



# When Things Fall Apart

How quickly family caregiving can go south

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**L**IFE IS FILLED WITH surprises. So, on the day that I drove my brother, Olivier, to emergency to be treated for a psychotic episode, during that evening when we sat in emergency for nearly 12 hours, when I finally left him, still unable to respond, sitting on his bed in the psychiatric unit, and then later when I called on my mother to see how she was doing, the last thing I expected to find was her standing naked, staring at her washroom mirror, experiencing her own particular breakdown and descent into dementia.

Family caregiving can be like that.

Family caregiving, for those unfamiliar with the modern usage of the term, is an informal, ad hoc process associated with family members caring for other family members who are experiencing an ongoing illness or disability, and whose existence would not be sustainable without some kind of support.

In a sense, before a name was provided, there has always been family caregiving—caring is, after all, what families do—but the contemporary term has evolved as modern medicine itself has evolved. As medical practice developed in sophistication and scale in the 20th century and became an integral part of western society's social contract, designed and controlled by federal governments and universally expected as a right by citizens, governments were confronted with a dilemma. Intractable medical problems, ones for which there were no quick fixes, required significant resources and proved enormously expensive. By using a family caregiving model, patients still requiring extensive medical attention could be released earlier from hospitals to their families, who with guidance from medical staff could provide the necessary support. Patients would enjoy greater comfort in their own home, greater autonomy, feel less isolated and receive more personalized attention. For individuals recovering from strokes, or coping with cystic fibrosis, or the early stages of Lou Gehrig's Disease, or any one of a variety of other chronic disorders, it made no sense to expose vulnerable patients to the viruses and germs that enter a hospital. And, from the government's perspective, the care was provided free of charge, and so a line item could be extracted from the healthcare budget.

In the 1960s through the 1980s, another major component of health-care followed this trend: the care of patients with mental illnesses. Up until the early 1960s the prognosis for the treatment of mental illnesses had been so poor that apart from a few mostly ineffective treatments (think insulin therapy—induce a coma with insulin injections to shock the brain and somehow reset it—or hydrotherapy, in which the application of cold or hot water somehow has therapeutic value upon the brain) the dominant solution had become simply to isolate and aggregate psychiatric patients. Enormous asylums and mental institutions were constructed, ostensibly offering “care” to patients suffering from mental distress.

In the late 1950s and 1960s, however, new drugs were invented that promised a better outcome for psychiatric treatment; patients were not entirely cured by these medications, but the most obvious symptoms of mental disorders were mostly controlled. Medical professionals soon realized psychiatric patients were better served practising their social skills in the community rather than being warehoused in institutions. As psychiatrist Werner Mendel wrote in 1976 in his “The Case for Closing of the Hospitals,” “The hospital as a form of treatment for the severely ill psychiatric patient is always expensive and inefficient, frequently anti-therapeutic, and never the treatment of choice.” The concept that evolved out of this was that patients would, instead, receive care and attention in the community, and by doing so would become more fully integrated into society. As psychiatric institutions closed, though, funds that were supposed to follow patients into the community to create these services never really did. Instead, as Andrew Scull observes in his book *Madness in Civilization*, “In the midst of all the excitement about the replacement of the mental hospital and the breathless proclamations about the



virtues of the community, it seems that few people noticed the degree to which the new programmes remained figments of their planner's imagination.”

Which remains the case today. Every official report in this country—see the latest Canadian Mental Health Commission's “Mental Health Strategy for Canada (2012),” and every government-funded report prior to it—declares mental health care to be woefully underfunded. And the community services component is particularly neglected.

**F**AMILY CAREGIVING IS A TERM, I MUST confess, that I've never much liked. It sounds too neat, too clear, too tidy. The impression it lends is that there exists a particular paradigm: someone who gives care, and someone who gets it. In my experience that model is too simple.

Our family has lived alongside schizophrenia for 40 years. My younger brother, Ben, was diagnosed in 1977, and in 1978, unable to see a good outcome in his future, took his life. My older brother Olivier began displaying delusional and paranoid thinking in 1979, and following a diagnosis of schizophrenia in 1980, and his own attempted suicide, entered Calgary's Holy Cross Hospital psychiatric unit. When Olivier was discharged from the unit, jobless, adjusting to his medication and its debilitating side effects, and struggling with the new reality of living with a life-long illness, he moved back in with my mother. That living situation went through many adjustments, some of which Olivier and I chronicled in our previous book, *Bitter Medicine: A Graphic Memoir of Mental Illness*.

My mother provided financial and emotional support for my brother. In return, Liv provided emotional support and companionship and physical assistance for her. My oldest brother Nic and I stayed close and provided emotional support, assistance with groceries, communication back and forth between a variety of medical and government agencies, arranged transportation to medical appointments around town, and facilitated emergency interventions when health situations arose. The combination of all these intersecting efforts allowed life to carry on. What we all provided was less a direct give-and-get than an interconnected, complex network of care, like a spider's web.

But it wasn't pretty. The truth was it more closely resembled the flawed, wonky structures generated by those spiders given LSD during lab experiments in the 1960s than the glorious, dew-dappled symmetry you might spy hanging from some branches on an early morning walk. It was a web fashioned as much from good intentions and competencies as from compensations, mistakes and frailties. It sustained and supported, but only barely. Snap a single thread and everything tumbled away.

When I realized my mother was displaying signs of dementia, I could sense that particular thread shearing, and for three or four years my family scrambled to construct a new web.

I knew that finding a solution—a solution transitioning out of the previous situation that would benefit both my



brother and my mother—would be difficult. I just didn't understand how difficult.

For one thing, everything about my mother and Olivier's living arrangements was so entirely meshed. They co-owned an apartment and split the monthly condominium fee; they shared grocery expenses, utility expenses, telephone expenses, daily household responsibilities; provided help and emotional support for one another in a thousand different ways. As well, both of them were creatures of habit and had nearly 40 years to establish a comfortable routine.

Once my mother began manifesting signs of dementia, the living situation deteriorated rapidly. Nic and I tried to solicit medical help, but my mother, always independent, resisted intervention. She began to fall, so we had railings installed and obtained an alarm bracelet and necklace. She responded by “losing” the bracelet and refusing to wear the necklace, and continued to fall. When she lost the ability to prepare meals or clean herself, we arranged for home care to assist—she vigorously rejected it. The phone was disconnected and the utilities went into arrears because bills weren't being paid, so I took over the finances. She grew physically ill and contracted infections. The conditions around the apartment became unsanitary and dangerous. As the situation spiralled downward, my brother's mental state became precarious.

At times it seemed like we were playing a perverse game of Whack-A-Mole—whatever problem emerged we hit, only to have a brand new problem instantly pop up. We couldn't arrive at a collective solution because my mother wouldn't agree to one, couldn't even agree that there was a problem, was adamant that she remain home where she could provide care for her Olivier, and at least initially her family doctor was unwilling to offer any clearer diagnosis beyond what he

characterized as “age-appropriate memory loss.”

Obtaining medical assistance or advice in this situation was difficult because each separate medical branch viewed the other as representing “the problem.” In the eyes of Olivier’s medical supports, my mother and the increasing complications of her dementia represented the problem. I received a call from a member of his psychiatric support team telling me I had to do something. Did I know how challenging my mother was, how unsustainable the situation was becoming for Olivier? He was depressed, I was told; the living arrangements were unhealthy. What was I going to do? But from the perspective of the paramedics who arrived in one instance when my mother fell, and who took her to the hospital to see if she had any broken bones, my brother’s mental condition was the complicating factor in her untenable living arrangements. What was I going to do about that?

**D**ESPERATE FOR ANSWERS, I enrolled in a couple of online courses, one on dementia and one on caregiving and dealing with psychosis—at this point my mother was already beginning to see and hear things. I discovered we were far from alone in our family-caregiving distress. There were, in fact, many, many people struggling to find a way forward as their family aged, not just in this country but internationally, and they too were unable to find answers or support. In the chat room provided for students, one participant from Ireland wrote, “My biggest worry is what will happen when I die. Who will look after my son? Some practical advice on preparing for this inevitability would be extremely helpful.” This sentiment was echoed by others, and in response another member of the chat group chimed in, “The anxiety is there on the other side too! My parents are getting elderly and I’m really anxious about how I’ll cope without them.”

Which perfectly reflects a few of the central weaknesses associated with family caregiving. There’s no particular training involved in family caregiving beyond what you find or improvise. As Carol Levine writes in her article “Family Caregiving” on the Hastings Center website, “Although family caregiving has always been an important kinship obligation, changes in demographics, workforce patterns, healthcare economics and service delivery have resulted in dramatic change in its extent and complexity... Family caregivers are expected to provide the level of care that only a few decades ago was reserved for hospitals. But they are typically not trained or supervised.”

The books I read and the online courses I took certainly helped, but at no time did I feel like an expert as I struggled to develop solutions to the problems that arose, or even especially competent, and I often felt overwhelmed. When my brother experienced something that looked like a seizure—clutching the back of a chair, his body rigid and trembling—I wondered: Is that a symptom of undermedication, overmedication, or is it an entirely new disorder? When my mother insisted that the plumber had stolen her dentures, or imagined that a host of uninvited guests had spent the night partying in her home, or when she fell and wouldn’t permit home care staff to lift her or even touch her, what was the procedure, I wondered, that I should follow?

In addition, very little support or advice can be found to assist with transition as caregivers age. In an institutional model of care, of course, if a doctor or nurse or any of the staff of a hospital falls sick or must leave or retire, they are replaced. That option doesn’t exist in most families. There may not be any children, or spouses, or in-laws with a particular skill-set available, or who live in proximity, or who have the financial wherewithal to take up these duties.

Nor is the relationship between family caregivers and hospitals and medical staff at all clear. Doctors and nurses frequently don’t know what to do with family caregivers, how much information to share, what kind of medical privileges or responsibilities they can or will authorize. As Levine continues in her article, “...professionals often turn the question (Why shouldn’t families care for their relatives?) on its head: Why don’t all these meddling families just stay out of our way?” While some in the medical profession are more open to including family caregivers, in my experience this is very hit or miss. I’ve been informed in Emergency to step back, told not to interfere, informed by doctors that they aren’t permitted to disclose information about prescriptions that I may actually have to administer. I may be part of “a team,” but I’m always made to feel like the very most junior member.

I WOULD HAVE PREFERRED TO WRITE ONE OF those articles that chronicle triumph over adversity and conclude with an uplifting message and a ringing endorsement of future solutions. Instead I can only share a story of very mixed results—one that ends with questions rather than a solution.

Because my mother was unwilling to let anyone else care for her, and because the dementia advanced at a pace that outstripped any preparations we could put in place, and because the living situation for Olivier was so chaotic and presented such a risk, my mother ended up being moved to a long-term care facility—the very last place she wanted to be.

And dying in the last place she wanted to die, as it turned out. On New Year’s Eve, 2016, she passed away from pneumonia. I wish to heavens my family had been able to coordinate an easier, clearer, cleaner, less troubled, more organized transition. That transition was enormously difficult for Olivier, emotionally trying, difficult to work through. He’s doing well now, but the adjustment to a new living arrangement tested him. Tested all of us.

The irony of the family caregiving model is that while there’s no particular protocol to follow, the responsibilities are vast and

there is an enormous capacity for resulting feelings of guilt. When my mother finally moved to the transition unit of the Rockyview Hospital, she wept bitterly as soon as she realized she was never returning home, her biggest fear being how her son would survive. “Who will make sure he takes his pills at night?” she cried, certain she had failed him. And when I spoke with Olivier the day after my mother left, his biggest worry wasn’t for himself, but that he might have failed in his duty to look after our mother.

 ARCHIVE: Who cares for Alberta’s caregivers? (Oct/Nov 2005) [albertaviews.ca/archives](http://albertaviews.ca/archives)



There are millions of earnest, desperately unprepared, underqualified families providing care for ill or aging relatives the best way they know how, improvising solutions for medical troubles they’ve never been trained to recognize or treat—an enormous number of them ill or aging themselves. They are hanging on as best they can, but they need help.

Hospitals can barely accommodate the present numbers of patients, let alone hope to accommodate in a conventional way the enormous numbers of aged looming on the horizon. And as the family caregivers the government relies on to perform caregiving in their homes falter, how will the healthcare system cope? The Alzheimer’s Society of Canada estimates that 564,000 Canadians currently live with dementia and that in 15 years those numbers will increase to 937,000. The odds are good that many of those nearly one million elderly individuals are presently caregivers themselves.

“Most of the arguments for supporting family caregivers rest on economics: family caregiver assistance is essentially irreplaceable,” Carol Levine notes. “Beyond the loving relationships embodied in family care, there is simply not enough money, nor are there enough workers, to replace family members as the broad base of the workforce.”

This is absolutely true, and it will continue to be true. But if the family caregiving model is to be employed, some serious thought must be given to the notion of transition.

It’s long past time we had a hard look at the family caregiving model and determined how it can be better integrated into the healthcare system. What supports can be provided? What will happen when a significant number of our caregivers themselves require care? Whose needs will be met, and how? In a medical system that only barely—and very informally—acknowledges family caregivers, who will offer support and mediation when things go sideways? When so very much is at stake—lives, after all—what support and guidance can be provided? ■

*Clem and Olivier Martini’s book The Unravelling, about their family caregiving experiences, launched in September 2017.*

