

Taken from Kathleen M. Banchoff, Ed. (2008),
***THIS LITTLE LIGHT OF MINE:
STORIES AND POETRY FROM FAMILY CAREGIVERS***
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Story is our only boat for traveling on the river of time, but in the great rapids and winding shallows, no boat is safe. —Ursula Le Guin

INTRODUCTION

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Last fall, a friend gave me the gift of a book of photographs³ to keep me company as I was writing—remarkable images of woods and rocks and water taken in the Dundas Valley along the Niagara Escarpment at the head of Lake Ontario. As I leafed through it, I was struck by the metaphor it suggested. A stream of water running through a valley is like the river into which caregiving sweeps us as we care for a debilitated loved one.

The same water that moves swiftly in one place, in another part of the terrain becomes a pond deep and still, sometimes reflective and sometimes ruffled by changing winds. Flowing out of another place, the water may fall swiftly over a cliff in lovely veils of mist or thunderously, breaking over great stones and taking everything with it. Then again, in another place, rocks and rills may slow it down to babbles and burbles, even meanders. Yet, it remains the same stream.

Caregiving moves like that, sometimes fast and perilously, at other times so slowly it seems that time has stopped and nothing ever changes. The immovable objects of physical limitation and the irresistible forces of love and personality shape each experience of it. Yet, it remains the same journey.

The rapids and shallows in caregiving are well-known to me. I have told stories about my caregiving, especially to other caregivers, and found the respite an appreciative audience can provide. Story, as John Dunne says, was the boat I had crafted for my journey and telling made a difference.

This is the third book for caregivers offered by the McMaster Centre for Gerontological Studies. The first two books grew out of workshops I conducted with Professor Ellen Ryan for family caregivers served by the Hamilton regional office of the Victorian Order of Nurses (VON): *Gathering Inspiration, Lifting Our Spirits: Reflections on the Spirituality of Caregiving* (2005) and *Passing on the Blessing: Stories, Tips and Tools of a Family Caregiver* (2006).

In the second book, I invited other family caregivers to share their lived experiences. These stories and poems are selected from the responses I received. Some storytellers are known to me; most are not. Some live in places I know in the United States; most live in Ontario and other parts of Canada. Some are professional writers; most are not. All are gifted with the ability to tell what they know, simply and sometimes even lyrically. They reflect the truth as they see it.

Read these caregiving stories as illness narratives, and you may come to appreciate, most simply, the situation created by the condition, disease, or trauma experienced by the person in care.

You will see in each caregiver's story the particular rocks and rills that channel the river where they are:

- ~ the side effects of cancer treatments (Cameron's *Wigged Out*),
- ~ the seemingly inexorable, progressive decline of those with various forms of dementia (Faraday's *The Covered Bridge*),
- ~ the ordeal of families of children born with life-threatening diseases (Lee's *Attentive Waiting*) and life-long challenges (Iskov's *All Too Soon*),
- ~ the increasing frailty of parents debilitated by age (MacPherson's *Ties That Bind* and Grove's *Thursday*).

Caregiving is often defined as "concrete, hands-on help with the activities of daily living." Those who shoulder much of the routine work of it are related to the person in care: spouses or partners, parents or children through several generations. Yet, the extraordinary work of caregiving is more than routine, and the connections established with it go well beyond the traditional family. People change, or fail to change, in ways that defy the boundaries set by the physical limitations of the caregiver and the medical realities of the cared-for. Emotions are often mixed, and surge as well as ebb.

As in the experience of caregiving, these stories and poems reveal their bewilderment, distress, and grief. But they also share their tribute, joy and laughter.

Consider:

- ~ the balance that shifts delicately in Rule's *My Lady*, or
- ~ the wishes and misses in the single story told poignantly in Wingfield's pair of poems entitled *Visiting Dad* and *From the Wheelchair*.
- ~ the conundrum that L. Banchoff's narrator faces in *The Other Daughter*.
- ~ the empathic grandmother who narrates Ince's *Lunacy* and creates a place to stand with far-away caregivers, or
- ~ the significant connection Novick forges in *Bella*.

There are four patterns in the light from each story and poem that draw the narratives together beyond the particulars of situations and relationships:

Love Defined: Love changes everything, even the definition of what is loving.

Grit and Grace: When you're a caregiver, as Rev. James Miller writes, you take what is, and you do what it takes, and sometimes there is blessing and even beauty.

Moments of Mercy: Even in the darkest times, an occasion may turn thoughtful, or someone will extend a simple kindness, and make all the difference.

Revelations: Caregiving changes us sometimes in an instant, and sometimes in reflection over time.

Several paragraphs at the beginning of each section use the prism of these narrative themes to refract the beams in each story and poem into more visible light. Read, and listen with your eyes.