



The doctor and the zebra

One hundred days: my unexpected journey from doctor to patient

David Biro

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An autopathography is a memoir of illness, an account of how it feels to be on the receiving end of medical care. Perhaps the most famous specimen of the genre is Norman Cousins's *Anatomy of an Illness*, oft cited as the story of how a patient bucked authority to laugh himself back to health. Doctor-written autopathographies have enjoyed a special status for centuries. In the 1600s, for example, Thomas Sydenham wrote about his gout with such eloquence that his description is now a classic. Some physicians have incorporated their own case histories into research publications anonymously. Others have proudly proclaimed their experiences, advancing the cause of neglected diseases through professional identification. Several editors have published collections of medical autopathographies: Albert Grotjahn in 1929, Max Pinner and Benjamin F. Miller in 1952, Raymond Greene in 1971, and Harvey M. Mandell and Howard M. Spiro in 1987. Clinicians are fascinated by the genre — perhaps because they are intrigued, if not intimidated, by role reversal, a frustrating if enlightening movement from active to passive. *One Hundred Days* is an entertaining addition to this tradition.

In 1996, at the age of 31, David Biro, a Jewish New Yorker, was only weeks away from his final examinations in dermatology. Married, athletic, Italophile and writerly (he had a novel in progress), he was happily set to share office and career with his dermatologist father. A vague clouding of his vision was quickly diagnosed as retinal vein thrombosis. But what caused it? After repeated testing with conflicting re-

sults, he is found to have a true medical “zebra,” the rare blood condition of paroxysmal nocturnal hemoglobinuria (PNH). The young skin specialist and his family fret over the uncertainty of diagnosis in the unfamiliar territory of hematology. Once they have a diagnosis, knowing what — if anything — to do in terms of treatment is even more challenging.

Biro's physicians at the Sloan Kettering Memorial Hospital are real hematologists, and he uses their real names. But their “personalities” spring entirely from the reactions they inspire in their patient, and those reactions vary from day to day. Biro contrasts shy but determined Hugo Castro-Malaspina, a marrow transplant expert, with the warm but cautious Lucio Luzzatto, an expert on PNH recently arrived from Biro's beloved Italy. Biro adores Luzzatto and wants to stick with him; but Castro recommends a transplant, and Biro hears “cure.” Impatient, and finding a suitable donor in his youngest sister, he opts for the transplant. It is clear, however, that his decision is conditioned by personality and transference as much as by the diagnosis. The rest of the book is devoted to the arduous consequences of Biro's choice.

The preparations are frantic and comic, especially the process of banking sperm. The pain involved in radiation and chemotherapy and the six-week imprisonment in a small hospital room are described in graphic detail. Biro suffers all the complications: exquisitely tender

radiation dermatitis that causes his scrotum to slough completely, severe mucositis of mouth and esophagus, hepatitis, unexplained fever, drug-induced delirium, weakness, weight loss and fears of impotence. Biro's parents, sisters and friends leap into action to provide round-the-clock support. His independent wife, Daniella, is put off by the intrusion as much as she is reliant on it to compensate for her necessary absences. While Biro's body falls apart under the onslaught of cytotoxic drugs and narcotic analgesics, his family and marriage are subjected to equally destructive forces. Yet all — body, family, and marriage — emerge intact, though altered by the experience.

Biro knows he is not the first doctor to learn that being a patient is full of unpleasant surprises. He portrays himself with candour: sheltered, naïve, privileged and perhaps even spoiled. By the end of the treatment, he appears less changed than his wife and parents by the intimations of mortality; however, he has more self-knowledge and greater understanding of how the ravages of illness can extend beyond the patient's body. Biro is conscious of and grateful for the ease with

which he obtains specialist consultations, but he glosses over the quick arrangements made for insurance coverage through inside contacts — an advantage that might be envied by less privileged readers in the US. His tale is interspersed with lucid explanations of bone marrow function and T-cell depleted transplantation, useful to anyone facing this procedure. But these explanations interrupt the personal tale of unusual family dynamics, which is, for me, much more compelling.

The strength of this book lies in Biro's superb portrayal of unique people and of the effect that one man's ill-



Fred Sebastian

ness had on them all. How many clinicians move into practice with their fathers? How many have mothers who would make daily house calls to rout out germs? Which of them would welcome the displacement of their spouse and colleagues by family, or expect this displacement to be tolerated for weeks on end? Excerpts from the diaries of both anxious parents reveal their fears and feelings of guilt. The diaries also

reveal that this book, planned even before the donor cells were harvested, reverts family confidence in a gifted son.

One Hundred Days, like Napoleon's famous comeback, does not end in closure but in ignominious transfer to St. Helena, an indeterminate but not intolerable island state floating between health and disease — a state we always occupy, although usually unaware. The irony is that Biro's continued fragility two years

post-transplant is no longer a product of PNH alone, but also of his treatment decision. What might have happened if his personality had allowed him to follow Luzzatto's recommendations and do nothing? We are led to believe he would be dead. But we will never know.

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Lifeworks

Man of the mill

Born in the year of Confederation, Dr. Robert Tait McKenzie left his mark on Canadian medical history not only as a pioneer in preventive and rehabilitative medicine but also as a highly skilled sculptor who celebrated the human form and human effort through his art. This life's work is hon-

oured at his little-known summer home, the Mill of Kintail, near his birthplace in Almonte, Ont., where he and his wife, a poet and pianist, worked and entertained from 1930 until his death in 1938. Situated on a 167-acre site some 50 km west of Ottawa, the picturesque mill remains as McKenzie left it. His studio houses

over 70 plaster originals as well as original bronzes of his sculptures, friezes and medallions. These works include *The Joy of Effort*, which was used as a model for Olympic medals in 1912. His rawly seductive *Masks of Facial Expression* (1931-32) record stages of physical exertion. *Onslaught* (1911) depicts a rugby scrimmage and is now the Ivy League football trophy. Dominating the studio is a plaster cast of the centerpiece of his impressive Scottish American War Memorial; the finished work is in Edinburgh.

Despite the significance of these works, they are endangered by underfunding. Much-needed repairs to the mill have been delayed since 1996, when provincial funding was pulled. The Mississippi Valley Conservation Authority (www.mvc.on.ca),



The design of *The Joy of Effort* (1912, 269 cm in diameter) is deemed to be one of McKenzie's most accomplished in the placement of the runners and degree of relief. The artist modelled it after a school of porpoises he once saw leaping through the water; his athletes have the same cresting movements.



Among McKenzie's seven larger outdoor monuments scattered across the globe is *Memorial to Jane A. Delano and 296 Nurses Who Died in World War I* (1933), located at the Red Cross headquarters in Washington, DC.

custodian of the property since it was opened to the public in 1972, is hoping to build a trust fund to maintain the site and increase national awareness of McKenzie's legacy.

McKenzie's ideas are still recognized as innovative by sport and health organizations across North America. After graduating from the faculty of medicine at McGill, where he excelled in gymnastics more than in academics, he became its first-ever medical director of physical training in 1894. McKenzie held the revolutionary belief that exercise was an in-

tegral component of preventive medicine. He became director of Physical Education at the University of Pennsylvania in 1904 and went on to become the first professor of physiotherapy in the US, specializing in treating deformities with therapeutic exercise. Many of the exercise, massage and hydrotherapy treatments he developed are still used. During World War I, McKenzie devised new techniques in rehabilitation; this work became a source of inspiration in his creation of war memorials in four countries.

Between 1900 and 1940 McKenzie's art was shown in 72 exhibitions world wide. Today the main repositories of his work are the University of Pennsylvania's Lloyd P. Jones Gallery and the Mill of Kintail. If a picture is worth a thousand words, these sculptures speak volumes of a life dedicated to promoting physical activity through medicine and art.

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The Mill of Kintail, near Almonte, Ont.

Room for a view

An exchange of gifts

The day had been too long again. The “start early, finish early” strategy had never really worked for her, and certainly not on Fridays. Outside, the premature darkness of late November that wrapped itself around the hospital like a mantle was made all the more dense by a steady drizzle that was trying to be snow but could not quite shine white. No comfort of a greeting-card scene here.

The hospital often seemed to her to be separate from the rest of life, like an island or a ship, a world unto itself. This insular quality had the effect of intensifying the sense of community, of shared purpose, within. Her hospital, she sometimes called it — and she really felt that in some ways it was. Eighteen years of caring for its seriously ill and dying patients. About three hundred a year ... over five thousand in all. Could it be possible? Each person, each story, unique. A rich legacy. She felt privileged to receive some of the lessons of living from those who, facing illness and death, had gained a crystal-clear perspective on what was valuable in life and what was irrelevant distraction. Lately, she found herself caring for family members of previous patients. This made more acute not only her sense of the passage of time, but also her sense of death as inescapable in the human community of which she, too, was a part.

And with these years came a cumulative burden of sadness. How could anyone be acquainted with such repeated sorrows and not be affected by them? Especially when she was as tired as she felt today. She had learned to recognize the signs of an overload of sadness: tears too close to the surface, trouble sleeping, increasing worry about the people in her own life. Fatigue could be an insidious enemy, causing her to lose perspective, second-guess herself, doubt her ability to help people. Illness and death were formidable foes. Sometimes she felt they held all the cards in the game, dictating how it would play out, allowing her little room to provide comfort. It was this sense of powerlessness that could trouble her the most, making it all seem overwhelming. Such a night was tonight. She needed a weekend away. She would wrap up a few details and head home.

But now her office phone was ringing. It was the evening shift nurse. She wanted to tell her about a twenty-four-year old man ... boy ... who had been admitted last night. He is dying, the nurse said. Might live until Monday. His pain control seems to be good ... that isn't the problem. The thing is he looks so scared. He won't let his family leave even for a minute. Seems to fight sleep ... won't close his eyes. He hasn't

said much to any of us. It can probably keep until Monday Then came a telltale pause. Clearly, she wasn't so sure. Do you think you could come, just for a few minutes? I know you can help him ...

Ah, the sweet appeal to vanity. But not really needed. She could feel a familiar pull, a powerful urge to help. It was always a mystery to her how the dying and those who grieved for them evoked this impulse in her time and again. They would look at death together — the patients and their loved ones with a desperate sense of urgency, and she of necessity one step removed, it not yet being her turn.

The ward had the look and tone of early evening: few people, subdued lighting, the soft hum of televisions and visitors' voices — the gentle ordinarieness belying the fact that, for at least one person, the tragedy of life and death was being played out too early.

The rooms used in such situations were strung along the far edge of the ward, removed from the buzz of the nurses' station. Some architect's idea of privacy, no doubt, but one that isolated the dying as though on a moored boat, still attached to the mainland but floating loosely offshore, ready to be released at any moment. His room was the one at the end. The door was closed; no sounds came from within.

She knocked softly and slowly pushed the door open. The room, in semi-darkness, felt close. People in chairs began to shift slowly to standing positions. Father, mother, sisters, brothers-in-law and friend made hushed introductions and offered their hands in greeting, acknowledging their shared humanity in the presence of grievous illness and death. They made room to include her. She noted their faces, drawn with worry, the tearful eyes that followed her to the focal point of the room.

The young man lay on his back, legs splayed, arms at his sides. He was tall, and his lower legs, heavy with fluid, extended outside the bedcovers. The word edema presented itself in her mind, as if to offer the protection of science, of her profession.

There was a luminous quality about him. He was so frail, so young. His head was hairless and beautifully round. His gentle searching eyes were large and dark against the pallor of the white sheets and his thin face. Despite his desperately ill state he shone in the room, exerting an undeniable presence.

She took his hand and sat down in the chair offered by his father. She told him who she was, and said that she wanted to help. His breath was rapid and shallow, his voice a hoarse whisper. He chose his words in isolation, for brevity and clarity. He had no energy or time to waste.

"Need help ..." He began to cough, and could not continue. But his eyes never left her face.

She stroked his hand, which grasped hers with surprising strength.

"Take your time," she said. "There's no hurry."

"Feel like I'm drowning ... going down. Have to hold on." Each phrase was interrupted by several rapid breaths. His head, raised slightly off the pillow as he spoke, fell back against the

pillows from the effort. Still, his frightened searching eyes never left her face.

She felt a powerful tenderness for this young man. The nurse had been right to call her. He probably wouldn't live until Monday. He would die soon, maybe tonight.

She knew what her task would be in caring for him. She would order medications to ease his breathing and anxiety and help him rest comfortably. She would speak with his family, apart from him, to be sure that they understood how ill he was, easing them toward the harsh reality that would come as no surprise. Sometimes families felt relief that the suffering would soon be over,

but this was always mixed with the pain of irreversible parting, and of wishing it didn't have to be so. For her part, she couldn't help thinking about his youth, about the loss of his dreams and the

dreams of those who loved him.

He stirred and began to speak again in a raspy whisper. "What's going to happen to me?"

After so many years, this was still the question she dreaded most. It was so direct, crucial, urgent, and could not be sidestepped.

What would happen to him, this young man she didn't know, who was leaving life too early? He would die, she knew that. Was that his question? Or was he asking what lay beyond death? She felt a stiffness in her back and shoulders from leaning over the bed, beads of sweat on her upper lip and forehead. Was it the heat of the room? Or the nature of his question, the intensity of this moment in time?

He inhaled again and spoke with more urgency. "What's going to happen to me?"

What did she tell her students? Always clarify a question before you try to answer it. Good advice. Essential step. So easy to say in the classroom, so painful to do now.

She heard her own words ... good words, but words that sounded too academic, too removed. "Can you tell me what's on your mind ... I can answer your question better if I know what you're thinking ..."

She felt herself holding on to him now, and her thoughts began to come quickly and with surprising emotion. "Don't go ... don't leave ... don't slip away yet. We need to finish ... I can help you ..." Her eyes pricked with unaccustomed tears.

"Dying," he rasped. "What comes next ... Is there anything after?" His eyes widened, his head was off the pillow again, and he breathed quickly as he clutched her hand.

The doctor was now firmly cast in the role of person, of fellow human. She had no place to hide. A person, not a professional role, was wanted. A person and an answer. There was no room for doubt, no time for "maybe."

For just a moment she could see it with clarity and power: his need and her purpose. Why they had been brought together at this crossroads in time.

"Yes," she heard herself saying. Her own voice sounded faint and far away to her. Then it became stronger. "Yes, there's much more. There's more love than you can imagine waiting for you. Love and joy. It's been promised."

"Yeah ... ? How?"

"I'm not sure how it works, but I do know it's there for you ... for all of us. We don't have to worry about how it happens. We can just let it unfold ... give ourselves up to it. It's all taken care of."

His head fell back once again. His eyes still held hers in a steady gaze, and he relaxed his grip on her hand somewhat. His breathing gradually became slower, softer, more easy. She sat with him in stillness. She could hear his family softly weeping. She had forgotten that they were there, the intimacy of emotion had been so intense.

"Okay," he whispered. His eyes closed. In a while, he slept.

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Art Explosion