressiveness, arm and hand gestures relevant to her affect and intent, such as spiraling, outstretched arm salutations, pointing, uplifted arms, and occasionally a grieving bowed head and drawn shoulders. It was a genuinely dramatic stance, narrated in voice and full body, even though she was sitting in a wheelchair. Much else was incongruous, such as: she was 92 years old, had experienced a horrific stroke a couple of months earlier that left her unable to speak with meaning (Wernicke's aphasia), and well, quite frankly, had never really properly sung before—at least not with actual musically relational pitches.

She was in the hallway of a psychiatric facility and you may be tempted to think she was simply fueled by craziness. No, she *wasn't* crazy; this was confirmed by the Head Psychiatrist who, after examining her, asked us why in the world had she been rushed there by ambulance from a rehabilitation facility. "She doesn't belong here," he added.

"She threw a cup of coffee at an aide," my sister answered.

I added angrily, "At an aide who was continuously abusive toward her."

Not only was Mother sane, but she was also clearly fighting to survive as a functional human being. I say this based on one essential observation: *she was singing in tune*. Bolstering my view is the fact that I'm a musician and classically trained singer with acute hearing; my scholarly pursuits focus on vocal development from birth onwards; I work musically with neurodevelopmentally-challenged, non-verbal children, whom I often cajole to communication with singing. And, crucially, I know my mother's voice.

We are descendants of "singing peoples" of the little Baltic nation, Estonia, which delivered the "Singing Revolution" for freedom from the then-Soviet Union. Consequently, it is no exaggeration to say that everyone participates in singing, even the people who have an out-of-tune singing voice. All my life, I heard my mother vocalize like something I can only describe as sing-song words landing on cotton candy; precision was not even on the horizon.

So, bewildered, standing in the hallway of this grand hospital on a hill, unnerved by the circumstances of her stroke and our rapid descent into Health Care's Administrative Hell, I was overcome by awe and hope when I heard her strong voice ring out perfectly in tune.

"How can you tell?" asked my sister. "She's not singing anything we know."

"It doesn't matter," I exclaimed. "The notes are in tune *with each other*!"

Ahhhh. It was too difficult to explain. If only Oliver Sacks were here, I thought—a famous neurologist who has published neurological insights into his own musical experiences—he would be inspired. The rest of the family was impressed by how robust mother's singing was, and how de-

spite her diagnosis of fluent aphasia (i.e. producing words that make no sense), the right words would now emerge when we sang songs from her childhood.

"Yes, yes, this pleases me, of course," I said to my sister, not wanting to dampen the enthusiasm, but I knew that more commonplace factors were at work. Because of cross-domain brain processing of speech and music, melodies may evoke words in aging, dementia, and even after a stroke, even though normal speech is robbed.

I also had read that post-stroke patients often undergo "personality" changes and may become more assertive or even aggressive, so the fact that our formerly mild-mannered mother's singing was louder and more confident, even strident at times, didn't surprise me as much either. In a way, it was similar to the lack of inhibition that allowed this politely raised European lady to hurl a cup of coffee at the bad attendant back in the rehab.

No, the truly miraculous process here, I believed, was evidence of the brain's plasticity—even at age 92, even after a massive brain injury. In order for her to sing this way (in tune), neurons in her brain had to rewire, grow new associations and interact in a complex auditory-perceptual-muscular action feedback loop to accomplish this new skill. Perhaps it showed that she did not have true congenital *amusia* to begin with, but the fact is that she had exhibited near tone-deafness up until this point. With children, or typically functioning adults, relative tone-deafness is something

that can be improved to an extent. But who would expect it at mother's age and in her medical state?

My view was that upon cell death in the specific speech-centered region in the left hemisphere that rendered her speechless, my mother's mind and brain made a desperate and heroic effort to recruit a (musical) part of the right hemisphere that was intact. The result was some kind of expressive vocal communication that could be combined for intended effect with other modes of expressiveness, such as gestures and facial expressions. As significant, it's recently been discovered that oxytocin, a powerful endorphin that produces a calm sense of well-being, is released by singing. Thus, she achieved both self-regulated, satisfying calmness as well as a kind of basic interactive communication. I was over the moon about it and kept trying to find ways to convey to everyone just how amazing were mother's efforts to save herself.

Ironically, in the end, the hospital on the hill, which I actually appreciated because it had the air of an old fashioned, restful sanatorium compared to hectic, dismissive, or abusive rehabilitative facilities, asked us to take mother away because "her continual singing was driving the staff nuts." Shocked, I realized they were serious.

They had let her impending transfer slip by for some time, as we looked for solutions to her continued care. But now, not only had they endured enough of her unusual, life-affirming talent; the social worker also stunned us by adding that with such a characteristic, she doubted any place else would take her either. I asked why they couldn't

sometimes sing with her, like we did—much to her joy and enlivenment and that of other patients. After all, this was truly therapeutic and made her continued life bearable and meaningful; it deserved recognition and deep support. It was an extraordinary self-initiated process that reflected the subtle possibilities of recovery within aging and massive trauma.

Eventually mother's singing, any vocalization, faded to null. When she died, at age 94, she was as silent as the silver swan, who "when death approached had unlocked her silent throat ... sung her first and sung her last and then sung no more."

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For a time afterwards I thought that was the whole story: even if I never totally understood the science of it, it still felt miraculous, and I simply wished the world could have heard what I did, experienced the full wonder of it. Then, in a writing workshop, I shared a version of this piece with a small group who had been together for years.

After a silence, someone said, "What a gift." By not blinking I withheld tears at the brim of my flooded eyelids, and murmured, "Yes, she gave

us such a gift."

My long-time writing companion, a clinical psychologist, looked directly at me and said in his deep voice, "No, it was her gift to *you*. She did it for *you*."

I shook my head, no; he misunderstood.

Very slowly, he said each word until it formed the full sentence, "You are the only one who would have received the full value."

The exhilaration and feat of joyous singing, my God, it had been an elixir my whole life, what I loved, and she knew it from the time I had been nicknamed "Little Songbird." I burst into full sobs. "With intent? But that's impossible."

The unrequited love of a mother with whom too much never got settled, the love of a mother whose fluttered song-like lullaby—the one she heard from her own mother in Pärnu, and which is one of my first memories—all coalesced in feelings and sounds that washed over me in that instant. Were these first and last perfectly sung sounds saying, "See, don't fear, I'm not done for yet. Hear me, these are your sounds, we can be here together"? I know no one can verify this with certainty. Wishful thoughts, they may say. But now I sing that hauntingly beautiful Orlando Gibbons song, as in my performances long ago for lute and soprano, when Mother sat in the aisles, and I close my eyes, lean my head on remembered breast. On such a reedy shore I sing about and to her, the silver swan.

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# Navajoland

Maureen Hirthler

After fifteen years in Emergency Medicine, I knew that I was suffering from "compassion fatigue." My emotional response to patients and nurses was increasingly negative, and I needed to reconnect with what I loved about being a physician. I decided to use two weeks of vacation and work for the Indian Health Service. I signed up for a locums deal in New Mexico.

One of my first patients was dressed in layers—white petticoats, floor-length full skirt, long-sleeved, high-necked blouse—and more turquoise than any trading post had to offer. A traditional Navajo elder, she considered a trip to the Indian Health Service Hospital to be a ceremonial occasion, and her trouble breathing would not allow her to disrespect me by not dressing appropriately.

"Grandmother," I said, using the preferred term of address, "that is the most spectacular necklace I have ever seen." Her daughter translated as the woman showed me several other necklaces under her outer blouse, four pure silver bracelets on her arms, and finely inlaid earrings. "I have to wear all my jewelry when I leave the house, or my lazy grandchildren will steal it to sell for drugs."

Welcome to Navajoland, where two worlds collide.

The new hospital in Fort Defiance, Arizona, was situated on a plateau not far from the Navaio capital of Window Rock. It was a fortified government installation on the outside, a bunkered and razor-wired bastion of the U.S.A. in the middle of a foreign nation. It could be locked down in a few minutes, sheltering the non-Navajo doctors from natural or man-made threats. Out here in the middle of nowhere, the fortifications seemed both excessive and insulting; only the proximity to Los Alamos and NORAD indicated some strategic importance to the site. Despite this, the Navajo Nation was scheduled to take over control and management of this hospital within five years, and was intensely proud of that. Inside, it was the cleanest hospital I've ever seen. All day long, Navajo were sweeping floors, cleaning windows, even shining door handles. The high desert dust never had a chance to settle anywhere.

There were few Navajo doctors at the hospital; most physicians were Caucasian and fresh out of residency, paying off student loans through public service. There was a single Emergency physician in town; others, like me, rotated through on a locums tenens contract. The nurses were mainly Navajo and approached their job quite seriously, since they never knew what quality of physician would appear on shift.

Grandmother's family undressed her and got her settled in bed. I had never seen anything like that. The nurses here did nursing—medications, vital signs—and nothing else. Families (who always accompanied their loved ones) were expected to undress the patient, bring them food, transport them to X-ray, and pick up their meds at the pharmacy. They knew better than to bother the nurses for non-medical concerns.

A Navajo elder in the ED was always seriously ill, and Grandmother was no exception. She needed emergent kidney dialysis—she was smothering in her own fluids—and would have to be transported to Tucson, the closest facility that had a full-time dialysis center.

Chronic renal failure requiring dialysis is a common problem on the reservation, probably a result of genetic factors. We had a protocol for treating these patients. Traditional Navajo medicine was considered an essential adjunct to Western practice, and Grandmother's other healer arrived and hung fetishes and sang the Blessing Way right in the Emergency Department while I arranged transfer. I was included as an equal partner in the search for a cure; the people were open to what modern medicine could do for them when religion faltered. The delay in treatment would be put to good use, as I gave her medications and her culture provided spiritual support.

Narrative was central to Navajo culture. The doctor-patient encounter took time, because there were stories to tell about the illness, the family, and the clan. Traditional Navajo could not be

rushed, and would often be insulted if the formalities were ignored at the start of an evaluation. The time required for translation often gave room for this process. I had to adopt a new approach to my patients here. I had to sit and listen and learn, almost a reverse interview. There was only this simple interaction; no demands, no entitlements, only the expectation of respect, an expectation that worked both ways. I had listened to Grandmother's story about her grandchildren; now she agreed to my treatment and I participated in her *sing*, a Navajo healing ritual.

Within that culture of mutual respect, my professional self felt at home for the first time. The practice of medicine here was fundamentally different from that in the world outside; we were creating a joint narrative.

A few days after Grandmother left for Tucson, because I had demonstrated respect for the Navajo culture, the rugs appeared. Women brought museum quality pieces, made on a traditional loom from the wool of local churro sheep and colored with plant dyes, for sale at a fraction of retail cost. A rug was a woven story and the weaver gladly explained the pattern and its symbolism. Every rug had a deliberate flaw; one did not tempt the gods by being perfect. There was also a thin thread that ran off the edge of the rug. This was the Spirit line, an escape route for the soul caught in the weaving. I did not see the relevance to my own life until years later.

There was another story, too, of the weaver's family: how the children raised the sheep for 4-H,

the men sheared them, the mothers and grandmothers dyed the wool and spun the yarn, then wove the rugs over a period of months. The families saved part of the money so their children could attend college.

The contrast between old and new was always in play. One afternoon, I walked into a room where a young woman was garishly painted like a nightmare clown. Her face was smeared with red and white paint and she was dressed in baggy old pants and a threadbare checked shirt. I immediately thought she was drunk or drugged. She laughed at the expression on my face and spent ten minutes teaching me about the symbolic meaning of Navajo clowns and their role in ritual narrative. There had been another type of ceremony that day, one designed to bring rain to these high, dry plains, and the Watersprinkler was an essential component of that sing. My clown had fallen off her horse and twisted her knee. I quickly got her set up with a splint so she could return to her essential role.

Alcohol abuse remained a serious problem, but on the Reservation, it was primarily considered a family issue, not a medical one. The Navajo had a genetic abnormality that made them both sensitive to alcohol and very tolerant of it, and most people had a close friend or relative trapped in alcoholism. Intoxicated Navajo tended to be very peaceful and non-violent, and so had little negative contact with the tribal or county police. If the Tribal Police brought an unconscious person to the ED, the nurses quickly instituted a protocol

with sugar, fluids, and vitamins that had them walking and talking in about an hour. They called the family to pick the patient up; if they were unable to do so, the Tribal Police took them home. Intoxicated patients didn't stay long in the department: the goal was safe, not sober, and the community took responsibility for that safety.

The Rez had other significant problems, of course. Methamphetamine use had decimated an entire generation. The addicts were not culturally embraced like the alcoholics; most eventually left the Reservation for the city because their relatives had zero tolerance for their behavior. Theft in particular was a huge issue, primarily because of the disrespect it involved.

This wave of addiction had a profound effect on the Navajo, and threatened their traditions, but the people responded unexpectedly. Grandmothers raised their grandchildren when parents disappeared to Gallup and Albuquerque. Weaving, once dominated by women, is now often done by men who were brought up sitting by their grandmothers' looms. The Navajo language is being spoken again, and the traditional ceremonies are being performed more frequently. Children are back to being part of extended clans.

At the same time, the Nation has built its own college, so that Navajo seeking higher education do not have to travel to Albuquerque. The already established nursing school thrives, and the first wave of Navajo doctors are returning to Fort Defiance.

The hospital had a robust clinic system, and continuing care usually meant a walk down the

hall. The pharmacy filled all prescriptions on site; as a doctor, you wrote for what was on hand in the formulary. The single-payer system worked smoothly here because everyone had similar goals. The patients were invested in the hospital; they were active participants in its creation, maintenance, and function. The doctors were self-selected in their desire to provide care while immersed in a different culture. In Fort Defiance, I saw how doctors, hospitals, and the community can work together.

Medical care was adequate, sometimes excellent, rarely poor, but often limited by available resources. Advanced treatment—chemotherapy, heart surgery, complex fractures—required travel off the Reservation. Not all medications were carried by the pharmacy. And yet, I never heard a complaint from a patient or a family.

The integrated healthcare system at Fort Defiance gave me something that I never had in my career: time, which is an essential component of narrative. The number of patients was never overwhelming. I didn't have to call outpatient doctors or make follow-up appointments. I knew exactly what was available at any given time, and the transport protocols were solidly in place. The nurses proudly did their job; there was no intrigue or gossip, at least outside of the community. They only cared that you were competent and respectful. Since I didn't have to bird-dog their actions, nor spend time arguing with and cajoling consultants to do the right thing, or tracking down family, my stress level plummeted. I could focus on the

patients, who forced me to learn to engage them in that space between cultures shared by stories. I didn't tell them what to do; they rarely disregarded my advice. I never felt like an adversary; no one cursed at me for not prescribing narcotics. I began to see that there could be a different way to provide health care, one that worked better for both doctors and patients.

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### Because I Did Not See

Deirdre Hennings

On s'est connus au café des trois colombes au rendez-vous des amours sans abri...

We met at the Café of the Three Doves the rendezvous of lovers without refuge...

Joe Dassin's lyrical melody washes over me recalling our joyous summer in Montreal, compelling my limbs to lift and linger in the evening air timeless again dancing for him as I used to warm and sweet, sensual and smiling. We kiss tenderly before I paddle off to make toast.

But before I sense anything he barks that it's burning.

I pop up the bread—untoasted, I see nothing amiss—but it's too late.

His over-chemo'd body slumps as he holds his stomach, pain clouding his face. "Why do you always do this?" he cries. But I did nothing except fail to notice an errant drip of soup waiting on the toaster top to burn.

Now he is nauseous again and the evening is ruined because I did not anticipate because I did not see.

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## Call Night

Nicole Leigh Aaronson

I had a bad feeling going into that night on call. Even as my co-resident signed out the patients on our consult list, I could feel my stomach knotting up.

Circling his finger at me, Dmitri asked, "What's going on here?"

Embarrassed, I snatched my finger, on which I had unconsciously started chewing, from my mouth. "I'm just getting anxious." The only thing pending was an OR case for a seven year old girl who had swallowed a coin that had become lodged in her esophagus. The pediatric OR had late running cases, and this case would not be able to start until one of the others ended and the room was cleaned. So that would happen at some point, but I probably had a few hours.

Pearl, the physician assistant who had been managing the floor patients, reminded me that there was a patient who had just undergone a major cancer resection with free flap transfer. This was an extensive surgery, in which a large portion of the patient's mouth and jaw had been removed and replaced with a section of bone and tissue

from his leg. Since the procedure involved severing and then reattaching blood vessels, the post-operative protocol required the on-call resident to perform hourly checks for the first 48 hours after surgery. These checks required pricking the flap, located in the back of the patient's mouth, with a 25 gauge needle to assure that the blood was flowing quickly and bright red in color. Pearl lamented, "Dr. Patel is worried about how the flap is bleeding. He's already asked me who's here tonight, so I'm sure he'll be calling you."

Great! Just great! My night was looking worse and worse.

No sooner did I sit down to look over my notes when the pager rang with a new consult. A patient with end-stage lung cancer had been admitted for dehydration during chemotherapy treatment and was noticed to be hoarse. He had been seen by one of the speech pathologists earlier in the day; she had performed a flexible larvingoscopy, insertion of a small fiberscope down the nose to visualize the vocal cords, and per report from the primary team had noted minimal vocal cord mobility. Her note in the chart described the patient's difficulty swallowing thin liquids and indicated that he should have only nectar-thick liquids but said nothing about decreased vocal cord motion. The patient's voice had been weak and breathy for 4 months and he was having no difficulty breathing, but once a consultation was requested I could not refuse. Although I knew the speech pathologist's exam had been recorded and was locked somewhere in the clinic, there was no way of obtaining this video after hours on a Friday, so my only choice was to ask the patient if I could scope him again. He declined, which I understood, given that he had found the prior procedure very uncomfortable, but I was frustrated as I could make no further recommendations without assessing the patient's vocal cord function. I wrote a note recommending outpatient follow up for repeat examination. What a waste of time.

I went upstairs to check the flap, which was actually bleeding well, and tried to catch up on some paperwork before the girl who swallowed the coin was ready to go to the OR. An hour passed. I checked the flap again, and I headed downstairs to the OR. On my way, I received a text from Dr. Ivy telling me that she was sending a patient to the emergency room of one of the other hospitals, with vomiting following a transnasal resection of a tumor extending from the nose to the brain. She wanted a head CT done and an update once I had seen the patient. I told her I was going to the OR but that I would see the patient as soon as my case was done.

I met the seven year old coin swallower in the holding area outside the OR. Seven is a little old to be swallowing a coin, so I was predisposed to think she was an idiot. I asked her flat out how it happened. She claimed to be trying to flip the penny out of her mouth, a trick she had seen some unnamed male friends do, when the coin accidently went the other way. Okay, so she was an immature seven. But she was so adorable, a chatterbox in Ariel pajamas, explaining that Ariel was no longer

her favorite Disney princess, having been supplanted in her heart by Frozen's Princess Anna. With her contagious smile and easy charm, I fell for her anyway. We brought her into the operating room, and once she had been put under anesthesia, I used an esophagoscope with a camera to look down her food pipe and locate the coin. Once I had the object in focus, I could see that the coin wasn't a coin at all; it looked like a button battery. Luckily for her, her esophagus still looked healthy, and there was no obvious burn injury from acid leaking out. Just as the battery was removed, my pager began to ring. I recognized the number of the pediatric emergency room, so I asked the operating room nurse to call over and see if it was something urgent. She said that the call was for a patient who had had an anterior neck mass excision earlier in the day who was now having some neck swelling and bleeding. Per the resident calling for the consult, the patient was perfectly stable with good vital signs, and I was not needed urgently.

I was waiting for the battery eater to wake up when my attending offered to wait in my place so I could go check on the new kid. When I got to the ED, I was about to look for the patient on the triage board under his chief complaint since the OR nurse had taken down neither his name nor his room number. Before I could even get that far, I ran into his mother who was tearing down the hallways looking for anyone who would listen. "It's getting more swollen. He's having trouble breathing. Help me."

I rushed into his room. From his dad, I gathered that he had been doing well until he had vomited and then started to have some oozing from his incision. Since that time his neck had begun to swell but the swelling seemed to be enlarging rapidly in the last 30 minutes. I looked at him. He had a tangerine-size swelling bulging out of the front of his neck; the small drainage tube that had been placed during surgery was still in place in the midline, but there was no blood leaking out. When I touched his neck, he winced in pain. He did not speak but he would nod to answer my questions, so I was not sure if he could not speak or would not speak.

"Does it feel tight?" He nodded yes. "Does it feel hard to breathe?" He nodded yes. "Is it getting worse?" He nodded yes. He was awake and alert and his breathing was regular. I looked at the monitor and saw that his oxygen saturation was perfect at 100 percent. But he was leaning forward in the tripod position staring at me with eves wide open, pupils dilated and not blinking. Even though he was not speaking, I knew he was trying to tell me that he was desperate for my help. And even though he looked stable, kids can crash quickly, going from oxygen saturation of 100 percent to respiratory distress in the blink of an eye. I knew that this little boy was bleeding into his neck and that I needed to open the incision and clean out the clotted blood to protect his ability to breathe.

The staff in the pediatric ED did not seem to share my view of the urgency of the situation. They had not set up any anesthesia equipment for possible intubation, and there was no physician to

be found. I asked for a Frasier tip suction, a narrower suction than the plastic ones readily available, and the nurses told me they did not have any. I asked for a nasal hemorrhage kit which I knew would contain one and grabbed a plastics suture kit from the closet. The mom was still frantic in the hallway.

"I am going to take care of this. This happens sometimes. I am going to take care of it, and he is going to be okay." I walked back to the boy and pulled out the drain from the midline of the incision. The head nurse wanted to stop and administer pain meds because she thought that the procedure would be too uncomfortable. I said no; any sedation could compromise the boy's ability to breathe. While I did not want him to be in pain, the risk to his airway was too great, and my paramount goal was to keep him safe.

I used a metal clamp to open up the sides of the incision to break up the clot and pushed from above and from the sides to drain out the blood. Over a handful of blood started spurting out soaking his neck and back and staining the bed sheets. "I'm so sorry. I'm so sorry. I know it hurts."

Out of the corner of my eye, I could see the father sobbing openly in the corner, tears streaming down his cheeks. "I know this looks bad but it's going to help. Does it feel less tight?" He nodded yes. He was blinking now. I told the parents that we needed to take him to the operating room to clean out the rest of the clotted blood, stop the bleeding, and close his incision. They signed the consent form, and I booked the OR. Filling out the paperwork,

I learned that his name was Ryan. Until that point, the fact that he was a boy with a post-operative neck hematoma had been all I had time to know.

My attending was pleased with my swift management of what could have easily devolved into an acute airway compromise. In the operating room, there was diffuse bright red bleeding. We evacuated another cupful of blood and controlled the bleeding with cautery. We replaced the drain to allow the egress of any blood that might recollect and loosely closed the incision. It was better if bleeding occurred that it leak out the incision rather than recollect under a tight incision and compress the airway. While I was waiting for Ryan to wake up, one of the physician assistants from the emergency department of the other hospital called to say that Dr. Ivy's patient was roomed and awaiting my evaluation. Ryan woke up quickly, and I rolled him into the PACU. I was long overdue for a flap check on my floor patient, so I decided to take a shortcut through the family waiting room, sure to be deserted at this hour, to get back to the top floor of the cancer pavilion. Ryan's mom saw me through the window and rushed over throwing her arms around me in a hug. "I was so glad when I saw you. No one was doing anything. I know you saved his life."

"Thank you. I know it was scary downstairs. I just wanted to make sure he'd be okay."

Just as I got into the flap patient's room, one of the nurses came running in the room to get my attention. "He's not my patient, but the guy down the hall is bleeding a lot from his mouth." "Did you call the intern?" I knew this nurse well, and although she was vigilant and cared deeply about her patients, she was prone to overreact and often called the senior when she did not like or trust the intern. Figuring it wasn't real bleeding and likely just old blood mixed with saliva, I was hoping my intern could go triage the situation and save me some time.

"She hasn't called back."

"Okay, I'm coming."

I was on my research block that month, away from active clinical duties, so I had not cared for this patient before. Checking my notes, I saw that this was a patient with tonsil cancer who was about a week out from a tonsillectomy. Yesterday, he had presented to the ED bleeding out of his mouth from the tonsil bed and was taken to the OR emergently for cauterization and control of post-operative hemorrhage. I vaguely remembered my chief resident Solomon, who had taken him to the OR, telling me just how bad he looked. He had been pale and clammy, with his blood pressure barely above the threshold to be read by the automatic blood pressure cuff. He had required a blood transfusion due to the drop in his blood counts on laboratory findings, but had been stable since the cauterization, with no further bleeding.

When I got in the room, he was sitting over the toilet dripping blood into the hat in the toilet usually used to collect urine. There was probably about a quarter of cup of blood in the bucket and the bleeding while persistent did not appear to be brisk or occurring at great volume. I asked the pa-

tient to gargle with some ice water. The ice water would help to constrict the blood vessels further slowing the bleeding and would clear out the old blood allowing me to get a better look at from where the bleeding was coming. Even with the gargles, I could not pinpoint a single bleeding spot. There seemed to be a somewhat diffuse oozing from the tonsil bed. At that point my intern for the night, a urology intern by training, came in and asked how she could help.

"I'll take care of this. Can you go do the flap check on my patient in 202?" The nurses were able to find me some silver nitrate sticks, which I used to cauterize the areas of bleeding. Silver nitrate causes a chemical burn which, while effective in causing hemostasis, is painful for the patient and has a terrible taste. But the bleeding stopped. I told him we'd be checking in to make sure he didn't bleed again and that we would draw another set of labs to check his blood counts but that hopefully the worst was over. I had to get to the other hospital; Dr. Ivy's patient had been waiting for hours. I left the nurses my pager in case of further bleeding and headed off to the garage.

On the drive to the other hospital, I turned on my own mix CD made years after mix CDs had gone out of fashion. It was halfway through track 16; I restarted it from the beginning and tried to catch my breath as Neil Young sang about his search for a heart of gold. Neil was just winding down as I pulled into the other garage. I found Dr. Ivy's patient and examined her. She looked fine on exam and her nausea had since abated. Her vision

was intact, and she denied leaking from her nose. The CT scan I requested over the phone had not been done yet, which normally would frustrate me but in this case was actually a good thing, since the physician assistant had ordered the wrong scan. At least now I could make sure the right scan was obtained the first time. Furthermore, no one in the radiology or emergency departments had noticed that the patient had a contrast allergy and would require a four hour premedication regimen, without which she could be at risk of anaphylaxis. I found the attending who had taken over for the patient at the eleven p.m. shift change. He agreed to change the scans and to start the premedication. I called Dr. Ivy to update her, and she asked for another update when the scan was completed.

I drove back to the other hospital, parked my car in the underground physicians' only lot, and went directly to the fifteenth floor to do my next overdue flap check. Once again, just as I got into Mr. Perez's room, Olivia rushed in to tell me that the patient down the hall was bleeding. "He's really pouring out now. You need to come right away."

This time the blood was coming continuously in a thick stream. There was at least a cup and a half full of blood in the toilet hat. "You're not going to put those sticks in my throat again, are you?"

"No. We need to do something more to control this bleeding. I'm going to have the anesthesia doctors come up and place a breathing tube to keep your airway safe. Then we're going to put you to sleep, and I'm going to put packing your throat to stop the bleeding. We'll be moving you back to the

intensive care unit, and you will likely be there a couple of days. We may have to take you back to the operating room to stop the bleeding."

"Do whatever you need to do."

I stepped out of the room and asked Olivia to call for the dangerous airway team. While anesthesia, trauma, and the SWAT nurses gathered, I felt my phone vibrate. It was my intern Sam, who was rotating that night in the ED. His attending had asked him to sew up a lip laceration that went through the red part of the lip onto the skin, and he wanted my advice on how to best approach repairing it. I told him I was a little busy but that I'd be there when I could. Anesthesia wanted to take the patient to the operating room for intubation to do it in the safest place possible. The trauma surgeon agreed to staff the case, and the SWAT nurses facilitated procuring a bed in the SICU for after the intubation. We wheeled the patient to the OR. While we were setting up for the intubation, I saw a text from Dr. Ivy. She had already seen the CT scan on her patient and felt that she had more air in her head than she had had immediately post-operatively, raising concern for a leak of cerebrospinal fluid. She wanted her admitted to the surgical intensive care unit, started on IV antibiotics, and made NPO for possible surgery the next day. I apologized for my delay and said that I would get her a SICU bed as soon as soon as I got out of the OR.

After what felt likely an eternity of waiting and what was actually about ten minutes, the anesthesia team proceeded with induction and intubation. Their procedure went smoothly, and I packed two

rolls of gauze against the tonsil bed in attempt to generate enough pressure to tamponade the bleeding. While waiting on the transport team to move the patient to SICU, I called over to the ED at the other hospital and asked them to book Dr. Ivy's patient to the intensive care unit. I was just beginning to feel caught up when the anesthesia team alerted me that the blood was already saturating and overflowing the packing. I repacked again, exerting even more force. We left the OR, but by the time we had traveled the three flights up to the SICU, blood was once again soaking the packing and dripping out the corners of the patient's mouth. I repacked again but knew that the packing would not be enough to stop the bleeding. This was clearly bleeding from a large artery that required a more definitive management.

I called my senior resident; our attending needed to be aware of the situation before we could further escalate care. Felix came in and agreed with my assessment that it was time to involve Dr. Yamamoto. Dr. Yamamoto, a known early riser, answered Felix's call on the first ring despite it being two a.m.; he agreed with asking the interventional neuroradiologist on call to do an angiogram and possible embolization of the bleeding vessel. With a plan in place, Felix called the patient's family while I went to see a consult that had been waiting in ED.

My ED consult was for a patient with anywhere from two days to a week of sore throat as she variably reported it during her multiple assessments. A CT scan done several days before that had showed a tiny area of fluid collection next to her right tonsil, but she had refused drainage at that time. She had been given a dose of antibiotics while in the ED and discharged home. She now was back with continued complaints of sore throat. When I got there, she was sound asleep; waking her required a combination of shaking her arm and shouting her name, and keeping her awake through my questions required significant effort. Once she was finally awake, she began to complain of severe chest pain. On my neck exam, she did have trouble opening her mouth, the hallmark sign of an abscess. She did have inflamed-looking tonsils, but I would not have suggested drainage for her if she did not have the CT scan from several days before and subjective complaints of worsening pain since then. I asked her if she would be willing to undergo incision and drainage, and she said, "I'll try anything to make this go away." I gathered my equipment and tried to talk her through the procedure.

"Don't tell me anything. I don't want to know what's going to happen."

So, of course, when I went to inject the numbing medication into the back of her throat she jumped away from me. "What the hell was that?"

"I tried to tell you that the numbing medicine was going to feel like a pinch and then a burn but you told me not to. Can we try again?"

She acquiesced, and after several minutes of deep breathing, she allowed me to put the needle in her throat. As soon as I started to inject, she grabbed my waist in her massive hand and pinched as hard as she could while pushing me down the bed away from her.

"Try not push me away from you or I can't see what I'm doing, ma'am."

She then turned looked me in the eyes and defiantly held up her middle finger to my face.

I stayed calm, despite the stinging where her fingers had dug into my waist. "Do you want me to continue?" She allowed me to aspirate the collection, once again pinching me while I inserted the needle, but refused further drainage. I would have fought harder if I thought she really needed further drainage and if I could have stood being in her room a minute longer. But I was exhausted and tired of dealing with her and her dramatics. I told the ED provider to place her on a course of clindamycin to treat what was likely just a bad case of tonsillitis.

I found Sam who was with his lip laceration patient a couple of beds away. It wasn't such a bad cut, but she was a pretty young girl, and ordinarily I would have taken him through the laceration. But frankly, I was exhausted and didn't really have the time to spare since I needed to round and write notes on all the floor and ICU patients by five-thirty. So I gave Sam a few pointers on the types of suture to use and apologized for being so incoherent. He was forgiving of my uncharacteristic stinginess with my attention, as he was worn out from his night as well and looking forward to the end of his shift at seven.

Since Felix was already wide awake and had nothing else to do to fill the time before our attendings showed up for formal morning rounds, we decided to go see all the patients together. We started with the adult patients, who all looked as expected, and then moved on to people I was more interested in: the kids. The battery swallower looked fine. She was eating, with no complaints of pain in her throat or chest. On exam, she had no crepitus, which would be concerning for a hole in her food pipe, the most serious possible complication of an esophageal injury.

We left her and moved on to my neck hematoma patient in the PICU. "How are you feeling, Ryan?"

"Great."

Sleepy as I was, it occurred to me that that was the first time I'd heard his voice. Ryan's mom said, "He told us that when he talked before it felt like he was swallowing air and it made it hard to breathe. He remembers everything."

Ryan said with the matter-of-factness of a seven-year-old sobered by his own life experience, "I was dying. The lady came and put a long needle in my neck. It hurt, and she kept saying she was sorry. She saved me."

I checked his neck, which was soft and flat, with no evidence of re-accumulated blood. There was a scant amount of old blood that had leaked from the drain as expected. He looked bright-eyed and ready to go. "You look good as new. We'll move you out of the intensive care unit this morning, and if you're still feeling well this afternoon, you'll get to go home."

As we walked out of the room, I said to Felix that helping Ryan had been the only thing that had made my night worthwhile.

"You did a good thing. He could have died if you hadn't done anything." I sat down and wrote my notes. Dr. Yamamoto came to round on his patients and told me that when his patient was done undergoing embolization, he wanted me to go down to the interventional radiology suite to remove the packing. That way, if there was any rebleeding, it could be addressed immediately before the patient left the procedure room. I worked on the discharge paperwork for the floor patients who would be going home that day—there were five—and waited for my pager to ring. It rang about an hour later. I went down to down to the Interventional Radiology suite and removed the rolls of gauze. I suctioned the tonsil bed vigorously to remove the old clot and to induce any bleeding that was going to happen. There was no bleeding. I used the next hour to wrap up the remaining paperwork and then quietly made my exit, happy to turn over the hourly flap checks to Dmitri.

I moved my car back into my garage and called my parents on the way. They told me to get some sleep and that we would meet up later that day to prepare for a trip to Maine. I got into my apartment and texted my co-resident and ally Steven about how my call had been one of the worst ever. I brushed my teeth, stripped off my scrubs, and crawled into bed, my head throbbing and my legs aching. Just before I drifted to sleep I saw Steven's message, "Sounds like a rewarding night." I had to smile, because in a way it really was.

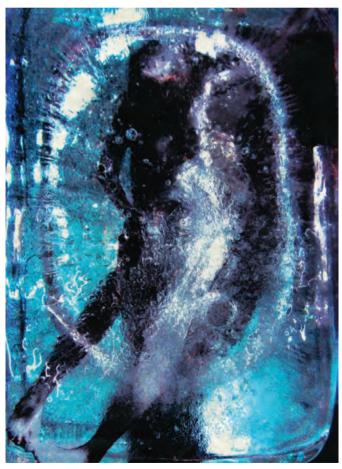
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# Numb Body

Darian Goldin Stahl



"Numb Body" | Encaustic toner transfer | 20" x 15"

This work concentrates on the complex emotions that accompany a medical diagnosis of chronic illness and the status of our fallible bodies. I am most interested in creating visual metaphors to foster an empathetic exchange with the viewer and those who live with disability or bodily unease. This artsbased research is a collaborative cycle of informing and reconstructing identity with my sister, Devan Stahl, who is a clinical bioethicist at Michigan State University and has multiple sclerosis.

My image making process involves photographing ephemeral sculptures that I create. For "Numb Body," I have taken a small image of a figure and frozen it within a block of ice. After photographing the sculpture, I translate the image through wax transfer printmaking to create the final print. This process that I have invented involves splitting the photo into color layers and printing them one on top of the other between coatings of wax that bind the toner. The resulting image is bright, dimensional, and rich.

"Numb Body" portrays a figure that is off balance but locked into place, which expresses the intermittent numbness that runs through my sister's limbs. I aim for viewers to identify with this figure, and come to find that we all carry anxiety about the functionality of our bodies and, more broadly, our mortality. When audiences see my work, even though they do not know my sister, they *feel* her and are filled with a shared, connecting reflection over the state of our ever-failing bodies.

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# Speaking Medicine: Reflections from a Sophomore

#### Clara Lu

Learning medicine has been much like learning a language. Just as we acquire new words, in medicine we master concepts and procedures not by memorizing but by using them—shakily at first, then intuitively, and finally with confidence and tact. In both, we become fluent by surrounding ourselves with the fluent. And so for me, the popular analogy of drinking from a fire hose has not rung as true as its alternative, an analogy of daily immersion in the deep repertoire of medical knowledge, from which I can only hope to gain eloquence.

Although eloquence remains far from reach, medicine after one year no longer feels foreign, just as a toddler understands a language to be hers without grasping at its full meaning. Toddlers of medicine, we novices pride ourselves in our hard-earned medical jargon, in the secret code of charting acronym upon acronym, and in the patterns and rhythms of a language we've begun to call our own.

But we learn to edit a language as quickly as we become comfortable with it. Within the hierarchy of clinical discourse, discerning when and when not to speak has become critical. And so we've learned not only how to highlight a patient's pertinent positives and negatives, but also how to filter information to favour our biases, how to conduct conversations that show what we know and hide what we don't.

There's danger in living a life thus encoded. Focused on using the right terms to belong, the right Latin to impress, the right number of words to mask our inexperience, we may not see how devoting ourselves to a single dialect can distance us from the poetry of our practice. If language can include, then it can also exclude; it can advocate or discriminate; it can wrench patients from or anchor them within their own narrative. Words, directed across rather than toward the hospital bed, can render a patient more powerless than their illness ever did.

It's easy to forget that beneath this professional face lies our core humanity, that beside the prose runs a common poetry we share with patients and colleagues alike. To embrace poetry beyond prose is to accept that our experience may not always find expression in secure, well-formed sentences, with the next phrase logically following the last—there will be tangents, derailments, caesurae. It is also to recognize those times when the best choice of words is no words at all, times when the best intervention is no intervention. Just as there is value in words, there is value in silence, cadence, and the reading between.

As he sought to define his life's calling, the composer Robert Schumann wrote of his "struggle between Poetry and Prose, or call it Music and Law" (Jensen, 2001, pp 34–35). There exists for us the same ancient tug between medicine's art and its science, between our empathy and our efficiency, between clinical intuition and evidence-based practice. Both are necessary, yet not always complementary—the Heisenberg principle at play in medicine.

But ultimately, to weigh poetry against prose is to ask the wrong question. However we choose to articulate ourselves—as poets, or scribes, or songwriters, or storytellers—it will count for nothing if we cannot first be listeners, drawing forth the patient's voice and placing the pen in their hand. Gifted daily with threads of narrative, we must listen until listening becomes the mother tongue, until it fills our throats with humility and conviction, until it alone teaches us that balance of poetry and prose that heals.

### Reference

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# The Invaders with thanks to E. Ellen Schmidt

Barbara Lydecker Crane

"It's small," the doctor says,
"but your cancer is invasive."

Instantly in technicolor I can see

a horde of Huns on horseback
in a thunderous attack.

Charging archers, wild-eyed,
pierce the unprotected sides
of villagers like me who cower
at the carnage and the tower
of smoke above each mountain town.

One Hun leers at my hospital gown ...

"That's all 'invasive' means."

At that invaders to

"The cancer has moved beyond a milk duct," the doctor continues.

At that, invaders pull in reins as horses rear and stamp.

Men dismount on dusty plains, set up a makeshift camp.

Will they stay or will they go?

I wait for history to know.

# Dancing in the Dark

Doctor, would you like to hear my light verse about cancer?

If laughter is the best medicine, it might radiate the answer.

Laughing in a CAT scan? A mirthful shaking can't blur

the end result, this finding of invasive cancer—nor will rants or

rhymes. I'm trying hard to smile but right now I can't, sir.

Tell me the steps, and give me notes. I don't do well with chance or

fate, but I will dodge the odds if I can be an artful dancer.

Barbara Lydecker Crane, of Somerville, MA, has published two collections of her poems: *Zero Gravitas* and *Alphabetricks* (for children). A new one, *Back Words Logic*, is due out soon.



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### **Palliatives**

Dan Campion

Three hours it took, to discard all the pills according to the rules for opiates.

We could have cured a lot of user ills had we been willing to ignore those writs, the hospice nurse and me. But she'd brought kits designed to render painkillers inert with cat litter and other sundry grits and agents, and we mixed until it hurt.

Then, all your analgesics turned to dirt, we bagged them up as per the regs, disposed of them the way we should. Goodbyes were curt. I sank into a chair as front door closed.

What had we measured: Suffering? Relief?

To cast out bitterness? Or welcome grief?

### The Readers

As nurse I played librarian, made lists—like yours of every title on our shelves—and spoke like earnest desk clerk who assists good patrons, ever searching for themselves. The medicines, the real nurses' names, the clinics' and the doctors' numbers—all set down: that's how a cataloguer tames untameable collection, hospice sprawl. And we were quiet in the reading room as ceiling rose beyond cathedral height and all us readers looked up from our tome while staying up to study late one night. You'd found a passage, marked it, took it home. I wrote a card and held it to the light.

### Sinew

Physicians learn the strings, but not who holds the crossed sticks that manipulate each move. Some think it clear, some hidden in the folds, and some don't care. Why trust what you can't prove? With push and pull the doctors test our strength, and we comply, exerting as we're told, or demonstrating by unchanging length of sinew that we're too sick or too old. Look here, says the anatomist, observe where tendon fixes muscle to the bone. The students nod, some viewing duct, some, nerve, but all sure their command of fact has grown. Our errors will sort out someday, like strands of sinew that lent virtue to our hands.

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## Once Upon a Time

Karen L. Armstrong

Can any story be a fairy tale?

For the heroine, imagine an eighty-year-old woman: slight, unsteady, stoic. She avoids physicians completely, until overwhelmed by debilitating pain. She refuses tests, refuses screening, hates hospitals. She is frank, but friendly. Without pain, she would live completely outside the world of health care. She has lost weight over the years, loosening her dentures, and her teeth slide like drawers as she speaks.

You compromise: you will assist with pain relief, she will come for an occasional appointment, will endure your questions, pokes, prods. For pain pills, she will come ... maybe once a year.

For the hero, imagine the woman's adult son, a stranger to you. His mother has always come alone. At first meeting, he sits in lotus position in the exam room. His wild, frizzed hair coupled with his long, thin body, give the appearance of a stalk of broccoli. He is tattooed and gap-toothed. Nicotine-stained fingers rest on his knees.

He has been loud at the front desk, demanding to see you immediately. Now, he remains seated as he speaks, almost childlike in his appeal.

- —My mother has fallen; she's been in bed for days. I can't get her up, she can't move.
  - —Why haven't you called an ambulance?
- —I wanted to, I asked her! She refuses to go. She hates hospitals.

Point taken.

For the castle: imagine a one-bedroom apartment. Trying desperately to become a two-bedroom, the orange-shag main living area has been subdivided by a tattered blanket on a string, partially obstructing the view of a plain mattress on the floor, a stack of dishes, a heap of clothes. Water stains crawl down the walls, cracked light fixtures dangle. Cigarette smoke dulls the colours, thickens the air. The TV chatters.

In the actual bedroom, imagine a single window without treatment, admitting late afternoon light. There is a single bed, and a chest of drawers. The yellows and oranges of the soft, filtering light spilling onto the bed would make a beautiful photograph, except.

Except.

The figure on the bed is naked, skeletal. She lies on a sodden towel. Her impossibly thin leg is shortened, and turned inward. She screams when you touch the leg. When her son helps to turn her over, you see that the skin has worn away on her lower back; there are tendons visible, and bone. You sit close beside her, bend over her, gently touch her protruding cheekbone.

—Mme. Labelle, your hip is broken. You have a pressure ulcer. You need to go to the hospital.

She turns to you—her teeth have been removed. She has sunken, wrinkled and dried into a crust. Her eyes, however, retain the clarity of two shiny beads.

—And what will they do for me there? Her voice is a whisper; surgery is out of the question, she is too ill.

- —We can control your pain. We can try to help you feel better.
  - —Why not do that here? she asks.

Pause.

- —Mme. Labelle, if you stay here, you will die. She actually smiles; her face folds and creases like origami as she reveals her gums.
- —Of course I will die. I will die if you take me there, or I will die if you leave me here.

Point taken.

For the magical being: imagine the ten-year-old, profoundly autistic granddaughter. Refusing to wear clothes, she shrieks periodically, or utters a guttural noise. Hands flapping, she weaves in and out of the conversations, through the rooms of the castle.

You speak to the son:

- —We should take her in.
- —She wants to stay here.
- —I know, but it looks like you have your hands full already.
- —I need some help; that's why I called you. That's why I came to see you. I need some help, but I can keep her here.

- —What about your family, her family, don't you have siblings?
- —They aren't here, they can't help. They live out of town, or they work. They don't think I should keep her here.

He is walking, pacing, endlessly moving. He steers his daughter back into the other room. He closes the bathroom door so she won't drink the hand sanitizer.

—She will die here.

Finally, he stops moving. He sags and leans on the wall.

- —I know that. She knows that. If you put her in the hospital, she will just die faster. She made me swear to her that I would keep her here.
- —But surely she knows that you might not be able to look after her along with your daughter. She knows that you can't do everything.
  - —But I have to try, don't I?

You gaze at each other, considering this question, for some time.

For the Fairy Godmother: imagine a physician, old enough to have seen many deaths, but new enough that each one still erodes you.

Imagine knowing that death is supposed to come with peaceful music, clean sheets, weeping family members at a bedside vigil, neighbours with casseroles and comfort. Imagine also knowing that death does not always follow the rules; that death can be messy, surprising, and inconvenient.

Possibly, you are not the Fairy Godmother at all, but the Witch. Which one calls an ambulance? Which one lets the heroine remain in the castle?

The Godmother (Witch?) should be granting the patient's wish ... but who wishes to die like this? Is she in her right mind? Can she make this decision?

Imagine asking these questions, then asking them again, and again: one hundred, one thousand times ... as weeks pass.

For extra characters, imagine a posse of Healthcare Workers, sent to assist at the castle, arriving armed with plastic tubing, gauze, and optimism.

Imagine horrified looks, telephone accusations, confrontations, and fear.

Imagine pain medication, clouding the heroine's mind.

Imagine seeing her vacillate between past and present, no longer able to discuss her own fate, laughing with her long-deceased husband, shouting that she is late. Late for what?

Imagine the hero—amid the moans of the heroine, the cries of the magical being, and the shouts of the posse—grasping desperately for you, begging for help.

Imagine mutiny.

No, every story cannot be a fairy tale after all.

The true ending is only death: in the hospital, with a tangled gown hiked up around the waist, with no one to push the button on the pain pump, with no one to give sips from the water glass, with no wishes granted.

And no one in the story lives Happily Ever After.

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## Nearing the Shore

Dale Guenter

I turned forty-nine a few years ago, entering my jubilee year, seven times seven, the grand sabbatical. I was infatuated with the ancient Hebrew tradition of jubilee from the scriptures of Leviticus—forgiving debtors, turning fields to fallow, releasing slaves, taking stock of the past forty-nine<sup>1</sup>. It is the year of great pardon, of recognizing sufficiency, of equalizing inequalities. I was sobered by this opportunity to properly launch into my second half, with some sense of being awake to the fact of a significant viewpoint in my journey.

From this, I followed a crooked path that led to a peculiar aspiration: to find a deeper friendship with my own death. I was struck by the words of John O'Donohue, an Irish Catholic, poet, philosopher, and a priest for 19 years. He left the priesthood when, as he put it, "I realized there was a lack of oxygen within the church." He died unexpectedly in his sleep at the age of fifty-two, having lived his life through the lens of Celtic spirituality. O'Donohue wrote this poem:<sup>2</sup>

From the moment you were born, Your death has walked beside you. Though it seldom shows its face, You still feel its empty touch When fear invades your life, Or what you love is lost Or inner damage is incurred. Yet when destiny draws you *Into these spaces of poverty,* And your heart stays generous Until some door opens into the light. You are quietly befriending your death; So that you will have no need to fear When your time comes to turn and leave. That the silent presence of your death Would call your life to attention, Wake you up to how scarce your time is And to the urgency to become free And equal to the call of your destiny. That you would gather yourself And decide carefully How you now can live The life you would love To look back on From your deathbed.

How shall we respond to dying? As this question crossed the path of my jubilee journey, and I pondered the absurd and undeniable truth of O'Donahue's words, I knew that this question needed to be my own. I would have to adopt this question, personally and intimately. It was time for me to explore how *I* might respond to dying.

The first character I needed to consider was tucked away among my earliest memories. Tina lived ninety-four incredible years. She was the sixteenth of nineteen children, preacher's wife,

mother of four sons, tiller of home, hospitality engineer, builder of feasts. She lived through many very hard times. They were hard because of having so little and needing to stretch it so far. They were hard because of a sixty-year marriage that came with some tight corners and tough hills. They were hard because of bones and bits that moaned and groaned but never quite let her go. Tina was a force. She poured herself into her living.

Tina was also "nearing the shore" from her earliest days to her last. Those who knew her well can recall only a few years near the end of her life when the words "I'm nearing the shore" did not pass through her lips. This phrase could be spoken through a sarcastic grin and bring her audience to laughter, or through the tears of some more intimate sadness of this life here on Earth. Tina was my father's mother, my grandmother. And as her grandson, I was often perplexed by that phrase and what meaning could be assembled around it. Why was she always dying, why would she say it out loud, and even more, why did she seem so comforted by it? *Mysterious!* 

Another important piece in this puzzle is my professional connection to palliative care. The first resting spot of my career was an inner city community health centre in Calgary, Canada. There, people with HIV stepped into my path and eventually became the grains upon which the crystals of my career and my personal life would form. That was the early 90s, when HIV was primarily a palliative enterprise. And that is where my love affair with palliative care was born. I found that meeting people who knew they were dying was deeply satisfy-

ing. And I think it was satisfying because of two lessons that came across better here than in any other area of medicine I had experienced.

The first lesson was the meaning of person-centred care. This is where all of the confused and misguided objectives of acute medicine, the obsession with data and treatment and fixing and cure, were finally dropped, and what the patient wanted and needed became precisely the most important agenda in the entire venture. What I learned and continue to teach my students is that there are only two vital signs in palliative care: comfort and contentment. And we have to measure those aggressively and repeatedly, turning away any temptation to start measuring other signs that will only confuse matters. These vital signs are entirely subjective, purely person-centred parameters.

The second important lesson that palliative care taught me was the importance of saying what needs to be said—opening Pandora's box, exposing the elephant in the room, unearthing hidden treasures. In part this is because time seems compressed. But more than that, I think it is because people who are dying reveal over and over just how valuable it is to talk specifically and directly about the things that people who are *not* dying won't talk about: future plans for home and family, preferences for level of care, guilt and shame, and even prognosis. I loved watching my palliative care mentors cut to the quick with their honest questions, and seeing just how often those resulted in sincere, relief-giving responses.

These two lessons were lessons in healing. Ironically, the most powerful healing I had wit-

nessed was at the death-bed, and so rare in the examining rooms of eternal life. *Mysterious!* 

Jim was my first true love. We met when I was thirty and we were both newly minted young doctors. Although he was healthy and vivacious and full of life at the time, Jim knew when we met that he had a terminal illness. This fact gave us both pause—me because I knew that a relationship meant I would be left alone at some point, though no idea when; he because he felt guilty, and maybe irresponsible, for dragging someone else into what could be a terrifying passage. But we somehow came to know that us being together was meant to be, and we were given three wonderful—and complicated—years of true love. *Mysterious!* 

Tina, Jim, and my palliative patients have taught me about living and dying all at once. We are all doing it, and it is one of the great mysteries of the human condition. It is a paradox, and I have learned that the choice of response I make in the face of paradox can propel my life in very different directions. A paradox is two truths, two conditions, two states that are seemingly, yet not really, contradictory—two situations that, like magnets with the same poles facing, seem to resist each other. A paradox is mysterious.

I will fight the battle for a cure—I will embrace a good death.

My body connects me to all of the treasures of this world—My body locks me in a prison.

I am human—I am divine.

It seems our human nature is to perceive paradox as a contradiction, an inconsistency, a problem that cannot be reconciled. I become impatient. I direct and control the discourse, and finally give up on one of the truths to embrace the other completely. This is dualistic, either-or, black and white thinking. It is hard to imagine that the two truths could live together within me.

But there is a wisdom that often lies at the ancient core of the most established spiritual traditions. This wisdom is that paradox is able to teach us our most important lessons and usher us into our most significant depths of living. This power is released only inasmuch as I am able to hold the dough of mystery formless without having to squeeze it out into a mold. In order to let them teach me, I must hold both truths together, at the same time, with as much conviction as I would hold each truth separately. They must be allowed to vibrate in my grip.

I wonder if this might be one way to befriend my own death. If I can see death and life both being here with me now and welcome all of the uncertainty that seeps through that admission, there is a chance that each might make the other very different from how it at first appears.

Live like I will live forever—Live like I will die tomorrow.

If I suppose for a moment that holding both sides of that paradox together really is good for me in some way, what would that look like? What if I was convinced that these two truths, when held together, could carry me to something more en-

compassing, something more resilient or more fitting? How would my life be different?

Tina spent her life "nearing the shore." I cannot know what she meant in this, and I suspect Tina did not know either. In some way, it seems she was allowing her death to rest close at her side, and that she was holding the truth of living and the truth of dying in her soul fearlessly. To some degree, this must be true, since it was so much easier for her to speak the words of herself than it was for others even to hear them, let alone speak this of themselves. My suspicion is that she was, in fact, more comfortable with her dying than with her living, and that if she did have fear, it was less about death and more about her life here on Earth.

And as for Jim, from what I could glimpse of his soul, in the presence of his illness, death and life were both welcome guests. Some grace had found him and allowed him to hold the two without fear. Together they formed a harmonic chord, two notes that, when put together, were better than the sum of their parts. Many who met Jim felt touched by a unique presence of spirit.

I wonder if it is possible to befriend my own death when I have only had to face it in the abstract. I think the fear that makes me turn away from dying is usually a fear of what I will lose in life, rather than what might come after. I fear losing the chance to watch nieces and nephews grow into their personhood, missing the opportunity to forgive others and myself for our shortcomings, that I will not have achieved something important and notable, that I will not be able to love more deeply or to dance more beautifully or to be noticed. Maybe

what I fear is being unfinished or incomplete. Maybe this is what makes me hold the mystery of both living and dying like a prickly branch, and holds me back from being instructed and enriched by it. In order to hold both the truth of living and the truth of dying as dear companions, I would have to move beyond this control, entitlement, and ownership of self to some other possibility.

And as I let these thoughts simmer, I am convinced that it is not possible to wrestle this paradox head-on. I cannot *will* myself to *achieve* this transfiguration of fear. Such a deep acceptance as this is not something I can achieve through task and toil. Rather, an acceptance like this must come through grace, which comes through a silent attention, inviting openness, listening through mind, heart, and body.

I now recognize this as my perfect notion of "prayer": a prayerful existence in everyday life, a prayerful contemplation. In this kind of prayer I can discover a heartfelt posture of surrender. In spiritual terms, surrender is not a giving up, or even an ending. Surrender is, rather, a giving over, an entrusting. It is the end of being the one in control, the end of being attached to my identity, and the end of judging myself. It is the act of declaring that what I think of as *me* is not only *me* but much more than *me*. It is freedom, connection to all of humanity, and connection to the divine.

After her husband's funeral, Elaine summoned me to her home. Chemotherapy for her own lung cancer was scheduled to resume and she wanted to know whether it would be "OK" not to have any further treatment or investigation. She asked whether this would be like committing suicide, whether she was giving up, whether it was wrong and she should continue to fight the battle. And although I am certain I could not find the right words at the time, I wanted her to be able to consider giving over rather than giving up. Rather than looking at a decision to end treatment as defeat or failure, why not look at this as a full-on embrace of the life that remains and the yet-unknown possibilities that might unfold? If she could give both her remaining life and her impending death over to the great mystery, entrust the unattained hopes and unmet expectations and terror of suffering, maybe she could have both death and life in every day that remained. Although I suspect no words like this were ever spoken to her, there was no doubt that some grace found Elaine and her life took on more resolve and richness while befriending her death and refusing treatment.

I wonder if every battle for a cure should be accompanied with a campaign for surrender. Where would that take us?

The Franciscan Richard Rohr says:

The ability to stand back and calmly observe my inner dramas, without rushing to judgment, is foundational for spiritual seeing. It is the primary form of "dying to the self" that Jesus lived personally and the Buddha taught experientially. The growing consensus is that, whatever you call it, such calm, egoless seeing is invariably characteristic of people at the highest levels of

doing and loving in all cultures and religions. They are the ones we call sages or wise women or holy men. They see like the mystics see.<sup>3</sup>

Am I ready to die—am I ready to live? Some days I think I am succeeding at lovingly holding those both. I wonder how any readiness to die will hold up, or how fleeting it might be in the face of a serious threat. I cannot know. And really, it's not the point. The point is that in befriending death now, life is more awake in every day. To live every day like it is my last, yet living like I will live forever, has some very practical implications. I must speak the truest truth I can in every human interaction, say what needs to be said right now, forgive what needs to be forgiven, thank who needs to be thanked, and hug who needs to be hugged. Today. I must also recognize loss, disappointment, and failure as the small "practice deaths" that they are, where my control and ego and effort are best surrendered and I await some other mysterious possibility. Plus, I must eat properly, drink in moderation, exercise, and save enough money to support my circle to 100. The list stretches on.

I am watching for signs that this journey might change my approach to patients. I think it has already, because for many the death bed is the first time these questions have been permitted to seep into conscious grey matter for further inspection. And at times I have felt as though my patient and I can join in our dying together, which is a comfort for them, and instructive for me.

## Notes

- 1. Leviticus, Chapter 25.
- 2. O'Donohue, J. (2008). *To Bless This Space Between Us: A Book of Blessings*. New York: Random House Inc., p. 72.
- 3. Rohr, R. (2009). *The Naked Now: Learning to See as the Mystics See.* New York: The Crossroad Publishing Company, pp. 32–33.

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## Like a New Snake: A Fable

Adrian Chapman

Jonathan had been playing dead all his life. He'd do it even when there wasn't the slightest vibration of an approaching creature—when there was no possibility, that is, of a threat against him.

Relinquishing the thrust and flex of muscular exertion, he'd exhale softly, letting out a gentle hiss. Before he knew it, he'd be curled luxuriantly, motionless in long grass, on the fringe of woodland or the edge of a pond. And if the mood took him, it could happen in an instant. He'd go from life to death in the flicker of a tongue, and splay himself out on a riverbank in a cataleptic trance.

Playing dead was the easiest thing in the world and afforded tremendous contentment and reassurance. If anyone came upon him, they'd just ignore him. When they were gone, Jonathan could slither around a bit and giggle to himself, or if the sun was out he could do a spot of basking. And if he wanted to, he could always play dead again.

There's nothing unusual in any of this, though. This is just the way some kinds of snake like amuse themselves.

Lately, however, the old pleasure of playing dead was wearing thin. Jonathan wondered if this was down to the time of year. He was feeling dull and dusty. When he examined his reflection in the pond, he saw that his eye scales had become milky blue. But this was all to be expected.

Usually, when he was molting, Jonathan felt at a slight distance from the pulse of life. His head didn't feel quite connected to his tail. He wasn't a happy snake; but, it must be said, neither was he an especially unhappy one. Life slithered on in a middling sort of way. This year, however, things were different. One moment he'd be overcome by lethargy, and the next, he'd be thrashing himself around for no reason at all. When he played dead now, he wasn't really sure if he was dead or alive.

Others of his kind always became so excited at this time. Take Ivan, for instance, a serpent who'd been annoying Jonathan since his school days and who was his long-term rival for the affections of the seldom-seen long, sleek, and lovely Amanda.

"Skin-shedding time, Jon-Boy! I can't wait," said Ivan. "I'm going to be bigger, I'm going be brighter, and I'm going to be better. I'm ready to tip the scales again!"

Jonathan usually just ignored Ivan and the others who'd hiss about the pleasures of molting. Good for them, he used to think, if it was all a matter of release and reinvigoration. And if all their talk about feeling like a new snake was nothing more than nonsense, well, let them talk anyway.

But today Jonathan was piqued by Ivan's words, and he saw with dreadful clarity the reason

why: he had to admit that he had never felt contented in his own skin and couldn't envisage ever doing so. Now that he reflected on the problem, he was sure this unease had been building up for years. He'd done well at school and everyone had urged him to continue his studies. But to him, his success meant nothing; he'd had to swallow too much whole, and nothing much excited him now. He'd lost his taste for knowledge—in fact, he'd lost his taste for everything.

And so he slid from riverbank to riverbank and from wood to wood, rarely encountering others. He told himself he was searching for something but wasn't sure what. Really, his thinking never got very far, or even anywhere at all. Worst of all, his favorite pastime, playing dead, now afforded him no joy: what was once a delightful game had become a terrible compulsion.

One evening, he found himself over at Ivan's, where he curled up in the corner of the room and half-watched TV. His mind became more and more restless and his coils more and more flaccid as a property-buying show fronted by an unconvincing fox was followed by a cooking program presented by over-excited orangutans. But then a shiver of electricity ran through Jonathan, and his tongue started darting frantically: it was Beast Vision's flagship current affairs program, News Bowl—an interview with someone called Theo, a snake psychiatrist who, Jonathan learned, now proudly called himself an 'anti-psychiatrist.' Many, it was said, considered him a philosopher of madness, and some thought him a sort of contemporary shaman.

He was being asked by Helena, a very elegant red setter, about his new book, *From Snake in the Grass to Snake in the World*. But Theo refused to play the interview game. He was hiccuping and flopping around, hardly able to keep himself on the sofa.

Asked if he was drunk, he replied, "So what if I am? Maybe it helps me bear the profound unreality of this ridiculous little show."

And then he seemed to fall asleep. Helena woofed politely while moving on to the next item—at which point Theo jolted on the sofa and began hissing drunken imprecations.

Now here, thought Jonathan, is a real snake: one, perhaps, who can really understand me. Contemporary life, epitomized by the shallowness of the media, was unreal—profoundly unreal, just as Theo had said.

As soon as Jonathan could, he bought Theo's book, and he found himself fascinated by a chapter on skin shedding and alienation. Doctor, antipsychiatrist, philosopher or shaman—whatever he was—Theo seemed to be addressing Jonathan personally. An appointment with him, thought the young snake, might be his only chance of sidewinding his way back into a livable life.

And so he found his way to the clinic on the outskirts of the capital.

There was no couch in Theo's consulting room, just a couple of beanbags. The walls (which appeared bluish to Jonathan, as did everything) were soft white in color. In the corner were a desk and a drinks cabinet. The rest of the room was blank,

featureless—a canvas for the imagination, Theo liked to think.

The two snakes lay down, each on his own beanbag. No one spoke for a long time. It was Theo who broke the silence.

"What I like about you, Johnny, is that you're different from other snakes."

"The reason I can tell you this," he continued, "is that every snake is unique. There's a singular 'thisness,' a distinctive vibration about each of us."

He was slurring his words and had obviously been drinking. But he intrigued Jonathan, who was most flattered at being addressed as "Johnny."

"I don't care about making you happy," continued Theo. "Find someone else to help you adapt to the idle chatter of the crowd. There are plenty of shrinks around for that. I'm interested only in the truth: your truth."

This was exactly what Jonathan wanted to hear. At last here was someone who would take him seriously.

"And you can think what you like about me, Johnny. I'm a messiah, a holy fool, a snake oil salesman—whatever you like. What matters is what you think and who you are."

This, thought Jonathan, was an invitation for him to speak, and so he began.

"As an infant, I never felt really close to my mother. She always seemed to resent the effort needed to protect me from—"

"I don't want to hear about your infancy," interrupted Theo. "I couldn't care less about your

mother or your father or your siblings. And I'm not interested in the long, sleek and lovely—"

"Amanda? You know about Amanda! That's amazing."

"Amanda, Deirdre, Deborah, Philomela: the names change, but they're always long, sleek, and lovely."

"You mean she represents the preoccupations of the crowd?"

"You catch on quickly, snake. So let's steer clear of the clichés, shall we? What I'm going to suggest is that you go over to the corner, where, behind the drinks cabinet, you'll see a saucer. Drink some of the rainwater-colored liquid you'll find there."

"What is it?"

"It's a little something our ancestors used to sup before the advent of so-called civilization. It's something that helped them find themselves. And it was particularly helpful during the trauma of molting. Want to try it?"

It was an undulation of just two or three body lengths to the saucer. But what Jonathan drank was to take him far from the movements of his everyday life.

"Just sip it and tell me what's going through your mind," said Theo.

After a few minutes, Jonathan spoke: "Is it getting hot in here?"

Ah, it's beginning, thought Theo. Just a word or two from the experienced therapist would start the process.

"Hot, Johnny?"

"Yes, hot. I'm wrapped up in a soft, delicious warmth."

"Where are you? Tell me, Johnny."

"I'm in the egg of the world, Theo. It's the place where dreams come from. It's where the fever of creation is enacted over and over again."

"Fever?"

"A dreadful miasma rising out of swampland. I can see the particles, molecules—shimmering three-dimensional webs—I can't tell you how beautiful—and they're slowly drifting over towards me, over to my tongue."

"Tell me about the smell, Johnny."

"The scent goes from my tongue and down my lungs. A delicious tremor flickers through me: something horrible, Theo, horrid but wonderful."

Jonathan fell silent, and Theo, experienced in these matters, didn't press him into speech.

The curious scent joined with the warmth that was surrounding Jonathan, and the heat-smell infused itself into his thoughts—thoughts of Ivan and Amanda entwined in melting undergrowth, and Helena, the red setter TV dog, with her long, well-bred snout, looking confused and elegant.

And how strange Jonathan seemed to himself—now no longer himself but somehow prior to or beyond his everyday serpent-hood, and moving toward something in the near-distance that he sensed might be his long lost home.

Now was the moment, Theo knew, to recommence the conversation. "Where are you now, Johnny?"

"I'm approaching a river. The River." As he gazed ahead, Jonathan strained to be at one with the water, and to fit himself to the reflection of the snake that rose from the water's surface.

And then he fell from his beanbag to the floor and began laughing.

"Let yourself laugh, Johnny," intoned Theo, seeing that his patient simply couldn't contain himself. "That's right: a great big, cosmic chuckle. Let it all out."

But it wasn't just a chuckle; for now Jonathan was unrestrainedly sobbing and trembling.

Theo wasn't disconcerted in the least. "It's all good, Johnny. Let it happen, snake."

What happened was that Jonathan's fit of laughter-despair took him, after what seemed a thousand years—longer, perhaps, but really time no longer had any meaning—to a place of stillness and openness and light where he experienced the most expansive sense of coolness and calm he'd ever known.

Although he couldn't say why, he knew he couldn't stay in this place, and, overcoming an obscure but leaden internal resistance, found himself actively making the choice—and the making of a free choice was most important, it seemed to Jonathan—to undulate slowly and deliberately, and at last more rapidly and confidently, towards the edge of woodland at once entirely familiar and completely unknown.

What happened next was this: he let his body sway from side to side, and then found himself deftly wriggling out of his old skin, which was left inside-out on the floor of Theo's consulting room. It was a sight that even the seasoned psychiatrist felt privileged to see.

Jonathan looked around him into the soft white light of the room. The blueness in his vision was gone now, and his muscles were strong and elastic. Brightness, he just knew, was emanating from the full length of his body.

Theo admired the clarity and shine of his patient's scales. "So tell me, Johnny," he asked him. "How do you feel in your skin right now?"

"I feel," said Jonathan, "like a new snake."

"And what are you going to do with your life now?"

He wasn't at all sure what he was going to do. He might study. He might write something. Or he might do nothing at all. Now "doing something" with his life no longer seemed urgent. He saw no need to make quick decisions and was open to wherever his desire might wind him.

In the meantime, he told Theo, he'd thought of a way of marketing his preoccupation with playing dead.

"I'm going to work part-time as a living statue and part-time as an artist's model," announced Jonathan. This work would bring in some money while he digested the experience of his trip in Theo's consulting room and decided on his future.

"And I might take up meditation," he added.
"You're on your way now Johnny"

"You're on your way now, Johnny."

The two lay curled in silence at the end of the session. Jonathan was perfectly contented, lost in

the afterglow of his visions. Theo was ready for another drink.

It was hard work babysitting patients who were off their heads and going who-knows-where on their inner voyages. Sure, Jonathan seemed a whole lot better than when he slid in. He'd shed one or two illusions, certainly. In time, he'd find a couple of others to make up for those he'd lost, Theo knew.

Anyway, it had been a powerful experience, for sure, and the patient would make a good case history for the new book, which was proving a devil to get finished. *The Curling Away of the Skin Ego*: yes, that sounded good. Or maybe *Jonathan: A Snake Resurrected*—that would be even better.

The patient made his way on to the beanbag again and, coiled in its folds, was breathing gently, his tongue slowly flickering. Theo, ever the experienced professional, didn't want to puncture this newfound peace and so left it a moment longer before speaking again.

After a rebirthing session, the therapist needs to be at his most artful in guiding the newborn back into the everyday world. Theo always thought that the patient must be allowed adequate time to knit the fibers of his or her new self into place.

But eventually he had to break the silence: "And you'll not forget to make the transfer to my bank account?"

"I'll do it straight away," replied Jonathan as he wound his way to the door and the new life that awaited him beyond it.

"Take care, snake," said Theo as his patient slid away, and he himself undulated over to the drinks cabinet.

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