

Caring for mom: a tale of red tape

Health-care system kept us in turmoil as she got worse

By **ANGELA MOMBOURQUETTE**

IT WASN'T really a huge surprise when, about two years ago, I got a late-night call from my older sister. "Mom fell, I think something may be broken, come over." For as long as I could remember, my mother's life had been an ongoing series of serious health problems. Frankly, the phone had been bringing me bad news about my mother for almost 30 years.

Lately, my mother, Mary Florence Mombourquette, had

EDITOR'S NOTE: Recent stories in The Chronicle Herald about long-term health care elicited this tale about one family's ordeal and another on page A4 about one patient's roommate.

been having trouble looking after herself at home. She was heavily medicated for arthritis pain and seemed to be losing some of her cognitive abilities. She had already fallen several times.

But this night would be the start of something, or the end of



Angela Mombourquette, at 13, is shown with her mother, Mary Florence Mombourquette, in 1976 in Saint John. (Contributed)

something. My mother was hospitalized, her ankle broken in two places.

It finally seemed like the time had come to make a change. The time had come for our family to

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Mom

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begin the painful process of getting my mother into Nova Scotia's long-term-care system.

After talking it over for a couple of days, my sister and I called a meeting with the head nurse, the social worker on Mom's floor and a doctor from the geriatric assessment unit. We explained our concerns: She had started burning things; she was hearing voices and answering the door in the middle of the night; she had locked herself out of the house several times. She couldn't understand her bills or balance her chequebook anymore.

At home, she had been getting the maximum amount of home care and had an emergency call system installed in case of falls, and my sister lived just downstairs, but all of those things no longer seemed like enough. We were worried she might burn the house down or have an even worse fall. She needed constant care.

The initial response from the health-care system, and the impression that stayed with us through the entire process, was one of resistance to taking on her care.

From the moment my sister and I made the decision, we had to push every step of the way against forces that never seemed to be on our side.

The doctors felt that our mother was in pretty good shape despite her congestive heart failure, lack of mobility and slight dementia. She was only 76, after all. Why couldn't we just take her back home?

We insisted that it was no longer an option. My sister was burned out. She had been doing almost all of the care for our mother for more than 16 years. She had her own serious health issues.

Taking my mother into my home was not an option. I would not have been able to hold down a job and care for my mother. Plus, my mother and I had a difficult relationship at times, and it could have been a disaster.

I think of myself as a good person, an open-minded and generous person, and a good daughter. But aren't good daughters supposed to be self-sacrificing? Isn't that why parents have children, to look after them in their old age?

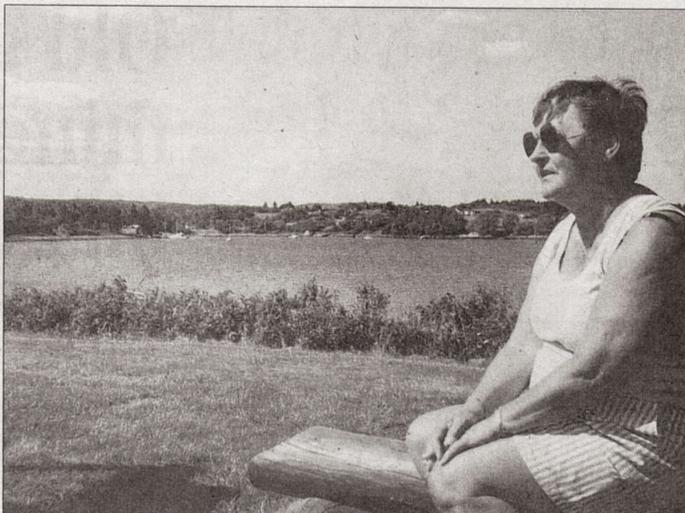
I was plagued with self-doubt about whether I was doing the right thing.

We asked to have our mother assessed by the Health Department to determine whether she would qualify for long-term care. We quickly learned that the assessment system, for better or worse, controls the fate of every person who enters into long-term care in Nova Scotia.

I can only describe the process as discouragingly superficial, frighteningly dependent upon personal (albeit professional) opinion and extremely fickle.

A care co-ordinator visited our mother. She spoke with her for about 10 minutes. She spoke to our mother's nurses. She read her chart.

Our care co-ordinator was candid with us. She wasn't convinced that our mother needed long-term care. Her inclination was to recommend that she be sent home. The social worker became our advocate and managed to persuade her that the need was real. The care co-ordinator relented and recommended the lowest level of care — in residential care facility, meaning that she would need no more than 90 minutes of daily non-



Mary Florence Mombourquette is shown in family photos, above, in 1989 in Chester, and below, in 1971 in Niagara Falls, Ont.



medical support, including medications, bathing and meals.

She submitted her recommendation. For some reason, the placement co-ordinator above her, who had never met our mother, disagreed with the assessment and slotted her into a completely different category: Level II, the highest level of care.

When we finally received the letter of assessment, more than two months later, we weren't sure we agreed with the decision. I asked the placement co-ordinator to explain the discrepancy and received a vague reply about a "checklist." Still, we seemed to have won the first battle: Our mother was finally on the waiting list for a bed in a long-term-care facility in Nova Scotia.

It had been explained to us that it could take three to six months before a place became available. We had heard about the lengthy waiting list and thought we were prepared to deal with a few months of uncertainty.

It would turn out to be a long haul. Our mother waited eight heartbreaking months. If we had expected it to be that long, maybe we would have been better able to cope. As it was, every day began with a faint sense of hope — today could be the day — and ended with disappointment. We were all waiting to start the next phase of our mother's life.

Over the following eight months, we never stopped wondering where our mother might be on the nebulous "waiting list."

No matter how many times I asked (and I asked often), the social workers could never show me an actual list. They couldn't give me a number. Maybe it was

because there were people with three different levels of priority all waiting for the same placements.

Whatever the reason, I couldn't seem to get information about where she stood in relation to everyone else.

There was also a lot of anxiety about the wait. Although we had indicated to the Health Department our mother's choice of facilities, we were told she would have to accept the first available bed within 100 kilometres of where we lived. My sister and I worried about having to drive up to 200 kilometres every time we wanted to see our mother.

We had been forewarned that when an offer did come, my mother would have one day to decide whether to accept it. If she refused, we were told she would be removed from the waiting list. Not moved to the bottom. Removed, and essentially chastised, for not being prepared to accept whatever was offered.

So we waited. We were told there was a hospital unit where people like her could live in while they waited. But of course there was also a wait to get in there. After taking up a chronic-care bed for about a month, she was transferred to the transitional care unit in a wing of the Victoria General hospital in Halifax.

Transitional care is classified as an alternate level of care, run by the Capital district health authority.

Residents are required to pay for their accommodation, although the cost is lower than if they were in a long-term-care facility. The unit at the VG houses 59 people.

Half of the unit is a locked ward, mainly for dementia patients. My mother was on the "free" side.

Video

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EDITOR'S NOTE: Visit our website for an audio slideshow called *Memories of Mom*. Also, you can tell us what you think about the issue of long-term care.

Visiting my mother there almost every day for seven months was nothing short of depressing. I can only imagine what it felt like to live there.

Stepping off the elevator, visitors are greeted with dingy "hospital green" walls and a flickering, dimly lit hallway that seems abandoned due to the clutter of broken-down equipment piled up in a nearby corner. If they take a wrong turn, they end up in the hematology day unit, cheerfully decorated with bright hand-painted tiles, a fresh new floor and all the lights turned on.

If they turn back and follow the seemingly abandoned hallway that smells faintly of urine, they will find themselves in the transitional care unit.

Entering the unit itself feels a little like stepping back in time. The rooms have that old-time institutional feel and were designed so long ago that many of the washrooms don't have space for a wheelchair or a walker, even though everyone I knew there used one or the other. The toilet-flushing mechanism is a foot pedal that most residents are too unsteady to operate. During my mother's time there, many of the rooms had leaky ceilings, and patients were always being moved around after a heavy rain.

My mother was advised to try to "normalize." Get out of "hospital" mode. Get dressed every day. Bring in any clothes she could fit into her tiny locker, or ornaments she could fit onto her tiny bed stand. We tried to make it cheery but perhaps more than anything else, my mother intensely missed being surrounded by her own things. She couldn't feel at home when she only had space for a few blankets of her own, some flowers, trinkets and a few photos. It was impossible for her to settle into such a temporary place.

We took her to see several nursing homes, and together we chose a favourite. We were comforted to find a place that was fresh and bright, and where the

staffers were friendly and welcoming. She began, cautiously, to look forward to her future there.

But about six months into the wait, as I routinely asked again about how much longer it might be, the social worker casually informed me that my mother had been reassessed and was now qualified only for a residential care facility, not a nursing home. I hadn't received any notification of the reassessment from the Health Department; somehow, this bit of paperwork had fallen through the cracks.

This news threw us all for a loop. We had not taken Mom to see any residential care facilities, and it meant that she would not get to go to her place of choice. She was very confused and upset. She had been having a hard time adjusting to the whole idea of a nursing home, and now her expectations had been shattered again.

In the meantime, some kind of administrative error led to my mother being told she had a placement and the following day being told that there had been a mistake. She was devastated. From that point on, she found it hard to disguise her bitterness about the entire process.

Finally, weeks later, we were notified that a real placement was available at a residential care facility. In order to qualify, however, she would have to prove that she could walk about 200 feet, unassisted, three times a day, to get to her meals. Could she do that? We weren't sure. Our hopes were high, but now she would have to prove that she met the criteria for a facility that the Health Department had already told us she met the criteria for.

We went for a tour and a test. She could do it. Slowly, but she could do it. And she liked the facility — thank heavens. We moved her in two days later to a nice semi-private room, along with her big comfy armchair, her dresser and a whole closet full of clothes.

But we would have one more frustrating Health Department policy to experience.

After about three months in her new home, our mother developed a serious cardiac arrhythmia and ended up in hospital for almost a month. Care facilities are required to hold a bed for only 30 days. (We weren't told her bed might be held longer if a written request were made.)

So in addition to our concern over our mother's grave illness, we were extremely worried that she might lose her hard-won place in the system. Her doctors sympathized with our concerns, and she was hurriedly released just under the wire into the middle of a Norwalk outbreak at her facility.

My mother was nothing, if not a survivor. She did contract Norwalk, but survived, yet again. Her health problems continued to bring challenges, but — at least for the last few months of her life — she had a comfortable home and the support of many warm, caring staff. And I, finally, had some peace of mind after such a long and exhausting process.

She finally passed away this past October. Looking back on the last two years of her life, I wonder why they had to involve so much negativity and struggle. We were only trying to do the best for our mother. Couldn't the health-care system have tried harder to do its best for her?

This article was first published in the June 2007 issue of The Nova Scotia Policy Review. Angela Mombourquette is a freelance journalist based in Halifax.