

## On Losing A Polio Mom

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When you are a child you think like a child, like the 9-year-old I was.

Boxed in an iron lung – trapped in a bed, the horror of food at mealtimes, resolving not to cry during therapy, saying goodbye yet again to those who mattered most. Those were the day-to-day dramas that filled my head. There were also joys: getting up first time in a wheelchair, a picnic with parents, floating to that sweet spot in the therapy pool where staff couldn't reach me – such a powerful surge of pleasure, a momentary autonomy.

I didn't think about survival or walking again, about the weight of lost dreams, life-long responsibility and dependence. I was but a child.

I had no idea of such things until I grew older, eventually discovering my mother's diary of those early polio years (life threatening illnesses, her fight to get me

in school, battling authorities, acceptance) and, many, many decades later, finding my own self in the place she once was as a parent. It hadn't been easy for her, a mother of four with an often absent father and no community supports at the time. It wouldn't be easy for me.

The role reversal was gradual. My mother lost her energy and abilities slowly. The changes were so subtle others could not see them, and at times I wondered if the problems I saw were imagined. At first I was puzzled, frustrated, even angry at her illogical, independent behavior. I had no knowledge of aging or early dementia. Once I began to understand and to recognize some of my own tenacious traits, to see myself in her, many situations became humorous rather than helpless and much more manageable.

As adults, our mother-daughter relationship had always been one of autonomy and respect for each other. We lived together with separate lives, friends and interests. We had no difficulty encouraging and supporting each other's interests in traveling and exploring new ventures. I was the wage-earner who went out to work each day. She was the homemaker. In many ways, we were the best of friends.

We discussed major decisions, including what she wanted to do as she got older. I needed to know her choices so that I could honor them, but she could not, would not, broach the subject. I did not want to take over or make decisions for her. Lurking in my own past was the awful knowledge of what it feels like to lose autonomy and control over your own life and circumstances, to have others assume what they think is best for you.

If my mother wanted to move to a retirement residence or ultimately a nursing home, we could begin the process together, but she could not, would not, decide and the months and years ticked by. We finally



Maisie Jean (Ramsay) King, mother of Audrey King.

applied to a number of nursing homes, but my mother rejected all of them one by one when a bed was offered. The time never seemed right.

I increasingly took on the homemaking role through hired help. I assumed responsibility for her medical needs and appointments. A major merger was threatening my employment situation at the time and post-polio challenges were emerging. My tenacious will had always been able to overrule any physical limitations. But my body, it seemed, no longer listened. I had no choice but to give up work.

While I was hospitalized yet again with serious pneumonia and on life support, family members placed my mother temporarily in a nearby nursing home. I visited her on the way home from hospital discharge. She was miserable, desperate to come home. I could not leave her there.

I knew all too well the fear, the feeling of abandonment, the helplessness of nobody listening or understanding. My own memories were too powerful, too imprinted on my brain to resist. During those early polio years many people, including knowledgeable healthcare practitioners, had encouraged my mother to place me in lovely homes that existed for people like me. She had refused and by doing so, provided me with a rich family life and profound opportunities to achieve in both education and career.

As the months and years went by my mother's dementia and physical needs

increased. I brought in more and more daily help. Often her brilliant wit and reasoning shone through. She didn't want a bath today. She didn't want to eat – why should she? Why were we pushing her around like a child? It was a challenge trying to understand, interpret and balance competency versus choice.

Giving a person choice, enabling them to be who they want to be, assisting them in doing what they are driven to do – that's what genuine support is about when it comes to persons with physical disability. How and why is it different for someone whose thinking and reality is altered? For someone whose competence is variable?

Many times she insisted on going to the basement to her car, driving back home to Saskatchewan, getting up and cooking for her long gone kids. We tried to humor her, inevitably frustrating everyone and often increasing the distress.

***“I learned how to fight, to charm, to write, to advocate effectively.”***

My mother wasn't the burden. She just happened to be the bearer of physical and cognitive deficiencies that made her dependent on bureaucracies providing support. It was the system that I had to battle constantly to get more caregiver hours, to manage healthcare specialists who contributed nothing but greater challenges, not to mention the wasted expense of society's health care dollars. It was dealing with the multitude of unhappy caregivers who left my mother in a mess for the next caregiver to clean up.

I was constantly in the middle. It was like running a business with employees who expected you to solve problems but would not take direction because they were not accountable to you. (The exceptions were the ones I hired who also bore the brunt and burden of incompetent government-funded caregivers.)

I learned how to fight, to charm, to write letters, to advocate effectively.

**Audrey King** contracted polio in 1952. A rehabilitation psychologist for 30 years, she is an author who writes and speaks to international audiences, teaches at a university and is a consultant on ventilator issues. She was involved in founding the first supportive housing, outreach attendant services and direct funding programs in Ontario and chaired the first Ontario March of Dimes Post-Polio conference after attending PHI's first conference in 1981. Her mother, Maisie King, died in June 2012, six weeks shy of her 101st birthday.

I discovered the shock value and unimagined “power-up” potential of being a quadriplegic caregiver.

At the worst of times I periodically wavered in my decision to keep my mother in her home with me. Each time I inevitably decided it was easier for me to keep an eye on her care, intervening and advocating as needed if she stayed.

Aside from the transportation challenges of visiting a nursing home on a regular basis, I would have no influence and little awareness of what was happening to her when I was not there. I already had equipment at home she could use – a Hoyer lift, an extra wheelchair, a commode, a ceiling track lift over the bathtub. As an experienced user myself, a healthcare professional and a certified teacher of Ontario’s personal support worker curriculum, I could supervise and teach others in their proper use.

My 30-year career as a psychologist in a rehabilitation setting gave me knowledge of systems, budgets, negotiating skills and human resource techniques. How could I not put these skills to use for someone who had invested so much of herself in enabling me to grow and develop and become the person I was?

I learned much from my once proud, independent mother throughout her inevitable decline. I saw grace and humor in the face of the humiliation and embarrassment that her failing body caused her. I marveled at her wit and charm, at her ability to appreciate what caregivers did for her, even in the face of pain and suffering. Her tenacity and determination carried her through to the end.

She wanted to leave this world. She felt her job was done and she didn’t want to be a burden. She said it so many times and in so many ways. But we, myself in particular, would not listen. We mounted a continuous concerted effort to get her to eat, to get her dressed and out of bed each day. It was clearly painful and exhausting. All she wanted to do was sleep.



*Maisie King with daughter Audrey King (center) and granddaughters, Carole-Anne and Lynda King.*

I felt relief when she finally left us – both for her and for myself. I felt incredible lightness and freedom. The burden was gone. I felt guilt for my lack of grief until I realized I had lost her long before, and my grief and sorrow had been stretched over many years through the heart-wrenching ups and downs of each day. I had already grieved the loss of the marvelous mother she had once been.

My guilt then shifted to a guilt about keeping her alive, in spite of her strong wishes. Was I selfish in not wanting to lose her? Whose life was it anyway? I still ask myself.

When I get old and decrepit enough to consider life not worth living, will those more able than I, those responsible for my care, listen to me? Will they hear what I am really asking through my confusion? Inevitably, it isn’t as simple as having a living will. When you realize that someone loved you so immensely and completely that they invested their life in removing the massive early boulders blocking your way, forging your life’s path that enabled you to “walk” in her footsteps, it’s not easy to let go. ■