

Ars Medica

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Editorial

The mandate of a new journal evolves with the content it receives. A hopeful net is cast but what is caught is unpredictable. How the pieces are then assembled involves no small mystery—editors read submissions, hold what they’ve read in mind, discuss (occasionally battle), select, then carefully position works on the written page. The editors of *Ars Medica* knew that we wanted to honour stories in a time when human communications in general are being truncated. We were specifically interested in presenting accounts of illness and healing, changes in the body, and encounters with “the health care industry,” where the very act of diagnosis imposes an anti-narrative thrust.

Too often the richness, idiosyncrasy, and texture of a story are lost in translation to some form of “treatment plan” or other clinical distillate. Patients and their families suffer for it, but so too do nurses, therapists, doctors, and other “providers.” If you chisel away too much at a fundamental human imperative during thousands of hours of a work life, the capacity to listen to and in turn tell new stories may be insidiously damaged over time.

As the submissions for this issue flowed into our hands, they reassured us that stories suppressed in one context will find expression in another. Laurie Rosenblatt quotes Michel Foucault in warning us about “case histories” and their tendency to “objectify and subject.” She then allows us access to a powerful, unadulterated narrative she uses with students at Harvard to undo the damage. A woman’s long battle with cancer is fought with humour and hope on the page—ingredients that seem to fade as she reassures us and herself that perhaps they have not.

Good stories have a beginning, middle, and end. Perhaps good issues of literary magazines do too. This third volume opens with Doug Guildford’s images of ancient life forms. It then shifts to Anne Marie Todkill’s narrative of a pregnant woman fretting over the extermination of mice in her Edinburgh flat. We have anxious concern for these small, linked life forms she describes and somehow recall Freud, who could tell a clinical story in a way that both educated and moved us. Gretchen

Roedde, a family physician with extensive experience in international health, shows us the road of stories encountered as a travelling doctor. In her “A Life on the Road,” she encounters stories in *medias res*, often moving along the road before a particular story “ends,” though it becomes part of her own journey and ongoing story.

Three of the “middles” in this issue of *Ars Medica* are constructed by female tellers—Alison Pryer, Jessica Handler, and Anne Elliott—whose mothers or sisters have been lost to the decay or proliferation of cells. Their accounts seek to bring these women to life in new, previously unexplored ways but also to allow them much deserved rest. Beginnings and endings germinate paradoxically in ways that only well-constructed narratives can allow. Other stories of illness are offered by Ellen Case, Peter Scott, and Matt Oakes. Those of us who work with students (or weary colleagues) would do well to share them when issues related to multiple sclerosis, pancreatitis, or migraine appear on the curriculum or pop up in “case rounds.” Stories make “old-hat diagnoses” new again and allow us to recover our imagination and empathy, whether we be professional caregivers, the ill person who is “sick of himself,” or a family member attending the umpteenth, seemingly pointless follow-up. We never know our bodies as well as we think we do, in sickness or in health. In “Creative Process” (a regular journal feature), J. R. Carpenter “tries her body on for size” in ways that shock and delight and dare us to rethink our own physicality.

Then there are endings. Bob Maunder tries to select music to honour a dead colleague and friend. Merrill Joan Gerber reflects on the pain of her mother’s life as she heads into a longed for death. Herman Gottlieb does not give up connecting with a demented man until he finds him gone. Catherine Belling knows what it means when her father forgets to take a family photo. Pass this third issue of *Ars Medica* on to a friend or patient or caregiver or administrator or passionate reader. Let each, in turn, shape this journal by sending stories, poems, or images of uncharted struggles longing to shared.

Table of Unidentified Contents

A Portfolio of Intaglio Prints

Doug Guildford

I have been living in downtown Toronto for the past twenty-five years. Toronto is my social and cultural base. The diversity, here, feeds, supports, and reassures me.

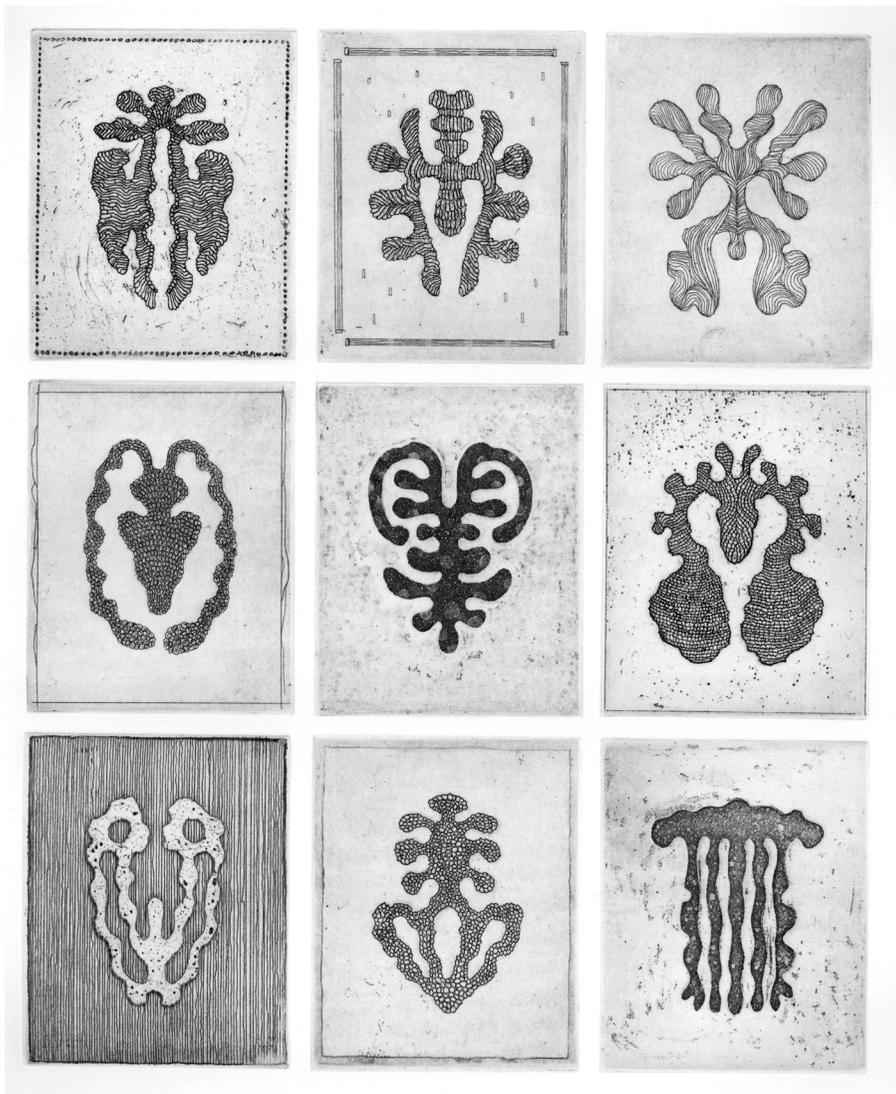
Concurrently, however, I have returned each year to my place of origin, the Atlantic coast of Nova Scotia, where I inhabit the amphibious zone between the tides; a quasi-land of shapeshifting, addition, subtraction, and flux.

This is my wilderness area. It is my reference point with the natural world and my creative source.

My art practice is firmly rooted in drawing. Drawing works for me, both as a language for problem solving and as a tool for self-reflection.

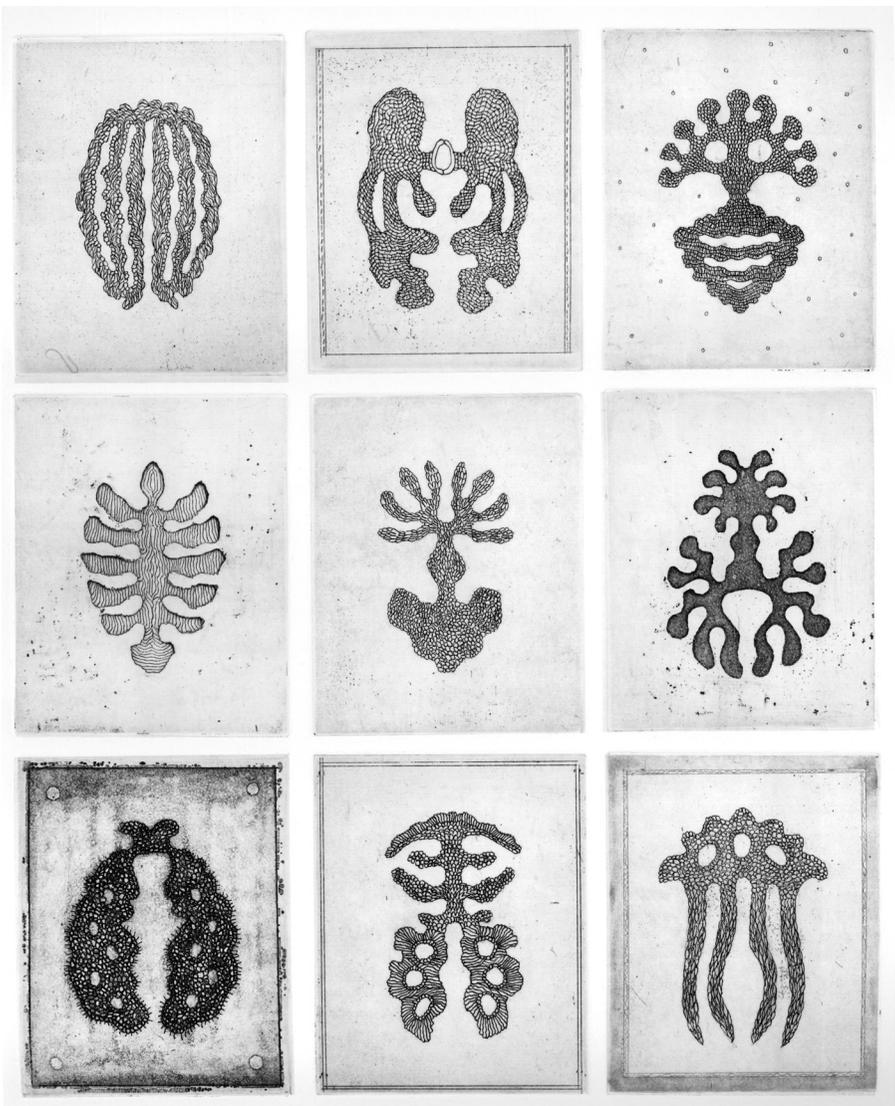
I see the drawings and the prints as notations or lab notes, a compulsive kind of journal entry, and, perhaps, a distillation of accumulated knowledge.

I am continuing to develop an ongoing and extensive body of drawing and print-work based on my evolving “glossary” of graphic terms (an automatic shorthand for my take on the universe). This language is based upon my experience and observation of life forms at the edge of my native shore. It is a calligraphy that wanders suggestively between male and female and lays claim to the ambiguous terrain of the intertidal zone.



Spring Thaw (2004). Etching, 32 x 26 cm

Doug Guildford prints at Open Studio, teaches sessionally, and is represented in Toronto by Edward Day Gallery. His work is showcased globally over the Internet by the Centre for Contemporary Canadian Art (www.ccca.ca).



Mid Winter (2004). Etching, 32 x 26 cm

Mice

Anne Marie Todkill

“It’s not a painful death,” the man from the Cleansing Department told her. “Their blood thins, and they gradually get weaker until they expire. It’s a humane poison, not painful.”

Presumably a mouse does not notice, or mind, getting weak. A mouse, like any animal, does not question its own state of being. A mouse simply exists and survives. Or not. In any event, regret doesn’t enter into it.

“It’s also used in humans,” the man from the Cleansing Department said, “to prevent stroke, as I understand. Of course, they don’t call it rat poison in that case.” He made a soft sound in his throat, as if to indicate a humorous intention.

Wouldn’t a mouse feel fear, at least, Sophie wondered. Wouldn’t it know something was wrong? *Nor dread nor hope attend a dying animal.* That brutal poet, Yeats. Why should dread be missing from the psyche of a mouse? Mind you, dread is more than fear. Fear arises from the body, dread from the mind. What did she feel toward childbirth: dread, or fear? Three and a half weeks to go. She did not feel happy, the way she should. She felt apprehensive. Do mice feel apprehension?

Stop this, she told herself. This is too much, too neurotic, seeing parallels everywhere, every bit of experience looped around every other bit, tangled up and vaguely sinister. She shouldn’t be having these thoughts. The pregnancy is normal, the baby is normal, she must dismiss all thoughts that are not normal.

Even so, Sophie was uneasy about the mice she must poison for the baby’s sake. This business about the thinning blood, the painless fading away, wasn’t true. A poisoned mouse bleeds to death, from cell to cell, in

all its vessels and capillaries and interstitial spaces, all invisibly, on the inside.

THE MAN from the Cleansing Department was called in after a mouse ran under the table one evening at supper. It happened to be one of the rare occasions when Sophie and Michael had guests.

“Good heavens!” Maureen had exclaimed.

“Oh, do you have mice?” her husband had said lightly, in a tone he might have used to ask whether they had redecorated recently.

“One or two,” Sophie lied, as casually as she could manage. She had spent most of the weekend on her hands and knees plugging up crevices in baseboards and cupboards. She wondered if this accounted for the peculiar pain she was now feeling under her ribs.

“You’ll want to see to that,” Graham said.

“Goodness yes,” Maureen said. “You won’t want this to cope with when the baby arrives.”

“Quite right,” Graham said. “Where there is one mouse there will soon be several.”

This was not only fatuous, in Sophie’s view, but incorrect. It was possible to be bothered by just one mouse. This was the case, Sophie happened to know, in the flat below, where her neighbour had been engaged in a battle of wits for a couple of months now with a mouse. One mouse. Her neighbour was sure of it. Not a family of mice, and not a succession of mice, but one, The Mouse, to whom she attributed guile, wilfulness, daring, persistence, and all other qualities necessary in an arch-enemy. “I’m going to get that mouse,” she had told Sophie, clenching her teeth, “if it kills me.”

In Sophie’s mind, the mice in her flat were not tormentors so much as supplicants. They were a disadvantaged population claiming their fair share of resources. They were storybook mice who had lost the prudence or the self-effacement to keep hiding behind the wainscoting. She did not see them as enemies, but as a social group exerting a plausible claim. Who was she to insist they camp someplace else?

“What the powerless call justice, others call inconvenience,” she had said to Michael. She presented her view of the indigent mice as a caprice, a thought experiment, a joke.

“I get it,” Michael said. “Proletarian mice. Insurgents. I quite agree: we must side with the revolutionaries.” Evidently he was enjoying this.

Which made Sophie feel a little less crazy. The defect was not in her thoughts, really, but in their tone, their emotional overlay. It was the baby doing this to her, no doubt. Pregnancy had made her reactions strained and over-scrupulous. She could no longer make out what was tragic and what was merely unpleasant. Three blind mice and a farmer’s wife. This was low comedy, merely. She considered the farcical battle downstairs, her neighbour setting off a mousetrap with the end of a pencil to demonstrate how it worked. “That little bugger’s going to come along,” she had said, “and snap! I’ll have him!” She would cut off its tail with a carving knife.

“But you know,” Michael was saying, “the problem is that once the mouse population increases you’ll want to wipe them all out. It’s a territory thing. You’ll feel threatened. Sooner or later, it will be war. Very ugly.”

Sophie could feel her mood collapsing. “I’m going to have a nap,” she said.

She lay in bed for the rest of the afternoon, staring at the wall-paper, the ceiling rose, the egg-and-dart cornices. Her hands and feet were throbbing. She felt like a hot-water bottle filling up. She was filling up with apprehension, she supposed, but also with a slow, dull pain. She felt heavy enough to fall through the bed. It’s just fatigue, she reasoned. She tried to imagine the opposite feeling. Imagine you are shrinking, she told herself. Imagine you are light as a mouse.

THE FIRST MOUSE that Sophie had discovered was rummaging in a bag of kitchen scraps under the sink. She heard an unaccountable noise behind the cupboard door, which she then opened to discover that the garbage bag behind it was rustling and bulging. She did not think “mouse.” She thought only that something odd and sinister was happening. A little scream leapt out of her mouth.

“What?” said Michael, from the doorway.

“There’s a mouse in the garbage,” Sophie said, realizing in that instant what sort of thing would explain the rustling and bulging.

“I didn’t know you were afraid of mice,” Michael said.

“I’m not. I didn’t know it was a mouse. That’s why I screamed.

Because I didn't know what it was."

"How do you know there's a mouse in there? I don't see any mouse."

Sophie tapped on the bag, which had stopped moving. She shook it a little, and it started to rustle and bulge.

Michael stepped back quickly.

"I didn't know you were afraid of mice," said Sophie.

"I'm not," said Michael.

"Poor mouse," said Sophie "It must be hungry."

They exported the mouse in its capsule of rubbish to the front curb. The next day, as it happened, was collection day. Sophie assured herself that the mouse would nibble a hole through the bag and free itself before it got scooped up in a little paradise of peelings and crumbs and rubbery pasta and hurled like Stuart Little into the back of a truck.

"YOU CAN DO two things," Graham informed them. "You can get a cat. Or you can call the Cleansing Department."

"I don't like cats," Michael said.

"The Cleansing Department," Sophie said. "What a thing to call it."

She found the number the next morning, as Graham instructed her, under Lothian District Council in the Edinburgh directory.

"DO YOU HAVE any children?" the man from the Cleansing Department asked her. He was a short, square man with a mildly apologetic air, which Sophie interpreted as belonging to the social apparatus of exterminators. The embarrassment was on her behalf, not his. Whether for having a mouse problem or, more narrowly, for not knowing how to deal with a mouse problem, she was not sure.

"Do you have any children?" the man from the Cleansing Department asked her.

He was deciding where to put the little red plastic saucers that he had brought with him and was now filling with little blue pellets of grain.

For a moment Sophie thought that he must be extremely unobservant, or else rather stupid. Or perhaps he was reluctant to refer more plainly to her condition.

"Any little ones that might get into this?" he persisted.

Now she saw: he meant children already born. Of course. One would

not expect a pregnant women to eat rat poison. Whereas a toddler might. Little grains, a pretty, unnatural blue.

“No,” she said. “No children to worry about, in this case.”

By tacking on the phrase “in this case” Sophie hoped to present herself as rational and self-aware. Her situation was not only plausible, but normal. Anyone might have a problem with mice. Here she was: anyone. Similarly, anyone might have the added attributes of being pregnant, and of being ignorant of how to get rid of mice, and of having a partner who was similarly ignorant (and afraid of mice). This was a normal situation, to which there would be some normal solution. She simply needed to be told what the normal solution was, and then go along with it.

Still, she felt as if the conversation were swooping around her, like a great black bird, circling but not landing anywhere.

“Do you have any children?” the man from the Cleansing Department asked her.

She looked at him blankly. She had a falling-away sort of feeling, like *déjà vu*. This sort of thing had been occurring rather often lately. It was difficult to sort out whether it was her mind repeating itself, or events.

“Any little ones who might get into this?”

Ah, of course. He was referring to children already born, children exterior to her. Impossible to explain to the man from the Cleansing Department that she considered her state of motherhood already factual; that her vigilance and apprehension with regard to the physical hazards of the world were already, on behalf of her invisible child, extreme. Impossible to explain the psychological blurring of imminence and immanence, two words that face one another across a metaphysical chasm, at a distance of only one letter.

“No,” Sophie said, instead, wondering if she had already answered. “No children to worry about, in this case.” She wished that the man would stop talking for a moment while her thoughts caught up with themselves.

“Do you have any children?” the man from the Cleansing Department asked her.

Sophie had the impression that the kitchen floor was tilting downward to the right, which made the man from the Cleansing Department look as if he were stooped in one shoulder. He was a short, square man

with thick rough hair that stood up in spikes when he took his hat off at the door.

“Any little ones that might get into this?”

For a moment Sophie considered answering “Not yet,” or “Almost,” but thought it would be unkind to force the man from the Cleansing Department to cast an awkward, congratulatory glance toward her distended abdomen.

“Do you have any children?”

The rat man was short and square and had rough black hair that stood up in spikes, making him look disorganized. He took off his hat at the door with a deferential air intended to conceal, Sophie knew, his commitment to rational violence. *This man knew death to the bone*. Yeats again, that loathsome fascist. With his little blue pellets, *man has created death*. Or, in this case, the rat man. The word *loathsome*, floating loosely in her mind, bumped up against *Lothian*. She sensed that there was some meaning here, but her thoughts kept travelling in a loop. She felt as if she needed to sit down, but was not sure how to present this idea to the man from the Loathsome District Council Cleansing Department, who stood before her, all innocence, unaware of being lothian, or of looking like Yeats (as it now occurred to Sophie) with his chiselled nose (funny that she had not noticed it immediately) and the shock of black hair that stood up like spikes from the top of his head.

THE MAN from the Cleansing Department began to distribute the mouse bait, opening the cupboard under the sink and setting the little red saucers down at the back, pushing a few more behind the washing machine, using a telescoping stick with a paddle on it, which he pulled out of his kit.

“Am I going to start finding dead mice about?” she had asked.

“Not likely,” the man from the Cleansing Department had told her. “They generally go back to their nests to expire. Or under the floorboards. They shrivel up to nothing. There’s no smell.”

“Is it painful?” Sophie had asked.

If a mouse has any importance, it is unaware of it. A mouse has no sense of potential, or fulfilment, or time. A mouse is not disappointed by its own demise.

“It’s also used in humans, to prevent stroke,” the man from the Cleansing Department had said. His black hair was blurring into the rest of the room, which for some reason was beginning to go dark

“THAT MAN made me nervous,” Sophie told Michael later that day in hospital. She was tied to a machine with an automated blood pressure cuff. “I think he brought it on.”

“What man?”

“The man from the Cleansing Department. He put poison everywhere.”

“Poison?” said Michael.

“He hid it,” Sophie murmured. She was flushed and drowsy with magnesium.

The machine squealed softly as the cuff inflated, pinching her arm. “He’s hidden it all over the house,” she said, and began to weep.

SOPHIE DID, of course, find dead mice for a long time after that day, the day of the night when her tiny daughter was rescued by Caesarean section from her panicked womb. One of those mice was revealed when she removed the panelling beside the bathtub to investigate a leak reported by the neighbour in the flat below. There it lay, as thin as its skin, on bare wood. Others were exhumed by some men from British Gas who, trying to locate a blockage in the copper heating pipes, found an undisclosed number under the floorboards. And there was the little body she discovered under the kitchen window, behind the sink, when she peered down to find a knife that had slipped out of the dish rack. The corpse lay there for two more days before she found the resolve to push it out with a broom-handle and scoop it up with an empty cereal box. She buried it under a shrub outside, although most people would find it strange, she realized, to go to this trouble over a mouse.

Anne Marie Todkill is senior deputy editor at the *Canadian Medical Association Journal*. In 1999 she launched CMAJ’s arts section, “The Left Atrium.”

A Life on the Road

Gretchen Roedde

Ibis

Sacred ibis (*Threskiornis aethiopicus*). Common, with black curved bill and black head, neck, and legs. White plumage with black edges. Singly or in flocks near marshes, agricultural lands, coastal grounds. 89 cm. Family *Plataleidae* (ibises and spoonbills). Large water birds with long legs, ibises with decurved bills. Silent.

The sacred ibis, high in the trees above the cool gardens of the Kampala Sheraton, reminds me that I am in Uganda, far from my Canadian home on a strange voyage. My official work is international development—this time reviewing the outstanding success of HIV/AIDS reduction in Uganda.

But along the path I learn other lessons.

In the bar I meet an American-Trinidadian, Ted Siedle. Ted is here to meet his father's murderers. He hands me a small book—a judicial summary of the deaths of two American journalists, Messrs. Stroh and Siedle. In 1971 they were murdered by Idi Amin's army in the Mbarara Uganda barracks. They had been travelling in forbidden areas to investigate a massacre of Acholi troops by non-Acholi army colleagues. Ted tells me that he has come back to learn more of what happened.

And to say good-bye.

The details in the small booklet are sparse—the chief justice who held the enquiry had to be hidden in the American ambassador's car to be secretly removed from Uganda before the book with his findings could be

released. Findings explaining that disappearances of the Americans had in fact been murder, by the army, presumably sanctioned by Amin.

Ted needs to talk. He speaks with his hands, makes strong angry gestures. “I was seventeen. I had left the country the week before to visit a girlfriend in Norway. I never saw my father again. It took two years of work and a lawsuit against the Ugandan government to find out the truth. There is still too much I don’t know. I can’t move on in my life till I do this.”

In Uganda, he met others bereaved in the same struggle, heard stories about that Acholi massacre, about bodies beaten with firewood sticks and thrown into farmers’ fields when dead. A few did not die. When they regained consciousness, they struggled back to the army barracks—the only home they knew, even though that was where they had been nearly beaten to death, and where they were killed once they returned. The government of Uganda played a strong role in organizing Ted’s trip. Although this army fought against dictators like Obote and Idi Amin, they were trying to heal wounds committed by those other armies. Those days, in the local Ugandan newspapers there were extensive discussions about the role of the American CIA in backing and maintaining Idi Amin. Idi Amin, who used tribal dissension to pit Acholis and non-Acholis against each other, to stir up hatred against the South Asians and to expel them.

WHILE TED GOES UPCOUNTRY to meet the men who had buried his father, I take a day off to go whitewater rafting on the Nile with colleagues, departing from Jinja. It is a terrifying adventure, with four Class-5 rapids—really tough, but so compelling that for a day we forget work and thrill with frequently being thrown out of the raft and drifting past crocodiles, seeing lazy ibises high above us. There are two rafts, each one led by two or three professionals—a mix of Aussies, Zambians, and Ugandans. At noon we land on a small island in the middle of the Nile and lunch together and meet the others. The other boat carries policemen from Holland and Canada—part of an international response to gather evidence in the Rwandan war crimes tribunals. This Ugandan trip is an R and R weekend for them. It is their first assignment in Africa.

As we eat our simple but wonderful lunch of salads and buns and fish,

they complain about how long it takes to sift through the documentation. Some of their colleagues are from other developing countries in Africa and are thrilled to be on UN per diems and want to drag out the process as long as possible. The Dutch and the Canadians, on the other hand, are eager to get back home and are impatient, not so much at the length of time it all takes but how every time they find evidence that leads to Belgian or French complicity in the Hutu/Tutsi massacres, they are told “hands off.” This is just to convict Rwandans, not the Europeans who each fuelled a side in tribal animosity, playing their own colonial games.

We return to our rafts and look up at huge trees along the shore towering against the sunset. Looking back at us like sentries, several sacred ibises cast dark tall silhouettes. Imposing birds, lacking obvious grace but full of presence, they sit in watchful guard over the scene below.

THE NILE has its source at Jinja in Uganda and flows upwards through Sudan into Egypt. Borders simmer with hatreds and rivalries: the south of Sudan a base for Kony rebels just ending the war in northern Uganda; Uganda a base for the southern Sudanese struggling against the powerful Nilotic people—the Arabic blacks who control Sudan from Khartoum.

On another mission, this time for Germany, our international team had travelled to Darfur to assess the possibility of strengthening primary health care for the people of Darfur and the internally displaced refugees who had been sent there.

That was 1989, long before the Darfur genocide we in the international community are learning about as though for the first time.

But back then? Trainloads of Dinka refugees arrived in Darfur, then were set on fire. All died. We found a slave camp of Dinka and other southern tribal boys labouring for an obese Arab businessman, making furniture for him to sell. In leg irons and chains, sleeping thirty to a small room. We had to sneak out to the Médecins sans Frontières refugee camps, because our Sudanese hosts did not want us to see what was really happening. The aid agencies turned a blind eye—Sudanese permission was needed to monitor troop movements in Libya or Chad. Whoever was going to win the war in the south with its oil and gold reserves was the side to befriend. There was little response to the Canadian television documentaries of slaves of Dinka boys on the march.

All so predictable that the current horrors of ongoing cultural genocide in Darfur could have been acted against earlier.

As we gathered in line for our return Egypt Air flight, passengers separated by gender for boarding, I lined up with the kohl-eyed Muslim women. Veiled and hennaed, they stood peacefully. Their waiting was filled with quiet, hushed voices, unlike a Western room filled with impatient travellers.

Movement forward is slow, but there could be peace in the waiting.

Ibis—symbol of the soul, sacred to lunar deities (Egypt); devotion and perseverance (Christian art).

Peacock

PEAFOWL: male, peacock (*Pavo cristatus*). 210 cm. In the wild, haunts thick, well-watered jungle in hilly country. Shy and difficult to see. The cock's tail is carried just off the ground.

We are driving in a heavy-duty Land Cruiser, bumping over mountainous roads, swaying and bouncing, nothing to see but bush—and then a bright flash of blue astounds us, ceremonial splendour, arrogant toss of the head, and around turns the peacock, back into forest cover.

Earlier we had been walking on a winding mountain path. Ahead we heard chanting, drumming. We kept to the side of the narrow lane, and a procession of men appeared, carrying a bier on which was carefully balanced the body, draped in red, of a woman who had died in labour at term. In this part of rural Nepal, women have a one-in-twelve lifetime risk of dying during pregnancy, labour, delivery, or just after birth.

In the community that day, these words from the husband of a woman in obstructed labour who needed transport to hospital for a Caesarean section: “She cannot go. Her duty is to stay here and feed the water buffalo. After her work is done she can stay in the barn to deliver her own child. If she dies, it is fated.” Or yesterday, the young malnourished mother of two girls, forced by her husband (from an arranged marriage to pay off a family debt) to conceive again so he could hope for a son, resorted to an unsafe abortion once the pregnancy was discovered. She was close to death when we saw her, in the small hospital, brought there by her parents.

Watchful.

Unlucky.

Vain.

Violent.

Evil.

Another peacock and another time, Malawi, 1990. I spend the morning in the mud hut of a traditional birth attendant, seeing how carefully she delivers the women who come to her, how well kept her home is, how clean. In the afternoon, a change of clothing and a shift of emotional gears, follow the long sweeping drive, past uniformed guards who salute us—to the presidential palace for tea. Across from us, graceful on the ceremonial lawns, a sweep of blue and green, a haughty arabesque as the tame peacocks remind us we too are on display.

There are three of us partaking of pancakes, Canadian maple syrup, cucumber sandwiches, and tea. There are at least as many waiters, white jacketed and tall, standing ready to serve. Mama Kazamira offers us more tea. She is the architect of Hasting Banda's career, "the lifelong ruler" of Malawi, and is the real power behind the throne. He is not well and is only brought out for official tours, carefully surrounded by handlers who make sure he only sees what is permissible, and is kept sheltered from the grim realities of the country. His first wife (who was English), and children—dating from his medical training and OBE days in England—have conveniently disappeared. I try not to think of the rumours, Mama Kazamira's role and that of her consort Kamuzu Hastings Banda in the disappearances and death squads.

We discuss some concerns. A Canadian charity had donated some used clothing for Mozambican refugees, which instead was sold and the proceeds used for two dialysis machines and their reagents, kept for a lucky few affluent patients. Mama Kazamira assures me this was her wise decision, a good cause too, as good as that of the refugees. I ask about other needs, high rates of malnutrition, under-equipped health centres. With her eyes partially closed, nodding her head, she looks like a huge bullfrog sunning herself sleepily on a lily pad. She assures me, what little malnutrition exists is cultural and due to ignorance, as are the deaths of young children from diarrhea, pneumonia, measles.

I had earlier been advised by the crusty orthopedic surgeon with whom I was working that "there is no malnutrition in Malawi." And the newspapers tell me Banda, the Supreme Ruler, has declared his official

“crop inspection tours reveals best maize crop ever.” Also in the papers one visiting ambassador compliments Malawi for being “self-sufficient for food.”

Somehow this isn't reflected from our visit here, UNICEF citing one in five children dying before the age of five from malnutrition and infectious disease. We have met women in the villages whose husbands work as indentured servants on Banda's vast tobacco estates (all assets in the country retained by the leader and his official conglomerate, Press Holdings). The village men aren't allowed to leave the estates until the end of the harvest because they have been “loaned” a bag of maize for which they haven't paid. Even though their own children are starving, they aren't able to earn money until the end of the season, by which time some of their children have died. Nor is this self-sufficiency reflected in the massive food aid given to offset the large tracts of arable land devoted to non-foodstuffs like the tobacco plantations we have passed. And the “best crop ever” is the maize, burned brown in the fields from the lack of rain, worried villagers seeing one lost crop while last year's harvest stores have already been finished.

The worried villagers are everywhere, but few risk telling us these stories, well aware of Secret Service informers, including our drivers. One medical colleague was disturbed when one of Banda's political enemies was brought to hospital, ostensibly from a motor vehicle accident. But he felt uncomfortable telling me about it. He knows that to stay in the country and continue to provide good medical care to needy people, he cannot mention the gunshot wounds or comment when he sees the death described in the official press as an unfortunate traffic accident. Only praise is permissible.

The next day the cook of a friend I am visiting asks for a medical excuse for his wife to release her from being drafted as one of the group of “official praise singers” who accompany Banda and his entourage. These women wear his face on their kanga cloth dresses, and sing and dance ecstatically as the Supreme Ruler tours his kingdom. Women drafted for this role are said to be required to be sexually available to any in the official party: married men are not happy to see their wives leave them for this mandated tour. I write a letter, outlining that for health reasons his wife cannot be considered: asthma exacerbated by long dancing and

singing, diabetes needing more regular meals than would be received while travelling.

While we are talking, a peremptory knock at the door disturbs us. The brown uniforms of the youth wing of the ruling party can be seen goose-stepping from house to house to collect money. Failure to “donate” leads to later visits, beatings, thefts—so both Africans and expatriates manage nervous smiles and come up with the contributions they hope will be sufficient.

Before we leave we spend time in the hospital, assessing orthopedic training of clinical officers. One orthopedic assistant proudly shows us the limb he saved on one soldier whose leg was blown up when he was patrolling trains in Mozambique. Officially Malawi helped oppose the South African-backed Renamo fighters. Unofficially Malawi traded with South Africa throughout apartheid and arranged with Renamo to spare trains carrying Press goods across Mozambique to the coast.

A decade later, Banda and Mama Kazamira, together with their aide John Tembo, were convicted of fraud and misappropriation of millions of dollars during their reign, though acquitted in 1995 of ordering the political assassination of four opponents in 1983. Slowly the country is rebuilding, dealing with the ravages of AIDS, other illnesses, and poverty.

The many eyes of the peacock’s tail symbolize watchfulness, the feathers unlucky and considered a form of the evil eye (Buddhism); the peacock is the mount of Karttikeya—the god of war (Hinduism). The vain male peacock courts its mate with pride: this royal bird, symbol of the sun, its tail reflecting the heavens and its eyes the stars.

A Life on the Road

We had been visiting small family-planning clinics, trying—with Canadian financial assistance—to help broaden their work to reproductive health, adding STD/HIV prevention, safe delivery, post-abortion care, and support to end violence against women. In our pickup truck we had a crew cab (my two Tanzanian colleagues in the bench second seat), two seats in front (myself as team leader and the driver/project coordinator), and the open back of the truck where our CBDs (community-based distributors) joked and relaxed in the swaying truck on dusty, seldom travelled roads.

We were tired, trying to do the usual: too much in the short time available for a project evaluation. Ahead was a man with a bicycle,

desperately trying to flag us down. On the back of the bike was a basket, and in the basket, his pregnant wife whom he was bringing on the four-hour bike-trip to hospital.

We stopped to offer help. This was her fifth delivery; she had been advised to have this higher-risk babe in a hospital. Labour had started five hours ago and she was unable to reach her husband until a messenger found him at work on the *shamba*, or family farm. The husband was needed to bring money and to accompany her. Standing beside the bike, toothless, face wreathed in smiles, was the labouring woman's mother. We offered to transport the family in our vehicle. My colleagues moved from their seat to the open back of the truck, along with the husband and his bike. The mother-to-be and her mother moved into the bench seat—the older woman with a bag of pots and rags to assist with a delivery if needed.

I asked the driver, through translation, how long the woman had been in labour. Five hours. And this was her fifth child? Did the grandmother know how to deliver? Yes. What did she have available for delivery? She proudly pointed to the rags and the pots. The labouring woman was silent, but then gave a small worried sigh.

I turned around and lifted her skirt and saw the head crowning. With meconium staining. Still twisted around in my seat, I took one of our bottles of water, poured it over my hands, crossed myself (as did the smiling grandmother), and unwrapped the cord from around the neck, delivering the baby while we were still driving. Seconds later, with the blue-faced infant not crying, in spite of my desperate efforts to spank some kind of response, a small health centre came miraculously into view. I asked the driver to get a midwife quickly, to tell her we had a flat baby, newly delivered in the truck. Out came the Tanzanian midwife, pulling on gloves, with a basin and suction for syringing the mucus from the babe's mouth and nose. She managed to get the baby to give a lusty cry, before delivering the placenta. Moments later we were helping mother, child, and grandmother into the little clinic. Mom was hosed down on the cement floor, the infant placed on a weighing scale. I washed my hands with iodine soap, suddenly remembering the HIV prevalence in this region. The father and his bike came next, wreathed in smiles. We left a bit of money as a gift and carried on.

THE NEXT MONTH, we finished up work in strengthening primary health care in Upper West Region, one of the poorest parts of northern Ghana. Because of insecurity and tribal fighting just south of us between the Dagombas and Kokombas, our Danish government donor asked us to wait for a military plane to evacuate us later in the week. My colleague was a Ghanaian public health nurse who could see her husband and four children—she was expecting her fifth—only if she made the road trip through Kumasi on the fourteen-hour journey from Wa to Accra. We decided to chance it, following a convoy of English road engineers who were being evacuated.

It was 4 a.m. when we left, amid Muslim and Christian prayers from medical colleagues. Somehow we were separated from the road crew. Six hours later our truck was surrounded by fifteen to twenty armed men with guns and poison-tipped arrows. We didn't know if they were Dagombas or Kokombas, but had heard the reports of pregnant women disembowelled, children taken out of school and shot, their heads on stakes along the Tamale road, of churches burned to the ground for harbouring offending tribes.

We slowed to a nervous stop. I rolled down my window. With a huge smile I started to shake hands with as much flourish as I could, with the snap and clasp of the well-choreographed handshakes of the region. Big grins greeted me—"Good morning, *nasala* (white person)," the men smiled. Others crowded in to get a chance to shake my hand. One of the men pointed. I looked to my side, to our box of bottled water and made a movement as though to offer it. No, no! They pointed again—this time to my camera beside the box of water. Smiling, they pointed their guns and arrows, for a photo. And for another. Then, with a wave and more grins, we were permitted to carry on our journey, back to the open road.

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Funeral Music

Robert Maunder

I've thought too much about what songs should be played at my funeral. Why? I'm in pretty good health. I'm not too old. One of my jobs is to listen as carefully as I can to people who are sick or dying, which may be a factor. Like a lot of people who love music—like that idiot in the car beside me with his windows rolled down and his stereo cranked up—I want other people to hear what I hear, which may be a factor too. My friend Ken died. He had the same job, was not too old, and was in pretty good health until he got sick. Ken knew the difference between J. J. Johnson and Robert Johnson. It's about time I put some of this on paper.

I have never got around to compiling my funeral playlist, although I have managed to find the time to make CDs in honour of cars, girls' names, blasphemous songs, top-forty radio songs from 1972 (a five-CD extravaganza!), and songs about walking ("Walk on By," "I Walk the Line," "Walk Like an Egyptian," etc.). It is probably not lack of time that has prevented getting my funeral list down. As Jim Cuddy sings "I don't need a doctor to figure it out. I know life's passing me by." So it's about time that I put some of this down.

I'm not the only one thinking about funeral music. When I sent this essay to Jon, Ken's friend and mine, he replied with a list of the songs he wants at his funeral, which is attached like a codicil to his will. In Nick Hornby's *High Fidelity*, Rob, Barry, and Dick name the best death songs, in memory of Rob's Laura's Dad's death. That very awkward triple possessive phrase seems to me to convey the quality of misplaced ownership that runs through *High Fidelity*, as it runs through some relationships

and many music collections. Maybe planning your own funeral music is a last stab at trying to own the space between people that is never really under your control. And Hornby, it turns out, has thought out the funeral playlist for himself. In *31 Songs*, he says he wants his mourners to hear a live version of Van Morrison's "Caravan" when they meet to finally contemplate his life. Everyone remembers the opening scene of *The Big Chill* when the little church organ starts to play "You Can't Always Get What You Want." So maybe revealing my pathology in a list of funereal pop music is not too aberrant.

There are problems in finding the perfect pop song for a funeral. For one thing, a song's meaning may not be found in its words. Maybe that shouldn't matter; people choose hymns for sentimental reasons more often than theological, I suspect. Nick Hornby notes that the words of "Caravan" are not actually about death at all (the most memorable part being "laa laa la-la, la-la la"), but they convey something about life, and the music captures something in his soul. Hornby also hears God in the second verse of Rufus Wainright's version of "One Man Guy," which goes to show either that finding the divinely apt moment in pop music reveals personal idiosyncrasies or that God chooses odd moments to reveal himself to atheists.

Jon too has picked songs that aren't really about anything universally relevant to the bereaved. Unless you find Leon Russell singing, "I hope you understand but I just had to get back to the island"—a deeper metaphor than is probably intended. However, the song has attached itself to his life in a way that makes listening to it a sharing of something personal. I am planning to be there when that song plays, although it is just as likely that it will be Jon at some other chapel doing the listening and I will be finished with doing altogether. Most of us who gather to say goodbye will know that there are a couple of important islands in Jon's life, and so we will find those words relevant in their own way. Or John Fogerty singing, "Put a candle in the window 'cause I feel I've got to move," which would be maudlin and insufficient if it were not for the music, that voice, and the connections to Jon's person that make it matter.

Then there are awkward words. Hornby worries about what the people at his funeral will do when Van starts to introduce the band. My

problem is that the lyrics that best convey what I want to say to my friends are often found in songs about bad relationships and breaking up. Ignoring whatever that may say about the state of my closest connections, it is troubling that I need you to hear the phrase that struck me as exactly right and ignore and forgive the parts that are out of place. Essentially, I need you to read my mind. That is a common problem with the impulse to share music and stories. “I want you to read this” so often means “I want you to experience what I experienced when I read this,” which is asking for something rare. And so for my funeral list I have suppressed the songs that too greatly strain good sense and decorum. Elvis Costello’s “All This Useless Beauty” is out. Too bad, the chorus sums up a world view that is close to my heart with near-perfect irony, reverence, and resignation—the view that some of the best moments in life are those in which we can apprehend at once both life’s beauty and its complete lack of any given meaning or redeeming purpose. “What shall we do, what shall we do, with all this useless beauty?” Unfortunately, those lines anchor the complicated story of a pretty ugly relationship.

Or the problem of the Clash. The Clash have never performed a song that was in any way appropriate for a sacrament. But I would be happy to think that you listened to them in the car on the way home. The Clash have it all—passion, anger, righteousness, and humanity played really loud, a connection to a good time in my life (nineteen), and not incidentally a connection to almost everyone else who has found his way into this essay (Ken, Jon, Hornby, his character Rob, John Cusack, who played Rob in the movie). Human connectedness is the other theme that I want to permeate my funeral. Connectedness is a virtue that “All This Useless Beauty” undermines, and that won’t do. Funeral songs have got to have it all. So here is my list.

“John the Revelator,” by Son House. I am not a religious man, but I may be a carrier. I don’t think it is biblical content that makes this song feel right, anyway. Son House makes the consonants sound like vowels, rushes and truncates the words. There isn’t much content—it’s the blues. The one-man call-and-response sung against the bare instrumentation of two softly clapping hands is passionate and lonely and yet engaged with the articles of the singer’s faith and with his audience. Especially

the audience, because this song is sung to someone, maybe someone who needs convincing, and I would rather have this played at my funeral than any hymn that I can think of. I guess this is my “Caravan.”

There was a time when I would have wanted Laura Nyro’s “And When I Die.” Except it would have been Blood, Sweat, and Tears’ “And When I Die,” because I was a teenager, and had never heard of Laura Nyro. She was seventeen when she wrote it. The idea that so appealed to me—“And when I die, and when I’m gone, there’ll be one child born in this world to carry on”—is an idea for teenagers. It assumes that the great tragedy of my dying is the loss of *me* and this will be remedied by the birth of another little rebel in my image. As Jim Cuddy also sang, “I don’t think that anymore.” Or as Bob Dylan said, strapping on his electric guitar at the Royal Albert Hall concert twenty-five years earlier, “It used to go like that. Now it goes like this.” Someone else said that when he lost his religious faith he was left for the rest of his life with a “God-shaped hole in the universe.” The image stuck with me. Ken’s death will leave a Ken-shaped hole in my universe. It is a hole about the size of a person, which I will tolerate. Imagine what a Ken-shaped hole looks like to his kids or his parents or wife. There are bigger holes yet to come for me. So sure, when I die there will be the loss of me, but that’s not the tragedy. It takes growing up to realize that the tragedy of a death is all those people walking around with holes in their universes. And one child born in this world to carry on is a good thing, but it’s beside the point.

“Shine,” by David Gray. “Shine” is a gift for those who cared enough to come say goodbye. It starts at a relationship’s end, and offers redemption in shared promise. Promise (not a promise, but hopeful possibilities) can be shared by those who can no longer be together. “Dry your eyes. We’re going to go where we can shine” means dry your eyes and go do something amazing. Ken left messages for his friends that made us feel something like that, and it makes me happy to think of passing it on.

There are songs and artists you hear unexpectedly, and sometimes the moment stays with you. I remember the first time I heard “Smells Like Teen Spirit” on the car radio with the same clarity as when I heard on another road that Gretzky was traded to Los Angeles. I could tell you which stretch of highway I was on and what the weather was like. No doubt part of the appeal of “Shine” is that I first heard David Gray sing

it when I had not heard of him, when he was an opening act at the El Mocambo. It was the first time Lynn and I had been out alone together since the birth of our first child a year earlier. Gray was young and surly, cursing at the sound coming up through the floor from the bar below. The music was lovely, and I was very excited to be on a date again. I went out and bought a cassette the next day and listened to it a lot. That album was hard to find for quite a few years, which made it more special, like a good secret that you want to share.

“One,” by U2. The story of this song, as I heard it, is that the band was not getting along and the music was bad. They fought and left the studio angry. Maybe it was over. Bono came back the next day with a song that says that our salvation is found in caring for one another. They played it and everything changed. “We’re one, but we’re not the same. We get to carry each other, carry each other.” My funeral friends will need to ignore the accusations. I don’t really intend you to squirm through “Have you come here for forgiveness? Have you come to raise the dead? Have you come here to play Jesus to the lepers in your head?” The message of fellowship, however, is worth the squirming.

“Hallelujah,” the Leonard Cohen song, but in the version sung by John Cale, an arrangement that is heartbreakingly simple and beautiful. This is a song that in the first place is about the power and beauty of music, and in the second place about discord in actual relationships (“I’ve heard there was a secret chord that David played and it pleased the Lord but you don’t really care for music do you?”). It is sad and resigned, and somehow the music and the repetition of the hallelujahs manages still to celebrate.

Maybe there’s a God above, but all I ever learned from love
 Was how to shoot at someone who outdrew you.
 It’s not a cry you can hear at night.
 It’s not a pilgrim who’s seen the light.
 It’s a cold and it’s a broken Hallelujah.

Hallelujah. Hallelujah.

CELEBRATION THAT TRANSCENDS PAIN and disappointment rather than ignoring it is precious.

Four songs are probably as many as a funeral can stand, but on

the trip home I hope you listen to the version of Dylan's "Knockin' on Heaven's Door" that Warren Zevon recorded while he was dying of cancer, and "Lean on Me," and "Stand by Me," and anything by Van Morrison where he tells you to turn up the radio. There isn't enough time for all the music. Nothing fills that hole.

IN MEMORY of Ken Citron. With thanks for the music to Jon Hunter.

Songlist

- Blood, Sweat, and Tears, "And When I Die," by Laura Nyro, *Blood, Sweat, and Tears*, 1969, Columbia.
- Blue Rodeo, "Rain Down on Me," by Jim Cuddy, Greg Keelor, *Lost Together*, 1992, WEA.
- , "Til I Am Myself Again," by Jim Cuddy, Greg Keelor, *Casino*, 1990, WEA.
- Cale, John, "Hallelujah," by Leonard Cohen, *I'm Your Fan: The Songs of Leonard Cohen by . . .*, 1991, EastWest.
- Costello, Elvis, "All This Useless Beauty," by Elvis Costello, *All This Useless Beauty*, 1996, Warner Brothers.
- Creedence Clearwater Revival, "Long as I Can See the Light," by John Fogerty, *Cosmo's Factory*, 1970, Fantasy.
- Gray, David, "Shine," by David Gray, *A Century Ends*, 1993, Caroline.
- House, Son, "John the Revelator" (traditional), *Son House: Father of the Delta Blues; The Complete 1965 Sessions*, 1992, Columbia Legacy.
- King, Ben E., "Stand by Me," by Ben E. King, *Atlantic Rhythm & Blues 1947-1974*, 1991, Atlantic.
- Van Morrison, "Caravan" (live) by Van Morrison, *It's Too Late To Stop Now*, 1974, Mercury. The studio version was originally released on the *Moondance* album in 1971.
- Nirvana, "Smells Like Teen Spirit," by Kurt Cobain, *Nevermind*, 1991, DGC.
- Rolling Stones, "You Can't Always Get What You Want," by Mick Jagger, Keith Richards, *Let It Bleed*, 1969, Abkco.
- Russell, Leon, "Back to the Island," by Leon Russell, *Will O' the Wisp*, 1975, The Right Stuff.
- U2, "One," by Bono, Adam Clayton, The Edge, Larry Mullen Jr., *Achtung Baby*, 1991, Island.
- Wainwright, Rufus, "One Man Guy," by Loudon Wainwright III, *Poses*, 2001, DreamWorks.
- Withers, Bill, "Lean on Me," by Bill Withers, *Lean on Me: The Best of Bill Withers*, 1994, Columbia Legacy. The single was released on the Sussex label in 1972.
- Zevon, Warren, "Knockin' on Heaven's Door," by Bob Dylan, *The Wind*, 2003, Artemis.

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A Picture Made of Sound

Anne Elliott

TWO THINGS I fear becoming: (1) a hypochondriac, (2) a narcissist.

THE TECHNICIAN hands me a gown and looks down at my questionnaire clipboard. "You're young," she says. "Why you here?"

I'm a hypochondriac. "Family history," I say.

"More than one family member?"

"Yes."

She nods gravely. I look at the wall.

OH, I FORGOT, one more thing I fear becoming: (3) my mother.

I see her in a photograph, three years diagnosed, four years from dead. She, in a black formal gown with glass beads hanging lopsided across her front, earnest eyes peering up at her violin. The photos in sequence, a film strip. A long drag of the bow, a goofy grin. You can see the cacophony in the photo, the scratchy waves exiting the swirly soundholes, the almost-there pitch of the violin beginner. "My father never let me learn violin," she used to say. "He said the sound would drive him crazy."

"You're fifty years old," said her therapist. "He lives 500 miles away. He can't hear you from here."

I wasn't so sure. That noise had a way of hanging on the breeze.

"CAN I HAVE THAT?" I ask the X-ray technician. I collect pharmaceutical pens, use them to write in my notebook. "I'll trade you my Nexium for that Tamoxifen."

She shrugs, hands me the pen, wraps the lead apron around my middle. No, not pregnant, not even close. I wonder if all aprons are lead in some way, along with their strings, heavy and poisonous, sucking women and their offspring down to the bottom of the pool. The apron feels cool and good, though, this time, like a heavy heirloom quilt pinning me into bed.

“Hold still.” I know the drill. Hold my breath, squish each side like blemished double-D cider apples, horizontal, then vertical, then angular, then a magnification of the area they seem to be watching.

A MONTH AFTER she died, I went to St. John the Divine, where a violinist played in the columbarium. I didn’t want to interrupt, so I sat just outside the entrance, closed my eyes, and listened to his pure notes reverberate in the hollow marble room. Chaotic with its own past, notes remembered from the phrase just before, occasional dissonance, but mostly complementary harmonics, like the echo in a canyon or cistern.

The violinist stopped. I heard a man ask him why he played in the columbarium. Wasn’t it obvious? “This is my best audience,” said the musician, then bowed a long, high, naked open fifth, ending the conversation.

THE DOC ASKS if I can stay for ultrasound. Sure, I know the drill. I never see her, this doctor. She hides in a room full of slides and films and computer screens, like the Wizard of Oz. I re-gown and move to another room, where a new technician notices my notebook. “You’re a writer?”

“Yeah, well, it’s more of a hobby.” My own scratchy sounds, practising, trying for something pure.

“Hobby, yeah, right.” She can see right through my thick hide of self-effacement, straight to the part that takes itself too seriously. “My son is a writer.” On the wall, a clear image of an unborn baby’s face, a new soul, a picture made with sound. “I wanted my son to really do something with his writing, you know?” She squirts warm gel on my bare chest, begins the long process of looking for lesions. “He was so good in school, he got an award even from the *Daily News*.”

“Wow.” The light is dim. Her screen glows, echoing blue on the acoustic tile ceiling.

“But he had to get an MBA. I told him, OK, so if you are in business, at

least try publishing, you know, surround yourself with what you love.”

“That makes sense,” I say.

“You write for a living?”

“No. I work in an office.” Hardly surrounded with the stuff I love. “But if I didn’t, I wouldn’t be here.”

“Insurance. True.” I look up at her little screen, a black-and-white image of my own fat and blood.

“Anyway, who listens to their mother, right?” Then she blushes. She has seen my chart, knows mother is a weird word. A pause, as she types into her keyboard. “So, is your mother all right?”

“Nah, she’s gone.”

“I’m sorry.”

I decide to keep it clinical. “Well, she was diagnosed in the eighties. A lot has changed.” I think of my new pen: “Tamoxifen—that wasn’t around yet.”

“Yes, and the screening tools,” she lightens up. “Wow. I got into this field just as it was exploding, about ten years ago. I got to see some of the miracles happen.” She glides the sensor over my skin, shooting sound into my body. “You know, it was a woman engineer who figured out how to use harmonics. It’s chaotic, you know, the way the sound echoes back. Used to be you’d get only a fuzzy picture. But she figured out how to analyze the chaos, so now we can even tell what kind of tissue we’re looking at.” Her eyes bright, echoing the harmonics on the screen, she loves her work, is surrounded by what she loves. “Like here,” she clicks a pointer at a dark mass, “now we can tell this is just a cyst. No cutting.”

“No unnecessary radiation.”

“Exactly. And check this out: a woman invented this too. See, the machine gives off hot air. So they put this sleeve here for the gel, so the machine just warms it up. A man wouldn’t’ve come up with that. It’s too practical.”

Mom used to say things like that. Irritating, sometimes, but not always. Some kind of warm gel is welling up in my solar plexus. I swallow it back down.

“The things we women go through,” says the technician, as she starts in on the other side.

I think of Dad, stroking Mom’s bald head, sometimes for more than

an hour, to lull her to sleep. Going through something too.

The technician stops. "Check this out: see this thing moving here?"

I see it. I feel it. It's the edge of my nervous heart.

"Pericardium," she says.

"Oh." I knew it had a better name.

THE UNIVERSITY where Mom worked has an engineering scholarship in her name, for minorities and women, under-represented in the field. This year it went to a gal who plays violin in her spare time. I wonder what miracles she will witness. Or engineer.

I think of her, this stranger, her future facilitated by my mother's lack thereof, as I put my clothes back on and walk into the midtown evening. Against the hard city harmonics, honks and sirens, the hypochondriac pipes up: another year clear! The narcissist is almost disappointed: an illness could be my ticket out of the office and into my ready notebook. Think of the material!

And Mom, she's quiet, for the moment. I think she's busy. It's just another day. Maybe she's practising, back in the columbarium, with her new teacher, surrounded by what she loves. It's been twelve years. She might even be good by now.

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Case Study Monologue

“There’re Only So Many Things You Can Make a Joke About—Then You Stop”

Laurie Rosenblatt

Abstract

The efforts of medical educators to teach effective professional communication to trainees have often foundered on the complexity of the task and difficulty in measuring gains. Brody, Charon, DasGupta, Frank, and Kleinman have each suggested that personal clinical stories and the comprehension of a patient’s story structure are the foundations of empathic understanding. By telling stories, people organize and understand experience. Thus, one possible use of stories is to provide a way for physicians, nurses, and trainees to shift back toward the patient from the positions of distance that protects them during the performance of treatments and procedures that may be painful to the patient.

This paper presents the entire text of a patient monologue and discusses the use of the creative non-fiction monologue as a narrative teaching tool. These monologues have been used in pilot programs at the Harvard Medical School as a way of focusing learners on their own responses as they begin to look at the personal and professional effects of witnessing suffering.

The audiotaped interview came from a study approved by the Dana-Farber internal review board, and permission to use both the interview and the resulting monologue was obtained from the subject and her surviving partner.

I'll first present one creative non-fiction monologue in full and then discuss the educational uses of such monologues in more detail. This case report monologue was constructed from an interview with a forty-year-old woman living with advanced breast cancer.

Monologue

I WAS TWENTY-NINE YEARS OLD when I was diagnosed with stage 3 inflammatory breast cancer. It's the worst kind. I had surgery, then high-dose chemotherapy, a bone marrow transplant, and finally radiation.

After that I was OK, in remission, until four years later. One day, I felt like I couldn't breathe and I thought I had pneumonia; it turns out I had fluid in my left lung and around my heart. I had a mass on my hip as well. So I had several operations to get the fluid out of my lung and my pericardium. And then I did another round of chemotherapy with Taxotere, that really kicked my ass. For me, it was worse than the bone marrow transplant. It was horrible—hor-ri-ble! It caught me by surprise, because I never got sick from Adriamycin. Everybody was amazed about that. It just didn't make me sick that way. I felt shitty, of course, but I think the thing that really made the Taxotere much worse was that I'm allergic to it, so they had to pump me full of steroids before they could even get it into me. And this sounds really shallow, but the worst thing about it was I gained fifty pounds. So I was fat and I was bald, and I knew it. During the transplant I was much better, because I was so out of it: I didn't give a shit. This was just emotionally a lot harder. The first time with chemo I thought, *I'm gonna kick this thing's butt, move on with my life*. But the second time, it was, *Oh, my God, this thing is never going to leave me alone*. Another year of my life spent, trying to save my life at the expense of living my life.

When I got the recurrence, all my friends were going to graduate school and starting to have families—and what am I doing? Chemotherapy! That was hard. I felt like I was really falling off the road. I felt that at the beginning, but I thought, *Well, it will be one year, no big deal, it won't change my life*. And it did.

I'm not saying that I'm glad that it happened, but there were positive things that came out of the first time around. It just got really difficult the second time. A lot of it was emotional. I had bigger issues than I thought I would about losing my hair. I've always had body-image issues,

so gaining fifty pounds was not good. But thank God for the next pleural effusion, because I lost it all. I'm probably the only one that can see that as a good thing. You know you don't get cancer exclusive to the rest of your life. You go into it with all your shit; everything comes with you. I remember thinking when I was a kid, *I just can't wait 'til I grow up*. When I grew up, everything would be magically okay, I would have a great life, and I would have happy relationships. I've realized by having cancer, you never really grow up. You just get older. It all stays the same. It's just older. How disappointing. That's the hardest thing about having this illness: it doesn't go away. It's like my past, this crazy, dysfunctional thing that won't leave me alone. It's very cruel.

The third time, I ended up recurring in my right breast. I started radiation. And in the middle of the radiation the tumour in my lung started growing. I haven't been in remission for very long at any stage. This is my sixth recurrence.

I meant to say, when I got sick the first time, I didn't realize—everything happened so fast—I didn't realize that I was going to be sterile afterwards. Not that I wanted a kid then, anyway, but it's nice to have the option. And lately it's not an issue, it's just a very sad thing, because right before I recurred this time, my partner and I were considering adoption, considering parenthood. I felt that I was in a place where I could actually be a decent parent. So we were really excited. And for a while after I recurred, she would still talk about it, would say, "Oh, well, whenever this treatment's over . . ." And I'm thinking, *I'm going to be dead*. Or, *How can you talk about having a kid when all bets are off now?* I mean, as far as I was concerned, and am concerned, once you recur you are in a whole different category of cancer patient. It's going to kill you, sooner or later. It might be later, but it's still going to. This is going to be how I die. And so the thought of having a child is not a part of what I can do now. So every time the cancer recurs I think, *There goes another part of my life*.

I go from being an existentialist to thinking that there's really some karmic thing happening. But that's kind of been the theme throughout my life. My parents were very broken people. And so I had to get out of the house before I could go to college, because they couldn't help me. And it was a lot of work to be sane, to get out of Pennsylvania without getting knocked up, and to have a life. And then I finally got a degree, and things

were looking good, and I was applying to a master's programs in architecture, then here comes cancer. I just think that cancer is a metaphor of my family or something. I mean, they both just keep popping up. And then I decided to go back to school, Slam, the recurrence. And I haven't really been in remission since that recurrence. I've been in remission for a month here, couple months there, but it's really been a continuous thing. Part of me feels like a geriatric patient, I'm in my early thirties doing arts and crafts. I'm having a really good time. But I certainly don't have any long-term goals. And that actually worries me, because I remember my therapist from the Mind-Body Clinic saying you have to have a long-term goal if you're going to survive. So, I'm like, "Shit, I've got to get a long-term goal." I don't know what it's going to be. Right now it's just "Stay alive until September."

What I do now, if I can work, is design housing for community-development corporations, low-income people, people with AIDS—whatever. I always had a hard time with private client architecture because I just feel I'm too much of a social justice person. The housing I designed was different from any other public housing to that point. So I felt good about it. And then I got sick again, so somebody else took over that job and basically finished it, because I was out of work for over a year.

I guess the housing project seems even more important to me now that I know what it's like to get Medicaid. Nothing says disrespect like Medicaid. I have never been so insulted in my life as I have been at the pharmacy: whenever I whip out my card, it's amazing. Everything changes. You know, I've never had food stamps, but I have become more aware of how people treat you when you have public assistance. When somebody whips out food stamps in the grocery aisle, all of a sudden, the cashier has this superior attitude. It's humiliating. I have been in the pharmacy and taken out my Medicaid card, and they'll yell, "This woman here has welfare," "This is a welfare prescription," and I'm thinking, *Shut up*. I don't know why they have to announce it like that. They don't announce, "This person has Blue Cross." They don't do that. I think it's about punishment. I think it's about being punished for being poor. I'm feeling when I'm in line, and this is happening, that I somehow have to explain myself: "No, no, no, I've been to college," "I'm a professional person and I just had a bad string of luck." Why am I explaining this to

the person at the counter? It's none of their goddamn business.

When you have a chronic illness, you feel isolated for so many reasons. People just don't get it, and they get sick of it. I mean I swear to God my friends sometimes think, *Would you die already!* I mean, not really, but in some ways, it's like, "Shit, are you sick again?" When I first got sick, everybody was there, and I understand that people can only sustain that for a period of time. Then they've got to go to work and live their lives: "I'm sorry you're sick, but see you around." So it's interesting and frustrating how people react. And cancer is not like diabetes or lupus or any other chronic illness, because there is nothing that strikes terror into people like cancer. The only thing more frightening is AIDS. There's a stigma about having cancer—even among my peers. There's fear, especially from women my own age. They want to know what I did wrong, because they don't want to do that. So they ask, "Did you smoke?" "Were you not a vegetarian?" trying to find reasons to explain why this happened to me.

I understand that, but I also feel isolated, because life isn't going to wait for me. I was actually lucky when I got sick. I didn't have any health insurance, and it turns out that that was a good thing. If I had health insurance, I would have nothing, because I would have had to pay 20 per cent of half a million dollars. That's more money than I can come up with, and that's what the bone marrow transplant cost.

And it was horrible when I went back to architectural work. I couldn't do the job anymore. They gave me these little projects to do. When I finally got a design project that was going to be my own, it was an automobile dealership. I thought, *Are you kidding me? It's a box. It's a rectangle. It's got some doors. You don't need an architect for an auto dealership. I don't know how much time I have left, but I know whatever time I have left, I do not want to deal with that.*

So on the one hand I wanted things to be normal, but I had fundamentally changed. I was not the person I was before. Not in any way. In fact I didn't really want to be the person I was before, because it turns out I wasn't a very nice person. See, I was very much attached to my past before I got sick, and was still in that drama, or trauma—whatever. Being angry. I couldn't come to terms with crap that had gone on twenty years before. And I didn't want to. I didn't want to stop being angry. I didn't

want to let go of it. It felt like if I let go, then they got away with it, and just all this stuff attached to that. And then I got sick, and at some point I had an epiphany: *Why am I wasting all this time on that?* And letting go made a huge difference in my ability to empathize with other people or even sympathize, or see other people as human beings instead of “That’s a man and they’re this . . .” type of thing. I was very scared of life. After I came out of that experience of being so sick and almost dying, the real possibility of death, and living large for a long time, I realized that I just am not that person anymore. And now I probably have too much sympathy, but I think that’s still better than being cold-hearted.

My partner, Devin, worries that I’m going to die. It’s not that I don’t think about it. I just don’t think that it’s very productive, and I don’t really have time to indulge in that kind of thinking, ’cause I’m not really interested in dying, so I don’t even want to think about it. When I do think about it, then it’s “Oh shit, it’s not something I’ve come to terms with.” I had a friend who died of breast cancer, and she had a lot of diaries, and at her memorial service people passed around her journals and read out of them. And I remember one part where she was talking about how she said the other tumour in her chest was getting to be more and more painful, and it was harder for her to do her art, which was ceramics. She said death had gone from a mysterious thing in the corner to a friend. I’m not there, not even in the room.

I said to my oncologist, “I don’t ever want you to say that it’s time to think about the end of my life.” Because to me that means that she has given up. Even if she hasn’t, I don’t want to hear that. I just can’t imagine saying, “I’m throwing in the towel” and saying, “All right, I’ll go.” I thought, *Well, that’s why my friend died. She died because she let death in.* I really think that’s not true: she died because she had a huge friggig tumour in her chest, and it killed her.

Every time there is some progression of my disease, when I first hear it, I get really upset and scared. But that doesn’t last very long before I get really focused on the plan. Then I’m OK. It’s not really quality life, going from chemotherapy to chemotherapy, or the quality of life that I want to have, I should say. But it doesn’t ever occur to me to want to stop. That’s Devin’s big fear, that I’ll get tired and say, “I can’t do this anymore.” I have felt like that, and I’ve felt like that recently. I remember times when

I have been so sick, I have felt I could let go right now, I could just say, “Fuck it,” and go into that good night. As soon as I start to think that way, I think, *What am I doing? Stop thinking that. Don't.* And it's not to say I haven't planned my funeral. I've planned that a million times, and I don't know what that's about, it doesn't matter. I'm not there.

You see the thing is, cancer isn't really the worst thing that has ever happened to me. I think that that has a lot to do with why I can put up with so much, how I take it in stride in some way. I think, *Well, things could be much worse*, because they have been. It's not really denial when I don't want to think about death. I know that Devin and my oncologist and my primary care doc are very worried about me losing hope. They probably see that I'm more emotional lately, that's true, but it doesn't mean I'm giving up, it's just there's only so many things you make a joke about, and then you stop.

Discussion

THROUGH TELLING STORIES, people organize and understand experience (Brody, Bruner, Frank, Kleinman). The narrative positioning or point of view from which a story is told influences the audience's distance from the protagonist. Medical stories often feature patients but use the care provider's “objective” viewpoint as a way of focusing attention on the disease rather than on the patient. Such stories provide a way for physicians and nurses to shift away from patients to a distance that protects care providers during the performance of treatments and procedures that may be painful to the patient. But when the task is to close the gap so that empathic connection may occur, a first-person story may be more effective. Brody, Charon, DasGupta, Frank, Kleinman, and Polkinghorn have each suggested that personal clinical stories and the comprehension of a patient's story structure are the foundations of empathic understanding.

The case story has been used as a method of describing the symptom clusters of particular diseases since the beginning of medicine. In the nineteenth century the case history also became the foundation for the development of theories of disease. In thinking about monologue as a rhetorical style of case history, I'd like to think about it briefly in comparison to that of a case description written in 1895. Each case was put together after several hours of discussion with the patient. The 1895 story begins this way:

At the end of the year 1892 a colleague of my acquaintance referred a young lady to me who was being treated by him for chronically recurrent suppurative rhinitis. It subsequently turned out that the obstinate persistence of her trouble was due to caries of the ethmoid bone. Latterly she had complained of some new symptoms which the well-informed physician was no longer able to attribute to a local affection. She had entirely lost her sense of smell and was almost continuously pursued by one or two subjective olfactory sensations. She found these most distressing. She was, moreover, in low spirits and fatigued, and she complained of heaviness in the head, diminished appetite and loss of efficiency.

The young lady, who was living as a governess in the house of the managing director of a factory in Outer Vienna, came to visit me from time to time in my consulting hours. She was an Englishwoman. She had a delicate constitution, with a poor pigmentation, but was in good health apart from her nasal affection. (Freud 106–124)

The 1895 case is told in the voice of the physician who approaches the patient as Sherlock Homes might approach a crime—a rhetorical style that persists in the medical case histories of today. Something’s wrong with the machinery of the body/mind, and if the disturbance can be found, it can be fixed and the patient may go on her way, cured. There is considerable evidence that Freud in fact did not treat his patients in such a detached manner, but in this report he stands outside of the patient’s experience and describes the story of her symptoms with technical language and surgical detachment.

In contrast, the case study monologue shifts the locus of understanding from the doctor’s observations to the patient’s experience. By “hearing” her voice we gather a sense of her values (independent, egalitarian, and alternative) and the challenges she faces trying to fit herself into the treatment setting. In a brief span we learn where her vulnerabilities might reside, as she struggles with the changes in identity and the physical humiliations of disease.

Yet the subjective quality is also an illusion. I constructed this “telling” by taking sixty-two pages of transcribed interview and reconstituting a story in the patient’s “own words.” Construction (or reconstruction) of the patient’s narrative in this way is as much mine as Freud’s construction is his. However, the monologic construction has a different

teaching agenda, focusing attention on the woman's sense of self and experience of her own illness that complement the more detached, technical understanding of her disease. Positioning myself within the patient's experience allowed me a greater understanding of the interface between the patient's life and her illness. Reconstructing the patient's narrative mitigated my suffering as I cared for and ultimately lost this patient. So finally, the constructed monologue also serves as a memorial.

On the other hand, Michel Foucault calls on us to take care with our procedures of definition and description. He describes the emergence of the medical case report as a watershed, when personal narrative evolved from the flattering portrait under the control of the subject to a "mechanism of discipline" in which the narrative exerts power and defines its demeaned subject. Prior to the late 1800s, the written personal story conveyed a laudable type to be emulated, a characterological sermon of sorts, or served as a historiography of the wealthy and powerful man, a ritual of his power. With the medical case report, Foucault warns that "the child, the patient, the madman, the prisoner . . . This turning of real lives into writing is no longer a procedure of heroization; it functions as a procedure of objectification and subjection . . . [and] features, measurements, gaps, and marks that make him a 'case'" (12, 202–203).

With Foucault's caution in mind, I have used monologues like the one discussed here to teach students with different levels of clinical experience—from nurses and physicians in practice for many years, honing their skills in palliative care, to first-year Harvard medical students in a course called "Living with Life-threatening Illness." We attempt to close the gap between the patient's perspective and that of the student's self-protective distancing and encourage discussion about how, as care providers, we handle and use for healing the information provided by a patient's story.

First-year medical students read monologues to prepare for weekly small group sessions of eight students and two faculty co-leaders. Reading outside of the group allows students to go as quickly or as slowly as they wish or need and can create a buffer around the painful material. The monologues provide a way of introducing first-year students to the experiences, issues, and feelings they confront when they later meet their live patients. The reflection and discussion in the group gives students a

chance to think about their emotional reactions to the painful material and strategize about upcoming interviews with their assigned patient-teachers.

Medical students at Harvard report that the stories surprise them with how much each patient focused on relationships, self-image, integrity, and the life lived in spite of or around the disease (and how relatively little focus was on their doctors). They found the monologue included here difficult to follow, because it was painful. They focused on how upsetting it was to hear cancer spoken of in the style of their own talk, and in the context of concerns about career and relationships similar to their own.

Working with more experienced clinicians, we read monologues aloud, each member of the nine-member group taking a turn for a paragraph or two. Speaking the story makes it emotionally immediate. Hearing it in different voices makes the feelings and events seem closely shared, almost universal. By the end of the reading, several of these seasoned clinicians are usually crying. The discussion leads to personal memories of loss in their own lives and to the relationship between those losses and the challenges and rewards of a practice in which we try to alleviate suffering in people who are dying.

Summary

MONOLOGUES reconstituted from audiotaped interviews may be used as teaching tools, read and/or spoken, with students using different levels of clinical experience to approach questions of suffering, self-care, and the ways in which a person can be supported in maintaining a sense of integrity and self while facing death.

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Notions of the Archival in Memory and Department

J. R. Carpenter

Creative Process

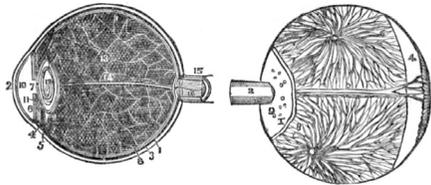
“Notions of the Archival in Memory and Department” began as a response to the discourse of disembodiment prevalent in the early days of the Internet. I never believed that the physical gendered body would be subsumed in an idealized information age. Even in our attempts to externalize and expand upon the processes of the brain through the computational and storage capacities of the computer, the precariousness of the biological body persists. It seems to me that somewhere along the way cultural theory veered away from body politics. In “Notions of the Archival” I have tried to examine, from the inside, not just the body, but also my body in particular. I have focused on the storage and retention of bodily memory in order to explore the relationship and/or disconnect between body and mind that has preoccupied philosophers for generations. The structure and philosophical bent of “Notions” is most heavily influenced by Spinoza’s Ethics, Part II: Of the Nature and Origin of the Mind. He writes, “The human mind is capable of perceiving a great number of things, and . . . is capable of receiving a great number of impressions . . . If the human body is affected in a manner which involves the nature of any external body, the human mind will regard the said external body as actually existing . . . Memory is simply a certain association of ideas involving the nature of

things outside the human body, which association arises in the mind according to the order and association of the modifications of the human body . . . The human mind has no knowledge of the body, and does not know it to exist, save through the ideas of the modifications whereby the body is affected."

In the Era of Forgetfulness and Wonder

I Wait for Language

I DON'T KNOW why this is happening now. I don't know why, in this era of forgetfulness and wonder, I am creeping around the inside edges of myself trying to explore, without sight, the texture of my knowledge; the superstructure of my understanding; the boundaries that I overflow. I am on an expedition to chart the inside of my body. Just under the terrain of my skin, poised as if at the edge of a glacial ravine, I am trying to document what is work and what is gender, what are guts and what are memories. What is humorous, from a local position, through the thin olive atmospheric haze of my skin that runs continuous from my arm to my hip to the lid of my eye?



I wonder at the thinness of my skin and how it is that I come to be on the other side of vision. The bulk of the technology of my eyes is dark matter in the interior of my body. Like someone who is blind posing for photographs, I position myself: dubious on the ridge of my cranium, jaunty at the crook of my elbow, historical at the fundus wall of my uterus, determined in the length of my back. I am suddenly far from my brain and naked without it. In the nooks and crannies and rocks and rivers of my body, I am trying myself on for size.

I am looking for something new. I am looking for something familiar to hold against so much newness. I sit between my esophagus and my windpipe wondering which nourishment to escort, excited by breath and drink and food for their newness to my body, for their potential for containing information, for being useful—these are things I can find words for, things I do not mind sorting and putting away.

Dizzy from spinning round
the hollow tubes of my ears,
I wait for sound.

I brace myself for the
ramifications of the movement
of tiny parts, the translation of
motion into information
edging toward
speech.



Beyond the gravelled slope of my tongue
I wait for language.

Textual Episodes

I wonder. If I scratch a note to myself, deep in the substance of one of my bones, will I know those words forever? Or will biology refuse to accommodate the character of written words? Will blood continue to rush by within its circuits without stopping to read, if indeed blood can read information other than that of oxygen and iron and alcohol and vitamins. Will the scratches ever fill in?



I cannot imagine a mark on my body any deeper than that of the memory of text burned into my retina, left smouldering in my brain. Every now and then I come across a scar of text embedded in my skin. If I can manage to think from inside, without my eyes, then the scar of words seems to float at the very limit of my body's gravity. Observed from outside, with the rigorous technology of the eye, a scar can seem very small, as if the text had barely wounded me, a small pocket of evidence of interac-

tion with alien substances, that is to say, not body meeting with body, a condensed version of a conversation between inside and out retained as memory in tissue demarked as special by its extra density.

Situations of the Amassed

The Peevish Brain



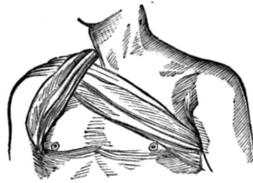
THERE IS TOO MUCH STUFF in my brain that I do not know how to find, and too much new stuff coming in at such a speed that I cannot possibly put like with like. I have saved every thought, even the old and useless ones, in no logic of specificity, in an antiquated ethic of accumulation. Is there is a way to clean old thoughts, to weed them out or to condense them?

I cannot remember where I have remembered things; I do not know where else to put things. Memory stored in the back is like carrying stones—thick, dense information I can never break apart, never get a grip on with the grey matter of my fingertips. I move around like a geologist in an ambulance, surveying the shifts in the strata of my trapezius, tapping away at lodes and mismatched conglomerate stone memories and rushing them back in plastic baggie liquid nitrogen preservation units. I stop only briefly to dump them in overloaded emergency storage units in my brain before dashing off again to the site of the dig. It is better not to store things in my back and then move them to my brain. Coming in the side entrance in the ambulance like that and not sticking around for pre-op, they never get a good room. It takes me forever to sort through the backlog of information I bring in from that kind of field trip: shelf after shelf of geodes and crystal and lava and petrified trees, and rooms of walls of drawers of fossils I can't even think about because I haven't the time to give them identification numbers or label them or make a list.

My brain wishes to entertain a sort of knowledge different from my body. Ambitious of its own accord, it invites texts and images and private jokes to stay, like perpetual house guests, littering the paths of my thoughts, folding out the sofa bed every night, laying down foam mattresses and sleeping bags in the furnished basement of my imagination. They crowd together at the breakfast table every morning and vie for my attention. Spinoza argues with the electric company, and Judith Butler

works in the bedroom of my brain, trying to dislodge the knowledge that once there was a little girl who had a little curl on the centre of her forehead, and when she was good she was very, very good, and when she was bad, she was horrid.

My brain is crowded. New places must be colonized for the sake of memory. In the morning, after a heavy sleep, my dreams linger high in my sides. My peevish brain resents this. It must think, What kind of place is that to keep a thing! Off to the sides like that, in the edges of yourself, under your armpits?



For almost a year now I have been remembering something or other in the ball of my left foot, a dull aching memory, like calcium, like an old wound I can't forget, like an old lover met only on the street when it rains. It's such a risk to travel all the way down there, through all of the danger inside of myself, to get to the bottom of it, as it were, to go to the actual site of memory and to admit that that is indeed my purpose. I keep going to my fingers instead and then raising my foot to them as if it were an eggplant or a stuffed animal or the *Sunday New York Times*.

In this dull hazy lumbering externalism the seat of memory is preserved—nothing ever gets done.



Nails and Hair

Nails and hair confuse me. Are they inside or out? If I put information there for storage, it is very difficult to retrieve again, to pull back into a wet part of my body. If I put information there, then I know I have given

that information up. It is only a matter of time before it will be removed. Nails and hair are places to store small hard dry things that I am finished thinking about. A slightly more precious place for storage than in the bowels as excrement—which, once excreted, has no redeeming qualities, no usefulness, no fond memories, no second chance—nails and hair can be saved. Snipped and clipped, they are a microfilm of static information that cannot be read, but can be saved all the same, like the climate-controlled stomachs of libraries containing water-damaged books.

Nails and hair collect things of their own accord. Dirt and oil and desire. When desire cannot be contained inside any longer, when it has saturated all of my senses and rests in no one sense, I touch my thumb-nail with the tip of my tongue, the flesh is held by my teeth.

At night, when the outer limits of myself become confused with bed-sheets and blankets, my tongue skims my lower mandible in memory of retainers and the dislocation of teeth. Over a decade after orthodontia, my gums still remember the tightening of the beginning of each month, the alien regiments of metal and plastic, and now my wistful tongue bemoans their absence.

What Part of a Body Can Safely House Absence?



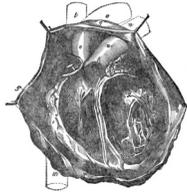
DEPARTURE gets under my skin. It ruffles me; it sets my hair on end. I do not like to be in the same place as it. Impending departure sends me running. When the idea of departure has set in my teeth, entered my nostrils, dried my lips, arched my back, and cracked my cuticles, when it has crept inside of me, I want to creep outside of myself. Too afraid to be there when absence kicks in, my brain ploughs ahead of itself, onward toward the next situational device.

I do not want to be in my hands, for they have held the weight of departure many times. I do not want to be in my womb or my bladder, in which departure is a regular business. I do not want to be in my stomach, which remembers departure very well, my stomach that dreads and shrinks at departure and festers at emptiness.

I wonder. How can a body of mass accommodate emptiness?

The Speed of Blood

MY BODY has never forgotten itself. Not yet. So far it has always known what to do. If my brain could be everywhere at once inside my skin, I'm sure it would begin to notice patterns, to learn a vocabulary, to ascertain the technique of certain physicalities. If my brain would remember outside in the way it remembers inside, I would not forget; I would not need to remember. If my brain would secure itself, my hands would remember themselves; they would steady themselves in their activities, my posture would come to its senses. If outside were to come to practise inside in terms of labour, what a massive geometry could come into being: crochet on the scale of cellular regeneration, organization on an intestinal model, collection through soft membranes, thought at the speed of blood.



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All Good Things

John B. Lee

Words I Cannot Say in English

Warren Zevon died
of the longest word in the language
forty-five pneumococcal letters
and
he could not breathe a breath
like the sudden
stilling of the wind
when summer falls on its back.
As a boy in the playground I'd seen friends
gasping like lovers
unable to say "I am not dying"
as they lay settled to the earth
like the dust after horses.
If I could only with delicious simplicity eat
the alphabet as a child eats apples
learn all the Latin names
for flora in one perfumed exhale
my face a candy crimson
listen to someone else
lost in offstage whispers to the apron
defeated by *honorifzcabilitudiinitatibus*
the labour lost in the mouth
like digging a well in wet sand

oh, I am all
for joyfulness and erudition
all for the mischievous
antidiseestablishmentarianism
of the heart
I'd have the secret meaning
of all the words
I cannot say in English
and give you seven greetings
none but I
would comprehend as sad farewells.

The Greying Over

A little girl sits
fluttering her hand
like a wounded sparrow
on a stony beach
where the lake is plumed with foam
and shell shush and green glass
under the best and most beautiful
blue weather
hers, an animal innocence
as pure and simple
as the rub of water
clarifying colour and darkening
the blurry shadow of itself
what with a cold stream thrilling the swimmers farther off
the point and out where a school nibbles past
in silver shoals of flicker and response
and all of us are human here in every direction
but when her mother
slaps her hand
she learns
by the moral nastiness
of adult thoughts
the greying over

of what it was to be herself
 how complicated it becomes
 with every little loss of light
 the gathering in of moments
 we remember
 for all the blind walking we must do in our own night-dark houses.

Clapperdudgeon

The day you came to the house
 to deliver the poet Les Murray
 and give me the news
 of your cancer
 you also came with the gift
 of a word
 you know I might love
 for the consonant wag
 of its tongue handles
 the way that it bells in the mouth and the mind
 like a church of the valley
 or a school of the town
 this very *clapperdudgeon*
 this beggar's mort
 patches the day like a tramp
 with a water-quilt heavy as heaven to wade
 to the stitches
 and rather than weep
 for by the surgeon you're cut like the killing of sheep
 we joke—old marsupial man
 you might slip your free hand
 in the slit of your gut
 like a general's pose
 you might carry your wallet
 or *joey* your young
 O-possum, oh pal
 I am sad
 as what the dog shakes

and wish the world weren't
made of axes
for blunting the skull of its soul

and we laugh
like *clapperdudgeons*
mending our time
with the thread of a talk
poor tongue
it wants a better word for friend

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Returning to My Mother's City: Journeys in Love and Loss

Alison Pryer

The Certificate

My mother died ten years ago this year, but it was only a few months ago that I found the courage to read her death certificate. She had kept her many illnesses secret from my sister and me. Yet each time I talked with her on the phone, she swore she was on the mend, getting stronger, feeling better. Now I'm left with this useless document. Does it describe the life she lived, or her thoughts, fears, and wishes while she was dying? Does it relate a lifetime of experiences and memories? Can it penetrate the secrets she kept so close, the dreams that were extinguished, the bitterness that she swallowed, or the voice that was silenced as she lay dying?

For a long time I clung to my sister's account of Mum's last days. Mum spent the last two weeks of her life in hospital. My sister, of course, tried to contact me, but my husband, Robert, and I were in India. We had seemingly disappeared into the desert towns of Rajasthan. All the while, my mother grew weaker and weaker. As she neared the end, she was given pain medication. She slipped into unconsciousness and faded away. "She didn't suffer," said my sister. "She was ready."

A few years later, though, my sister's story changed. Now I understand that this second story was the one my sister had wanted to tell

me, but I had not been ready to hear. My mother had been in excruciating pain. She struggled. She cried out. A nurse removed her oxygen mask, and although barely conscious, Mum gasped for breath until she asphyxiated.

Had Mum spoken with the doctors and nurses about her wishes? Had she welcomed an end to her suffering? Did she feel as if she had become a burden to others? Was she euthanized? I have no answers. In death, she has remained ever elusive and unattainable. The officious text of the death certificate provides no closure. Neither did her funeral service, which was held in a church she had never attended with a minister she did not know.

I have discovered that for those who are left behind, the death of a close relative, loved one, or dear friend may precipitate a search or re-search for meaning. This searching occurs through remembering, reconnecting to, and creating stories of the departed—their life, dreams, and death. Those who grieve stumble upon a hermeneutical journey, learning to intimately co-exist with absences, silences, the ambiguous, the unarticulated, and the uncertain.

Mother Tigress

FAR AWAY FROM JAIPUR in the shadow of Ranthambore's cliff-top fortress, where warriors once rode to their deaths on elephant-back, and where ten thousand women committed suicide after their men were defeated in battle, there is a timeless jungle paradise nestled among barren mountains. In this valley—a favoured hunting ground of maharajas past—is a lush forest fed by monsoon waterfalls that stream down sheer rock faces into still lakes clogged with water lilies. Crocodiles, sambar deer, gazelles, striped hyenas, leopards, langurs, vultures, peacocks, and egrets live in this hidden place on the edge of the desert—so do tigers, although sightings are rare.

As soon as Robert and I arrived at the palatial former hunting lodge, we hired a guide—a slight young man called Bablu, from the local village—to take us into the reserve in the back of a borrowed Toyota truck. Bablu drove us far into the jungle along rutted tracks, stopping only so we could look at the animals we encountered on the way. After an hour of travelling we decided to wait near a watering hole that Bablu said tigers sometimes frequented. As it was the hot, dry season,

Bablu speculated that we had the best possible chance at this particular spot. We watched the monkeys and deer drink from the clear stream while the sun set. A sudden dusk fell, and pandemonium broke out. The deer leapt away, the monkeys began to scream and swung high into the trees, samburs deep in the forest barked, and all the birds cried out. Just as abruptly, the entire cacophony ceased. We sat in suspenseful stillness for a few minutes until Bablu pointed out emerald green globes floating through the forest gloom. "Tiger's eyes," he whispered.

There were not just two green orbs approaching us, but many. Tigers are usually solitary creatures, but we had found ourselves in the midst of a family gathering: an almost unheard of occurrence. There were five altogether—a mother and her four, almost fully grown, cubs. They strolled along with regal elegance, simply ignoring us. But we soon discovered, with some alarm, that we were parked in the middle of their planned route. Tigers frequently attack when humans block their paths. But what could we do? If we turned on the truck's engine and tried to drive away, our behaviour would only be more disturbing to them.

The mother tigress came up to within a metre of our truck, her shoulder muscles rippling as she moved. She locked her beautiful eyes with mine. I could not move or even so much as breathe under her fiery green-yellow gaze. Like a rabbit frozen in car headlights I waited for the inevitable. She snarled, baring huge fangs. Then she simply turned her head away and walked around the jeep to the stream, realizing that her cubs were safe and we were no threat.

With a mixture of relief and awe we watched the tiger family bathe and drink in the dark rock pools. The cubs frolicked in the water, playfully swiping one another with their oversize paws. The mother tigress rested peacefully, even while a cub teasingly bit her neck. She licked her babies fondly, and they rubbed their faces against hers.

That night Robert and I ate a dinner fit for a maharaja in the wood-panelled dining hall. Afterwards we plunged into our own green rock pool—a gigantic tub carved from a single massive piece of marble. Then, our exhausted bodies fell into a contented sleep, our limbs entangled beneath starched cotton sheets.

Early the next morning we awoke to the jungle's raucous morning chorus. I had a paralyzing migraine. My husband grew fearful as the

hours passed, and I lay in motionless agony. The hotel staff called a doctor. We waited in vain for the doctor to come. But at noon the pain simply dissolved, and I arose feeling better. At brunch we learnt that our sighting of the five wild tigers—our mother tigress and her cubs—was considered so rare that it had been reported in the national papers in Delhi that morning.

Weeks later when the shock of the news of my mother's death had given way to gnawing grief, I realized Mum had lain dying in England at exactly the time we had met the tigress and her cubs in India. And I had been immobilized by pain during the final hours that she had suffered excruciating pain. The synchronicity of these two extraordinary life events—the death of my mother and my encounter with the mother tigress and her cubs—is astonishing. Sometimes I think of the tigress's fiery green eyes and wonder if Mum was trying to teach me about the graceful strength and the fierce pride of a mother's love.

An Absent Mother

I REMEMBER A CHILDHOOD of furtive conversations, closed doors, long silences, and quiet tears, interrupted by sudden, vicious, yet often predictable bursts of violence every now and then. No one heard my mother begging for mercy as my father beat her in the kitchen. Only my sister and I, two terrified little girls shivering in our nightgowns. My father was the consummate tyrant reigning with absolute power within "his" home. Yet he was also a pillar of the local community. So, following our mother's example, my sister and I learned to hide our pain and shame, and made sure we maintained a facade of middle-class decency.

Fearing for her life, my mother eventually fled my father, taking my little sister with her. My mother and sister carried only one small bag each, and the clothes on their backs. They had lost everything it seemed, including their sense of peace and trust in a benevolent world. I had left a year earlier, as soon as I turned seventeen. My mother told me much later that she was afraid that when my little sister also left home, she would be completely alone in that ancient Scottish cottage, and my father would kill her. There would be no one to witness what had happened. It was the possibility of imminent death, an animal instinct for self-preservation that made the final difference for my mother, not the instincts of motherhood. In all fairness to my mother, however, it takes profound courage to

live in such an abusive situation, and a greater measure to leave it.

After we had escaped my father, we lived like shell-shocked refugees. None of us talked about what we had experienced. Unexpectedly though, when I was nineteen, I remembered something that I had always known. Events from my childhood that had seemed distant and foggy became a kaleidoscope of memories coming into sudden focus. My memories were tiny fragments—just his touch, or his smell, or his look. With an adult's understanding of childhood knowledge that had been long suppressed, I remembered that I had been sexually abused.

Whenever I asked Mum about the past, she would only cry. But my sister told me that she and Mum both knew what had happened to me, and had sometimes even talked about it together. Strangely, my sister remembered more about the circumstances of my own sexual abuse than I did. I could remember only the constant threat of violence, and a pervasive feeling of deathly terror.

Now at thirty-something, whenever I walk past a mirror I can easily catch sight of my mother as I knew her in her thirties. She looks right back at me, and I am delighted and horrified when I realize that it's really me, with my mother's eyes and face, the same set of the mouth, and the skin around the lower jawbone just slightly beginning to soften with age. In a sense, my mother is always with me wherever I go. Yet, as it is with many survivors of childhood sexual abuse, my mother was an absent presence throughout my childhood, the parent who at crucial moments of my life was not there for me.

In so many ways, I have always felt my mother's absence. She was absent when she did not stop my father from hitting me, even—as she later confessed—when I was only a few months old. Absent through a long depression, sleeping through our school days and getting up just as we arrived home, pretending that she had been busy all day, though her bed was still warm. Absent in her emotional distance and almost total dismissal of me as her daughter. Absent when the abuse began. Absent when she repeatedly left me alone with the abuser. She somehow wordlessly accepted that this was how our family would be and that she would not intervene on my behalf.

Perhaps, at times, my mother thought of me, her firstborn child—and as she told me many times, an unwanted child—as the price of maintaining

a marriage. Certainly by the time she had been completely broken by my father, she was willing to betray the most sacred of bonds—that of mother and daughter—in order to survive the captivity and the daily re-traumatization of the violence and abuse. My mother's multiple absences have a metonymic presence and strength all their own. It is only now she is gone that my yearning for her presence has evolved, as has my understanding of her absences. I am able to explore her distance, her hostility, and her reluctance to mother with a little less anger and a little more tenderness.

Returning to My Mother's City

SEVERAL YEARS after my mother's funeral, I returned to London, her place of birth and mine. I always think of London as my mother's city. She loved this city dearly, like a grey old friend. Each day I found myself walking through the neighbourhoods that formed the landscapes of her heart and of my early childhood—Covent Garden, Bloomsbury, Holborn, Soho.

Here my mother—Kay—was known as Katie's daughter, and old neighbours from as far back as wartime would remark in passing how I looked just like my mother when she was my age. Here was the flat where Grandma and now my uncle lived. Next door was my mother and uncle's primary school. Across the street was the white Catholic church they had all attended. A short walk away was the old Berwick Street Market where Grandma and Mum used to shop for fresh produce. Each narrow street, and each small green leafy square forms a piece of the storied matrix, the tattered patchwork of my childhood memories.

Each morning of my stay I set off on a walk with no destination in mind. And each day I found myself following in my mother's footsteps. I followed the route from the Victorian tenement where I had lived as a child to my old primary school. As a child, it never seemed odd to me that I passed two opera houses on the ten-minute stroll through the Covent Garden Market. They simply formed the landmarks of my childhood. The market itself, with flowers and vegetables everywhere, the barrow boys yelling, and men with stacks of heavy boxes balanced on their heads as they walked through the stalls, this market was now gone. Now whenever I smell rotting vegetables I instantly return to a time when life

felt less complicated, more certain, sweeter, a time when I felt safe holding my mother's hand.

Many of the places I visited seemed just the way that they'd always been, like Bertaux's, a French patisserie in Soho. Once in a blue moon, my mother would take me there. In our Bertaux ritual, Mum and I would stand outside the store, me with my small face as close as possible to the window. We would then run our eyes over all the different kinds of confections. Sometimes she would point out something I'd missed, maybe a birthday cake iced with pink roses, or marzipan fruits lined up in perfect rows. On entering the store we would breathe in the aroma from the bakery upstairs, then on this heavenly inhaled sugar high, we would peruse all the delights again. Now was the time for pondering and dithering before finally making up our minds.

The same lady always served us. After we had chosen our cakes, she would make a box from flat card, folding it this way and that like the wings of a giant, white bird. Then she'd carefully lift each of the cakes into their nest with a pair of silver tongs. She tied up the box with a yard or so of red ribbon, and after my mother paid, it would be presented to me. I was usually allowed the honour of carrying our cakes—so carefully—across Shaftesbury Avenue and all the way home.

On this trip back home to London, I walked to Bertaux's, chose a chestnut cream pastry, my mother's favourite, and sat in the upstairs café, enjoying my treat with a strong coffee. The lady who used to serve us had retired. Apart from that, nothing had changed. I swear the smoke-yellowed walls and ceiling had not been painted since I was a girl. The same old plastic-covered chairs and Formica tables were there too. But no one comes to Bertaux's for the decor. For me, going to Bertaux's is a ritual that unites place, family, food, and love.

Even though my mother was far from rich, when she lived in this grey friend of a city she was always able to make beauty and sensual pleasure a part of her everyday life. She knew all the secret little public gardens and squares. She adored window-shopping. She loved the pleasures of good simple food in season; the world of music, ballet, art, and theatre in the West End; the splendid spaces of cathedrals, and the vernacular architecture of ordinary English shops and houses. It was my mother who taught me to understand and appreciate beauty, and to recognize its presence in

every aspect of daily life. I am grateful for this inheritance.

As I walked through my childhood haunts, I paid homage to my mother and to the gifts she gave me. By walking familiar streets, I reignited an intimate, personal relationship with place, where each feature of my surroundings was known and had a name, where every corner came alive through sacral connections of memory and generations of family experience. In carefully retracing childhood steps and recreating the rituals that my mother had shared with me when I was a young girl, I had slowly wound a blanket of maternal love around myself. One day as I sat before the Virgin and Child in a local Bloomsbury church, I realized that on all my long walks I had been seeking the dream of a mother's unconditional love for her child. Only then did my tears begin to fall. I had been invoking my mother's spirit and could now finally say a sweet, tender goodbye to her. This journey home to my mother's city had been a pilgrimage of love: a ritual of leave-taking, as well as a ritual of return.

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Daughter Cells

Jessica Handler

One morning in July, I sat in a hard plastic chair and let a lab technician strap my left forearm pinch-tight with a rubber tube. After the needle's sting, I turned my gaze away. Watching my body relinquish secrets, I was only beginning to learn that what it kept made me queasy. This blood test took longer than those I had sat through before. On this day, the lab technician filled test tube after test tube with my blood. Only after she snapped the rubber choke from my skin and touched my drowsing arm with icy alcohol did I feel steady enough to direct my sight back to the lab tech. On the counter behind her, half a dozen vials of my blood, viscous as tomato juice, stood upright in the kind of dimpled tray that might hold eggs. Every tube was jammed shut with a blue rubber stopper. On every tube was a sticker with my name on it: "J. Handler/Sibling."

I was nine years old and had come to the lab with my parents and my sisters to try to help piece together the genetic puzzle that had caused my sisters' health to fail. Susie, seven at the time of this blood test, had been diagnosed with leukemia the year before. Sarah, then three, had been born with an immune-system deficiency called Kostmann's syndrome. Her body was unable to produce an adequate amount of neutrophils, a type of white blood cells, and she was susceptible to every germ. Nothing was wrong with me.

Leukemia and Kostmann's syndrome are bone marrow failures. Leukemia is an overabundance of white blood cells, Kostmann's syndrome an almost total absence of them. Lack of white blood cells can be a side effect of chemotherapy (which is itself a treatment for leukemia),

but if you are born with it, you have a genetic anomaly. Both parents have to carry the rare gene for Kostmann's syndrome in order for the disease to be present in their child.

Leukemia, too, can be hereditary, or it can be the result of environmental factors. Scientists investigated the "why" of childhood leukemia long before my sister became ill. The studies are endless; one recent study claims nightlights as a culprit, other studies argue against microwave ovens, pesticides, or radon. Another points to exposure to industrial wastes like benzene. Leukemia can develop from a mix of causes, becoming a monster swaying to life when genetic predisposition to the disease meets a troubled natural environment.

Leukemia is common in children: some estimates say nearly three thousand new cases are diagnosed every year in the United States. Kostmann's syndrome is so unusual that, worldwide, it is seen only in about one in two million births. How did two out of three sisters develop hereditary disorders that live at opposite ends of a spectrum? Doctors pronounced us a bizarre coincidence. We were mystified, and so was every doctor we met.

Summer 1969

SHEPHERDED BY OUR PARENTS, Sarah, Susie, and I walked across the blistering black tarmac at Atlanta's airport and up rollaway stairs into the plane. The five of us flew to Durham, North Carolina, for a series of blood tests that might or might not reveal where our reverse miracle had come from.

We were sophisticated kids, accustomed to flying and the accompanying marvel of sitting down to breakfast in one city and to lunch in another. We flew to New York every winter to visit aunts and uncles and cousins and to trek through museums and giant department stores. When we were done, we ate with chopsticks in Chinatown. In the summer, we flew to Pennsylvania and to Massachusetts to stay with our grandparents. A two-day trip to Duke University was no more to us than another visit to another hospital. We were prepared to fulfill our responsibility to more doctors—interchangeable with the ones at home—and to our parents before we got to play in the motel pool or dress up to go out for dinner at a steakhouse. We were polite. We presented our left arms,

sleeves rolled up, for the needle. We gently flicked our fingers against the soft insides of our elbows to raise the big vein there, showing off just a little bit for the lab tech. Our frankness made her stare. We answered questions; how old each of was, how we were feeling, what was the name of Sarah's stuffed bear.

Intending to be helpful, I confided in Dr. B., a blonde woman who appeared no older than the nursing student who babysat us at home. "I'm the well sibling," I announced as I shook her hand. I noticed that she chose not to write this insight on her clipboard. After each of us relinquished vial after vial of blood and my parents completed pages of paperwork, we left the lab. Mom carried Sarah, Dad walked just ahead with a file under his arm, Susie and I brought up the rear. Susie fainted while we waited for the elevator. When she crumpled to the linoleum, my parents' calm shattered: Mom screamed, Dad swore, a male nurse in white came running. I was afraid. As sick as I knew Susie and Sarah were, any physical evidence of their fallibility had up until then been confined to the days when they were patients in a hospital. No one ever fainted or threw up or had a nosebleed in street clothes. I have never since seen a child collapse.

We did not go as a family for more tests after that single day. There was nothing anyone could tell us about why death sat so close by my sisters, and nothing anyone could do to shoo death away. There were no answers to the question of why two diseases struck my family like rogue lightning out of a clear sky, hitting my sisters and bypassing me. Genetics is a good guess. So is bad luck.

Fall 1975

I NEARLY DRIED UP and died of boredom on the subject of genetics in my Grade 10 biology class. Dissecting leathery cats and frogs unnerved me. Mendel and his peas blossomed into tedium. Our teacher's lectures on *Drosophila*—fruit flies—generated snarky remarks among the bored kids at the back table. We cracked ourselves up with puns like "be fruit fly and multiple," and learned nothing about this first draft of genetic mapping. "Ontogeny recapitulates phylogeny" stayed with me only because of its catchy, bumpety-bump rhythm. The phrase means that every embryo's development mirrors the entire evolutionary process; eons of

practised, mindless change whiz through the earliest moments of every organism like a time-lapse film. Having been studied some myself, I was secretly disappointed that I was not able to relate to the *Drosophila*.

Open my veins and coax information out. Find the answer to my parents' anguish and tell me if I will face the same. Isolate the random error in our genetic code as if you were fishing macaroni letters from a bowl of alphabet soup. Because I knew early on that a lab technician was looking for mutations in my family's cells, I believed that at our most primitive level, my family was different from others. If we had a mutation then we would be freaks. Almost immediately, I became fascinated by stories about Chang and Eng, twins conjoined by a band of flesh at their chests, or with tales of General Tom Thumb and his bride Lavinia Warren. Leafing through my parents' book of Diane Arbus photographs, I happened on a portrait of lunkish and tragic Eddie Carmel, who at a purported nine feet tall, towered over his stunned parents. I opened the book to "Jewish Giant in the Bronx" over and over again, wondering how Eddie could sleep comfortably in bed and if his back ached from bending so low to walk through doorways.

My mother tells me now that she and my father heard the whispers and felt the stares when they walked the halls of children's hospitals. Other parents were always empathic as they escaped their child's room for a blessedly vacant moment in the cafeteria or the gift shop. These parents were also relieved once they had made the obvious comparisons. They might have one child vomiting from chemotherapy, sleeping through post-op recovery, or dying, but in Susie and Sarah, my parents had two.

In elementary school I rescued Susie's stiff wig from the red clay playground dirt. A Grade 7 bully had torn the wig from her bald head and flung it, horrified, onto the dodge-ball court. Of course I rushed to save the hair, returning it like a furry pet to my stunned little sister. Of course we were the only children on the playground who knew how to place the hair on her naked head. Susie centred it like a hat, then mashed down hard, pressing a new strip of plastic tape into place against her skull.

Winter 1990

BEING THE WELL SIBLING meant agreeing instantly to be the donor for Sarah's bone-marrow transplant. This was no guaranteed cure, but any

source of rest for the weary. Envisioning exposing my hip or sternum to a needle to relinquish a quart of marrow made my knees go weak. The flesh between my shoulder blades crawled. Of course I would spend six months in a hospital for you. In one room I would grow pale and weak before my certain rebound. In the next, you would pink up, nourished from the meat inside my bones.

The idea was that my white blood cells might grow in Sarah's body and provide her immune system with a new start. Statistically, siblings—allogeneic donors—are the closest match.

"This is going to be harder on you than it is on me," Sarah said. We were talking on the telephone, me at the southern end of the Eastern Seaboard, she at the northern. Each of us was grown, or nearly so. I demurred and made comforting words, thinking I could deflect her fear. "I can manage a hospital stay," I said, all bravado. Anxious to feel nothing, I talked but didn't listen. I could never be her or understand what it meant to live her life. Her words bounced off me with a pinging sound. She was hail, I was a tin roof.

"That's not what I mean," Sarah said. Her voice was tight, testy. As if she were talking to a lost child, as if she were the big sister and I the small one, she went on. "When I die. You know that's what I mean." You won't die, I thought. You can't.

OUR FAMILY'S INSCRUTABLE GENETICS re-emerged with the results of my preliminary blood test. I was not a donor match for Sarah. Nor were our parents, aunts, uncles, cousins, or friends. Susie might have been a match, but she was dead.

Sarah and I talked around our disappointment, treading gently around the holes opening in our hearts. Her death was closer than ever, and we knew it. Instead, we laughed hard when we spoke about her new car, our mother's birthday, my boyfriend troubles.

From the outside, you couldn't tell that ours was a family with a genetic mutation. I am tall. I am big-boned and have dark hair. I look like what I am: a genetic combination of my parents. Had Susie lived longer than the age of eight, she would have been a tallish woman like I am. Her hair was dark and wavy, like mine. In photographs of the two of us together, I see now that her grin was wider than mine, a characteristic of personality rather than science. All of us sisters inherited our

parents' jutting jaw. We had in common the same swimmer's shoulders and broad rib cages. When she did die at the age of twenty-seven, Sarah was five feet tall, although I can hear her insisting that she was five feet one. She was also honey-blonde. Her hair colour was a genetic throwback some unknown number of generations. No one I can think of in our family is fair, but then again, the first cases of Kostmann's syndrome have been traced to Sweden. Most Swedes are blonde. Sweden is proximate to Russia, Poland, and Lithuania, where my grandparents, their parents, and members of generations rolling back in time were born. Genes have long memories.

In the sixteenth century, French surgeon Ambroise Paré addressed the titillation factor that attends the realities of being born different. In his *Monstres et Prodiges* he attributes thirteen causes of deformity and illness (thirteen being the timeless number for the superstitious). One reason was the disruptive presence of "demons and devils." Another cause, Paré claimed, was the pregnant woman's sitting in an "unbecoming manner," crossing her legs or pulling her knees under her chin. He was prescient in his suggestion of a ninth possible origin. That, he wrote, was "heredity and accidental illness."

Every time a cell divides, two identical new cells are made. These are daughter cells. When they divide again, you have two more daughter cells. Errors can occur. Not all genes from the original cell may make it into the daughter cell. Sometimes more than one copy of a chromosome develops in a daughter cell, diverting normal development. Most of us live lucky lives, the probability of our staying reasonably healthy asserted early in our genes. Our children should be born healthy, but sometimes they arrive ill-equipped, unable to dodge their fate. I am insensible of the potential for cruelty within my cells.

Spring 1998

MY HUSBAND AND I sat holding hands in an overheated medical centre conference room. We had come for genetic counselling. We had given blood, and now we had to listen to a dark-haired woman in a lab coat chirp statistics about mutations, defects, and the rate of healthy pregnancies for women in their forties. As she flipped laminated pages on a chart, my thoughts wandered to Mendel's peas. In my mind, the phrase changed—mutated—to "Mengele's peas." On the plastic cards in front of

us, blown-up photographs of someone else's genes, used as lecture aids, appeared to wind around themselves like tapeworms.

Having seen up close the losses I could experience as a mother, I wanted to know for certain that I would not meet my family's troubles again. Prove that to me, I want to say. Show me which of my parent's genes met and created mutations, or why my sister's genes altered in the womb. Show me which genes of mine, if any, are poised to communicate more bad news.

No one can guarantee me this peace of mind. Susie and Sarah would tell you that they were more than their illnesses. They were smart, beautiful girls. They had outrageous senses of humour. Susie once pestered our mother at a grocery store meat department until she surrendered and handed over some change for a pair of disembodied chicken feet.

"Mom, please," Susie pleaded. Pushing her nose against the curved glass case, she couldn't take her eyes away from the scaly, grey-clawed feet on ice. Mom took her wallet from her purse to pay the man, and Susie held her hand up for the white paper package. At kindergarten the next day, Susie used the splayed yellow feet as stamps in a dish of tempera paint. On her strip of paper (the other kids used raw potatoes cut in half to imprint flower shapes and smiles and trapezoids), ghost chickens marched across a paper road.

When Sarah was in junior high school, she signed notes "love and other indoor sports." She called me in my college dorm to tell me her first dirty joke. "What do you call a mushroom that's long and hard?" she giggled. "A fungi to be with."

We were three sisters, we were not freaks.

Wrestling with how our genetic makeup defined our lives has given me another taste of my childhood alphabet soup. I have learned that DNA is made of four chemical compounds; adenine, guanine, cytosine, and thymine. Called A, G, C, and T, they are the four-letter alphabet floating in everyone's bowl. I know enough now about the subject I loathed in high school to assign a basic concept to words like *chromosome* and *allogeneic*. That's enough for me.

When I look at photographs of Sarah and Susie and me, or read our aging diary entries and birthday cards and letters written in loopy girl-script, I see the truest things I need to know about the girls we were.

When the lightning that struck two out of three little girls can be named and the place where it came to rest in their bodies can be located, then a new caring person in a lab coat can pick up where an earlier one left off, and show me the scorched place inside my own body.

Jessica Handler is a candidate for an MFA in creative writing from Queens University of Charlotte (North Carolina). She is completing a family memoir, also entitled *Daughter Cells*.

It's Not a Headache

Matt Oakes

It always starts a day or two early for me. My eyes begin to close at the brightness of daylight and bulbs. Hoping to keep out the worst, I squint through heavy eyes. My neck stiffens like frozen rubber bands: coming apart at each movement, believing the stretch will release some of the tension. Sound becomes sharp in my ears. All the while there's a growing sense of constraint around my brain, inside my skull. It's called the prodrome, and not all of us get it, but for those who do, any combination of food cravings, constipation, diarrhea, mood changes, muscle stiffness, fatigue, or increased urination means it's coming. Whether an hour or a day, it's a warning to call home, call a cab, call the pharmacy, get the ice pack, a rolled hand towel, the eye mask, earplugs, a face cloth, a glass of water, and most importantly, to turn off the ringer in the bedroom. That can be the killer.

We're told to not call them migraine headaches anymore, because the term lends itself to misinterpretation and a general misunderstanding of the severity of a migraine attack or episode, as they're to be known now. It's not a headache, or at least not all of it is a headache. The headache is only one part—notably the most painful part—of a neurological disorder that affects one in eight women, and approximately one in twenty-four men. Most of the research into migraine episodes is incomplete or inconclusive, yet the consensus is that a migraine brain is more sensitive to stimuli than a regular brain, and that certain stimuli can trigger a migraine episode. It doesn't sound that bad, really, almost like a rash or a cat allergy. Unless, of course, you've sat in a room and watched a loved one go through a migraine episode from start to finish. You'd

quickly join the chorus, emphatically correcting everyone you met, "It's not a headache, dammit."

It's rumoured that Lewis Carol drew inspiration for *Alice in Wonderland* from the visual, auditory, and olfactory hallucinations associated with migraine attacks, which may be the best association to describe the second stage of a migraine episode: the aura. Consider Alice's vertigo, her inability to find words to describe her surroundings, her utter confusion when confronted with rooms with small doors and tea parties with mad hatters, her anxiety when being chased through mazes, and her absolute fear of hallucinations; these images begin to point towards the experience of a migraine.

My stage of aura begins, almost without fail, with a visual disruption in my left eye that causes whatever is just to the left and below my central focus to become invisible. If you sat with your head resting on your hand and I focused on your face, your hand would disappear until I shifted my focus to your hand, and then your elbow would disappear. After the visual disruption I'll begin to get any combination of tingling sensations in my tongue, lips, fingers, or entire hand, but always exclusively on the left side. General anxiety and confusion grow as each stage of the aura takes place, flanked by a increasing hypersensitivity to light, sound, and touch. Other people report flashing lights, wavy lines, spots, blurred vision, olfactory and auditory hallucinations, vertigo, and partial paralysis. The aura usually occurs without pain, but the loss of control and sensory perception can be frightening beyond words.

I've experienced an onslaught of migraines in the past few weeks. Normally, I can anticipate a migraine attack every six to eight weeks, depending on the season and my level of stress. I've had five in four weeks. The third in that series was unbelievable. "Debilitating" would be a mild term for it, "partial paralysis" a kind gesture. I've been seeing a chiropractor, and she told me that often in the course of treatment the body will reject the adjustments with a final bout of migraine attacks. The flu comes in bouts, this series of migraines came on apocalyptic horseback, and it was no comfort when my chiropractor expressed joy, believing it a sign of progress. I wanted to hit her. I returned, however, always hoping to avoid the next attack, which really is how migraine sufferers exist: recovering from one attack, but watchfully anticipating the next. Is my

hand tingling because it's fallen asleep? Do you smell that? Is there something wrong with the TV?

The headache, the third phase of the migraine episode, is by far the worst phase of the process. It is usually hemicranial pain, but can be bicranial, and accompanied by phonophobia, photophobia, nausea, vomiting, diarrhea or constipation, depression, anxiety, hot flashes and chills, dehydration or water retention, dizziness, and confusion. Most attacks occur at approximately six in the morning and can last anywhere from one to seventy-two hours—any attack that lasts longer than seventy-two hours is considered migrainosus and requires immediate medical attention. My headache begins once the visual disruption and numbness in my face and hands have worn off, and starts with a growing pain behind my left eye. The pain—imagine hot glass pushing its way through your eye and into your brain, only to shatter and throb—moves into the upper centre of my left lobe and beats incessantly. Second only to the pain is the pressure—the sense that my brain has suddenly swollen too large to fit within my skull, and is bruising as it pushes against bone. My headache, and I should consider myself lucky, usually lasts two to three hours, and never longer than four.

I imagine that the headache itself would last longer if it weren't for the drugs. I take 80 mg of Inderol as a daily prophylactic, as well as Feverfew, a herb mixed with camomile that is supposed to prevent migraine attacks. I used to take Imitrex, the grandfather of migraine drugs, but it is as awful as some migraines, and I would rather go without. Imitrex, and drugs like it, is associated with the fourth stage of the migraine episode, the postdrome. In this phase, the headache subsides, but a sense of depression, fatigue, and poor concentration and comprehension are common, and often attributed to the powerful drugs taken to combat the pain. In an effort to curb this phase of the episode I take only Advil Migraine during the attack, and suffer through the twenty-four-hour sense of shell shock drug free.

There are innumerable speculations about how and why some people suffer from migraines: food allergies, weather fluctuations, serotonin levels in the brain, heart-to-brain connectivity, smoking, stress, sleeping patterns, orgasms, spinal misalignment, and food preservatives have all been linked to migraine attacks. However, no matter the approach a sufferer

takes, how many combinations of treatment are initiated, no one seems to ever have been cured of migraines. For all the drugs, herbs, holistic treatments, and sound nutritional advice, the best I can ever hope for is a reduction in frequency. It's that loss of control that frustrates me the most; that I can do everything every whole-health website tells me to, and I will still get innumerable migraines in my lifetime; that each time the cycle begins I immediately roll through the days or weeks since my last one, searching out a cause; and that no matter how much I am loved and cared for through the process, I am alone, lying in a dark room, waiting for pain to end.

A few years ago I saw a neurologist who specialized in migraine research. After an extensive interview, neurological exam, and MRI, the doctor sat me down and told me that I had classic migraines and didn't need to worry about any other neurological cause. He wrote a prescription for Inderal, passed me a handful of Imitrex and other drugs, shook my hand, and welcomed me to the migraine club. I left his office realizing that this man, this expert in migraine care and neurological disorders, could never understand the despair and helplessness that accompanies migraine attacks. To him, variations in frequency and severity were indicators of progress or deterioration, and there was a club wherein camaraderie would lessen the pain. My neurologist hadn't realized that the fifth stage of a migraine attack, perhaps the worst of all, was hopelessness.

Matt misses looking for subway mice at Bloor Station, and can't yet remember the order of the North Shore mountains. He is currently working on a master's in English literature at UBC.

Getting a Grip

Ellen Case

My pharmacist and I are on a first-name basis. Lloyd fills all my prescriptions, notices if doctors make dosing errors, and advocates for me when my drug plan claims that Zanaflex or Celebrex isn't in their formulary. He's seen me go from anti-inflammatories to steroids, from muscle relaxants to anti-spasticity drugs. At the end of the year he gives me a printout of all my expenditures to claim as a tax deduction.

A month ago, while I waited for him to finish with the customer ahead of me, I looked through the canes. I fingered the polished hardwoods, admired the carved handles that give a person different ways to get a grip. These would be easier to hold onto if my hands get the same neuropathy my feet have. I tried to look as if I were sorting through the canes with an idle half-interest, the way you might page through an issue of *People* magazine in the checkout lane. So it would look as if I were thinking of one for my grandfather. Certainly not for me.

But Lloyd didn't miss it. He's discreet: he glanced around the small pharmacy to see if there was anyone else in hearing distance, but the store had cleared out after the lunch hour rush. I was picking up a new drug, an injectable interferon called Avonex. He put the syringe kit into a bag, took my cheque, and chatted with me about the way College Avenue is changing, but his bushy eyebrows stayed hunched together throughout the transaction. Then he tapped the box of interferon syringes with his fingertips and said, "I can tell from these that you've had a hard diagnosis."

I nodded. "It wasn't just a spine injury like we thought." I wasn't used to people bringing it up, but his acknowledgement felt welcome. "I guess

you know it's multiple sclerosis." I was trying to practise saying the whole two words.

"That's what I figured. I'm sorry," he said. If he said any more I was going to cry, and I think he sensed that, because he took a step back and spread his broad hands on the counter, and his eyebrows unhinged themselves from each other.

"You've got a good neurologist."

"I know."

"If there's research I can do, or anything I can order for you, you'll let me know."

"Thanks, Lloyd."

He tapped the box again. "You keep these refrigerated."

I left, making an effort to walk with grace and balance. If I can just walk normally, I can pretend I don't have this disease, I thought. But the strategy wasn't working very well so far.

I crossed the street and meant to step up onto the sidewalk, but my left foot didn't clear the curb. I stumbled and hit the pavement knee first. Half a dozen strangers quickly offered assistance. I had scraped my knee, but the hem of my skirt hid it from view. I waved off the helpful strangers, unlocked my car, and threw the Avonex onto the passenger seat as if it were the drug's fault.

That afternoon, the Avonex company sent a nurse to teach me how to inject. It was a hot August day, so I served us limeade. Betsy was red-haired, round-bodied, and Irish. She thanked me for the cold drink and told me to change into shorts. I had hoped she wouldn't notice my bandaged knee, but she was as sharp-eyed as Lloyd. "Did you fall? How?" she quizzed me. "Patients living with MS often have balance problems. You may be less steady on your feet than you think. Have you thought about getting a cane?"

"I have one," I lied. I didn't like being called an MS patient.

I washed my hands and then, following Betsy's instructions, peeled the sterile wrappings off a syringe, a bottle of saline, and the tiny vial of white powder. With Betsy coaching me, I speared the saline bottle, withdrew a millilitre of the water into the syringe, then withdrew the needle and stabbed it into the Avonex vial. "Inject the water slowly, or the Avonex will foam up," Betsy cautioned. Drop by drop I released it and

saw the white powder liquefy. I had such hopes for the contents of this vial. “You’ve read the booklet and watched the video?” Betsy checked. I had. I knew that Avonex is interferon beta-1, which is naturally produced in a healthy human body to modulate the immune system. For people with autoimmune diseases like MS, it cools an immune system that has shifted into overdrive. I hoped it would do this for me, and I had paid a \$300 co-payment to make this bet. I would experience a side effect of flu-like symptoms for twenty-four to forty-eight hours. To minimize these symptoms, Betsy had me pre-dose with four ibuprofen. I washed the tablets down with limeade.

Under her direction, I attached the actual injection needle. Then we looked at my thigh, and found the centre point, which was conveniently marked by four freckles. “You’ve got a touch of the Irish, too, I see,” she chuckled. “Now aim like you’re playing darts.”

I stared for a second at the four freckles, offered a prayer, and speared my skin.

“To the hilt. Good job. Now press the plunger.” A cooling fluid bloomed into my thigh muscle, and with it, I felt an infusion of hope. Betsy handed me a Band-Aid.

FOUR WEEKS LATER, I stood at Lloyd’s counter again to get my Avonex refill. I had parked in the same spot and negotiated the curb without tripping. I eyed the cane rack again and then tried to ignore them. They seemed to be eyeing me back.

Lloyd came out from behind the counter and joined me by the rack of antihistamines, in front of the canes. “One of these might suit you quite well,” he said.

“I don’t think I need one yet,” I said. Lloyd nodded. I wanted him to go back behind the counter where he belonged, but instead he selected a flashy blue aluminum model from amongst the more traditional wood ones.

“Of course. But I’ve seen you fall, and I don’t want you getting hurt.” Because it was Lloyd, I listened, though I wanted to tell him to mind his own business.

“No one wants a cane, especially at your age.” His eyebrows shot upwards. “But think of it as a walking stick. Hikers have used those for

centuries. Here, try this one.” I took the handle of the blue model. I had to admit it looked like a piece of flashy athletic equipment. I tried walking up the aisle to the greeting cards.

“Just let it go in rhythm with your left leg. You don’t lean on it, you just let it tell you where the ground is,” said Lloyd. I paced back up to the counter. “Good. You won’t have to look at the ground as much when you walk. That’s better for your neck, and you can see the world around you more, too.”

“My neck has been hurting,” I admitted. “And the metallic blue matches my car.”

“It’s definitely you. Think of it as an accessory.” He smiled and stepped behind the counter again to ring up the Avonex. The door chimed as other customers drifted in. I set the shiny accessory on the counter. “I’ll take it,” I said.

Ellen Case is an essayist, short-story writer, and psychotherapist in Berkeley, CA. She holds an MFA from Mills College and an MA in clinical psychology from John F. Kennedy University, CA.

Body Shop

Timothy P. Kelly

Asymmetry

The ribs, in their flare from the sternum,
are planed back like limbs on a windward bluff,
the long bone combs bent round in a tapering
ellipse until the ends, aligned and opposed,
are sutured down tight into the long dashed seam

of the spine. Above them, the stem of the neck,
bulb of the skull; below, the plumbed pedestal
of the pelvis, alabaster bird bath balanced
on convergent, pikelike legs. There should be
two shoulders; ball, socket, and three-cornered blade,
winging or snugged to the ribs, enabling the hand,
in all its mischief and grace, to travel out across

disorder, and grasp. She showed me, in 1978,
her feet, and when I took hold of them she bridled
and wouldn't allow me, for months, to examine
them again. They were, it turned out, different;
slightly asymmetrical: the right's toes clawed
and calloused, a shoe-size bigger than the left.
It was, in her mind, a deformation, a defining

characteristic, a deadly serious embarrassment.
I seized the monster, kissed it; kissed the ankle,

the knee. I begged her let me continue, a Jesuit,
upstream, baptizing and bringing to light all other
shrouded, stigmatized asymmetry.

Heart

1.

Muscles rest, save one, knock wood,
mine's ejecting nicely.
But mind that
the fearsome shushing
will one day stop

and the murmurs and orchestral valve clatter,
and the houselights
suddenly dim. And
we'll hold our breath.

2.

Parked one Friday night on Airport Road
under the sensational, starshaking jetpath,
she put my hand on her heart and asked me
to pledge allegiance. And there began
a recurrent dialog on constancy: two stroke,
centripetal, piston shot, bobbin and shuttle,
one ball dribbled constantly fifty years, no
let-up, in the same cavernous gym. Even if

you simply sit and acknowledge the wrack
your heaving mind tosses steadily on shore,
each thing luminous, held open patiently, like
a coat; even then, march-cadenced, the heart.
One spring Saturday, we watched the famous,
stump-like, aristocrat Russian sisters beat a rug
in the yard next to my grandmother's with two
tennis racquets, each of them grim-faced,

head-scarfed, grunting and whacking away
in a woolly cloud, from opposite sides, in turn.

Timothy Kelly describes his poems as body-centric. He works as a physical therapist (or physiotherapist, if you prefer) and teacher in Olympia, WA. His most recent collection (including the poem "Heart") is *Toccatà&Fugue* from Floating Bridge Press, 2005.

The Remainder

Herman Gottlieb

When I walked into the room, Russo was lying on his bed, his shirt pulled up and his pants bunched around his knees for my convenience. Willie had arranged him and the others like him in just this way, and she stood across the bed from me in her starched, white uniform, ready to hand me whatever I needed. In this eager stance was the message that everything here would be easy for me, that I wouldn't have to be here a minute longer than necessary.

I'm sure Willie provided the same level of assistance for the other specialists, yet the Sunnyside Home had trouble retaining voluntary physicians. Understandably, the tired forties decor and three hundred beds filled with the chronically ill did not appeal to those accustomed to working in bright, modern offices filled with animated, functioning patients. Nonetheless, I was willing to give it a try. It would be my way of giving something back to the community that for twenty years had given me a busy, private practice and a comfortable life.

Russo's mop of grey hair spiked randomly in greasy shards, his yeasty body odour and threadbare clothes indicated he was destined to be in Sunnyside for the remainder of his days. As I stood over him, slipping my hands into a pair of latex gloves and tearing open a plastic package for its polystyrene syringe, it occurred to me that nursing homes were full of remainders—of bodies, of minds, of lives—places in which nature's protean mathematics were limited to the inexorable divisions of aging.

Protruding from a hole at the bottom of Russo's belly, halfway between his lint-filled navel and his shrivelled penis, was a flexible, pinkie-sized catheter that drained urine from his bladder into a piece

of clear tubing, and from there the yellow waste dripped into a two-litre bag attached to the chrome bed rail. Russo had not been able to urinate for years; both that infirmity and his dementia were the consequences of a stroke. If no one changed this catheter, stones would form on the tubing like barnacles clinging to a pier, a situation that often lends itself to bleeding and infection.

"I'm Dr. Grove." I took the syringe, plugged it into the side port of the catheter and deflated the retention balloon. "How are you feeling today, Mr. Russo?"

"Go to hell!" he said in a loud, clear voice and without malice.

I glanced at Willie. She cracked her gum.

"He's always like that. Tourette's, or something." She bent down and put her face in front of his bespectacled eyes. "Mr. Russo! Say hello to Dr. Grove. He's changing your tube."

"Bitch!"

"See?" She straightened up. "And I know he likes me."

I removed the catheter. Tiny encrustations—stones in the making—coated the portion that had been in his bladder. A small gush of urine issued from the hole, trickled over his groin and onto the bed. Willie blotted the stream with a towel. I took a new catheter, put it in the hole, and pushed it into his bladder. Russo neither moved nor complained when I inflated the catheter's retention balloon.

"Mr. Russo," I asked, "what kind of work did you used to do?"

"Usher."

"Oh?" I looked up at Willie, wanting her to acknowledge my eliciting a coherent answer. "And where were you an usher?"

"Uck yo!"

Willie saved her snicker for the hallway.

I had a half a dozen more tube changes to perform on other compromised patients, though none was as colourful. Over the course of the morning I saw a wide range of function. Some patients were completely lucid, though bed-bound, and others spent much of the day strapped to a wheelchair, incapable of interaction, their eyes closed and tongues dangling from one side of their mouths. That some people came to such an end was not a surprise, yet Willie had saved the worst for last, where there was an entire hallway full of these semi-comatose unfortunates.

The fruity, cardboard deodorant trees dangling at intervals from the drop ceiling frame failed to mask their wretched odours.

She spoke to my astonishment. "Promise me something, would you, Doc?" Willie held the sleeve of my white coat as if petitioning an indulgence. "I say this to every one of you who comes through here. If you find me down, DNR. Do not resuscitate. Y' hear? No way I'm ending up like this."

"Shouldn't that sort of thing be in writing?"

"I want to hear you say it, just in case. Who carries papers?"

"OK." I waved my hands over her head in mockery. "You're a DNR."

"Thanks, Doc."

"But no more laughing when I talk to Russo."

Willie cracked her gum and gave me a sidelong glance. "You be messing with him, he'll be messing with you."

The next month, and every month for five years, I returned to Sunnyside for consultations and for tube changes. New patients came, some died, but Russo hung on. I looked forward to seeing him for his foul language, so refreshing in contrast to the silence or to the moans and complaints I heard from others. His words seemed to issue from some ancient repository of playground patois, and it made me wonder about the vocabularies I saved for various occasions. Our monthly ritual included my asking where he had worked. The question endured because I harboured a faint hope of tapping some unappreciated store of mental activity. Yet each time he replied, "Uck yo!"

One morning, almost six years from the time I first met him, I heard a different answer.

"RKO!"

I looked at Willie. "Did you hear that?"

"Hear what?"

"He didn't say 'Uck yo.' Maybe he never was saying that and was saying 'RKO' all along. Isn't that something? He was an usher at the RKO theatre! A mystery solved!"

"If you say so, Doc." She opened the package for a new catheter. "He seems the same to me."

"Let's see about that." I bent down to Russo's face. Dandruff and dust particles coated his glasses, but he rolled his dull, brown eyes toward

me. “Mr. Russo?” I saw his pupils dilate, indicating interest. A chill went up my spine with the thought I was witnessing a most extraordinary event—the recovery of cerebral capacities that had been lost for many years. “Do you know where you are, sir?”

He took in a deep breath, and spoke. “Kiss my ass!”

I stood up with a grimace and glanced at Willie, who did not bother to save her snicker for the hallway. Nonetheless, I felt a sense of completion as though I finally understood a garbled song lyric that had been eluding me since childhood. The feeling stayed throughout the day, no less the kind of reward I sometimes feel after having performed a successful operation in the face of what many deemed a hopeless situation.

The next month I was ready with a new question. I looked forward to the deciphering of Russo in the way I savour a difficult acrostic. When I entered his room it took me a long moment to realize someone else was in his bed. My first thought was to deny it, to move along quickly to the next patient, that it would be better not to ask and not to know.

Willie tugged on my sleeve. At least her tone was sympathetic. “Didn’t have the heart to call you, Doc. He died last week.”

I turned and left the room, unwilling to let Willie see the mist in my eyes, unwilling to admit how much I had been depending on Russo and the mystery of his words. If for only a moment among the thousands in any month, the small absurdity I shared with him had been enough to displace the larger reality, the one in which every Sunnyside patient reminded me of the inevitable decline of my own faculties. I recovered my game face and finished rounds.

After I handed off my worksheet, Willie walked me to the revolving door. She had never done that before, nor had she ever asked me the question she now tossed out like a lifeline. “Doc? You be here next month?”

I imagined the answers she had heard before and, as my eyes met hers, I knew she would understand all I had left to give her was the remainder of my smile.

Herman Gottlieb is the pen name of a surgical subspecialist who lives and works in the New York City metropolitan area. His publication credits include both invited and peer-reviewed contributions.

Getting Mother Buried

Merrill Joan Gerber

In memory of my mother, Jessie S. Gerber

Twenty years before my mother was to die, she phoned me to say, “I don’t want any transients at my funeral. I don’t want all that flowery baloney in the newspaper: ‘Adored wife, beloved mother, devoted daughter, cherished sister.’ I want absolutely none of that. I don’t want a bunch of strangers gawking at me, crying crocodile tears and coming back to your house for a party in my honour, stuffing themselves with food that you pay a fortune for, and pretending they’re heartbroken that I’m dead. And I don’t want a rabbi who never laid eyes on me saying how charitable and good I was, the way that rabbi we hired made up things about Daddy.”

“I’ll keep that in mind, Mom,” I assured her. “I’ll take care of it.”

MY MOTHER’S SONG and mantra for the seven years she was in the nursing home—paralyzed and on a feeding tube—was “I want to die. I want to be dead. I want to be in my grave next to Daddy, I want to lie quietly in peace. If only I could die.”

Her roommates all had better luck than she; one by one they faltered, declined, were comatose for days, and died. One after the other they were rolled out, to their peace, whatever it was to be. Each one of them had complained about my mother’s constant wish—to die, to die. They were all waiting till Jesus called them, a pleasant convenience but one not available to my mother, who believed in nothing but the beauty

and transcendence of music. She had been a pianist and now could no longer play.

I brought her tapes of Chopin, of Beethoven, of Schubert, of Tchaikovsky, of Mozart. I even bought her little plastic busts of all of them and lined them up on her bedside table—her little entourage of men. She'd always been a flirt, a woman who showed off her pretty legs by wearing short skirts. I'd sit with her, and we'd listen to the music coming out of the cheap portable player until my mother's eyes filled with tears. "It makes me too sad to listen," she said, time after time. "You better go now, you have things to do."

"Shall I turn on the TV before I leave? You could watch Oprah."

"No. I don't want anything. I don't want to think about anything. I just want it to be over."

And she'd commence to look at the clock on the wall, and I looked at it, too, that blank face of hours that she'd have to endure, one by one, till my next visit, or till she fell asleep, or till an aide came to turn her from side to side or change the feeding tube that pumped fluid into her stomach.

Every time I left my mother, I'd cry my way home. "I've got to get her out of this," I told myself. "No one should have to suffer this way."

MY MOTHER'S SUFFERING: you could say it was the theme song of my life. Shortly after I was born, she had all her teeth extracted. She suffered from migraines then—one theory was that "bad teeth" were causing her headaches. My earliest memories have to do with her retching in the bathroom as—after every meal—she removed her teeth to clean them. I never saw them, the teeth, the way I saw my grandmother's, sitting in a glass beside her bed. My mother's shame about her teeth was the reason she never smiled in pictures, the reason she found food a torment to chew, the reason she ran to the bathroom after every meal: I heard these sounds, her gagging and the sound of water running in the sink, all through my childhood.

When I was seven, and she was eight months pregnant with my sister, we were walking one day on Kings' Highway in Brooklyn, and two young men, one chasing the other about some dispute, knocked my mother down in the road. I saw her fall on her face, heard her scream, watched her roll on her round belly from side to side before she was able

to turn herself over. She had tears on her face as a man from the local fruit store ran out and helped her up, pulled her under the arms to an upturned wooden crate where he made her sit down while he called for a taxi to take us home.

Later, after the baby was born, my mother developed milk fever; milk had to be pumped from her swollen breasts. When she screamed, I had to run away, hide in my bed, cover my ears. It seemed my mother was always in pain, there was never a day she didn't press a wet washcloth to her forehead, that she didn't lie down with the lights turned off in her room, that she didn't beg her children to be quiet. As a child (who also sometimes lay down with a washcloth on her forehead, as practice for growing up), I thought that being alive might not be a good thing, not good at all.

Though it was not exactly my choice, I began to share her invalidism with troubles of my own. I developed heart palpitations; they came on suddenly, often when I lowered my head to pick something off the floor—my ball, my set of jacks, my crayons. I'd feel a crazy thump in my chest, and then the hoofbeats of panic took off, thumping so hard that I could see my chest wall flop in and out as if a battle were taking place around my heart. When it happened in school, I'd put my head down on the desk till the teacher inquired, and then I was taken to the nurse's office until my mother came to pick me up. She'd have to walk fourteen blocks through the Brooklyn streets, often in snowstorms or in rain, pushing my sister Bobbie's baby stroller. I remember sitting on the wooden bench in the school office, a terrifying limbo, until my mother arrived, alarmed, in the doorway, pushing my sister. I'd walk home with them, my heart ricocheting like crazy, and then, within an hour or two, the mad thrashing of my heartbeat would calm. One last thump, and the quiet normal rhythm returned, like a blessing. I'd stay in bed the rest of the day, reading, sipping chocolate milkshakes that my mother would bring me, dreading that I'd be somewhere away from home the next day and it would happen again. All the years I was growing up, my mother and I had this in common, this knowledge that we were soldered together by pain.

WHEN MY FATHER, at age fifty-five, complained of pains in his thigh bones, my mother convinced him to have a checkup. He hadn't been to

a doctor in twenty years. He was the picture of health: tall, muscular, sun-tanned, not a grey strand in his curly brown head of hair. In fact, he made his living by his strength, hauling old furniture into his antique store from the station wagon, dragging marble-topped armoires around, lifting cartons of books he bought at estate sales (boxes of which he gave me to read as I was growing up).

No one expected a death sentence. We heard it with disbelief: leukemia. Galloping death. Within three months my father was dead, his eyelid and lips eaten away by disease. ("I'm a fatalist," he said to me one day in his hospital room, "but I'll fight till the end.") My mother was not a fighter, but a giver-upper. I saw her give up at his funeral. I saw all the hope go out of her as we buried him in the rain.

My sister and I, just the day before our father's death, had bought a burial plot on a hill, high above a freeway. The two of us had gone cemetery shopping that day; we'd argued about the advantages of one cemetery over another: "This one is good, it's in a homey neighbourhood, there's lots of cars passing by, it won't be lonely for him." "But it's too noisy. How will he get any rest?" Soon we were making jokes: "This one is near a playground. Daddy always liked to hear the sound of children laughing." "But the smog is bad in this side of town." We'd start laughing for no reason; we'd lean against each other, laughing, as we argued the suitability of finding a suitable resting place for our father in eternity. (He wasn't dead yet, not then, as we spoke.) We'd been terrible laughers as children, we'd laugh in our beds at night until our father came to quiet us. "No more laughing! That's enough laughing!" and his words would send us into gales of laughter. He'd come back again. "Your mother and I need to get to sleep. We have to go to work in the morning. No more laughing!" and as soon as he'd left the room, we'd start squealing again, choking with laughter till we could hardly breathe. Once (we both remembered this) he came into our bedroom after the third or fourth warning, and he slapped us each, very hard, on the thigh. We gasped in shock, and when he had left the room, we turned on the light to examine the mark of his handprint, red on our skin.

That day, at the cemetery on the hill, overlooking the freeway, we bought two plots: one for my father, one for my mother.

AFTER HER FIRST YEAR of the seven years she spent in the nursing home, my mother would ask us every day, "Do I have a place next to Daddy in the cemetery? How will they know where to send me when I die?" We'd reassure her, "If you die, they'll call us. We know exactly what to do, don't worry, it's all arranged."

A FEW YEARS before my mother had the catastrophic stroke that paralyzed her right arm (it occurred in the hospital, where she was for routine tests!) and before she fell, five days later from her hospital bed, shattering her hip and rendering her immobile for the rest of her life, she was in my house, visiting us, having dinner with us, when she walked down the hall to my husband's music room and fell down a single step she forgot was there. She went flying, landing on her side. Her screams stopped my heart; the sound of them had always been the ultimate torture to me. I ran in and she was shrieking, "The pain, the pain!" I wanted to cover my ears, but I had to act grown up, had to call the paramedics. Two of my daughters were visiting from college. They huddled over my mother's body on the floor, listening to her scream. I wanted to beg them to run out of the house, not take in my mother's song of life: her pain and her message that all was pain. My mother must have turned her head just then, to see me cowering against my husband, sobbing, and she said, "Oh don't cry, Merrill. Don't cry." Yet when the paramedics arrived and cut off my mother's clothes, I heard her beg them, "Why don't you just shoot me now?" They stabilized her arm and shoulder, they carried her out on the gurney

In the hospital the doctor told us she'd broken both her wrist and her shoulder. The X-rays showed that neither one could be set. They gave her a sling, a splint, and a prescription for pills. She was crying in pain all the while the doctor was talking to me.

"Please, won't you admit her? She's in horrible pain. You can't just give us a codeine pill and send us home!"

"We're not allowed to admit her under Medicare rules," the doctor said to me. "If she'd broken her hip, we could. But a broken arm and shoulder don't qualify. I'm not allowed to admit her with these injuries," he said. "I could lose my job."

FOR TWO DAYS and nights, my youngest daughter slept on the floor beside my mother, who lay moaning on the couch in our living room. We spooned cooked rice cereal between my mother's lips. When she had to be walked to the bathroom, two of us would support her between us; her legs would buckle, and she would shriek if we moved her arm even a tiny bit. Her skin was waxen; her false teeth shone like stones in her mouth.

On the third day, I called a nursing home and said, "My mother has had an accident and broken her wrist and shoulder; the hospital won't admit her, but I can't care for her. Can you accept her there for a few days?"

They sent an ambulance. When the driver and his partner saw my mother's face, they said, "This woman is in very bad shape; she has to be taken to a hospital." This time we chose another hospital. I phoned a friend whose husband was a doctor on the staff. He examined my mother in the emergency room and admitted her at once: "Dehydrated, disoriented, in shock." He didn't worry about the Medicare rules.

AFTER SOME DAYS in the hospital, my mother was transferred to a nursing home. (Six months after her death, I read the little notebook my mother kept during those days in the nursing home. Always organized, always with a pencil in hand. She had for years—as a young woman—been a secretary to two New York state senators, Rabinold and Scribner):

It is so cold in here . . . awakened by the "And then" lady, and someone yelling at her to keep quiet . . . I cannot bear it . . . there are 2 others that can be unbearable, too—the man who screams at night "Help, Help Police!" and the woman who yells when people are trying to sleep, "Nurse, Nurse, don't let me die." It is so cold in here . . . I am one big iceberg . . . some person's TV, overpowering loud and deafening . . . Merrill, do you have my watch and ring . . . The pain is awful . . . They took me to activity room, it is a complete madhouse and I will soon be one of them . . . Dinner served, sent back the meat loaf, potato, vegetable, salad, sent it all back, got cottage cheese, canned pears, apple sauce, custard pudding, milk, chocolate cake, ate only a little and kept spitting it out, want to throw up. What will I do when I get home? Even the cottage cheese doesn't stay down . . . I don't even want to swallow . . . Earlier I tried to get glass of water from the side of the bed, I lost my

balance and fell, sprained my right ankle and wrist . . . no relief from the pain . . . Merrill, is my bag in your house . . . They left me in the toilet and forgot to come back and get me . . . I was screaming for help, banging on the wall, I couldn't stand up myself . . . they ignored me for hours . . . I thought I would die there . . . is so cold here, I will freeze to death.

Thus began my mother's long decline. She stayed in that nursing home for a month, went back to her retirement home, had other emergencies, nosebleeds, vertigo, a transient ischemic attack during which she was unable to speak, lost circulation to a toe that became gangrenous, and was again admitted to a nursing home. After it was clear that her toe was turning black and rotting, she was sent to the hospital for femoral artery bypass surgery; a vein taken from her hip was installed in her lower leg. The doctor said to me, "If she lives another year, and can walk during that time, I think this is worth doing."

My sister and I visited her every day, wherever she was, in whatever state of despair, anger, hysteria, depression that gripped her. We listened to her wrath, to her misery. Once, when I was there, they brought my mother lunch, broiled liver. "Meat meant for a dog!" she cried, "No one could chew this!" and she tossed the plate of food at the wall. "This is no life!" she cried. "This is no life! Please children . . . let me die, I want to die!"

IN THE WEEKS following her hip surgery, my sister and I watched our mother suffer the pain of blood clots that lodged in her lungs, heard her babbling wildly in a state of morphine-induced hallucinations, and watched her protest as leggings, designed to contract automatically around her legs, squeezed hard, day and night, to keep her blood flowing. She was unable to eat, but didn't quite die. A doctor spoke to us about installing a permanent feeding tube into her stomach: "She's hanging on by a thread," he told us. "She'll die if we don't put in a tube. If we do, you can't guess what troubles lie ahead, it's a Pandora's box. It's possible that she'll recover enough to eat on her own eventually, and if she does, we can remove the tube."

"Do it," my sister and I said. Her life still seemed of utmost importance to us. Though therapists came to visit her at the nursing home after her broken hip and her stroke, one to teach her to walk, one to teach her to

eat, my mother—never a fighter—found the obstacles insurmountable.

With the use of only one hand, she could not hang onto the parallel bars in the therapy room, and the therapist soon enough saw the futility of trying to get her to walk. As for eating (which my mother had never enjoyed doing at the best of times) with the use of only her left hand, she was clumsy, spilling food all over her gown and bedclothes. Furthermore, she could no longer insert and remove her dentures with only one hand, and eating pureed food in her toothless state horrified her. When aides tried to feed her, they gave her large spoonfuls, one after another with no interval between (they were rushed, they had many patients to feed), so that my mother gagged and had to spit out the food.

She gave up eating and depended for the rest of her life on the greyish-brown mixture that hung in an upside-down bottle beside her bed and was pumped via a plastic tube into a hole in her belly. Even that method of nutrition had problems; at one point the tube became blocked by scar tissue that occluded the opening in her stomach. Again, she required surgery.

On one of the days she was hospitalized for this new problem, I phoned the nurses' station and asked for a phone to be held at her ear. A nurse agreed to do this, but left the phone in my mother's weak left hand, and after the first few words we exchanged, my mother dropped the phone. I could hear her crying, "Nurse, nurse—I'm disconnected, come and hang up the phone." I held on, calling, "Ma, Ma, I'm still here," but apparently she could not hear me. Like a voyeur, I kept the connection open, listening to my mother's hard breathing, my mother's sighing. Moments passed. Then I heard a small sound, like a poem, like a prayer, issuing into what my mother thought was her private space: "I wish I were dead. I wish I were dead. Oh, I want to be dead in my grave next to my husband."

MY SISTER AND I learned of a community group called CAPS: Children of Aging Parents. They were holding an open meeting at the local synagogue, and Bobbie and I, often feeling at our wit's end about our mother's plight, decided to go to see if we might learn something about how to cope with her endless decline.

We were welcomed by two female "facilitators" and offered tea in Styrofoam cups. Eight visitors were present, only one of them a man, who

said he was there to learn about “resources in the community.” Going around the circle, we each gave a brief explanation of our problems: most of them were the usual: not enough time, not enough money, not enough energy to cope with the demands of our elders. Except for Bobbie and me, the others still had parents living either on their own or with them; the problems were similar—parents falling down, parents needing to be taken to doctors, parents unable to handle their medications or forgetting to turn off the stove, parents emotionally demanding, child-like, sometimes vindictive, sometimes hateful. Bobbie and I, much farther along in this journey, with our mother installed in a nursing home, felt somehow fortunate. She was cared for by others; we were no longer called in the middle of the night. We looked at each other and smiled.

Then, oddly, I sneezed. I sneezed and fumbled for a tissue, and found I didn’t have one. I reached blindly toward my sister, waving my hand to indicate that I needed a tissue. As she searched in her purse, she also sneezed! She looked up at me, her nose dripping, and I looked at her, mine dripping, and we began to laugh.

Incurable laughers that we had always been, we fell into deep waters here, laughing as we used to laugh as children when some particularly weird food lay on the plate, or at how the Jell-O shimmered on the spoon, or how the chicken wings looked silly detached from the chicken.

Here, in a serious meeting about desperate troubles (in fact, one woman was just describing how her mother would fall whenever she walked to the bathroom herself), my sister and I cracked up. We were minus all self-control, had not even a semblance of adult maturity. We had merely to sneeze and we thought it was the funniest thing that ever happened on earth. We doubled over in our chairs, trying not to laugh out loud, but we were beyond help.

The facilitators, two kind women, looked at us with understanding but not much amusement. They paused in their discussion, no doubt believing that in a moment we would get hold of ourselves and gain control, but their glances set us off again, and we grabbed hands between our chairs while new explosions of laughter shook our shoulders. We still hadn’t any tissues, our noses were running . . . and now, also, I had to go to the bathroom.

I stood up and staggered toward the kitchen of the meeting hall, and

my sister followed behind me. We were laughing so hard we could barely walk. I got a glimpse of the others in the circle, staring at us with disbelief. But it had gotten beyond us. My sister and I had been seized by some force that shook the laughter out of us till it turned to tears. Bobbie and I were racked with the violence of it, leaning against the sink, laughing and crying, but mainly crying, each trying to stop this fit, each trying to catch our breath.

My sister finally tore a paper towel from a roller over the sink and handed it to me. But I took one look at the little ducks on it and started on a new roar of laughter. We both wiped our faces and our eyes and our noses with the stiff paper towelling with little ducks on it. Nothing had ever seemed funnier to us in our entire lives.

As a last resort, my sister pulled open a kitchen drawer and lifted a corkscrew into the air, brandishing it at me. She glared, trying to threaten me into silence. But it was hopeless. We were not children of aging parents, we were lunatics of aging parents. We had lost it entirely.

My sister ran back into the meeting room, retrieved our purses, murmured some apology to the people in the circle, and hurried back into the kitchen to get me and lead me, though a side door, to the parking lot. She jumped in the car, turned on the motor, and sped us away, burning rubber.

By the time she dropped me off at my house, I was almost too weak to walk. I struggled up the steps and rang the bell, too exhausted to find my key. When my husband opened the door, finding me limp on the doorstep, he said, "It must have been quite a meeting. Want to tell me about it?"

THE LONGER my mother lived, the farther she seemed to be from dying. In fact, she rallied; she gained weight from the feeding tube. Her risk factors diminished because she no longer walked—and could not fall. If an infection was spotted, it was treated at once with antibiotics. Her physical health improved and her mental health declined. Each time I left her after a visit, I was filled with unbearable sadness. I could not rescue her, could not fix her, and could not free her from her chains.

As the years passed, it seemed to all of us, including her, that she would never die. We had long discussions with her about this: she

wondered, could we bring her a poison pill, could we shoot her? Could we take her out to the desert, leave her there, and let her die? She did not want us to go to jail; she asked us to call Dr. Kevorkian. The problem was that she had no fatal disease. She wasn't dying. But to that she'd always say, "Do you call this living?"

Her doctor marvelled at her tenacity. "I never thought she'd live this long with all that's wrong," he said. He began to catalogue her illnesses. Some we knew of—the stroke, the broken bones, the circulatory problems—but he added new ones: gall bladder disease, ulcers, gastritis, arthritis, enlarged heart.

From her eighty-fifth birthday to her ninetieth, she received birthday greetings from the White House signed by the president. In addition, when she reached her ninetieth birthday, which came the day after Thanksgiving in the last year of her life, the mayor of the town in which the nursing home was located sent her a certificate of congratulations for living so long. Balloons hung from the bedposts when the family arrived with her birthday cake. The nurse had sat her up in her wheelchair. But on that day she had not enough strength to hold up her head, or enough breath to blow out the single candle on the heart-shaped chocolate cake I baked. I blew out her candle for her.

She watched us with her burning gaze as we sang the birthday song. I knew she was aware I hadn't put the extra candle, "the one to grow on," on the cake. She had always been careful to do that for her children.

"Thank you," she said, and closed her eyes. "Could you tell the nurse I want to go back to bed now?"

Something took hold of her then, an infection starting in her lungs. The next day as I arrived at the door of her room, I heard the sound of a suction pump and saw a nurse bent over her, jabbing a plastic tube down her throat as my mother thrashed and screamed in her bed.

Fluid bubbled up in her throat, she could barely talk. The nurse said, "We have to suction her every hour."

"Please, Merrill! I don't want this any more. Let me die."

A portable X-ray machine was ordered; the diagnosis was pulmonary congestion, that's all it was. Nothing serious. The suctioning continued for days. I had to run out of the room every time the nurse did it to my mother. I felt the brutality of it, the impossibility of her existence.

She was a bug impaled on a pin. And I could not release her.

Then, two days after Christmas, the X-rays, ordered again, showed pneumonia in my mother's lungs. Within a day, her temperature reached 104 degrees. The nursing home director called me: "We want to send your mother to the hospital for aggressive treatment. They can give her IV antibiotics and put her on a respirator there so she can breathe better."

"No. Don't send her to the hospital. We'll be right there."

I called my sister. "I think this may be our opportunity," I told her.

"Do you think we can do it?"

"We can try." We sped to the nursing home.

My mother looked like a puff of air on her pillow. She tried to talk to us: "Girls, I want . . . I want . . ."

"What, Mom, what do you want?"

"I want . . ." but there was not breath enough in her to finish the sentence. I ventured to finish it for her.

"To die?" I asked.

Oh yes, she nodded, oh yes.

"Mom, are you really ready to leave us?" I asked.

Her eyes burned in assent.

"OK then. We're going to talk to your doctor. We're going to help you get relief. We're going to get you out of this, Mom. But are you sure you're ready to die? Are you ready to say goodbye to us?"

"Yes!" It took all her energy to say the word.

At the nurses' station, we called the doctor; the nurse, Bobbie, and I all spoke with him. He seemed baffled that we might not want the most aggressive treatment, but soon enough conceded that maybe it was time to turn the case over to hospice care, that maybe our mother ought to be allowed to put up the white flag.

When I went back to my mother's room, I said, "Mom, a hospice nurse is coming tomorrow to help you be comfortable. You will have medicine to help you sleep. You won't be in pain. You'll just go to sleep and you won't have to suffer anymore."

"Today!" my mother gasped.

When my sister and I left the nursing home, I drove north toward the hills and pointed out the window. Mt. Baldy, in the distance, was covered in snow. A circle of golden clouds hovered just below the peak.

I pulled the car to the side and parked—we both watched the mountain darken as the sun went down.

That night, my mother was given morphine, by IV, by patch, and by droplets under the tongue. The feeding tube was turned off, and the oxygen cannula removed from her nose.

By morning, she had disappeared into the depths of her private inner space. We called her name, but she did not respond to us. We pulled our chairs close to her bedside, stroking her arm, touching her face. The hospice nurse had not yet arrived, and Pearl, my mother's regular nurse, was reluctant to administer the ordered infusions of morphine. She felt my mother's forehead: hot. "Poor Jessie," she said. She brought a Tylenol mixture and injected it into the feeding tube. "She's comfortable now," Pearl said. "She's sleeping peacefully. She doesn't need morphine now. Morphine depresses the breathing."

"Yes, she does need it!" I said, and my sister added, "We don't want her to wake up." We looked at each other in the shock of what we had said. This time we didn't laugh. This time we were dead serious.

"Give her the morphine," we said to the nurse. "Give it to her now."

WE SAT with my mother all day, that last day of the year, my sister and I, my sister's son, my husband, my daughter who lived nearby. We talked to my mother, we played her Chopin's music, my daughter Becky sang to her. We declared our thanks and our love. But she was gone from us then. I watched her chest rising and falling with sharp little shallow breaths. She had almost got her wish. She was on her way to achieve it. And we were here to watch out for her, to be sure that nothing interfered.

It was New Year's Eve. The world was preparing for the end of the year, and my mother was making her way out of life. For hours, we watched her chest heave in little spasms of breath that kept her in the world with us. As it turned dark, we realized we hadn't eaten, we needed to leave. The hospice nurse advised us, "They don't like to die when the family is here. They feel your presence and they can't leave you. But why don't you tell her goodbye, and that she's free to go. They say that hearing is the last sense to go."

So each of us spoke to my mother, and then we left her there. She drew her last breath without witnesses three hours later. The nurse told

us that just after she died, a great flock of birds was outside her window, crying in the trees.

MY MOTHER had no transients at her funeral. No one cried crocodile tears. No strangers gawked at her. On the morning I was to bring her clothing to the mortuary, I sewed gold buttons on her soft red quilted bathrobe (the one that had little blue anchors on it). I wanted her journey in eternity to be comfortable. Bobbie and I brought the music of Chopin to be buried with her, along with the announcement of a book of stories of mine that had just been published, based on her life, called *Anna in Chains*. We also included the program for the funeral, which starred my mother playing a tape of the music she loved on her own piano: “The Entertainer,” a Chopin Nocturne, and “Sunrise, Sunset.” We also buried with her directions to my house, for the party where no one she didn’t like would consume the food I paid a fortune for, and where heartbroken was what we all would be.

It rained on the day of the funeral. At the chapel, the funeral director required that we look at our mother in the coffin, wearing her red quilted robe, and to sign a form saying it was she who was about to be buried. I signed—but it wasn’t my mother. She was already dispersed to the stars. We had no rabbi, as she wished. Each of us in the family said a few words about her, this tough-minded woman, our mother, mother-in-law, and grandmother who was so central to our lives. My daughter Becky played a tune on her violin, “I’ll Always Remember You,” and my daughter Susanna sang a Hebrew folk song. Our daughter Joanna sent a message to be read: “She was glamorous: she wore skirts and elegant shoes and a pin on her collar. She was modern and decisive: she liked her hair white and short, she didn’t like to cook and ate her meals out. She loved her grandchildren and let us know it. And we loved her.”

On my mother’s simple casket we had lined up the little statues of the great loves of her life: Chopin, Mozart, Beethoven, Tchaikovsky, and Schubert. At the gravesite, we stood as my daughters and others carried the casket to the grave, where my mother was lowered to rest beside my father who had died thirty-two years before. The sky was just clearing, and fog hovered over the distant hills. We all shovelled the traditional three scoops of dirt upon her coffin. A friend recited in Hebrew

the Kaddish for the dead. We left my mother there, with my father. My sister took my arm as we walked away from the gravesite: “I hope Mom and Dad go dancing somewhere tonight.”

Merrill Joan Gerber has published twenty-five books. *Anna in the Afterlife*, based on her mother’s life, was chosen by the *LATimes* as one of the best novels of 2002. *Anna in Chains* and *Old Mother, Little Cat*, a memoir, also draw from her mother’s life.

“Getting Mother Buried” was previously published in *Gut Feelings: A Writer’s Truths and Minute Inventions* (University of Wisconsin Press, 2003).

Taking Leave

Catherine Belling

For my father

Always, on the day she had to leave,
A he'd get out his camera and take her picture,
too many times, always in the same corner of the garden
by the *naartjie* tree, with the dogs, the cats, her mother,
but never him. He was always behind the camera
taking too many pictures, lovingly, as if, she imagined,
to keep her, somehow, at home.
Sometimes he'd send them to her later,
those glimpses of the glorious garden,
with her, awkward, already dressed for airports,
for the wrong season, half vanished already,
but smiling, with dog, cat, mother, brother—
smiling at him with his camera saying “just one more”—
she hoping she wouldn't miss her flight.

But this time he forgot.
Tired out from chemo he'd dozed off,
she had to wake him, with tea, to say she'd packed,
and only at the airport, pushing her baggage cart,
did he remember, stop, turn back, as if
they could all just go home again,
to that garden, one last time.

Catherine Belling teaches medical humanities at the Stony Brook University School of Medicine on Long Island, NY. She was born and grew up in South Africa (*naartjie* is Afrikaans for “tangerine”).

My Brush with OHIP

Peter Scott

I recently was struck with a brutal case of pancreatitis, the long-term side effect of DDI's usage, neuropathy being its short-term one. All day I was doubled over in a pain equivalent to birthing a baby, or so I'm told. Retching and trying every emetic I could find on the Internet, I found no relief for eight hours. When my entire bowel started convulsing, I looked up my symptoms and diagnosed the ailment myself. I went to St. Mike's emergency. I braced myself for the four-hour wait.

Amazingly, at triage I said, "I have pancreatitis."

They admitted me right away. Like, within two minutes I was whisked to the diabetics floor and put in a room with one groaning Mr. Grasso (not his real name). He had just had his gangrenous toes amputated. His wife kept a vigil by the bedside. I think she was Italian. Luscious daughters dropped by between their jobs. No more *Mambo Italiano* for Mr. Grasso.

A nurse named Ivana (not her real name) came by on silent loafers and hooked me up to an IV. My diet was instantly made a liquid one and all my meds save valproic acid (for the brain strokes) were stopped forthwith. The whole cocktail. A very good way to acquire a resistance. Ivana came back singing about the "happy, happy needle," which she was approaching me with. She shot 10 mg of morphine into my right arm. A serpentine bliss started to uncoil in my spine. A warmth I've never felt before blanketed me like an ocean surf. I can easily see why my sister was hooked on this stuff. I passed out for most of the night.

I was awakened early with a stealthy phlebotomist's puncture. They needed to see where exactly those pancreatic enzymes were at. They were through the roof. Around 800.

Next day a steady stream of handsome medical interns came in,

stared at me, while one poked and probed my abdomen for signs of pain and inflammation. The students remained stern, composed, inured to pain of all sorts. This routine was repeated three times until no less than twelve students had examined me. All the while I was wasting away. I didn't know it at the time, but the diarrhea caused by a liquid diet beats Dr. Atkins any day. I had lost 6 kg when the trip to the hospital was over. They kept me on 14 Bond for two days, then moved me down to 2 Queen. Ghouls galore. And I walked among them. In pink, fuzzy slippers. Ivana offered me a parting shot of opiated bliss, but I declined it. I was wheeled to a double room with no roommate.

I spent four days in there, total. A candy striper came by and, noticing the novel I was reading, *The Stone Diaries*, by Carol Shields, said, "Oh, I've read that." I think she was lying in her but was just making conversation. I was hungry to talk; she presented an ancient ear. She was about seventy and wore an AIDS ribbon. Some others came by with an assortment of art prints I could choose from to adorn the wall at the foot of my bed. So blankly it stood there now. Remnants of sticky tape adhered to it. I chose a primitive little thing by a Nova Scotian artist whose name I cannot remember. They went and got it, came back, and slapped it up. It was a little crooked, but I didn't say so. A steady stream of Filipinas passed through with mops and changed the garbage pails.

I had a huge fight with an intern and a coordinator over releasing me. I felt fine on Day 3 and really wanted to just go home. They objected and convinced me to stay the next day. I resigned myself to their pressure and, like a dog that's been kicked in the nuts, slinked off to my cage, I mean my room. I swore if I ever saw the little intern again, I would cry plaintively, "Let my people go."

The next day those vampiric blood-letters were back for repeat tests. More needle jabs, more tapes holding down more cotton swabs. In walked the heavy Dr. Top of Them All. He smiled heartily and shook my hand. Good grip.

"I thought I recognized that name."

He flipped through his notes. "We'll need an ultrasound. Make sure there's nothing down there."

"Like a stone?" I asked.

"Like a stone."

“OK.”

A porter took me to Imaging in a wheelchair from which he hung my IV bag. Those hospital gowns aren't very warm in the draughty halls. I sat in such a hall for forty-five minutes before getting onto an exam table. Then came the warm jelly. It feels quite amniotic, especially when they're massaging your abdomen where a foetus would be. It didn't last long enough. The ultrasound is one of the more pleasant of the hospital experiences.

I returned to my room to await the results. Dr. Gough (his real name) came in quite promptly and said, “Well, there are no stones.”

“That's a relief.”

“So, who's at home?”

“My boyfriend,” I lied. I could see where his line of questioning was going.

“OK. I don't see any reason to keep you any longer.”

I pounded the bed with delight. “Yes.” I cried, and beamed.

“Oh wait, the dietician wants to see you.”

In walked this bleach-blond with questions and advice about my diet. She had a nebbish intern in tow. Then in walked this other chick who was doing a survey for someone or other. Would I like to answer a few questions? I didn't know a few questions would take an hour. This questionnaire was bizarre: you had to trade off horrific side effects for the chance at more living years. I got very bored with it quickly. The computer spoke the questions slowly and was redundant half the time. Serious audio editing needed. I got through it and looked forward to just going home. I grabbed my things to go and the woman with the questionnaire handed me an honorarium of \$15. Well, that was welcome, not having bus fare home. The freedom I felt when I walked out the front door, free of the IV and breathing Toronto's filthy air, was a rush. I was exhilarated. I subwayed home up Yonge Street and caught the eastbound Wellesley bus too.

The nurses were amazing in there. The place ran like clockwork, and everyone was industrious in his or her niche. You want to send them flowers. I guess the nuns are still in charge at St. Mike's. They have Jesus and the Virgin Mary as their role models. If you don't act accordingly, you're out on your ass. They restored me to perfect health. So perfect as

possible. In four days.

I don't know what to make of this brush with death. I should be humbled or frightened but cannot find the energy for such emotions. Can't quite find that zone. It's just something that came to pass. AIDS is an accumulation of these small indignities. An ignominious end awaits anyone who hasn't realized this by now. Like Roy Cohn in *Angels in America*.

Speaking of Americans, it still appals me that eighty kilometres south of here in Buffalo, this little trip to the hospital would have cost \$25,000. I'd have been utterly bankrupted. So I'd say my brush with OHIP went the right way. I didn't even get a bill. Amazing, this place I call home.

Peter Scott is a forty-six-year-old writer living in Toronto. He has a math degree from Queen's and an E-business degree from the University of Toronto. He has been published in *Xtra*, Toronto's gay and lesbian biweekly.

Correction

We regret the error in formatting Shirley Adelman's poem on p. 110 of the previous issue. Her second poem should have begun with the title "Equal at Last."

Guidelines for Submissions

1. E-mail submissions are preferred, with Microsoft Word attachments only.
2. Poetry should be typed single-spaced up to two pages, and prose double-spaced to a maximum of 3000 words.
3. We will not consider previously published manuscripts or visual art, and a signed statement that the work is original and unpublished is required. Copyright remains with the artist or author.
4. Payment will consist of copies of the issue in which the accepted work appears.
5. Please indicate word count on your manuscript and provide full contact information: name, address, phone number, fax, e-mail address.
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New Featured Section

The Creative Process

Ars Medica will include a regular feature exploring the processes of creativity with one of our contributors. If you would like your submission to be considered for this section, please include a 200–300 word essay on how you came to produce the work, including comment on what went on during its creation. This will be followed by a Q & A, by e-mail, with the editors. The piece, essay, and dialogue will be published together.

NB: Submission to “The Creative Process” in no way affects consideration for regular publication in *Ars Medica*.