

Caregiving and Being in Touch

Lessons From My 85-Year-Old Mum and Me

C. HEATHER MENZIES

Cet essai retrace l'expérience personnelle d'une femme au chevet de sa mère mourante qui la fait revenir en arrière sur l'histoire de la santé et de l'éthique des soins. L'auteure admet que c'est la fin des spéculations autour des politiques actuelles qui remettent en selle l'éthique dans le système de santé maintenant restructuré par la technologie et un système efficace.

When I reached over the rails of the ambulance stretcher to comfort my mother the day she fell and broke her hip, I had no idea where that would take me. I only knew that with her dementia, she couldn't remember what had happened for more than five minutes at a time. Again and again, her bright, hazel-nut eyes reached for mine. "Why does it hurt?" she asked, sotto voce, because she was raised not to make a fuss and that part of her, her essential core, remained intact. Each time, I leaned in closer, one arm across her body to cup her head in my hand, to stroke her temple, her shoulder, her arm, and the other holding fast to her hand, absorbing at least a sense of her pain as she squeezed and squeezed to endure it. I explained that she'd fallen. Where? She asked. For the umpteenth time, I told her, "in your room at home," and so we passed the hours waiting with other ambulance stretchers lined up in the hall next to the crowded Emergency waiting room.

As I joked to someone afterward, we never ran out of things to talk about.

Briefly I was grateful for the "work" I'd put into changing our relationship a few years earlier, before dementia (some called it Alzheimer's) started unravelling her mind, so there was no baggage standing awkwardly between us. And because I lived close by and saw her weekly, I wasn't thrown off by the sight of her suddenly more pale and incapacitated than a few weeks earlier when she'd had a urinary-track infection. Otherwise, I might well have done as I was told that day when they finally had an examining room free and were ready to undress her. When the nurse told me to leave and go sit in the waiting room, I might have gone away. Instead, I kept holding Mum's hand and when her eyes sought mine, whether from pain or confusion at the pain or both, I was there leaning in close to steady her as best I could. To steady myself as well, and get my bearings on what to say and do next.

So the consultation with the doctor over hip surgery didn't happen stiff and formally in another room. It happened with both of us resting our elbows on the bars of Mum's gurney, leaning in toward her so she could hear, even though by then there was little she could understand beyond the brute real-

ity of pain and being alone, or not.

I don't want to romanticize this, nor make myself out as being heroic. I want to emphasize the very practical aspects of what I did and learned over the next 30 days—what turned out to be the end of my mother's life. I know there was an element of volition involved. I was determined to be there for Mum because I hadn't been there at my father's dying 19 years earlier. But there was also serendipity. At the seniors' residence, Mum liked to have tea sitting up on her bed, and since she hated wearing her hearing aids, I got into the habit of sitting on the bed next to her when I came for a visit. Since it was a single bed, we sat close together, our shoulders touching, our fingers laced together. This made it easy, when her capacity to talk in whole sentences started crumbling away, for body language to take over, filling the gap and preventing silences from feeling awkward. Every visit I could count on her remarking on how beautiful her tea cup was. And every visit when I agreed and pointed out that mine was pretty too, she not only nodded and smiled, within a minute she'd turn toward me for a kiss.

I was lucky that when we entered the bright echo chamber of the Queensway Carleton hospital that Thanksgiving Saturday in 2003, we



Heather Menzies and her 85-year-old Mum, Anne Menzies. Photo: Janet Menzies.

did so within easy kissing distance of each other. Some days later, I remember watching a man with his mother in a bed opposite my mother's in the ward. Like Mum, she had broken her hip. She lay there fretting, confused and unhappy, and the son sat several feet away looking just as confused and unhappy. I wanted to take him by the hand, get him to move in close. "Hold her hand, Focus on her eyes," I wanted to tell him. Because that's what I did time and again as I visited. The eye contact anchored me—well, the big smile of recognition, the "Oh, there you are; you've found me" helped a lot too. It got me past the incipient horror, nipped my own confusion in the bud. Somehow too, I was able to take in the evidence of her deterioration at a level that was deep with intuitive knowing. I look back at my journal entries from those days, and am amazed at what I noticed, because we were so attuned to each other, so intimately connected. "Her eyes have lost their shine," I noted on

October 21. Following her hip surgery, or perhaps during it, she had suffered at least one more small stroke, which left her largely paralyzed on her left side.

Though she rallied after the 21st, to the point that the nurses and social worker were talking discharge plan, my journal entries charted a different path. October 28: "She's shrivelled away so much, like a fire that's sputtering, throwing no heat anymore and barely any light.

"I let the nurse finish feeding her lunch. She was doing it so well, just shovelling the stuff into Mum's mouth and Mum keeping her eyes closed the whole time."

I focused on the practicalities: phone conversations with doctors, with the people at the seniors' residence who might or might not take her back, going through the forms for Mum's possible placement in a nursing home. I also focused on little things like tea, which was my barometer, my litmus test of her well-being.

"Would you like some tea?" A

slow smile. "That would be nice." Though increasingly, the straw would just sit there on Mum's lower lip. She lacked the strength, the mental focus and organizing power or simply the basic desire to suck.

Being that close gave me ideas I wouldn't otherwise have had. For instance, on October 31st I brought in her "Memory Book," a scrapbook of photos and stories I put together for her 80th birthday. I had a feeling that she wasn't taking in much of her surroundings any more; yet, if that were the case, it really wouldn't much matter if she didn't go back to her old room at the seniors' residence. Sure enough, as I turned the pages, it was clear how little any of the once familiar images meant to her any more. Then it occurred to me to just ask her: "Do you want to go home?"

She looked at me, puzzled. "I don't know," she said.

"Are you happy here?" I asked. "Yes," she said. That much she was sure of, I wrote in my journal that night, which clinched it for me,

helping me to put the case to my siblings when I got on the phone long distance that night to get their okay for the next step, finding an acceptable nursing home.

But equally, I had noticed something else. After she had said yes, she was happy in the hospital where they kept her dry and warm and fed, I wrote in my journal "then she

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closed her eyes again and let her head drop, nodding off.

"Her world has really shrunk, closed in," I wrote. "She is adrift in a dream state, a sort of amniotic sea of impressions and feelings. I imagine them as diffuse, not tied to specific memories, just a comfortable sensation, warm. Nutrients of a sort, but less to do with building up. More a letting it all slip away."

So even as I steeled myself to tour the nursing homes on a list of those in the area with available beds, some part of me stayed with this sense, and what my feelings about it prompted me to do. On November 5th, having done five tours of nursing homes, asking pertinent questions, making careful notes, I came to the hospital looking for my Mummy. I remember this clearly. What I had thought to do was prompted by my need for comforting as much as my desire to comfort Mum. In other words, I was empathizing with myself even as I was still trying to empathize with her, and from that empathy came

an idea. I found her in a Geri-chair at the end of the hall, propped up with pillows. I think I made us some tea, just from force of habit. Then I pulled my chair in close to hers, leaned in toward where her head was leaning, and pressed my forehead against hers. For a while, we just sat there breathing. Then I recited a poem she'd taught me one winter day after I came home from school in time to catch a last cup of tea with her, sitting up on the bed in my parents' bedroom. It begins "When day is done and darkness falls on the wings of night...." My voice cracked a few times but I got through it okay.

"That's lovely," Mum said, smiling happily. Then I sang to her, the songs I'd learned from her as a child. Silly ones like "Oh my darlin Clementine" plus the bittersweet "Just a song at Twilight." and, one of her all-time favourites, "Swing Low."

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Without that moment, I wonder if I would have gotten through the next few days. On the Friday, I arrived to find Mum thrashing around in her bed, the sheet pushed aside exposing her skinny bare thighs and the adult disposable diaper between her legs. By now the nurses had given up trying to keep her false teeth in any more than they did her hearing aids in her ears or her glasses on her nose. Her cheeks were collapsed inward, her mouth shrivelled and sagging open and though she seemed asleep, she moaned as though awake to some terrible pain and anguish.

"It was very hard to break through and make contact," I wrote that night. "Hard to move in close, to find the familiar, the Mum in the picture and tune in to that and tune out the rest, all the noise of her restless legs and arm.... I kept

diving, burrowing in, positioning myself close to her right ear, my left hand around her head and stroking her left temple. It took a long time. Half an hour maybe. But eventually she surfaced. She stopped tossing and turning, stopped moaning, and began holding my hand and squeezing it." Contact reestablished, I then contacted the nurses. They changed her diaper. "Is that better?" I asked after the nurse had left.

"Yes," she said softly, her face lifting slightly into a smile.

Three days later when they phoned to say "Your mother's not doing so well; can you come in?" I was there in a flash. When the palliative-care nurse took me aside to say "Your mother's dying," the shock of hearing the word out loud soon changed to recognition. After the necessary phone calls, I went straight back to Mum's bed, and spent the day stroking her face, holding her hand, washing out her mouth, brushing her hair, *not* leaving the room when they wanted to change her diaper and "freshen her up," putting thick socks on her cold feet, a quilt from the palliative-care office over her body. I sang the old songs, pulled out favourite stories and told her, this is what I will remember, this is what I cherish. I had a sense of her going down something like a birth canal, only this was toward the darkness and away from the light. She never opened her eyes, she never officially woke up. But I'm told she could still hear, and perhaps some sensation of touch was getting through as well. All I know is that her breathing got calmer and quieter until finally she didn't seem to need breath anymore, and she was gone. A good death, I told everyone who expressed condolences. For me as much as I hope it was for her.

Looking back, I realize it could have been better. Looking back, I sense some of the things that could be improved in caring for old people in hospital, close enough to the

end of their natural lives that they can as easily be dying as making a nominal recovery from whatever ailment caused them to be admitted.¹ I don't know what lessons can be generalized from my own experience. Perhaps its greatest benefit might lie in inspiring other daughters and sons, other people visiting sick loved ones in the hospital to be in touch with themselves and, through that, to be attuned to, tuned into, that loved one in the bed. I'm amazed at the insights that emerged from this rooted relationship. I'm also amazed at how the nursing staff picked up on them, even worked with them. Having left behind Mum's Memory book that day in the hospital, I was delighted to have nurses treat Mum much more as a person because they'd flipped through the book and learned things that she was in no position to tell them herself. Clearly, she was no longer the hip in Bed 2. The day after I'd sung Mum's favourite songs to her, I arrived to find a radio-tape recorder beside her bed, and music playing. Too softly for Mum to hear without a hearing aid, but that hardly mattered. It told me that some nurse was more attuned to Mum as a person now, that the bread crumbs I'd dropped had cued her into her own more caring, comforting relationship.

Above all, I realized how vital the care component of health care is, and how different it is from the curing side. I knew coming into this essay that health "care" has been dangerously transformed to mean a packageable service rather than a verb, "to care," in the context of a healing, caring relationship. I hadn't realized, though how much it meant "to care for" someone in their grief and suffering. Yet that's what my two-volume *Oxford English Dictionary* tells me is the case. Care originally meant someone's woes and cares, and caring involved someone being willing to take them on, to empathize and identify.

Actually, this is precisely the meaning of care practised in the first hospitals, in the western, European tradition. These were run by Roman matrons, including Marcella and Fabiola, applying the Christian parable of the Good Samaritan (Pelley 8-9). In a moving exegesis of this parable, priest-turned-philosopher Ivan Illich stresses that the Samaritan was moved by the plight of the battered and bleeding stranger lying on the road. Responding with a carnal, gut-level empathy for the man's suffering, the Samaritan takes the stranger into his care. In a conversation with Canadian Broadcaster David Cayley, Illich stressed two things: that the caring being expressed did not arise either from an abstract idea or from sense of ethnic or filial duty, but was inspired by the bleeding presence of this total stranger. He also stressed that the caring and relating to another human being involved was a visceral embodied act of identification and the "mutuality" that this implied (6).

Modern, science-based medicine, diagnostics and treatment have transformed health care considerably. However, the unquantifiable elements of caring for someone in their grief and pain remain central, certainly in nursing. Nursing theorists refer to the intimacy of an "I-thou relationship" (Bishop and Scudder 145) between nursing caregivers and their patients, of a dialogue of "shared attunement" (Bishop and Scudder 164) out of which the nurse can help motivate the patient to take on the business of getting better, or learning to live with what cannot be healed and made whole again. It can fall between the cracks of "patient-care" orders and "performance indicators" and all the other measures by which health care delivery is tracked and held accountable. Because, being integral to relationships, being the stuff of embodied feelings not disembodied facts, it can't readily be counted. But it still counts,

as I found in interviewing some Toronto nurses.

You can't do nursing properly if you don't listen," one of the nurses told me.

"With your heart as well as your mind," another added.

"And that takes time," the first nurse continued. "It takes time to observe and to listen."

I come away with a number of possible lessons for policymaking. The first is the need to respect what is needed in the "caring for" component of health care, as opposed to the curing side and its attendant functions of diagnostics and treatment. Each demands a different set of services, skills and priorities. But equally, each requires its own time-space. For instance, while diagnostics and treatments involve isolated moments of intervention often by strangers, "caring for" demands continuity of care *and* continuity of caregiver (Grinspun 24). As well, these more quantifiable actions, such as surgery and diagnostic procedures often involve a single person, even if importantly backed up by others, whereas the continuities

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of caregiving demand more of a team effort and the trust and commitment required to work well together, sharing even intuitive observations of what's happening and what might work best under the circumstances. (Koehoorn *et al.*) Remembering back to my mother,

I think of all the frustration involved in explaining to a steady succession of new nurses (many of them nursing assistants employed part time) that while my mother's name was Elizabeth Anne Menzies on the chart, she knew herself as Anne, not Elizabeth, and that's why she didn't respond when they said Elizabeth (and she herself didn't know enough to correct them).

Another thing for all of us to realize, as makers of our own personal and family policies plus contributors to institutional and public policy, is that we don't just live our lives on time – scheduled, clock time that is, with time off from the just-in-time task treadmill for breaks and so forth. We live in time. This is time as quality, time as pace and rhythm in relationships. Devalue this lived time, this experienced and attuned-relationship time in an institution, as has happened in the Canadian health care system with the turn toward quantifiable accountability, just-in-time staffing and performance measures, and even officially allocating more discretionary time for patient care won't keep the necessary balance. The balance must be struck at the level of how health care is governed within its institutions, in the medium of time-space in which health care is practiced on a daily basis. I see some hopeful signs in the interdisciplinary team approach developed in regional health authorities and also in community health centres, where nurses and nurse practitioners, generally being at the hub of patient relationships, quite naturally take on the role of team chairs and coordinators (Rachlis 209) The key, it seems is pretty simple: Providing maximum self-governance in the local here and the present now.

Elder-care leave and workplace flexibility strike me as another policy priority. Just as women (and some men) have struggled for day care and family-supportive workplaces, similar initiatives and organ-

izing are required here. I was lucky that, being a self-employed writer and part-time university teacher, I could make the time to be there for my mother, and to act as a go-between, interpreting her realities and bringing her needs to the attention of harried nursing staff. I realize too that until "caring for" can regain the status and support it needs in hospitals, the caring for provided by family members will be essential. But not everyone can volunteer their time the way I was able to, which strikes me as one more reason why self-help and advocacy groups of elder caregivers should form common cause with nurse unions and other organizations on the caring-for side of the health-care system. Elder caregivers like myself need to ensure that our time, our efforts and our presence complements and supports the time, effort and presence of paid nurses, and isn't allowed to replace it. Equally, nurses can use the support of elder caregivers to support the special needs in this growing area of health care. It goes beyond the scope of this essay to speculate on what these might be, but it occurs to me that whole wings of hospitals, or separate pavilions accessible by tunnels for easy patient transfer, might be developed, with more opportunities for continuity of contact and caregiving as a priority in the design and budget allocations. Again, I think of how time as well as space needs to be thought through differently. There's a difference between someone being in the hospital for surgery from which they are expected to bounce back like a robust rubber band and someone for whom post-surgery or other treatment gives way to a time that could best be described as a passage, a transition. It might be a passage into death as was the case with my mother. It might involve learning to live with a disability, or with diminished capacities after a stroke, or some other chronic illnesses. Accountability for health-

care dollars judiciously spent will mean completely different things in this area of health care.

There's much to think and talk about.

Heather Menzies is an Ottawa-based writer, teacher, mother, gardener, peace and social-justice activist. An adjunct professor (of Canadian Studies and Women's Studies) at Carleton University, Ottawa, she is the author of eight books, including the 1996 bestseller Whose Brave New World. Much of the thinking in this essay comes from her new book, No Time: Stress and the Crisis of Modern Life, forthcoming in April 2005. Douglas & McIntyre).

¹Actually, some 40 per cent of people do die in hospital, the majority of these the chronically ill and old (Rachlis).

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