

*Writing Down Our Years Series, No. 9*



**THIS LITTLE LIGHT OF MINE:  
STORIES AND POETRY  
FROM FAMILY CAREGIVERS**

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Ellen B. Ryan, Series Editor

# THIS LITTLE LIGHT OF MINE:

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# FOREWORD

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For more than 110 years in Canada, the Victorian Order of Nurses (VON) has functioned as a not-for-profit, charitable organization identifying and responding to health care needs in local communities. Since 1988, part of the VON's work has involved providing support and education to family caregivers. I was coordinator of Caregiver Education Programs for the VON in Hamilton, Ontario in 2004 when Kathleen M. Banchoff—a newly-retired lecturer from Providence RI—and Ellen B. Ryan—former director of the McMaster Centre for Gerontological Studies—offered to share their joint expertise in education and communication for the benefit of the families we served. They were proposing a great opportunity.

Together, we developed a workshop program of communication skills and assertiveness training tailored to the family caregiving situation. With several different groups of Hamilton area caregivers, Kathleen and Ellen conducted workshops and refined a set of communication tools and other helpful materials which have since become part of VON's National Caregiver Education Program. We have become convinced of the power of "story" to elicit insights and bring about transformative learning for family caregivers.

What I know from working with family caregivers is that they are often, as journalist Andre Picard described, "conscripted by love".<sup>1</sup> Notoriously caught up in the demands of their current situation, they frequently underestimate the power of their opinions and experiences and rarely get much chance to talk about those experiences. Watching Kathleen and Ellen at work, I have observed their persistence, compassion and dedication when drawing these stories out. They have the capacity to listen, not only with their ears, but also with their hearts. They glean rich stories from the experiences shared by those in attendance, and transform those stories into powerful learning opportunities for all present.

Kathleen and Ellen have also produced two books from this collaboration: *Gathering Inspiration* (2005), and *Passing on the Blessing* (2006), gems that continue to provide solace and direction for caregivers. This, their third book, extends the VON workshop learning experiences through the stories and poetry of family caregivers from many places in Canada and the United States.

I believe that the most credible people to speak to family caregivers are other caregivers: people who know the emotions, the deep fatigue, and who

<sup>1</sup>Picard, Andre: *Behind Closed Doors: the Struggle over Home Care, Conscripted by Love*, Part I; Globe and Mail, March 20, 1999.

recognize the need for hope, humour and perspective. From my own experiences as a family caregiver, I know there are indeed moments which define love in unexpected ways. Others require both grit and grace. Still others bring merciful respite, or revelation and perspective. This collection of poems and stories, thoughtfully punctuated with photography of watercourses in the Hamilton area, is at once eloquent, poignant and elegant. Taken together they convey a sense of the precious, of the surprises, even tenderness, discovered by caregivers.

Thank you, Kathleen and Ellen, for extending your efforts to bringing this collection of “lights” to light. Thanks to these family caregivers for sharing your stories with the rest of us; we need to know there are many ways to be a caregiver.

Finally, for you, dear caregiver, be encouraged to tell your stories and the stories of the person you are caring for. Sharing your challenges and the demands and rewards of your work as caregivers lights the way for our communities to learn how to best support you. We are learning to listen.

Anne Vallentin, Coordinator,  
VON Hamilton  
Caregiver Education Program



**Anne Vallentin** has been working with family caregivers since 2001, through the VON Hamilton’s Adult Day and Caregiver Service programs. Her nursing career has been mostly in community nursing. She has also been a caregiver to some family members. Anne has enjoyed various volunteer opportunities in community capacity building in her town of Cayuga, Ontario. At present, coordinating a building renovation and addition of the Adult Day Centre, work on environmental issues and fun with grandchildren are all parts of her life.

## ACKNOWLEDGEMENTS

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From the beginning, I want to acknowledge all those writers who submitted their stories and poetry. Here, I offer my unwavering admiration for your courage and creativity.

Besides the storytellers, there are a great many other people whose contributions to this book deserve recognition:

- The cover photo was taken from the windows of my house on Lake Erie by Ann Anas, designer for all of the books in this series and my faithful guide in bringing this book into print. My grateful appreciation.
- The photographs of waters in the nature preserves of Ontario were taken by Richard and Eleanore Kosydar, and are used with their gracious permission. My overwhelming gratitude.
- The look of this book is the result of the capable direction of Deb Berlo, Director of Brown University's Graphic Design Services (GDS) department, the skill of her staff, and the generous support of Tom Banchoff. My marveling respect.
- The narrative themes for these stories were suggested by the work of Anna Burack-Weiss in *The Caregiver's Tale* (New York: Columbia University Press, 2006). Her analysis of more than 100 memoirs of family care was, for me, a driving force. My continuing admiration.
- The themes themselves are the inspired ideas of Diane Given, who read all of the submissions with me, in different orders, and worked me through my fits and starts. My pleasure in your company.

In the end, my work on this and other books in the *Writing Down Our Years* series is a result of the warm friendship and professional encouragement provided by Professor Ellen Ryan. My humble thanks.

— KMMB





# INTRODUCTION

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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 (1994)

*A Fisherman of the Inland Sea* (NY: Harper Prism)<sup>2</sup>

Last fall, a friend gave me the gift of a book of photographs<sup>3</sup> 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).

<sup>2</sup>Quoted by John S. Dunne, CSC, in the opening of his memoir, *A Journey with God in Time: A Spiritual Quest*. (2003), University of Notre Dame Press.

<sup>3</sup>Richard and Eleanore Kosydar's *The Dundas Valley: Visions of Beauty* (2007), Dundas ON, Tierceron Press.

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<sup>4</sup>:** 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.

Kathleen M. Banchoff  
Providence RI, USA  
February 8, 2008

<sup>4</sup>*The Grit and Grace of Being a Caregiver* by Rev. James Miller (Fort Wayne, IN: Willowgreen Counseling & Consulting, [www.willowgreen.com](http://www.willowgreen.com))



# CAREGIVERS' STORIES AND POETRY



## LOVE DEFINED

*“These memoirs extend the notion of family caregiving beyond the hands-on caregiver... (and describe) the many benefits to be gained by the privileges that family caregiving bestows on those who practice it.”*

—Anna Burack-Weiss in *The Caregiver’s Tale* (p. 156)

Here we get a glimpse into the ways in which the obligations of love and the unexpected pleasures of caregiving touch and shape our lives. Caregiving redefines love or at least, defies the limits set by traditional definitions. Sometimes the writer uses only a few words (as in Philpot’s email with the subject line, *A Picture of My Mother*; Iskov’s evocative poem, *All Too Soon*, and Knill’s short reminiscence, *Long Distance Caring*). Others use longer narratives (Abrams’ *Making the Most of It*) to describe more complicated caregiving. They challenge us to consider what love is.

- The traditional notion of love between partners is achingly manifested in the everyday simplicity of Pitkeathly’s *A Personal Book of Hope* and Ryan’s *Dad’s Vigil*. The definition of “family” is extended here to include friends in Linklater’s *Lucky Neighbor*, and even the children of friends in Novick’s *Bella*.

- Love is the wonder that Holland finds in simple sharing (*When I Met My Grandpa*) and the conundrum that Stewart faces in *Filia*.
- The symbols of love grow out of the dirt for Griebing (*Tulips in Springtime Bloom*), emerge from the brusque language and the surprising quotations in Klein’s recollection (*Carrying On*) and materialize in what doesn’t happen in Haskin’s poem *Renovation*.
- The complicated difficulties of being loving for children and their parents are mirrored in Wingfield’s pair of poems *Visiting Dad* and *From the Wheelchair*; they are also artfully described in Leslie’s *Afterward*, and in L. Banchoff’s rich and deceptively spare imagery in *Clothespin*.





## A Picture of My Mother

Hi Ellen—

This note is about ... my mother's aging process and slip into senile dementia.

I have a picture on my desk of her leaning her forehead into a kiss from me, eyes closed with a smile on her face, and on the grubbiest piece of paper I keep meaning to replace, is written "Better to forget and smile, than remember and be sad".

To me, it means I should be happy she can still smile, that visits aren't sad occasions if I don't let them be that way, and all my time with her is precious and I won't forget any of it ever.

She'll be 92 in June.

Pass that along.

—Anne Philpot

*"Better to forget and smile, than remember and be sad".*



© Eleanore and Richard Kosydar

McCormack Pond in autumn, Dundas Valley ON, CA

## Tulips in Springtime Bloom

An upper Midwest wind whistled through the trees that crisp autumn morn.  
Door chimes signaled our postman, clutching a box wrapped in dark brown paper.  
Unfamiliar postage adorned the parcel, with special markings to 'keep cool'.  
My mother's eyes gleamed in eager anticipation—a passionate gardener—keenly  
aware of the colorful potential contained by the succulent Dutch bulbs.

Lovingly chosen that warm spring afternoon—a college boy's first journey abroad.  
His small gift—brilliant colors, single and double blooms, variegated petals with  
feathered tips—all dazzling features hidden in three-hundred drab little  
brown orbs.

Her joy evident while digging intently into the earth, carefully burying each corm in  
damp soil.

The promise of fresh blossoms—new life—held by each successive spring.  
Intense shades—magenta, orange, red, pink, violet—a scattering of early white crocus  
and golden daffodils amongst the tulips.

When the spring blooms faded, other flowers offered a constant summer bouquet in her  
carefully tended gardens.

She beamed with pride as neighbors and passersby stopped to chat, admiring her grand  
floral display.

With age, the homestead grew less serviceable—the stairs a burden, the winters too  
harsh, the distance too far.

Options considered, difficult decisions rendered, a new reality undertaken.

Relocation of a parent disrupts lifelong roots.

Even for this seasoned traveler, a move equivalent to her first journey.

The bulbs, pulled out of the land on that last summer day, had divided and multiplied,  
filling nine large bags.

"You might want to forget a few for the new owners," she whispered as I dug into the  
hard ground.

A bright new home, accessible, more conducive, and just down the road.

Fresh flower beds were specially cut into the yard—to accommodate the transplanted  
tulips—like our transplanted lives.

With the next spring, another proud display for new neighbors and new passersby.

Her muffled call for help came early that cold spring morn—the sky still dark before the  
break of dawn.

In several hours, the sun would warm the tender leaves piercing through the soil.  
Days floated together.

I gripped her hands in the sterile confines of intensive care.

Contemplating an unknown future, I whispered of the impending blossoms and unending  
love.

A slight fog blanketed the horizon that damp spring morn.

Together alone—I held her in those silent moments—

And much too soon, we were alone—together.

Her greatest gift to me.

That afternoon, the house was ardently quiet, save for the gentle rustle of a spring breeze  
and the faint ringing of her windchimes on the porch.

Clusters of tulips swayed in the warm air, their verdant stalks at full attention, their  
radiant petals now in vibrant bloom.

Has it really been two decades since that box arrived?

Time slips by, yet each spring brings the joy of new flowers—the vivid hues a new  
beginning.

A river of tears has moistened the ground.

Soon a 'For Sale' sign will be planted in the rolling lawn.

As my spade breaks the rich dirt, I remember to “forget a few” of the tulips for others.

—Tomas L. Griebing

## Carrying On

When I first read through the preamble in the request for submissions of stories or poems for inclusion in a publication, I was at a complete loss to understand what the editor was looking for: “Family Caregiver.”

What a wide range of activity this covers! Did the editor want to address the daily caregiving involved in rearing a family and perhaps managing sick periods while carrying on with the demands of normal living? Or caring for a spouse or a parent in a short or long term physical or mental decline? Something in between? All of the above?

What I can talk about is the experience of a spouse who cared for his loved one for over 17 years.

This quotation from the *Rubaiyat* of Omar Khayyam sums up my residual emotion after the recent death of my wife.

*Ah! Love. Would that we could  
With fate conspire  
To grasp this sorry state of  
Things entire.  
Would we not shatter it to bits  
And then,  
Remold it closer to our heart's  
Desire?*

I am living in a caregiving institution, which means that I see the whole gamut of family caregiving, from the devoted to total neglect, from the insightful to the

unaware. To me this indicates that anything like a “manual of tips” for caregivers would be very “person-specific”—applicable only to very similar people or situations.

Generalities in care already abound in the educational material for professionals, but personal stories are truly best absorbed by people who relate to those specifics. In family caregiving, it comes down to the personality, the quality of the relationship and at least to some extent, the grasp the caregiver has of events as they unfold. And believe me, degenerative mental disease is very dynamic.

This is our abbreviated story.

Some 17 years ago, my wife (she would have been about 63) sensed something wrong mentally, perhaps a return of depression, which she had had previously. She went to see the psychiatrist who had treated her before. This doctor astutely diagnosed that this time her problem was not ‘psychological’ but ‘neurological.’ Subsequent tests ruled out brain tumors and gradually, as the disease asserted itself—forgetfulness, confusion—her family doctor diagnosed, “probably Alzheimer’s Disease.”

She had still been working as a social worker and driving, but began to show signs of paranoia, which at first I did not spot. She broke with her best friend, and

with her brother, quit her job (because the boss was 'out to get her') and our relationship became quite strained. I even left her several times before I became aware of the paranoia and that her stories of these persons' hostilities were psychotic.

However, we were always reunited by our little diabetic, aging dog, who needed insulin and much care. I would call home to check on her and when my wife confessed her inability to care for our mutually loved pet I would use this as an excuse to return home to my wife.

She began wandering, but in her car, getting lost in Milton, Mississauga, Kipling, you name it, and the police would phone me to come and get her. They will not cross county or municipality lines to bring a wanderer home. I eventually took her keys away, precipitating a further period of stress between us. Her wandering continued.

I should break off the narrative to tell the reader that we lived in Burlington at that time. I let her wander as I was not going to be her jailer, but would follow her on foot at first, then in my car, as I was having severe arthritis problems in my knees. I always managed to persuade her to get in the car and return home,

As time went on, she became more diffi-

cult to deal with. At one point she attacked me with a spike heel. Another time she broke the window of the door of a room where I had locked myself in to get away from her. She refused to go to the hospital so I called in the CCAC<sup>1</sup> to assess her for home help. Needless to say, I had by this time taken up all the household duties except for hiring professional cleaners for our large house. The CCAC put her on the waiting list for a nursing home, but in those days, about 2000-2001, that was a three-year wait. They offered visits to bathe her but that was not much use. She had become incontinent by this time and would regularly wet her bed in the middle of the night, requiring a bath immediately. Bathing became more and more difficult, as did toileting.

I wasn't at the end of my rope but damn near it when Lady Luck finally smiled on us in January 2002. She fell and broke her hip. Once in hospital, the provincial authorities took over. After her convalescence, she was assessed as unable to return home to my care. Ergo! They found a nursing home in one month. This was a crowded, converted motel with no air conditioning and while the physical care was probably O.K., with summer coming up and her C.O.P.D. (chronic obstructive pulmonary disease)

<sup>1</sup> Community Care Access Centres are the local point of access to community-based health care services in many parts of Canada.

THIS LITTLE LIGHT OF MINE:

acting up, I persuaded the CCAC to find another place, which they did within two months.

Spring of 2002, and new government-sponsored nursing homes were popping up like daffodils. She was moved to a lovely new facility in Burlington where finally I was relieved of all the physical burden of care and I could provide what I could do best, companionship, activities and TLC (tender, loving care).

I was there daily from opening to bedtime. She never had to experience what I see so often among long term care residents—loneliness and the feelings of being abandoned.

When the present facility in Hamilton opened up in the spring of 2004, featuring TC (total care) and assisted elder living on different floors in the same building, I sold our house and moved us in here. She passed away in November 2006 and I have stayed here.

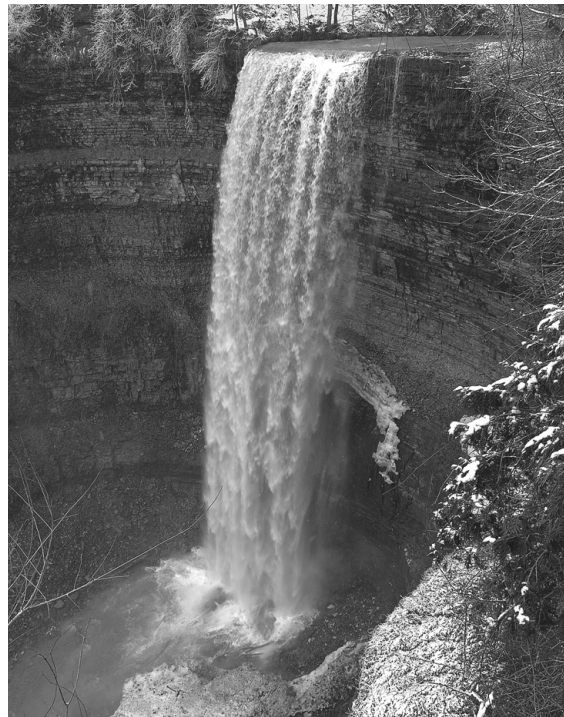
To summarize the lesson from our story, I don't believe one can give many tips to other caregivers. Situations and personalities are so very different and constantly changing. Love and intelligence will determine the quality of caregiving.

Speaking strictly for spouses, my versified motto is:

*When lust is gone,  
Love carries on.*

—Bernard Klein

*"...finally I was relieved of all the physical burden of care and I could provide what I could do best, companionship, activities and TLC."*



© Eleanor and Richard Kosydar

Tews Falls in Greenville ON, CA

## Renovation

She's packing up his clothes for Community Care  
 boxing the photos and mementoes from the dresser.  
 Already she is planning to use the insurance  
 to reconstruct the space he left in her heart.

She keeps the Day Care going, her life blood;  
 She had paid him to come home and work for her,  
 build the playground, renovate the basement rooms.  
 Now she's running on routines he made possible.

Her son visits her in full flight. To stop,  
 even to pause, to let in the vacant cold  
 is not her way. She is the maker, formulator,  
 the long suffering one you say 'sorry' to  
 and never hear her speak it back.

He wanted to see his mother grieving, wanted to be leaned on,  
 He remembers her flight from the bedside in those last hours,  
 twelve, twenty-four,

    she prayed he would survive,  
         squeeze her fingers just once more;  
 thirty-six, forty-eight,  
     she prayed he would be taken  
         and him heading for the break point—  
 seventy-two hours he might recover—  
     and when on the third day he died  
         she was there at his side.

He didn't see his mother lift the shirt  
 to her face and fill her nose with his smell,  
 didn't see her reach for the pill bottle  
 to silence the rage at being left,  
 no one to insist upon  
     no one to carry forward  
         no one to—  
 the other word he had never heard her say—  
     help.

—Dave Haskins

## Visiting Dad

I won't ask how you are, Dad  
He would tell me in a thousand words.  
I'll say, it's good to see you Dad.  
He'll grunt—It's about time.  
I feel guilty because I'm forty  
And don't move as eighty does.  
I'll say—let's go for lunch  
And buy you a new suit.  
Then he'll say,  
Your Mother always bought my suits.  
Then I'll feel guilty again.  
I can't bring Mother back.  
I'll say, how are the meals?  
Are you eating well?  
He'll say—no it's not the same  
Nothing tastes like home.  
I'll say—Who is at your table now?  
Is Jim still there?  
He'll say—Jim is gone—and no one talks.  
I'll tell him—Joel and Aaron play hockey.  
We get up at five for practice.  
He hardly hears and doesn't care.  
I hug him and say,  
We'll bring you home for lunch on Sunday.  
He stares past me.  
What should I say?  
How can I make him come alive?  
Why do I feel guilty?  
Goodbye Dad, I'll see you soon.  
In the parking lot, I weep  
And feel guilt rising in my throat.

—Naomi Wingfield



## From The Wheelchair

Here comes my son.  
I can hear him saying—  
Must go to see Dad today.  
I wish I weren't an obligation.  
I wish he would just drop in  
Unexpectedly.  
Not always on the same day.  
I remember how I hated  
To visit old people, sick people  
When I was young.  
He won't say—How are you Dad?  
I'd try to keep it simple.  
I wouldn't tell him  
How hard it is  
To have a girl  
Cut your toenails.  
I'll try to be cheerful,  
But what can I tell him?  
I should tell him  
How I'd like to see Joel and Aaron  
Play hockey.  
I wish he would remind me  
Of when he was young  
And I taught him to skate.  
I wish he knew how I miss his Mother.  
I wish I could tell him  
What's in my heart.  
The time is too short.  
I'll do better next time.  
But will I?  
The time is too short.  
Goodbye, Son.

—Naomi Wingfield

## Long-Distance Caring

Because of a job opportunity, my husband and I found ourselves raising our children several hundred miles from our parents. As our parents became older, we made trips more frequently to visit and to check on them. Then, my father suffered a stroke. I was 34 and busy raising my own children. My two sisters and I quickly got home to sit with mother at the hospital. I thought then that the first 48 hours were the worst as I continually prayed for Dad not to die.

The next seven months proved to be much more difficult. He was paralyzed and recovered only about 70%, both physically and mentally. After three months of care at home, Dad moved to a nursing home with physical therapy facilities. He realized what a toll his care was taking on Mom. My sisters and I staggered our visits to be of whatever help we could but we were miles away, with children and jobs of our own. We certainly felt guilty—when I wasn't helping Mom I felt guilty and when I was with her I felt guilty, as I wasn't taking care of my husband and children. There seemed to be so little that we could do when we couldn't be there in person.

In time, we noticed Mom trying to cope with daily visits to him, managing all the financial responsibilities for the first time, and keeping up the house. We changed our ways of helping. On our visits home, we gave her a chance to sleep, brought the

books up to date and balanced the check book, let her talk and, of course, we spent as much time with Dad as we could. The weeks we were in our own home we all talked by phone. We began checking with Mom's neighbors, found an old friend who set up as her accountant and arranged for a housekeeper. We handled ourselves this way for seven months, until Dad died.

Twenty-eight years after our first fumbling attempts with my Dad's care we found ourselves at Mom's bedside, and also for my father-in-law. Still, we had to travel to care for them but this time, we got help in place more quickly, learned to work with neighbors and friends, set up financial assistance and were not afraid to ask for other family members for help.

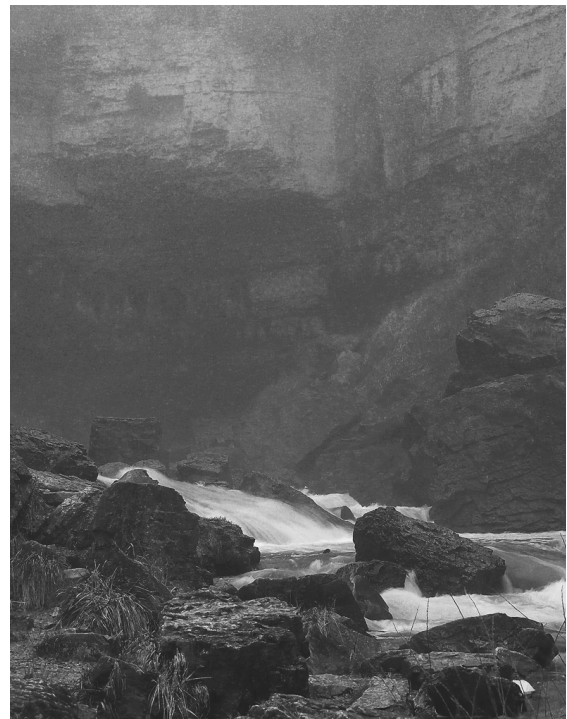
My husband said something striking at the time, that we were setting the example for our children as we were caring for our parents. That, he reminded me, is what our children will remember when it is their time to help us. Eventually I came to peace with the idea that we were doing the best we could to love and give care—even from a distance.

—Barbara Knill

## All Too Soon

All too soon  
my little boy  
will be fully grown.  
But all his adult life  
he can't be on his own.  
He'll need someone  
to care for him  
each and every day;  
someone to help him  
wash and dress  
and supervise his play.  
I hope he'll have a friend  
who'll understand his smile  
and be there when he's lonely  
and stay with him awhile.

—I.B. Iskov



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Base of Webster Falls in Greenville ON, CA

## Making the Most of It

The role of a caregiver varies greatly according to their circumstances. For the past 8 years I found myself a caregiver for my mother, my husband and my daughter. Each situation was an entirely different experience.

My mother began to have memory problems at age 80. She then lived alone in her own two-story house about one hour's drive away from me. I contacted CCAC and we put in place meals on wheels and the visiting homemaker. I would phone every morning and evening and if I didn't receive an answer I would call a neighbour to check on her. I found long-distance caregiving to be very stressful and it required a lot of creative problem-solving.

After a few months her situation deteriorated and the time seemed right for a move to a nursing home. It was a very painful decision but by now her safety was at risk. It was not an easy adjustment for her but she settled in and I wanted the staff to know what a marvelous person she was. I put together a photo album/biography of her life and she loved to go through it with her visitors and staff. Family pictures adorned the walls and we visited regularly.

The staff became very fond of her and she enjoyed the activities they provided. I remember the day she passed away, the

young girl at the reception desk greeted me with tears rolling down her cheeks. My mother had a way of making dear friends wherever she went.

My husband was diagnosed with multiple myeloma in 1998. At that time we were told this was a rare form of cancer with many treatments available but no known cure. Jack simply refused to accept or acknowledge that this disease would take his life. As his wife and caregiver I supported this attitude.

He had five years of chemotherapy, radiation, blood transfusions, a stem cell transplant and many different drug regimes, but he would not give up. During one crisis the head nurse took me aside and insisted that I have 'the conversation' with Jack to discuss his wishes for funeral arrangements etc., etc. I ignored her advice, he survived the crisis and we carried on as before.

He made the most of every day and learned what really mattered in life. We made trips to the family cottage, flew out to BC to visit relatives, threw a big garden party, celebrated our youngest daughter's graduation and our son's marriage. We went to grandparents' day at our grandchildren's school and took time to be with family and friends whenever possible.

Yes, we had many difficult days during the five years he was sick but we never gave up hope and that enabled us to face the future. At the time of his passing we were planning a cruise to Alaska.

You often hear the saying “life is what you make it” and we made the most of our time together.

Twenty four years ago when our daughter was born and subsequently diagnosed with Down Syndrome we didn’t know what the future would hold. We were determined to give her every opportunity to grow and develop to her fullest potential. We became her parents, her caregivers and her advocates.

She had infant stimulation, speech therapy, nursery school in a regular setting, fully integrated elementary and secondary school and she holds down two part-time jobs in the community. She has a wide circle of friends and is an active member of her church and youth group. She and her girlfriends go out at least once a month and have enjoyed several vacations together.

As a caregiver/advocate there are medical appointments, phone calls, e-mails, letters and meetings to attend that all help to make life as inclusive as possible. At present I am proposing a plan for a

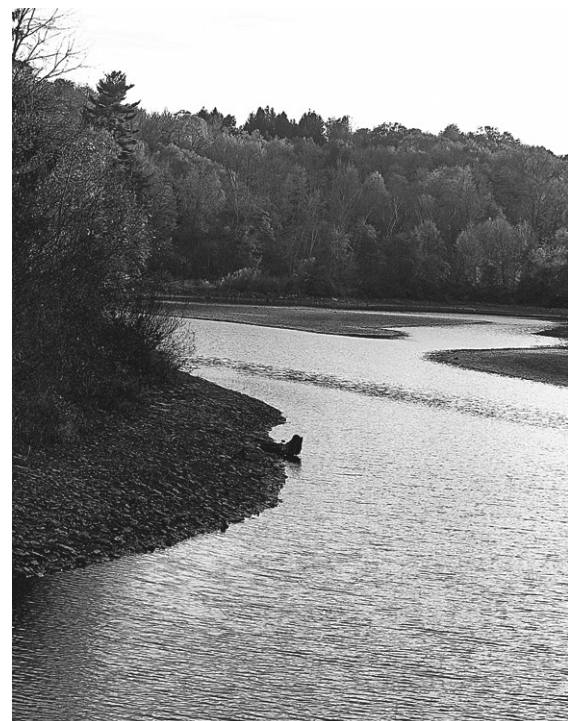
supported independent living situation. I am hopeful we will receive the funding needed to make it a success.

My daughter has a full rich life in her own community. I am proud of her accomplishments and am confident the future holds many exciting adventures for her.

Caregiving takes many forms and although they each come with unique challenges, they are all very rewarding.

—Carole Abrams

*“Caregiving takes many forms...”*



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Stream at Crook’s Hollow, Greenville ON, CA

## When I Met My Grandpa

Grandpa was never the chatty type but when he came to live with us after Grandma died I remember being taken aback that I really didn't know him at all. Until that time, we all tended to flock to and around Grandma. When she was gone, it was such a surprise to find this stranger living in our midst. Eventually, I would find great comfort in having been gifted with the time to get to know someone who had in fact been present in my life from the beginning.

Grandpa was already very sick when he came to live with us and deteriorated further rapidly; it seemed he made the decision that he didn't want to be here without her. I never thought of him as an emotional person so I was shocked to see him fall apart when she died.

I knew the basics. Grandpa had a horse and buggy transport business in the Old Country and was able to barter and trade throughout the war to provide for the family. But when motorized transport took over, he came ahead to Canada for a couple of years to save enough money to bring his wife and four children over. For the first year they stayed in Mrs. Caccioni's basement on Clement Avenue right across from the old train station. He worked on Roger's Pass and in the mines and then landed a position at Sun Rype where he stayed for 35 years.

His story was like so many other immigrant families at the time but in five short months, I was introduced to the details that would distinguish him from the others. I learned that he loved chocolate-dipped strawberries and those chocolate covered marshmallow cookie things. I had never seen him eat sweets; his idea of dessert was slicing fresh peaches into his wine glass. We shelled hazelnuts together at the table and sometimes, he reached out and held my face in his hand. He would call me over by patting the cushion beside him.

I remember being pleasantly surprised that he wanted me just to sit with him, where I could study the stories and travels in his stiff labor-worn hands. He told me stories about his beloved baby sister Linda. I had never thought of him as a brother or a son or anyone else besides my Grandpa. I saw how much he adored my mom for taking care of him.

He had developed emphysema years earlier and later lung cancer but didn't have a whole lot of time or patience for doctors. He found it hard to respect a guy in a white coat telling him to sever his love affair with wine, cigarettes and even olive oil. To set them straight, he would simply tell them, "water is for washing, milk is for baby cows and wine is for drinking." You can imagine his delight when Dad took him to a doctor

that told him that a glass of wine every-day is good for the heart. “Lui, lui e doctore! (Now that’s a doctor!)”

Grandma died in the spring during the bloom and Grandpa joined her when the leaves fell. I’ll always be grateful for that time in between when I met my Grandpa for the first time.

—Tana Holland

*“He wanted me just to sit with him, where I could study the stories and travels in his stiff labor-worn hands.”*

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Sulphur Creek in winter, Ancaster ON, CA

THIS LITTLE LIGHT OF MINE:

## Bella

“Bella”, means beautiful in the romance languages  
and that she was.

Bella was my mother’s best friend,  
she became my aunt, my friend.

She was spirited and magnanimously generous.  
Widowed at a young age, she raised a daughter  
while coping with a broken heart.

In time the daughter would develop severe  
physical and mental problems.

They didn’t see each other very much.

I remained consistently near except when Bella disappeared.

We doggedly looked but couldn’t often find her.

In time Bella settled into a wonderful home for the aged.

I visited often. Slowly, my beloved Bella was  
changing. She would steal and wander and forget.

Totally unaware, she would go for walks, fall and break bones.

One time she made international headline news  
when a St. Bernard dog attacked her. I took her  
to court and fielded media questions. I tried to be  
there for her. I tried being a friend,  
chauffeur, animator, and social convener.

One day after returning home from visiting Bella,  
I noticed I was very tired. After a few days I would perk up.

Then after another visit, I would become sad and tired.

I began to realize it was the visits that were depressing me.

I didn’t know this Bella anymore.

She looked familiar but the exotic, enticing woman  
was gone. After a few years of my inner turmoil, I made a decision.

I couldn’t go anymore. The cost was too high.

She was well cared for. She didn’t know me.

She was in a different world where I wasn’t privy.



In my heart, I was still there for her.  
In spirit I would, could never forget her.  
But I couldn't go to see her. I felt such guilt,  
remorse, burdened.  
I tried to speak of this but couldn't. I would carry this alone.  
If we are all interconnected, and I believe we are,  
Bella and I are not  
separate. What is a visit anyhow?  
This is my tribute to a wonderful person who  
shouldered her own burdens.  
She laughed, sang, traveled, marveled,  
never failed to stop and acknowledge  
a child. Then this world started to slip from her  
until only her body remained.  
I wrestled with the question,  
"Where does my obligation start and stop?"  
In time I had to weigh my cost against a self-imposed duty.  
Some will judge me. That's o.k. I can live with me.  
I could never sleep knowing that an opportunity came  
to honour a wonderful person and I didn't respond to that chance.  
These words are my homage to Bella in  
all her forms, smells, sounds, swirls, noise and grace.

—Honey Novick

## Lucky Neighbor

My friend Helen tells me that her daughter regularly reminds Helen how lucky she is to have me as a friend. And I guess that's true. In Helen's life I am what is called a natural helper. I am her friend and neighbor and I provide informal (free) support. For about 12 years Helen and I were neighbors living across the street from each other. The last eight years we have been neighbors in each other's hearts as she lives in a seniors' home. I visit her regularly and still refer to her as my neighbor.

How do I sum up what neighbors we have been? We loved and supported each other through 20 years of life. Her husband died. My husband died. I had cancer. Two years later she had cancer. We witnessed each other's struggles with the decisions and actions of our adult children. We shared meals together; we shared tears, and a whole lot of laughter. There were times I rescued her like the time I ran across the street in my nightgown and winter boots after midnight in response to a desperate call, "I'm sorry for bothering you, Gail, but I fell and I'm stuck in between and bed and the wall." And there were times she rescued me with kindnesses and favors when I felt battered down by life in general.

With twenty years difference in our ages we brought different histories to our relationship. I brought feminism and she

brought traditionalism. She often stated that she wished she had known me when she was younger for my opinions and politics might have led her in a different direction. And if I liberated her, she grounded me. And who can say which was more beneficial?

We are two women growing older together. And now as Helen approaches the end of her ninth decade her memory is not as sharp. So she tells me the same story five times. So what? So she confuses details and mixes up stories. So what? Good friends love each other and one thing is for sure Helen loves me and I love her.

To say that I am a good friend only tells half the story. We are both good friends to each other. Over the years our lives and circumstances have changed and like good friends we stuck it out and grew into our ever changing roles. So the last number of years I have offered more practical support. And the last few years I listen to the repetition of stories. We don't travel as far as often because it is increasingly difficult for me to maneuver her wheelchair into the back seat of my car. But there are many things we still do. I visit her at Grandview for a meal at least once a month. We watch sitcoms on television in the early evenings. We attend the annual resident barbecue and the Christmas tea.

We sit outside in the summer and inside  
in the winter. We watch the seasons go by.

My life has been enriched through  
knowing Helen and having her as my  
friend. We are both lucky.

—Gail Linklater

*“We sit outside in the summer and inside in the winter. We  
watch the seasons go by.”*



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Cootes Paradise, Hamilton ON, CA

## Clothespin

My mother's silvered clothespins,  
connected by a rusty hinge the way  
that old couples hold up one another,  
were used to clasp receipts  
and categorize coupons.  
Behind the garage, some pins lingered  
on the dragging line like dried sardines.  
She lingered too, hollowed eyed,  
dirty in her blue checked robe,  
thin in her pushed-forward body  
trying to water the last rose bush  
and feed the dogs without bending.  
Ninety one years old  
sixty years in the disheveled Tudor,  
I thought she might live forever  
or at least outlive me  
empowered by her obstinate grip  
and the rejection of help.  
I might well find her dead  
near the clothespins  
overshadowed by the prolific fig tree  
surrounded by a final ornamentation  
of lush persimmon globes,  
or was it best to pull her away  
let her die not as she wished?  
Conscience and community required  
that she be twisted  
from her shabby partner, as worn as she,  
a shared problematic plumbing,  
spare, shriveled walls, crumbling  
bones, and a crazed garden  
which expanded as she receded,  
faded and unhinged.

—Lynore G. Banchoff

## Afterward

All too often in the past ten years I've found myself sitting at the bedside of a loved one and watching, helpless as they have died. Not only has the experience altered my perception of that person (who doesn't want to remember a loved one as carefree, laughing and enjoying life rather than wasting away in a hospital bed?), but it has often led me to wonder the reasons why we let this happen.

Yes, it's universal to want to spend just one more moment with that special loved one, to keep them with us just one second longer.

When my father died suddenly and unexpectedly on an operating table a few years ago, I remember feeling cheated—not just out of another moment with him, but also of the chance to say good-bye. Ironically, he was having a kidney with a tumour on it removed. It was the desire to prolong his life that led to an instant death.

But on the flip side, is it any easier to watch someone die slowly and be given months, perhaps years of long and painful goodbyes?

Just a few months ago I was sitting at my mother-in-law's bedside as she passed away. And although it had been weeks since we'd been able to exchange any sort of meaningful communication, it

was at the moment of her death that I started to weep uncontrollably. Why did I weep then rather than at the moment our communication ended? Perhaps because there was always hope that we'd have that special connection again. We want to hang on. Apparently no matter what the cost.

I met my birth father (I had been adopted) shortly before he was diagnosed with cancer and suffered a slow and painful death. Ironically, I watched one father die slowly and lost the other one suddenly.

Despite my experience at having known what both are like, I still can't say which was the worst. While I didn't know my birth father for most of his life, I got to know him and the rest of my birth family as he slowly wasted away and died. It is certainly an intense way to get to know people.

I don't at all question the desire we have to hang tight onto a loved one and to care for them until the bitter end. Because there's always hope. But more than that—there's always love. And that never dies.

—Mark Leslie

THIS LITTLE LIGHT OF MINE:

## Dad's Vigil

What can I say to convince you  
sitting at the hospital every day  
is where I need to be

I know through all these weeks  
your mother is often barely  
aware I am there

I know you worry I'm wearing down  
how city driving tires me now  
how little time I take for myself

I know you fear for my heart  
since that day in Emergency  
one floor below

What can I say to convince you  
her respirator breathes not just for her  
the monitors trace not only her life-signs

What can I say to convince you  
my memory is talking to her  
my peace is our hands entwined  
my heart is her heart

—Ellen Bouchard Ryan



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Stream at Crook's Hollow, Greenville ON, CA

*"my memory is talking to her  
my peace is our hands entwined"*

## Filia

What can I say to convince you?  
This is what I need to do.

What can I say to convince you?  
He knows I'm there.

What can I say to prove  
I'll return to you?

I can only say,  
My heart is yours,  
But also part of his.  
So now,  
Give us leave to part in peace.

Nothing is what I should have to say,  
For you know  
Death will bring me back to you.

—Grace Stewart

## A Personal Book of Hope

Throughout my husband's long and insidious illness, I have come to appreciate, firsthand, the motto of Hamilton's St. Joseph's Hospital.<sup>5</sup> "It is an honour to serve the sick", it simply states.

Indeed, during the past five years, it has been my privilege to care for David throughout his relentless deterioration. Along with tremendous sorrow, David continues to fill my days with joy, my nights with thanksgiving, and my life with meaning.

Where is that written in all the depressing literature about Alzheimer's?<sup>6</sup> I vow that one day I will write about those moments which crop up to delight and console at the most unexpected times, those moments which serve to ease a great hurt. Perhaps I will quote excerpts from Our Personal Book of Hope, a sort of journal which I began in 1990. The first page reads:

*Dedicated, dear David, to you and to our abiding love.  
Yours, as ever, forever. M.*

Three such entries in my journal read:

*June 30, 1990*

*Today, we began the experimental drug program. Very hard for both of us. But when the program researcher asked you to write down any sentence, you wrote, "I love my wife" ... That made a hard day easier. Remember that sentence, Margaret, in the hard days ahead.*

*April 18, 1991*

*You try so hard to help me, honey. Last night, you offered to get me a drink. With your fragmenting memory you returned, holding two ice cubes only.*

*June 14, 1991*

*Today I asked David how long he has loved me. He looked at me solemnly and replied, "Oh honey, for eggs and eggs and eggs ..." I have loved you for ages too, honey, and always will.*

<sup>5</sup> Located in Hamilton, Ontario

<sup>6</sup> Today, it is my non-medical opinion that David's symptoms were more consistent with Lewey Body Dementia, a form of dementia similar to, but distinct from, Alzheimer disease. Parkinson-like symptoms and visual hallucinations are associated especially with Lewey Body Dementia. Happily, David's hallucinations always seemed pleasant. He often "saw" an infant and would warn me to be careful that I did not step on "the baby." David clearly appeared content and happy, even at these times.



In this journal, I also recorded encouraging excerpts from the literature on Alzheimer disease and many other sources. One passage that I found reassuring early in David's illness is from *The Loss of Self* by Donna Cohen and Carl Eisdorfer. It reads: *Alzheimer disease challenges the intimate bonds between human beings. For husbands and wives, though, the love may deepen. A special grace and beauty mark those who have learned to live with the disease and continue to find ways to enjoy each other.*

**Postscript:**

On Saturday January 15, 1994 at 11:20 p.m., time met eternity as David and I wrote the final chapter of this love story. Alzheimer and Parkinson diseases have fled, but our love remains.

This story is dedicated to other couples who are facing similar challenges and who are now writing their own love story.

—Margaret Pitkeathly

*"Along with tremendous sorrow, David continues to fill my days with joy, my nights with thanksgiving, and my life with meaning.."*



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Below Webster's Falls, Greenville ON, CA



## GRIT AND GRACE

*(This is) the language and a job description for the activities which consume a large part of our lives as caregivers. Their truth is a hard-earned, lived-into reality which resonates and enriches our own.*

—Anna Burack-Weiss, *The Caregiver's Tale* (p. 141).

Here are the voices of those who do what needs to be done with grace and style, and grit and determination. Stroke, dementia, the challenges presented by orphaned grandchildren and developmental delays, heart-stopping diagnoses, and debilitating chronic illness—these are only the starting places. What lingers is a sense of the precious that these storytellers create with their telling.

- It's hard to see past the grinding routine in Santoro's *A Step Away From Heaven*, or the crushing responsibilities in Ince's *Lunacy* and Banchoff's *The Other Daughter*, but listen to the poetry these writers create out of drudging reality.
- Let yourself get caught up in the frantic pace Geary sets to capture the sense of crisis that opens *Listen, One More Time*, and catch your breath at the way that Preda closes the circle of life in *The Healing of My Soul*.
- Consider the grace notes in the way Aylott survives her caregiving responsibilities in *Loving Hearts*, and the hard-won insight Gottesman gains in *Milestones*.
- There is a special grace in the laughter created by Cameron's wife in *Wigged Out* and Ryan's uncle in *That Man*, and in the gentle humor used by Reichental to describe her creative problem-solving in *When Three Makes Company*.
- Fasten your seatbelt before you ride the rollercoaster of medical developments that Baker and her family take in *News About Tori*. Or dive into the rollicking humor produced by the antics of the family in Edey's *The Words the Cat Took*. In both, you will experience the grace to be found in the gritty places.



## Loving Hearts

Alzheimer Disease is very devastating both to the person who has it and the family who is caregiving.

My mother passed away December 23, 1996, and I still miss her very much. I cannot believe that I was meant to experience this disease in vain. The initial reaction of some people might be to want to forget as quickly as possible, even deny the fact that this disease was part of their life. Yet, this disease is real and affects many in the family outside the afflicted. I had great difficulty resuming my regular life which had been put on hold during my caregiving days. This disease had completely consumed every waking minute. To make sense of what I went through, I write and pass on, in any way I can, how I coped while my mother was ill and for a period after her passing.

I had always said I would care for my mother in her old age. The time came when she was obviously not able to cope with everyday living. I told her it was time after she lost her purse in her kitchen. In the beginning she was really happy to know that she would be living with us. But, moving day was not the happy one it should have been as Mother did not understand what was happening. This was the beginning of the very hard road I would travel.

The last couple of years when the disease took over the person I knew as my mother, it was extremely hard to understand what was happening to her. This self-confident, independent, well dressed and all knowing person became unrecognizable. As the brain cells deteriorated the personality kept changing. It was helpful to learn about the disease so that I could understand what was happening even though I suffered extreme heartache and confusion. I knew I was not the only one dealing with this but it was still a lonely existence. It did help to remember, "This too will change" when a new personality emerged. It really tried my patience and sometimes I felt I could not possibly put in another minute. I would argue with the new personality and try to make it understand and wonder who has the problem here.

Sundowning, which is a personality change occurring in the late afternoon, was especially hard. At these times Mom would want me to call Dad, who had been dead for fifteen years, to come and get her right after work. She let me know emphatically he had no business leaving her with us. I would spend time going to the phone and pretending to call, and because her memory was not longer than ten minutes, I made many

trips. We laughed when my spouse said “what if I go on the extension and tell her I am Ernie (my dad) and she is to listen to us and just wait until I get there”.

Sometimes yelling, sometimes calling for help when the phone rang, I had to explain, more than once, that we were not holding my mom against her will and that she had Alzheimer disease. The brief periods of making sense were the scariest of all; they really threw me for a loop. Repetitive phrases were also hard to cope with. She would always want to go home and at first I thought she meant her apartment but realized later that it was Ireland, where she was raised, especially after she began to say her mommy and daddy would be mad. She made a habit of putting on two sweaters, two jackets, winter boots and coat in April and sitting in the front room waiting to be picked up. The clothes in her closet were bundled up and brought to the front room daily. I would hang them back up and down they would come again all bundled up. I tried to stop her to no avail and she would come at me if I even touched them. This went on for a few days until I regained my sanity and thought, ah ha, I will hide most of her clothes and leave just a few. For a while she accused me of stealing her things, then forgot about them.

I tried to find things to occupy her like straightening out my button and thread box. She did it so fast that I got stuck for things for her to do. She liked doing dishes and knew they had to be done, only she did not realize that the soap had to go in. If I went near her to help she would yell at me so I had to let her do them and just take them out later and redo them.

Not everyone has a volatile person to care take. I listened to stories of people who were caring for really docile and friendly loved ones and oh, how I wished that was my case.

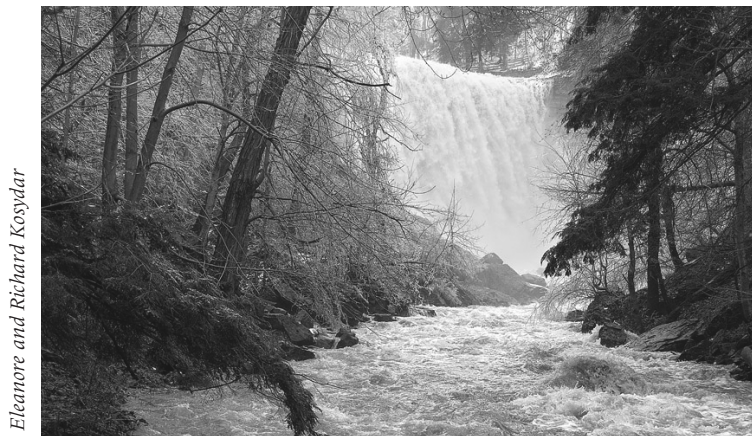
I had been put in touch with the Alzheimer Society by this time and what a blessing that was. I would call the support people just to be able to say how I was feeling and vent my anxieties. These angels taught me about the disease and ways of coping. I went to a caregivers’ support group and met others who were in my situation. I went out and talked, showed movies on the disease and told some of my story. I saw the nodding heads and the knowing smiles. They knew there was life after caregiving and hope while they were going through it and perhaps for the first time, knew they were not alone.

It has been eleven years now since my Mother passed away and she left me a

legacy to write. Through writing and volunteering, I spread the word of hope to whoever needs it. I needed and received it so I am giving back what was so freely given by loving and understanding hearts called the Alzheimer Society of Thunder Bay, Ontario.

—Patricia Aylott

*“Not everyone has a volatile person to care-take...  
oh, how I wished that was my case.”*



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Webster's Falls, Greenville ON, CA

**A Foreword to *Lunacy***

.....

The crisis of the AIDS epidemic in Africa prompts many different reactions worldwide, from the major organizational work of the Stephen Lewis Foundation in advocating, supporting, fundraising, to the groundbreaking book by Stephanie Nolen, 28: *Stories of AIDS in Africa*, where she puts a personal face on the overwhelming statistics of the epidemic.

Some Canadian grandmothers banded together to form the Grandmothers to Grandmothers Campaign; they raise funds for and awareness of the plight of African grandmothers raising their orphaned grandchildren. And some young mothers, like Marika Ince in the beautifully felt poem to follow, make the imaginative leap into the heart of a grandmother. The huge scale of unimaginable devastation spread across a continent is beyond imagining.

By entering the heart of one grandmother as she dreams of her family, in Canada and in Africa, Marika draws our imagination into the centre of the family, source of healing and support.

—Lisbie Rae

Grandmothers of Steel  
Hamilton ON, CA  
part of the Grandmothers to Grandmothers  
Campaign

.....



## Lunacy

I lean into the pane  
search the night sky  
The moon is full and bright  
much as my life has been

I am a grandmother now  
I wait for Sunday visits and invest in RESP's  
wonder who they will become and what they will do with their lives  
just as I wondered about their parents when they were my babies

I gaze on ancient craters  
Sea of Serenity, Sea of Tranquility  
Bay of Rainbows, Lake of Dreams  
Memories dance across her radiance  
first steps, first words, first days at school  
Graduations, celebrations,  
Just enough loss and sorrow to enrich the joys and pleasures  
Tides of life

The children I love return with children of their own  
I shower them with treats and trinkets  
travel and opportunities  
There is so much I can do  
for them

I gaze on ancient craters  
Sea of Crises, Ocean of Storms  
Marsh of Decay, Lake of Death  
The story of another grandmother surfaces  
sails across her shadow scarred face  
carries me to the dark side

THIS LITTLE LIGHT OF MINE:

You too, became a mother  
gave life  
Felt it flow in the clasp of tiny fingers  
Under the same silent witness you lived simple joys  
first steps, first words  
Proudly watched them walk to school  
uniforms, pencils, books and fees  
paid for with chickens  
Each morning brought hope  
brighter than the rising African sun  
Their lives would be better than yours

Some fell in love and married  
Others paired off and on  
More little fingers and toes

Then came Slim.

Natural order  
overturned.

Now you hold their hands  
Wrap your own fingers around those too weak to curl  
Feel life ebb

as one by one  
the children you bore step past you  
beyond life

The day comes when your last child, your youngest daughter  
mother of three  
lies on a straw mat and  
you promise her what you have promised the others  
Each word torn from your heart  
reverberates in the enveloping emptiness

The chickens are long gone.

Grief and loss  
Shame and fear  
Will not pay for uniforms  
pencils, books or fees

Neither will prayers  
nor curses  
feed their bellies

The moon brings only cycles of loss  
Her shining face shrouded in death  
You should be sitting under the shade of a baobab tree  
Your grandchildren laughing at your feet  
their mouths and hands sticky with sweet mango juice  
expectant faces turned towards you in hopes of another story, another song.  
Instead you sit only when it is too dark to move  
when her light is gone and your legs are swollen with weariness and work

A tragedy intensified because  
you are not alone  
because there are too many children  
too many orphaned grandmothers

You are not alone

I step back from the pane  
wonder why  
a moon so full and bright  
does not fall from the sky

—Marika Ince

## Listen, One More Time

When the doctor arrived, we had her lying propped up among the pillows on her special daybed. We were in a panic, her voice coming in tiny rasps. Seeing the fear in her eyes, watching her trying to breathe, for god-sakes, through her closed-up throat and out from behind her small stash of prescribed pain-killers for rheumatoid arthritis, we could hardly breathe ourselves.

Her longtime doctor friend carried a black leather satchel as he came through the back door. Stethoscope hanging barely inside. And boxes of little grey pain pills. Through the kitchen. Swish. Somebody ahead of him, through the dog-leg hallway into the dining room, then through to the living room. He knew the way without our help.

She needed to be downstairs again to be looked after by Father, she had said, and had asked several weeks before to have her special motorized bed hauled down. The doctor dropped his coat into the gunmetal-blue lady's chair beside her and looked sadly at our mother.

There she was, looking straight up, the ceilings 10 feet high, the drapes an ornamental sateen of the same gunmetal blue as the chair, morgue-like. Perhaps she sensed she was lying in state, an ironic comment on her inner chaos amidst the prim Victorian furnishings. Like most small town royalty, she was terribly bright, but almost entirely self-educated and proud of it.

"Well, well, what have we this time, my dear people?"

My sister had already told him over the phone. Ann, long-winded getting the details right, stumbling with the emergency of it all, trying to sound authoritative, doing a take-charge, to-hell-with-the-delicacies, brow-beater of a call. The sort of dramatic flurry that Father could never quite manage with the white-collar crowd, doctors or lawyers. Obviously not. He simply hung up when offered the chance to call again on Monday.

But Ann working the phone, bouncing that furious bundle of our mother's over-taxed energy off her own tongue, squeezing it through the unreliable conduit of phone receiver, telephone lines, County call-station, into the doctor's one good ear, and out through the pen in his other hand. In my mind, that call was an absolute miracle.

So the doctor had quickly driven up the hill to our parents' home. But now he was glancing down with a growing look of regret at this chronic case, perhaps pondering the benefits to the family if the short cure was death. "You won't make it through the night, my dear, if you can't stop being so neurotic." He smiled at his joke. A remarkable bedside manner. One that should empty graves and send corpses out to look for marching bands and clowns. Yet he had been through this mortality routine

many times; she had been practicing it on him for more than 30 years.

The rest of the family went out to the kitchen to discuss how my mother would meet her end. Ann crying. My mother looking at me. "Goodbye, goodbye," she suddenly mouthed, unvoiced but for the rasp-words I was not prepared to hear from her. I wasn't up to speed on her gradual decline, being the adult daughter who had lived out of town until now. This seemed a new twist in the drama.

I let go of her shoulder. "Wait," I said, and left her briefly to join the others.

"Ann, she is saying goodbye. What else should we do? Maybe the hospital?" Abruptly, Ann, fired up for another go, collared the doctor. Less loudly this time, but still he had to say it, "Nothing anyone in any hospital can do for her now. It's just about over. It's her time. She's playing her last hand."

"Nope, nope!" Ann banged on the kitchen table. "Let's get her to the hospital, at least one last try. You phone them to get her admitted; you're the doctor; we'll get the ambulance; they'll have oxygen; call now!"

The doctor, looking slightly less argumentative, knew denial when he saw it. The lunatic rant of family guilt, neglect or worse. The hope of the medically naïve. The waste of time and energy when death was sure

and imminent. This was a doctor who had been through war and known death at its worst. Not something timely like this.

But Ann steamed ahead, dialed the operator and exploded, "Emergency, quick!" She slammed the phone into the doc's hand and banged out the door. "I'll use the neighbour's phone to get the ambulance."

The doctor sighed. An ambulance would be coming, no doubt a few minutes sooner than death. He easily found his way through hospital protocols, finagled a deal with somebody, and got Mom on their admit list. His end of the lingo sounded official enough to us. We relaxed slightly, let him hang up.

Now we could only wait for the ambulance, tell Mom of her coming deliverance, breathe for her if we possibly could, or at least will her to stay low and not strain for air.

Small town goodness, the ambulance arrived in under ten minutes. A pair of matching paramedics, young, click-clicking out of the van with a stretcher. "No, go around to the front door. You'll have to turn the ambulance around. Can't get this through the dog-leg hallway." Suddenly, trance-like, time was just dragging now.

They hauled her through the yew trees, past the Japanese maple, and the junipers surrounding the Victorian verandah. "Not today, not today," my heart kept

bleating. Finally, she was in. I squeezed into the ambulance behind Mom's stretcher. No problem, they said.

Ann drove Father to Hamilton, full of impatience in her small car as they chased behind the ambulance. Ann, always thinking, truly projecting a yet-alive mother into the hands of her next saviours. Father and I just passengers in separate vehicles, just riding, numb, refusing to be anywhere, not in, not out of our heads.

Wondrously, the next day we heard from Mom in critical care. They told her she had been twenty minutes from brain dead. Too little oxygen. She had been lucky.

Now she had a team of specialists in rheumatoid arthritis paying attention. She was encouraged to give her life history, the life of a long disease. She had student doctors soothing her, happy for her narrow escape, listening, taking notes. But the senior team determined she had an enemy greater than just arthritis - she had osteoporosis too.

So she became a more-than-willing case-load. She would stay in touch after she got home, she promised. But she could be with them perhaps six weeks, maybe more, really getting to know her team, making new allies, new colleagues in understanding her disease, even acting as a minor celebrity on the ward, if need be!

After all, she had been doing her own research for years, trying out diet cures,

water cures, California miracle cures, wind-up beds, and health-food-store vitamins; and oh, yes, the little grey pain pills that her own dad had taken after the war, something she still preferred for her own pain. But here she was, now, in the best, newest hospital in Canada at the time, if not in all of America.

Mom speedily returned to chronic normalcy. Pain that she knew well, nothing new to fear. She finally came home, pleased with herself. Home for roughly another decade and a half of celebrating her success at staying alive, and home for a few binges of local hospital hopping. And for more research into chronic pain and arthritis. For reading preventive health journals. For writing to governments about chlorine and fluorides in the water. For challenging the pesticide companies for what she felt were their contributions to asthma. For bullying the department of highways into getting proper signage at a dangerous corner, because somebody died there needlessly.

And she lived to meet all three of her grandchildren, latecomers that they were, and thought them beautiful, but often beyond her comfort zone for lengthy visits. She preferred to write letters. Talk on the phone endlessly. She even managed to write a letter to world-renowned physicist Stephen Hawking, to advise him of what she thought might work for his chronic disease. In her waste basket, we frequently

saw envelopes from alternative-medicine research teams addressed to Dr. K. Geary. She had only a grade 10 diploma in book-keeping and typing. But she made it her later life's work to look for ways to help those with chronic disease find comfort and prevention where possible. She was a leader in alternate medical thinking.

She was back in charge of her own itinerary. When I had the opportunity to drive to Lake Louise in the summer of 1989 to visit then-teenage daughter Elanor sling-ing meals at the Chateau, Mom put herself into hospital for one of her rests, "Just until you get back," she said. But this time the wolf was at her door, big time. She had quit her old doctor. And her new doctor decided that in all fairness to our dad, Mom had to stop making her frequent in-and-out-of-hospital holiday junkets. She needed a better plan. So this doctor refused to let her out this time until we had secured a permanent nursing-home residence. Unhappily, we did so.

The home we chose had a fine reputation for its day. However, there were times we became alarmed at her constant bruising. Alarmed at the way she kept howling, telling us about the voices coming in through the ceilings and walls.

We finally were able to move her into palliative care at a local hospital. Less doped and taking extra vitamin supplements (which she had me sneak in to her), she managed another few months of what

was becoming osteoporosis torture. She dreamed of getting well. But her muscles were sagging more and more, and the nurses were not pleased with the strange vitamin capsules they found in her locker. I could see she was swallowing them less and less easily, afraid they could eventually choke her to death. Finally, I stopped supplying them. She let go of trying. She said goodbye again April 10, 1990, and this time she meant it.

What I learned from that period of caregiving was threefold:

1. I learned a new respect for my parents' intelligence and their perseverance in learning about themselves and their needs as they aged.
2. I learned that in the world of medicine a good team that listens can do what a non-listening approach to medicine will never be able to accomplish.
3. And finally, although Mom is no longer here to make it happen, I learned that orthomolecular medicine combined with disease prevention may someday catch up with my mother.

Living past 80 may even become a pretty sweet piece of birthday cake, if all the right professional team players are finally in place, if families become educated beforehand about their actual responsibilities, and if we all can stop living in mortal fear of aging.

—Linda Lee Geary

## Wigged Out

Lynne lost all her hair after radiotherapy. She wanted to get a wig so we followed the contact address. It was in a joke shop!

Can you imagine the trauma of cancer treatment to be followed by getting a wig in a joke shop? We went in, surrounded by gorilla masks, little ballet outfits and a host of other joke items. By this time we were past wondering when a bright and breezy lady took Lynne by the hand, gave her a big hug, and took us through to a little room stacked floor to ceiling with wigs and hairpieces.

After five minutes we were all laughing and giggling as Lynne tried on the most outrageous wigs of all colours and styles. How we laughed, people kept coming in to see what was happening.

Things calmed down then and we began the more serious business of actually trying on some wigs.

You know what was amazing? Lynne was really excited as she could choose any colour—she had no hair of any description. That started off the laughter again, and finally, she made her choice and left the shop proudly wearing her wig to the applause of the shop assistants who had not met a person so determined to bring laughter and fun to what could have been an emotional occasion, particularly for any woman in such a position.

Lynne died after a four year fight with breast cancer but I won't forget the glorious time we had together in the joke shop.

—Peter Cameron



## That Man

Uncle Maurice was grateful to talk during my long-awaited visit. It was our first real conversation, as my mom and Aunt Yvette had always held the floor in family visits over the years.

The week before, he had helped settle Aunt Yvette in the nursing home. Due to the decline in his own health, doctors had urged him for months to make this change for his wife. Acknowledged by all as my smartest relative, Aunt Yvette was now almost speechless with mid-stage Alzheimer's Disease.

Before driving the short distance to the nursing home, we sat down for a cup of coffee. During this time, Uncle Maurice regaled me with anecdotes about That Man.

In the evenings, Yvette often enjoyed sitting with Maurice to look through the photo album from their recent 50th wedding anniversary celebrated with their three children and five grandchildren. Sometimes, she wistfully pointed at him in several of the photos, uttering "That man, That man."

Early one sunlit morning Maurice met Yvette on the stairs. He asked her why she was carrying his suit from their anniversary party down to the basement. In response to his startled inquiry, she said, "That man is not coming back."

Summer ending, time came to put away the patio furniture. Maurice left Yvette

in the kitchen as he went through the patio doors to begin the task. She watched with interest as he carried chairs and tables to the garage in several trips, returning to the kitchen from the garage when finished. Yvette became anxious, beginning to wave wildly. At last, it dawned on him what was needed—he must deal with That Man, who, in her mind, was still outside. He went out through the garage, so that he could come back through the same door through which he had originally gone outdoors. When he re-entered the kitchen from the patio with 'job-well-done' satisfaction, Yvette was greatly relieved to see him.

In September Maurice set up for an afternoon in the kitchen to please Yvette, even though he never eats dessert. They worked together cutting apples and preparing pastry. They left the warm pie in its cinnamon cloud on the counter. Upon their return from an afternoon outing, she exclaimed with joy, "Look at what That Man left for us!"

Uncle Maurice had learned over time not to take these instances too personally. After all, Aunt Yvette was sometimes frightened by her own face in the mirror. Telling these stories to caring listeners helped him to see the humour in his everyday circumstances.

—Ellen Bouchard Ryan

## News About Tori

Dear Friends,

I've been thinking about this letter since Tori turned three on July 19 of last year! At that time I thought: I really ought to send out a birthday photo and Tori's news. It didn't happen. Then Tori started going to school on a bus, and I thought: I really ought to send out a school pic and some news about Tori. It didn't happen. I did, however, manage to send out just a photo of her at Thanksgiving. Good for me! But still, there was NO NEWS. Then Hallowe'en came, and again I thought: I must send a picture of her costume along with SOME NEWS. It didn't happen, etc., etc., etc.

I have finally decided my avoidance of NEWS has really got to do with the tricky business of explaining how Tori is doing without sounding like we're feeling sorry for ourselves or unhappy in our new-ish lives as parents. And so I will preface Tori's story by saying how every day we are blessed by her presence and how she makes us very happy, even with the challenges.

She is growing prettier every day, and if I may be allowed to be a totally biased mom for a moment, there are many times in a day when I am stunned by the beauty of her facial features. (We aren't supposed to brag about our kids' looks, but I do it quite regularly.) She is also

continuing to show her talent for music. Tori is really just beginning to come into her own. As I said to a friend recently, "She is a great mystery who is gradually revealing herself."

(For example, as I write this it is after 10 p.m. and she's hollering politely to me from her upstairs bedroom, where just last week she was moved into a "big girl bed." I have already been up there once in answer to many earlier calls, only to find that she'd managed to pull her oxygen prongs off her face—we tape them on each night—and she's lying there smiling at me... I tape them back on, tuck her in, start her night-night CD, and get back to the computer. Minutes later she's "singing" for me again! Let's just say her "attitude" is developing quite nicely.)

Most of you are too far away for us to see regularly, but we're glad to be able to stay in touch via cyberspace. The last time I wrote was one year ago, a few months after we'd learned that Tori had epilepsy and was adapting to an anti-seizure medication. Her eyes had just been successfully operated on to give her new lenses (having had cataracts removed at two weeks of age) and she was about to get ear tubes. On the eye issue, Tori's ophthalmologist is very happy with how her eyes have developed. As for the ears, Tori's last set of ear tubes

have fallen out and she won't need them again. All very good.

However, the epilepsy situation is not so great. Tori has only developed a little bit beyond where she was a year ago, and is still very much like a ten-month old in her babbling and daily care. She is stronger and holds her head up better when we carry her around (oh, and she's almost 40 pounds now!) and at times she is more vocal than she ever used to be. She is also connecting better with her eyes, that is to say she appears to actually notice some things that she wouldn't notice before. Her laughter (smiles and belly laughs) has increased—and when she laughs she is extra CUTE CUTE CUTE.

Tori still doesn't have the cognitive connections to enable her to roll over or sit up on her own. She will sit quite nicely in your lap, however. Sometimes she'll do something just once, and never repeat it or not repeat it for a very long time. For example, recently at school she did sit up for five minutes on her own, leaning forward on her hands. She will likely do this again one day, but it's unclear if she will ever be able to get herself from lying to sitting. Before the epilepsy, from about five months of age to a year, she used to roll over both ways and grab and hold her toys very well. To date she is still unable to hold onto ob-

jects. Luckily what she really loves is to play her various pianos, which she only has to hit! She is also very keen on Baby Einstein DVDs, so we bought a small player for her wheelchair tray so she can view the DVDs up close. It's hilarious to watch her sometimes as she "talks" to the program or laughs her head off at some puppet or other. Speaking of puppets, just recently we began using "Ernie and Bert" puppets with her, and to see her react to them like they're little people is very funny. Today she actually seemed to be having a conversation with Ernie. I laughed and laughed.

Tori is officially in a wheelchair, and we officially have a van and house with a ramp now, and signs on the street for disabled parking, and where we live, THIS is a DEFINITE bonus! Parking is often at a premium.

One of the big changes was when Tori started morning preschool at John Dolan, a school for about thirty exceptional children from age three (Tori) to age 22. It is a fantastic place, where Tori and her eight classmates share an excellent teacher and three teacher-assistants. The principal and everyone we've met there are amazing people and we are SO LUCKY to have them. They love Tori and all their students so much. One of the things she loves is going to the "Snoezelen Room" two times a week. It

is a huge darkened room full of stimulating light-sound games.

Recently Tori and a fellow student were chosen to represent their school on Telemiracle, the Kinsmen's annual provincially televised fundraiser. Two teachers helped them to cross the stage to present a cheque for the money they'd raised. It was the first time in the long history of Telemiracle that anyone from John Dolan had been on the show. Art and I were in the audience, bursting our buttons. Unfortunately Tori was a little fatigued for the cameras. The next day it turned out she had pneumonia! Considering how sick she'd been, she did so well up there.

We don't know how long Tori will go to John Dolan. We are hopeful that she'll still develop in such a way that she can be integrated into a typical school. If the epilepsy has just caused an interruption in her development, then maybe she can catch up somewhat to other children with Down syndrome. But if, in fact, the epilepsy has damaged her brain, well then, she may never walk and her speech may be limited. Like I said, she is a great mystery and we have learned how important it is to take it one day at a time.

Our most recent experiences with Tori's health have involved the aforemen-

tioned pneumonia. Tori had actually been doing so well in staying out of the hospital. She had a brief bout of it in November, 2005, and then went for fourteen months without any hospital visits. However, since this past December 28 she has been in hospital for three pneumonias, and the first time it was combined with another respiratory infection called RSV. She got out from the last bout on April 5. We are so grateful for the terrific pediatric doctors and nurses we have here. We are getting to know them quite well.

(In the space of three months we spent almost a month of days in the hospital. Art and I have "shift work" down to a science now. So, if you haven't heard from us lately, well, it's because we're desperately trying to catch up on making a living!!)

I mentioned the oxygen earlier -- this was one of the bonuses of being in the hospital the second time. An apnea test was done and it was determined Tori could probably benefit from night oxygen. Sure enough we saw some remarkable changes in her alertness and personality once she got enough of it at night. We will be going to Edmonton sometime in the next few months to have a more thorough apnea test done for her.

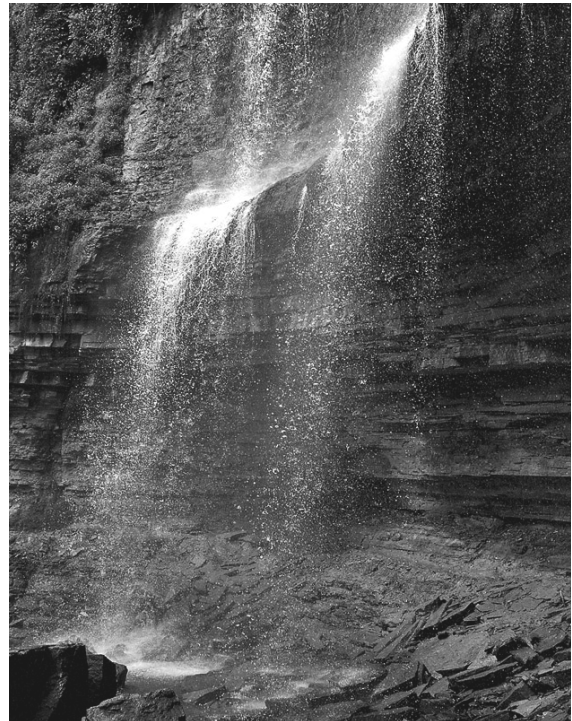
One of our great joys is singing to Tori. She seems to remember songs and has her favourites. For example, at Christmas she couldn't get enough of "Deck the Halls"—especially the "falalala" parts. "Rudolf" was also a big hit. Right now she just loves "Waltzing with Bears"—sometimes she even laughs on the lines that are funny! Go figure.

Thanks for your interest in Tori. Hope you have a great spring and summer.

—Brenda Baker

*"And so I will preface Tori's story by saying how every day we are blessed by her presence and how she makes us very happy, even with the challenges."*

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Webster's Falls, Greensville ON, CA

## When Three Makes Company

I read somewhere that more than half of China's elderly people would rather live alone than with their children. According to the results, the traditional ideal of family life in China—with up to four generations living under one roof—appears to be disintegrating. In North America, the statistics seem to reflect a similar trend. I unfortunately could not find any accurate statistics on the number of grown children taking in their elderly parents into their homes. Could it be that these exceptional adult children who are willing to take in a parent and offer them an alternative to a senior residence or worse are keeping quiet out of fear? We after all remember poor misunderstood Norman in "Psycho" and what became of his efforts to harbor a parent. No wonder this group isn't speaking out. Until now...

How come we don't see more elderly parents living with their adult children, I mean of course if they would like to and the conditions are convenient for everyone concerned? For those of us who are 40 or older, we belong to a new generation of caregivers, sometimes referred to as the "Sandwich Generation" or if you are like me and your family is food oriented, the "Let Me Make You a Sandwich Generation!?" Either way it represents adult children feeling squeezed between the needs of an aging parent and their

own personal needs. You see I am said "sandwich" filled with guilt and peppered with conflicting loyalties.

I find myself in the precarious position of attempting to please my husband (best described as Darren on "Bewitched"). Remember his sardonic enthusiasm for his mother-in-law? And then, there's my mom—a hybrid of a sweet "Mr. Magoo" one minute and the fiery tongued Sophia ("Ma") character from the "Golden Girls" the next. At times I find both relationships quite challenging. Who comes first, the husband, who you vowed to honor and obey (well, ok, that one is a bit of a stretch, more like listen to occasionally) or the parent who brought you life? Upon my father's death, I have admittedly developed a more over protective relationship with my mom. I find myself just wishing we could all live like they did in the show "The Waltons". Here nestled in the far foothills of the Blue Ridge Mountains, (most probably so no one could hear them yelling at each other), a household of grandparents, parents and several children, lived under one roof and spent their dinners around a long wooden table serving up heaping loving spoonfuls of mashed potatoes and wisdom.

In order to create my own version of such collective harmony in the home, rather than have my mom move in full time, which she really does not want to

do, much to my ecstatically relieved husband, I have come up with a temporary compromise. I invite my mom over for weekend sleepovers, holidays and whenever I can swing days off from work. The once called "Guest Room" is now secretly and especially when not in earshot of my husband called "My Mom's Room". It's definitely an adjustment when we have her over. Whether it's adjusting the TV to a volume that she can hear as well as several houses two streets over, or adjusting the thermostat to warmer in the winter, and warmer still in the summer, because my mom does not like air conditioning, adjusting our lives when she is over is what we do.

Simply put I would not have it any other way. I welcome my mom's company and cherish this time we spend together. My mom, husband and I, have fused into a familiar threesome appearing at various venues like movies, malls, restaurants and even resorts! This situation may be far from ideal, we do after all get on each others nerves. But the bottom line is that we can offer my mom a change in scenery and change to her routine. And if this means a change in ours, then so be it! And to borrow a title from my mom's favorite funny movie, you won't see me "Throw mama from the train" any time soon ...I can't speak for my husband though.

—Wendy Shade Reichental

*"You see, I am said 'sandwich' filled with guilt and peppered with conflicting loyalties."*



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Sulphur Creek in Ancaster ON, CA

THIS LITTLE LIGHT OF MINE:

## A Step Away From Heaven

"Christy. Christy! Christy!!"

He calls my name again.

"What? What do you need?"

"Did you give me my pain pill?" he asks.

"Yes, Uncle Joe. I just gave it to you five minutes ago."

"OK. Thanks hon."

I take a deep breath. Remind myself how much I love this man although he is driving me crazy.

I try to get him to talk with me about the old days. A task that at one time was not a chore.

"I'm too tired" he replies. "The news is on. You've waited too long to ask me."

I tell him once again that I want to preserve his tales on tape for my children.

A momentary spark glimmers in his typically sullen eyes.

"I'll have to cut out the X-rated parts," he teases.

He'll talk for five minutes and then ask for a drink.

When I return with the ginger ale the news is on and I know there will be no more talking tonight.

"You going to be here for Seinfeld?" he asks me.

"Of course."

I try my hardest not to miss our evening ritual. The 7:30 Seinfeld episode on FOX.

Our nights are divided into two parts.

pre-Seinfeld.

post-Seinfeld.

No matter the storyline our conversations remain the same.

"Got the right channel on Uncle Joe?"

"Why certainly!"

"That Kramer, he makes the show."

"George is such a cheap bastard."

"Good."

A month ago the show often drew true laughter from my Uncle, but now that he is down to 140 pounds and his back hurts he tries not to laugh. Tonight is Thursday and that pleases Uncle Joe because it is a double Seinfeld night. The closing credits of the early show prompt my uncle to ask for his '8 o'clock coumadin'.

"How many tonight, Chris?"



“Just one, open up.”

I plop the pill into his mouth and stick the straw in so he can swallow it down  
with cold spring water.

He always knows when it isn't spring water.

He always wants it cold but never wants any ice.

“Back at nine, tonight's double Seinfeld!”

Of course.

Nine o'clock comes quickly and I return to the room, this time with the bedtime  
pills.

“Do you want any more to eat before you take your sleeping pill?”

“No.”

“Are you sure?”

“Yeah.”

(A month ago, I would be upstairs and hear him moving around on his own.

I find him in the kitchen shoving donuts, or salami in his face.

uh-oh.

I tell him he shouldn't eat after he takes his bedtime pills because he will get  
indigestion and not sleep well.

I tell myself that when he doesn't sleep well, I am certain not to sleep at all.

He makes a face and grunts

“Your poor sick uncle weighs 150 lbs and you won't let him eat half a sandwich.”

I start to explain to him that he is eating more than he has in the last three  
years, but cut myself short.

He will hear and believe what he wants.)

I explain each pill to him, what it is for, how many times a day he takes it.

He used to refuse to take anything without this litany but more often now he says,

“I'll do whatever you say, you're in charge now.”

I drop the pills into his awaiting mouth like the mama bird feeding worms to  
her young in the nest.

After several attempts the pills all go down.

He is crooked and slouched down on the mattress.

“Ready to straighten up?”

“OK.”

I lower the hospital bed to a flat position and take hold under his armpits.

“You have to help me Uncle Joe.”

THIS LITTLE LIGHT OF MINE:

One

Two

Three

AGHHH!"

"Good. It's a good thing we have strong women in this family.

Fix the pillow."

Stay strong, I tell myself.

"OK. Thanks hon. See you at ten for my pain pill."

Last month my dad and my uncle had a fight.

"Your father tells me I'm a dope addict, you think I don't know that?"

His cardiologist got him addicted to Percoset. Kept giving him more and more  
without thinking of the consequences.

We finally got him off that, and now he takes a non-narcotic pain medication  
Ultram.

Even as Uncle Joe's memory slips, he never forgets to ask for Ultram.

He never has trouble swallowing that magic pill.

It's 10:05 and the pharmacy is closed for the night.

Kisses are exchanged and I set the timer on the TV.

"Call if you need me."

I have an intercom upstairs but I don't really need it.

His moaning seeps through the ceiling and I feel it in my heart.

He is sleeping better now thank God.

Just an occasional Tylenol, emptying of the piss in his urine bottle.

Each night I pray that he won't call me down in a half-alive, half-dead state like he  
did that one night.

As I was fixing his pillow he grabbed my arm (although he is weak all over his  
grip is surprisingly strong) and said,

"You're so beautiful Chris, I hate to leave you."

You're not going anywhere Uncle Joe; you are here in your room, a step away  
from heaven.

or the night he was in so much pain and wanted me to make it stop and I  
couldn't and he cried,

"I think you should put me in that home, Regina. I'm too much trouble for  
everyone,

they'll treat me good there."

This from the man that only a month before cursed all nursing homes and  
declared he would never go.

But then there are the good times  
baking homemade bread  
storytelling  
eating polenta  
watching him talk in his sleep,  
march in his sleep,  
reach for his wife in his sleep, in peace.

How do you live with a man who wants to die?  
What can you do to make him want to get out of bed?  
and  
Why can't you know how much longer he has to live?  
I want to tell him that this is hard for me too, hard for everyone.  
You are not the only one in pain.  
But I know that would be selfish, a momentary release for me and a haunting  
reminder to him that he is a 'burden'  
Plus he warned me when I asked to live with him.  
He told me that the nights are bad.  
In sleep and near sleep the old are closest to death.  
He sees the light, but for some reason does not move toward it.  
Is he going to die soon? If I knew I would let him lie in bed and revel in his  
state of resignation.  
His soul and spirit seem all but dead, but the many deficiencies in his health  
do not add up to terminal illness,  
just constant pain and suffering.  
"Lord help me. Why are you punishing me?"  
he cries as he walks the narrow passage from his bed to the dining room.  
Though he is six feet tall he looks so small, hunched over, afraid he might fall.  
I forget how bad he looks.  
I am desensitized to the fact that he looks like a living corpse.  
The man that looked like a suave movie star in his youth could not star in a movie  
about survivors of the Holocaust.  
I pick up pictures from Christmas this year and am taken aback as his face  
glares up from the photo.

THIS LITTLE LIGHT OF MINE:

Let me leave this place, his eyes cry.  
This was his expression, on Christmas morning, after I asked him to smile.  
How can I ask anything of this man?  
He has lived his life,  
never claiming to do anything but treat people kindly,  
bet on the horses,  
caddy,  
build some roads,  
share his stories,  
fight with Mame,  
cook great bread,  
help raise my dad and uncle, but not try to replace their father,  
lay train tracks,  
walk the dogs,  
sell 50-50 tickets,  
bet on anything,  
venture the high seas in the merchant marines,  
learn that World War II wasn't about patriotism but watching your buddies die  
    around you,  
mangia,  
give out envelopes to the kids on their birthdays and Christmas,  
pray to the Blessed Mother,  
love my aunt purely.  
He tells me as I am in search of a job, for direction  
"Remember, your old uncle never had any purpose in life.  
I was like a leaf floating down a stream.  
I went wherever the current flowed."  
But now I must witness the end of that stream,  
the water of your life evaporates each day as you drift toward the end of your  
    time with us.  
I try to smile around you as much as I can.  
Shower you with kisses, keep the tears to myself.  
I want you to remember me smiling and laughing with you,  
just as I will remember your dancing eyes and the timbre of your voice  
while you are telling me your stories.

—Christy Santoro

## The Healing of My Soul

The years have gone and now, you are gone too.  
Our mutual heartache and pain  
suffered no boundaries  
today seems utterly devoid of reason;  
so much anger  
so many years  
squandered in a maze of futile struggles  
unable to escape the labyrinth of differences;  
yet, before life had run its course  
we salvaged our mother-daughter relationship  
savoured a minute degree of mutual respect.

You brought me into this world gave life  
I cradled you as you left it gave peace  
our bond sealed for eternity in your death.

—Stella Mazur Preda

*“so many years / squandered in a maze of futile struggles.”*



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Midreaches of Spencer Gorge, Greenville ON, CA

## Milestones

Becoming a caregiver personally has been part of my evolution out of narcissism into a state of empathic concern for others.

The deaths of my parents were milestones along the way, providing a universal portal through which I entered a state of mind, where another's welfare was equally important to mine. We find this "State of Grace" in those inspirational "Aha!" realizations that are supreme, quietly private and self-reflective.

While my mother was dying (or making her life transition) from leukemia in 1988, I was experiencing an ongoing state of personal challenge. It was a journey into the pragmatic realization that there was something greater than just living stories of what is happening to me right now. For years, I have known that life's reality is shaped through underlying beliefs held in the unconscious mind.

Over the resistance of my Dad - who was stuck in his own neurotic, co-dependent relationship with Mom and an unshakable denial of her profound health crisis - I insisted on a second medical opinion and arranged for my mother to receive full-time nursing care at home with regular chemotherapy at the Oncologist's office rather than in the hospital.

This period of initiation into personal care-giving was made more complex by my chronic lack of self-esteem and life-

long resentments between our nuclear family members. Resolving these festering issues was at once daunting, if not downright nearly impossible, yet ultimately achievable by an unswerving commitment.

I did not prevail in convincing Mom to receive the alternative care that had been originally envisioned by all concerned. This was due in part to her passivity and an inability to stand-up against unrelenting pressure from a husband of fifty years. Dad's view was to follow the beaten path of least resistance, i.e. "Our Doctors know best and treatment in the hospital is the only way to go..." and, "I don't want this stranger in my house taking care of you!" I gave up too easily, instead of insisting that we should try an alternative approach, so passionately debated, at least for a period of time .

Dad released the marvelous nurse practitioner we had found. Mom returned back to the hospital for her treatment, got pneumonia and died about six weeks later. My hatred and blame towards my father remained smoldering until seven weeks before his death some ten and a half years later in 1998. I valiantly continued to search for release and redemption during that decade, but still remained a victim and held captive by unresolved childhood hurts.

When Dad was heading towards his own transition, my sister Gina convinced him to choose in home care several years earlier rather than entering an assisted living or nursing facility when the need became apparent. The practitioner found by Gina and his insurance company was a God-fearing, awesomely talented lady named Violet, who served as role model for our family until our father's death.

In the period immediately before he passed away, Dad broke his right arm. He had already lost a considerable amount of weight over many months. He could no longer feed, clothe, bathe or toilet himself without help. Gina and I (his only children) were from the Northeast while he was living in Florida and until then had been fiercely independent, even with Violet helping him full-time on our behalf.

My father no longer was able to sustain himself even in a basic way and I took advantage of the U.S. Family Leave Act to spend considerable time in his home. Miraculously, we then made up for so many years of having no relationship through creating one of an intimate caregiving exchange that changed both of our lives and souls forever.

During those final weeks, we were privileged to be able to participate in his care along with Violet. Simple acts of feeding

and cleaning another person, wheeling him to the doctor and most poignantly, washing his few remaining thread-bare clothes in the laundry helped me realize how much I felt for Dad unconditionally. Not having kids or a life partner, I found it awesome to care for someone other than myself.

The story, or experience, became bigger than holding onto past wounds. Such old and tired resentments were released to a large degree. I was free to love not only my father, but all that is, including me, from the heart-space where God or Source lives. Dad and I became unified (and ultimately with my sister), as our deep desires for mutual acceptance and requited love were met through a shared giving that was without question, nor conditioned from unhealthy or previously failed demands.

The last time I saw Dad when we said goodbye, he cried in my presence unlike any time before. He shed a huge silver, pearl-shaped tear and asked me not to leave. I wanted to remain and savor our precious space of intimacy. Yet through forgiveness, this exquisitely sublime moment of magnificent breakthrough was a crucial step in becoming the compassionate, caring person I am now, endeavoring to walk in the footsteps of our Master.

—Steven J. Gottesman

## The Other Daughter

“If you were my real daughter, you would stay here”  
said my 90 year old mother as I passed her  
on my way to the living room  
in search for a place to sit.  
She perched on the high kitchen chair  
once used at the sink and now at the table  
set with coupons and paper towels.

To by-pass a verbal spiral  
I said: “Never met that daughter,”  
and headed for the multi-locked door  
as she raised her voice in final declaration:  
“And don’t you count on handling my estate.”  
I turned and said into her right ear:  
“Do what you want Mom. Put it in writing.”

Her body, brain and relationships  
inhabited a house of cards, and I had  
a crumbling spine of impatience.  
I turned my back on her  
manipulative press to stay  
in my childhood room occupied by  
the accretions of time, the excretions of mice,  
an unventilated space where windows  
were locked by stacked possessions  
and fears of the great outdoors.



She sat on the vinyl perch and chatted  
 like an authoritarian squirrel,  
 obsessed about the neighbor's proliferating  
 sex business and the stolen gas piped  
 into their enterprise from her hijacked meter  
 near the electrical wires placed so that  
 when someone came to her front door  
 the brothel stopped the white noise machine  
 that bellowed through her bedroom  
 to block the sounds of sex.  
 After the women did their business  
 the boss lady shook a bell to announce: "Time's up."  
 Used disposable sheets filled the trash cans out back,  
 cars of the men and workers filled up the streets.  
 The duplex of prostitution  
 ran water between the houses to hide  
 the tracks of theft, and she knew  
 they were trying to force her out.  
 The other daughter can't be found to stay  
 so for the night I stepped onto the porch  
 to breathe in the silence and leave  
 the empty street behind until the next day  
 when the only daughter my mother has  
 will come back to the draped windows  
 and blast of heat to negotiate  
 the paths of the present and the past  
 and listen for sounds that can't be heard.

—Lynore G. Banchoff

<sup>8</sup>This poem has been previously published in The Ontario Poetry Society Newsletter, Vol 2, No. 2, Sept./Dec. 2001.

## The Words the Cat Took

It is a good thing old age comes so late in life. It gives you the time to develop the resources to deal with it. There is a lot of noise in Harry's room—too much noise really—given that this is a hospital and the official beginning of visiting hours is still an hour away. There is a lot of noise, but not quite enough to cover the sound of the too-loud voices coming from the hallway.

It is the morning after the stroke, the morning after the big one, the whopper, the cataclysmic stroke of all strokes, the stroke that stilled his good right arm and turned his leg to jelly. It is the morning after the cat got Harry's tongue.

Harry's room is a double room shared with a stranger. Harry would like to share the bathroom. For the moment that is out of the question because he is trapped in his bed. But Harry is not a man to be trifled with, and already he is having an influence, holding court from a horizontal perspective, using every muscle that moves, conducting the family through a modified game of charades.

"Bedpan," cries a son. Bedpan is, on that morning, a guess of enormous importance, a guess you would want to make in case there wasn't much time.

"No!" shouts Harry. It is a firm no, a definite no, the kind of no a three-year-old shouts when you try to put his shoes on.

But it is music to the ears of the family. Maybe the cat that got his tongue has left some important words for Harry.

"Water jug!" cries a granddaughter. Thirst might be the problem.

"No!" shouts Harry.

More guesses. "Close these curtains!"

"No!"

"A tissue for your nose?"

"No!" And then Harry says, "There!" A sigh from the family. Another word left by the cat.

He says it again. "There!"

But where? We try again. "Pull up the blanket?"

"No!"

"Crank up the bed?"

"No! A breath. "No! No! No! No!" And then, a flash of anger hot as fire, "Damn it all!"

Shocked silence from the family. Can Harry really have said that? The cat who took the words must have a sense of humour. Harry has never been a man to swear. But then, communication has never been so difficult before, so promising and so daunting at the same time.

We pause to collect our thoughts. But silence will not do. It is noise we need now, noise. Make more noise! If we make more noise it might be impossible for Harry to hear, for us to hear the too-loud voice of

the young doctor echoing in the hallway just beyond Harry's door. Only a moment ago that man came right into the room and said, "If Harry's wife is here I would like to speak to her about a do-not-resuscitate order. We don't have one on the chart."

Not a word did he speak to Harry. Presumably he was in a hurry. He wanted to get a do-not-resuscitate order on the chart. In his hand was a clipboard and he would likely have had the full conversation then and there had one of Harry's sons not risen to guide his mother to the door. There might have been a quiet room in soft pastels where Harry's wife might have sat to discuss this difficult issue. But just outside the door the doctor stopped abruptly, turning back to continue the conversation, addressing himself to Harry's wife.

Harry's wife was tired, but she was not a woman to be trifled with. "Harry made a living will," she said, getting the upper hand. "We brought it with us last night when we came in the ambulance. Maybe they still have it down in Emergency. He didn't want to be a vegetable."

The doctor was unimpressed. The word 'vegetable' was not on any of his forms. But that was the word Harry had used. What did he mean by that anyway? He meant he did not want to be passive, so passive he could be thrown into a pot and

boiled up, so passive that others would have to tend him, keep his basic systems going. He wanted to be active, interactive, involved in the rhythm of daily life like a human being would be involved.

Inside Harry's room there is no sign of vegetablehood right now. Harry is definitely not passive, not even close. He is, in fact, the centre of attention. It isn't even visiting hours yet, and there are already a lot of people in Harry's room, two patients, seven visitors. In the who-can-have-the-most-visitors competition, Harry has a definite lead, five visitors for him, two for the other guy. It is a difficult situation in some ways. Hospitals never quite know what to do about visitors. Visitors are good for the patients, but too many visitors can be too much of a good thing. Visiting hours keep things organized, but patients need their families in times of crisis. If the cat's got your tongue your family can speak for you—sort of.

The too-loud conversation in the hall is very short, as impromptu standing-up conversations among strangers tend to be. A granddaughter rises to make a chair available to Harry's wife as she comes back in. One way to control the number of visitors is to control the number of chairs. Harry's room has only four chairs, but we don't mind standing. Things are pretty active anyway, what with Harry trying to give us a message we can't un-

derstand, and all the guessing going on.

There is a better chance of solving the puzzle now that Harry's wife is in the game. She ought to be exhausted, having spent last evening and most of the night in the emergency ward. This does not seem like a good time to discuss the too-loud hallway conversation, so we ask instead for her help with the game. We have exhausted all possibilities, made a hundred guesses. We have surveyed the ceiling, surveyed the floor, and still Harry persists. Whatever it is he wants to say, it must be very important.

"There!" he cries in agitation, the way an ignored messenger of war might cry when bringing news of an impending attack. "There!"

Harry's wife has been his wife for 55 years. She knows him pretty well, well enough to predict that he will not give up until we have finally understood whatever it is that he wants to communicate. He has never been a man to give up. Anyone who knows him will tell you that. This is the man who insisted on finishing high school at a time when farm boys were not offered a full education. This is the man who went to war, cleaned guns, fell in love with a Welsh nurse, sacrificed his wedding day for D-Day in France and later married her in his army boots because he had no other shoes.

"He is looking at your chair," she says to a daughter. It is not twelve hours since the cat got his tongue and already she is developing a skill in telepathy. "He is looking at your chair. Stand up will you?"

This is definitely going to be a challenge. Yesterday he could marshal 60,000 words. Today he is limited to five, including no, there and damn it all. It's quite a loss when you consider it, 59,995 words wiped away in a single night, gone, but not forgotten.

He has not forgotten them. She can see it in his eyes, know it from his history. Once they lost a daughter, a happy, laughing, bouncing daughter. One moment she was swimming in the river and the next moment she was gone. And there was nothing left to do but pull her lifeless body from the weeds where it was tangled. There was grieving, unfathomable grieving. There was heartbreak so deep that tears could still pour out forty years later. What is the loss of 59,995 words and a good right side compared with the loss of a daughter? Can a mere stroke be expected to vanquish a man who has lost a daughter and still not given up?

He has not given up on whatever it is he is after. Now, if his wife is guessing correctly, he is deeply concerned about a chair, the chair where another daughter is sitting. At her mother's command she

stands, and he smiles. They are making progress. But he is not finished yet.

This is a farm boy who started university at 43, survived a major heart attack at 58, studied French at 75. He taught math to bank tellers, computer science to students of business. This is a man who crossed the U.S.S.R., cruised the Amazon. He is a historian, a genealogist. His thoughts are not always simple.

His daughter is standing and he is smiling and still the puzzle is not solved. Is it something about her? No, it seems to be something about the chair. No, not about the chair, but about the bed next to his. No, not about the bed next to his, something about the visitors to the man in the bed next to his. What can it be?

And then suddenly the puzzle is solved. It is the chair. The visitors of the other patient only have one chair, and we have three. We have their other chair. We took their other chair and we need to give it back to them. So we give it back to them. Now both of his visitors have a chair. Two chairs for them and two for us. It is the thing Harry would have told us to do in the days when he had the words. We are cheering now, cheering the way we would be cheering if one of us had won ten thousand dollars on a TV game show.

Harry is not a vegetable. He is involved. We do not know it yet, but in the face of his

new life, Harry will be more resolute, more resilient, more resourceful than we ever imagined he could be. We do not know it on this morning, but he has six more years, six more years of laughing at family parties, winning at cards and crying occasionally for his lost daughter. More words will be reconnected, names of people, names of objects. He will proudly display newspaper articles and army medals. He will give to charity, attend church, go to the bank, sign his name with his left hand, walk, fall and walk again.

On this difficult morning, when he knows there are still some things he can do, he chooses to hope there will be more things he can do as time goes on. He has always been a learner. Just this morning he began learning how it feels to be disregarded, as if he were invisible, invisible because he does not speak a language that can be understood by people in a hurry. And so he begins to take charge, to rally his family and friends. To us he will not be invisible. It will take more people to solve a problem. It will take longer than it used to. But we will do the best we can. This is not the only game of charades we will play. It is the first of a thousand enactments, enactments leading to guesses, guesses to fill the spaces, millions of spaces left by the thousands of words the cat took.

—Wendy Edey



## MOMENTS OF MERCY

*One never meets just Cancer, or War or Unhappiness (or Happiness).  
One only meets each hour or moment that comes. All manner of ups and  
downs. Many bad spots in our best times, many good ones in our worst.*

—C.S. Lewis, *A Grief Observed* (p. 29),  
quoted by Burack-Weiss, *The Caregiver's Tale*

Here are the “good spots”. While there is much to be endured, sometimes there is a connecting moment between the caregiver and the cared-for which provides a quiet glimmer.

- There is simplicity in Jones’ poem, *The Caregiver*; it’s the little things.
- Remembering the fox in Faraday’s *The Covered Bridge* and the baseball games of another time in Thornton’s *A Visit to the Dairy Queen* are unadorned, simple gifts from the loved one to the caregiver who tells the story.
- The husband in Connolly’s *Devotion* and the daughters in Rule’s *My Lady* and Lenartowicz’ *Talk to Me, Ma* are the heroes in these poems. These are finely-drawn images of constancy, imaginative play and faithful memory.
- Dickson’s *Healing Touch* is a tender reminder of the powerful gift of presence.





## My Lady

The first time Mom required my help to bathe  
I was worried she might feel ashamed.  
She'd always held her privacy so dear,  
maintained it raising her six kids right here –  
one bathroom, two small bedrooms—what a place!  
Its few square feet a measure, now, of grace.

I helped her take her clothes off, bathrobe first,  
until she stood there naked as at birth.  
A pear-shaped bottom, tiny sleeping breasts,  
a wisp of hair as white as all the rest,  
and still the elegance I'd always known,  
a self-containment that was all her own.

A maid-in-waiting, I offered her my hand  
then carried out each calm and kind command.  
The towel I draped around her at the end  
we both knew was a cape with ermine trim.

—Bernadette Rule

THIS LITTLE LIGHT OF MINE:

## Talk to Me, Ma<sup>9</sup>

Language is relative,  
a gesture, a wink, an uplifted corner  
of an ambiguous mouth.

You say “patrz!” pointing at the dog,  
sleek fur glistening outside your window.  
I correct with “look, ma...it’s look!”  
and suddenly  
you turn,  
inspect me sternly  
like you used to;  
you say: “I know.”

My heart beats, clattering in my chest.  
My Mother’s back!

You look at me and ask my name.  
And my certainty collapses.

Language is emotion,  
a memory, a sound, a taste  
of foreign familiar things.

You say “you know?” with such pride  
after a long diatribe in Polish  
about your kids, your husband  
your life—hard but yours.  
you smile  
you weep  
admonish to remember  
like you used to.  
I say “Pamiętam, ma,”  
I remember.

Language is boundless.

You talk to your granddaughter  
who speaks none of your language yet understands it all

<sup>9</sup>Dedicated to two amazing mothers, grandmothers and great-grandmothers—Caroline Osowiec and Maria Jaworska.

a strange cacophony of sounds and tangible  
heart-wrenching emotions.  
Language, not words bridge the gulf between you  
erase the disease  
erase the pain.

Language is in the present.

I sit by your bed, hold your hand  
unable to speak  
yet eyes so alive  
“Talk to me, ma, talk to me”

—Magda Lenartowicz

*“I say, ‘Pamientam, ma,’  
I remember.”*

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Princess Point (Cootes Paradise), Hamilton ON, CA

## Devotion

He talks non-stop, lovingly,  
attempting conversation  
with a shrunken form  
dwarfed by a hospital bed;  
it doesn't respond.

Some years ago  
(it doesn't seem that long)  
they romped in daisy fields  
together.

She was as strong as he  
as they playfully arm-wrestled.

But illness  
cruel rapist  
ravaged her body and her mind  
and there she lies  
weeping, moaning.

He tries to feed her jello  
as if this simple act  
restores normalcy.

He eagerly awaits  
to bring her home;  
he will take care of her  
alone  
until she dies,  
grateful for moments  
sacred gifts.

How strange it is  
some husbands  
don't make time  
to say  
"I love you".

—Gaiyle J. Connolly

## The Covered Bridge

When Owen was diagnosed with Alzheimer's we decided to put our home in the country on the market and to move back into the city. Even with me taking over the role of driver, we both knew that we needed to be closer to our children and our church community, not to mention public transport and medical services.

An attractive apartment, walking distance from the city centre, became available before the house was even sold and we made the transition from country to town without too many regrets. We were only a thirty minute drive away and so, whenever we found ourselves longing for the smell of pine trees and wide open spaces, we would head back to our old haunts and the walks and woods that had become part of our lives.

As the years passed, and Owen's condition worsened, memories of the old house played a darker role for me. Watching someone you love change from an intelligent, well-informed and self-motivated man to a frequently confused, utterly dependent person has taken its toll on me. No longer his soul-mate and lover, I have become his caregiver as if I were his mother and he my child.

The thought of living this way for years to come—as I know others have done—was and is unbearable. But how to bring a loving end to this prolonged

ordeal? A newspaper story about a couple in our situation who had 'ended it all' by taking their own lives kept coming back to me. Driving past our old house one day, I saw myself—as if in a dream—driving through the weather-worn railings at the side of the road and into the ravine below.

Not far from our old house there is a covered bridge that used to be the destination of many walks—on our own or with family groups. The hour or so round trip to the bridge and back became the traditional Thanksgiving Day walk and ideal for any occasion that required working up an appetite for a celebratory meal. Taking the smaller children by the hand, we would rush across the busy highway to the quiet rural road that led to a beautiful valley, green and tranquil in the summer months, richly colourful in the fall. Around a curve and down a steep incline lay the covered bridge. A small wooden structure bridging a tiny creek that wended its way through the valley.

A few days ago, on the first really warm day of spring, Owen surprised me by suggesting we take a walk to the covered bridge. I was surprised because almost invariably I am the one to suggest a walk and where we might go. He always agrees, but rarely takes the initiative. Driving along the highway we

## THIS LITTLE LIGHT OF MINE:

lapsed into our usual silence punctuated by Owen asking (as he does at least a dozen times a day, every day) what day of the week it was. I gave the same reply each time and (I hope) in the same tone of voice.

The repetitive questioning is something caregivers grow used to after a while—I think we may even miss it when it is no longer part of our daily lives. A woman in one of our Alzheimer’s support groups made us all laugh when she told us that, after being asked the same question many times over, she had finally lost it. “Right.” she said to her husband, “Ask me that question one more time and you pay me a hundred dollars!” He didn’t ask again.

Arriving at the parking lot not far from the bridge, Owen and I walked slowly up the hill taking in the sparkling air and stunning beauty of the meadow and hills beyond. The days of walking side-by-side have long past—now we walk each at our own pace—me in front, “stepping it out” as my children tease me, and Owen (hands clasped behind his back) taking his own time a few paces behind. I sometimes reach out and take him by the hand, drawing him along. But it takes some effort to do that and on that day I enjoyed the sense of freedom as my arms moved to the rhythm of my footsteps.

Then, for the second time that day, Owen surprised me. Once, years before, we had seen a fox on one of our walks not far from the covered bridge. It was winter and the sight of this gorgeous creature, its rust-coloured fur standing out clearly against the white snow, was truly unforgettable. “Remember the fox?” Owen asked and I could have hugged him. A shared memory; such a rare and precious gift.

The covered bridge lay just around the corner down a steep incline. The sign “bridge closed” that had greeted us as we started our walk had made us a bit wary of possible winter damage as we drew closer to it. Cautious by nature, Owen was particularly concerned that the bridge may not be as sound as it looked. But, stepping beneath its arched wooden walls, it seemed fine and just as we remembered it. The creek flowed free of ice beneath our feet and there was a sense of peace and well-being as we stood together in that familiar place.

Looking back as we climbed up the hill away from the bridge, it became obvious why motorists had been warned not to proceed. Winter had played havoc with the surface of the dirt road on the far side of the bridge. Immense cracks and potholes scarred the surface, making car travel to the bridge hazardous. The road made me think of the rocky, difficult path that lay ahead of Owen and me.

But then I thought of the covered bridge, sturdy and unchanged by the assault of ice and snow. A place of sanctuary, filled with memories that we can both still share.

Owen mentioned the fox again as we retraced our footsteps back to the car and

we walked the rest of the way not only in step but with our arms intertwined. I chose not to drive past our old house on the way home. Instead we headed for the ice-cream shop in the old village.

—Jane Faraday

*“But then I thought of the covered bridge, sturdy and unchanged by the assault of ice and snow.”*



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Spring Valley stream, Ancaster ON, CA

## A Visit to the Dairy Queen

My grandmother takes my grandfather  
by the hand, leading him into Dairy Queen –  
though she's three-quarters blind,  
she's the steadier on the feet of the two of them.  
"Take my hand, oh Lord," my grandfather says,  
"and lead me not into temptation. And help me  
find out what the hell is going on."  
Every week, he's more and more confused,  
every week, he's less and less himself to us,  
yet my grandfather's familiar sense of humour  
still finds a way to stream out of him,  
seemingly without his knowing it,  
the way his urine now streams out of him  
into the plastic bag strapped onto his leg.  
"Would you like a coffee?" I ask him.  
"No, I'll just have to go to the bathroom.  
It's a bugger when you can't urinate."  
"But you don't have to, you have a catheter,  
you're hooked up to a urine bag."  
"You mean it's automatic?"  
He sways and falls back, we prop him up.  
Trembling, bewildered, he's a visitor now  
out in a strange ordinary suburban day.  
Unable to hear very much, unable to remember  
what decade it is, or where he is,  
and between the anti-psychotic drugs he is given  
and the who knows how many strokes he has had,  
unable to talk without slurring his words,  
he's a comedian doing a drunk act.  
Or he's an elderly clown, his running shoes  
and jogging suit three sizes too big for him,  
his socks constantly annoying him,  
his crazy hair flying everywhere,  
his nose bearing a large scab –  
the result of his latest fall.  
"What's your birth date?" the nurse asks him.  
"Bill."  
"No, what's your birth date?"  
"Oh, March 18th, 1905."  
"Your first name is William, right?"



“Right, William for short.”  
“How’s the coffee, Bill?” the Care Aide asks him.  
“They must be re-doing the roof.”  
“How’s the pizza, Bill?”  
“Call the city, see if they need a man-hole cover.”  
“How’s the chili, Bill?”  
“I didn’t know there was a cow pasture around here.”  
“Would you like some ice cream?” I ask him now.  
“Do they have ice cream here?”  
Oh yeah, this is the Dairy Queen. Okay.”  
He finishes the ice cream in a minute,  
most of it running down the furrows in his chin  
or splattering down his jogging suit,  
and I clean him up, my grandmother,  
serviettes in hand, trying to help,  
dabbing away but missing the ice cream,  
and I load the two of them back into the car.  
Halfway between the Dairy Queen and Cedarview Lodge  
my grandfather becomes agitated –  
he wants to know where my grandmother is staying.  
“At the suite where you used to live,” I tell him.  
“Where’s that?” he asks. “What’s the name  
of the place we live at now?”  
The questions go around and around,  
the same two or three, repeated over and over  
until, suddenly, he points ahead.  
“Look!” he shouts.  
We’re passing a playing field by a school  
where boys are beginning a soccer game.  
“Remember?” my grandfather asks me now.  
He’s smiling at me, reminding me,  
with impossible strength of gentleness and care,  
of other days we have spent together,  
and cheering me up, as he so often has,  
making me forget now even about his own state,  
the watery, childlike light in his eyes  
perfect, still intact, still all blue sparkle,  
keeping his pathways to me clear.

—Russell Thornton

## Healing Touch

Take her frail and painful hands  
in yours.

Gently press misshapen joints  
with tenderness.

Those hands  
were molded year by year,  
by touching other lives  
with love.

A tired smile shows  
that pain,  
still present,  
for a moment,  
is bearable.

When flesh is worn  
or damaged past repair,  
touch with care –  
the only healing  
left to share.

—Robert C. Dickson

## Poem—The Caregiver

Things caregivers just naturally do,  
Make all our lives brighter and happier too –  
It might be the warmth of a smile,  
Or the time someone takes to visit awhile.

It might be a hug or a heart-to-heart talk,  
A companion who's willing to go for a walk.  
It might be a favour, a kind helping hand,  
A listening ear, the words, "I understand".

They're all little things, but we know beyond doubt  
Each one's at the heart, of what life's all about.

—Anna L. Jones

*"It might be the warmth of a smile."*



© Eleanore and Richard Kosydar

Stream, Dundas Valley Conservation Area, Dundas ON, CA



## REVELATIONS

... (These are) the hard-earned truths ... of authors who measure themselves against the demands of an unalterable situation and emerge with an altered sense of self, a changed world view.

—Ann Burack-Weiss, *The Caregiver's Tale* (p.141)

Here are transformational experiences—waterfalls in the writers' awareness which takes them to another level. The drama lies in what happens to the caregiver and the ways in which the caregiving journey changes us. Occurring in an instant, or over time in recollection, the changes on which these writers reflect take us to a new level of understanding of ourselves both as caregivers and as well as the cared-for.

- The revelation may be simple, like the sudden awareness that comes to Wingfield in *Caring for Grandmother* and Grove in *Thursday*, or
- It may be happy and proud as ML Banchoff is when she writes *Working Family* and Brown is in the lessons she shares in *Things My Mother Taught Me*.
- It may be dramatic, as in the quiet disclosures shared by Buzzell in *Listening at the End of Life* and the hurly-burly pace of Denny's *It Was a Hot Summer Evening*, or
- It may be difficult, as are the lessons MacPherson must teach herself in *Ties That Bind* and Piskorowski-Adams' reluctant admissions in *A Wandering We Shall Go*.
- Finally, it may be gained only through recollection, as it is in Lee's *Attentive Waiting* and Thornton's *Your Keys*.



## Thursday

How is it possible that a small weeping child could look down and find her own hands gnarled with eighty years of life?

But that was how it was yesterday. Sitting on the peeling porch, everything about life seemed too much to her and though she didn't know it herself at the time, it was really her own mother's arms that she was crying for. I could have gotten up to comfort her but I've learned that my hugs aren't good enough at a time like this.

I stared at her salt and pepper eyebrows. Watched her squinting in the afternoon sun as she tried to talk through her sobs. I had thought we were discussing changing the carpet in her living room. And painting the walls. Lord knows they need it. For her, I might as well have said "Let's turn your whole world upside down."

I should've been more sensitive I guess. Just the day before, Dr. Attridge had told her that she needed eye surgery. Surgery and decorating are a stressful combination to contemplate—at least for those of us who don't find decorating fun. I sat respectfully quiet as she spoke and sniffled. Trying to keep my million things-to-do from distracting me.

Only now, on Friday morning, do I realize that we are working at odds in the biggest way:

Me, eager to get things in order. Wanting to accomplish five things at once. Trying to get us prepared before the next step. Before mom has another health crisis I want to have a system in place. Want her to have hired help. Maybe get a live-in. Or if we need to sell the house...

She, wanting to slow everything down. Resting in each moment. Just being here. Keeping everything the way it is for a while longer. Forever if possible.

Who am I to say that she's wrong?

Maybe I need to throw out my whole list.

—Paula Grove

## Attentive Waiting<sup>10</sup>

*I used to think I was put on this earth for one purpose alone. I was placed here to grow corn. And I was more than content with my lot. I thought I loved my life. I enjoyed and was satisfied and took my meaning and the sole meaning of my existence from the nurturing of this weak, hybrid, cultivated, pampered, green little plant.*

These were the words of my cousin, that day, in the gentle picnic rain on a summer Sunday, sitting outside the shadow of the shelter in lawn chairs in a small consanguinary circle of maternal family. They certainly weren't common to our talk. Although rooted in farming, as most conversations were with us, these words were throwing their seed over the wall and falling on fallow, in the metaphysical rural, rain-rich earth of land beyond our lives.

*I was so obsessed with my crop, I used to time myself between farms. I'd seek and find short cuts, quick roads, paths to shave a few seconds off arrival so that I could be there in the field. I'd go walking the rows. I'd know each plant among thousands as a prosperous man might know his many children. I'd instruct my young workers. Give them heart to tassel. Hope to harvest. Don't stand at the start of your row and despair for the multitudes before you, but rather, stay where you are—then, when you're there, stand at each stalk and be present in the silk of your doing the work at hand.*

*Then your day will be done, your labour complete, the hours full. And they listened.*

*Each year came. Each season required. In the winter, I thought of the spring. In the spring, I outwaited the frost and the wet. I was patient with land. I worked it like weather. I watched while my neighbours broke ground too soon. They just couldn't learn.*

*And then, one day, five years ago, my daughter gave birth to a son who no one thought would survive. I'd be there in London, simply waiting and waiting. I'd be thinking of home and the work of the world. I'd leave the hospital and speed to the field where I mounted the tractor and worked. But at each round of the headland, at each culvert and turn of the ditch, at each force of the fence, I'd feel the wheel turning toward London taking me back to that bedside, back to that vigil.*

*You have to know—I could do nothing but be there. But I was compelled by the feeling that I had never done anything more important in my life than that. I was simply waiting. There was nothing I could say. Nothing I could actually do to make any real difference. I was never more helpless. Nor have I ever done a better thing.*

*I had thought my purpose in life was to grow corn. It took me over fifty years to learn that the most important thing I had ever done was to simply be there.*

<sup>10</sup>Attentive Waiting was originally published in *Left hand horses: Meditations on influence and the imagination* (2007), Black Moss Press.



*To be present. To engage in that attentive waiting.*

*I suppose I had been compelled by a fruitless obsession all my life. Now I know, the true heroes are those who are willing to give up everything for what really matters. To be there for others. To simply wait and do nothing was*

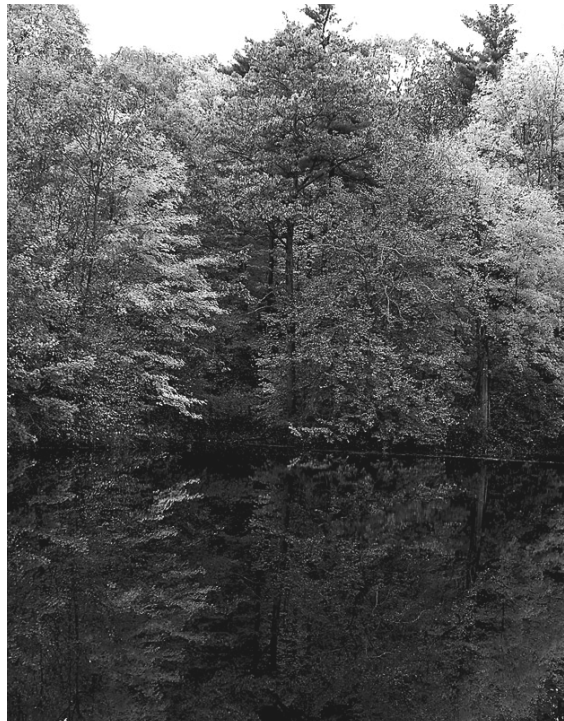
*the greatest and most heroic and best thing I have ever done.*

*And the learning of that lesson is the greatest gift I have ever received, he said.*

Tomorrow he waits again.

—John B. Lee

“The most important thing I had ever done was to simply be there. ”



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McCormack Pond, Dundas Valley ON, CA

## It Was a Hot Summer Evening

It was a hot summer evening in July and I was outside power sanding one of my antique interior doors. I stopped to go inside for a glass of water and heard my telephone ringing. It was Lifeline calling to say that my Mom had pressed her emergency call button but that they could not understand what she was shouting to them from her bedroom. Her receiver was in the living room and they could only make out that she was having trouble with her legs. I told them could get to her within two minutes.

I found her lying in bed. She could not move her legs, could not talk very clearly, looked a grayish colour, was struggling to breathe. I felt she was having a heart attack and asked Lifeline to call an ambulance. The fire department and paramedics arrived without delay.

In the emergency department (my brother had already arrived) staff attended to her immediately. The cardiologist intern advised us that Mom was having a massive heart attack because of a large blood clot in a heart valve. Mom lay there frail and helpless, labouring so hard to breathe. The intern asked my permission to proceed with the clot blaster (a procedure that I remembered had saved her from a previous heart attack and is done in two injections).

After the first injection, bleeding in Mom's lungs prevented the intern from administering the second. He told us that half was not enough to blast the large blood clot. Because of her weight (84 pounds), her age of 64 and her weak health, she would not survive by-pass surgery. So there was nothing more that they could do for her.

They transferred Mom up to CCU and put her on a Dopamine pump, a life support procedure that assists heart function and thus increases air to the lungs. I telephoned my Mom's twin brother who arrived shortly after. My uncle had had heart by-pass surgery ten years earlier and had a pacemaker. He also has dementia and I am his acting Power-of-Attorney, looking after his needs as well as those of my mother.

I consoled my brother and my uncle who could not handle the situation, and also attended to Mom and the nurses, who regularly came into her room to see if she needed more morphine. I stood there watching Mom for hours, asking her from time to time if she needed Gravol for her stomach or if she was in any pain. She could only respond with one word; each time she said, "No".

I limited questions to her as she was struggling for survival, having spent hours using all of her small body's energy. At this point it mattered only to me that she was as comfortable as possible. While my uncle and brother went downstairs for coffee, I rinsed the cloth on my Mom's forehead. It was the only thing I could do for her.

My mother has extreme asthma and is in the later stages of emphysema. I suddenly realized that I had forgotten to ask her about something she does each time when rushed to hospital. I bent down and asked if she had put her 'JP' on her forehead earlier. She had not, so I told her I would go downstairs to the chapel to get some holy water.

I went into the chapel to say some prayers for my Mom and help for my family with their anguish. I asked Jesus and God to guide me through this difficult time. Also, I asked whether it was her time to go home to them, and if it was not her time to go, tell me how to help her. After 15 minutes, I felt a calmness around me. It had been a long time since I had prayed alone in a church or chapel.

I also felt the presence of my Dad who had passed a few short years ago. A voice ran through my head and told me

that it was not her time. I felt everything would be okay. I also realized that in order not to miss anything, I would have to remain calm and be in tune with this inner voice.

My father's words ran through my mind, reminding me that not everything is as it seems; hospitals, doctors, specialists and medical tests are not always correct. Dad had also said to question everything and take things into your own hands instead of accepting what professionals say. Research, ask questions and look for alternatives. If my Dad and his current wife had not done those things, he would not have survived as long as he did.

I realized that perhaps Mom had a chance and that I needed to act. My Mom has always been a fighter through surgeries, lung cancer, COPD (chronic obstructive pulmonary disease) and chronic depression. As small and frail as she was, I knew she was struggling as hard as ever for survival.

I thanked Jesus and our Heavenly Father for this message and for the holy water. I went to the coffee concession to ask for a small paper cup. I put a little holy water into the cup and made my way back to Mom.

Mom had always licked her finger and wet her forehead to spell 'JP' which stood for 'Jesus' Property'. It was very important to her. I dipped my finger into the holy water and put the 'JP' on her forehead. This seemed to please her and she had a peaceful look on her face.

It was early morning around 8:00 am when the head cardiologist came into the room to talk to me. My uncle and brother left to stand in the hallway to avoid hearing the news. The cardiologist sat down beside me and proceeded to say, "There is nothing more that we can do for your Mom. I have reviewed all the tests confirming that she has had a massive heart attack."

I asked, "Are you sure that there is nothing else that can be done for my Mom?" He said, "The massive heart attack has destroyed what was left of her valves and her heart. She has two other damaged valves from a previous heart attack. She is brain dead and she is only breathing because of the dopamine pump, not on her own."

He then said, "We will soon shut down the dopamine pump and increase her morphine. Shortly after, she will stop breathing."

I asked, "How long after the dopamine

pump is shut off will Mom stop breathing?" He said, "Within a minute or two. She will not be aware and will not be in any more pain." He added, "Shortly, we will need your permission to proceed."

My inner voice kept telling me that she needed more time to heal from this heart attack.

I told him, "I am not knowledgeable in cardiology and realize that you are the professional in this field, but I know my Mom is not brain dead. She can hear us talking and is fully capable of understanding everything that is going on."

He said, "That is impossible. Look at her. She is lying there, brain dead."

A thought came through my head so fast that I spoke it before hearing it. I said, "Is it standard procedure to just shut off the pump? If a heart has a chance to beat on its own, won't turning off the pump be too much of a shock?"

He began to get agitated with me and said, "This is protocol in all cases like this. Her heart will not beat on its own."

I said "I want the dopamine pump to be gradually decreased instead to give my Mom's heart a chance." I knew at that moment, that this was not my own thought, because again the words flew

out of my mouth before I had any awareness of them.

His arms flew up above his head and he shouted at me, “You are being very unfair to your Mom in her suffering and also to your distraught family in the hallway. By prolonging this, you are being very selfish and cruel to your Mother.”

I said, “I do not care how you feel about me. This is what I want.”

He shouted again, “You are wrong. Her heart will not beat on its own and you should accept it.” I did not budge.

Then he said, “Fine. I will let the nurses know and that you will advise them when to proceed, but please do not prolong it much longer,” and he quickly left the room, angry with me.

I walked over to Mom and asked her, “Mom, did you hear what the cardiologist just said about shutting off the dopamine pump and that there was nothing more that they can do for you and that once they shut it off, you will no longer be able to breathe?”

Mom said to me, “Yes”. I asked her, “Is there anything at all that I can do for you?” She paused for a minute and said, “More time”. I said “Okay, I am going to go down to the chapel and I’ll be back

within an hour. Is that enough time? Mom replied, “Yes”.

Then I let the nurses know I would be back shortly. I thought Mom needed some time alone to say her prayers and to come to terms with this final moment of her life.

I sat in the chapel and prayed that I was making the right decision about the dopamine pump. I also said that if it was her time to go home to them that I would accept that. I asked for guidance and for help for Mom. I left feeling strongly that my decision was right.

On my way back to CCU (Critical Care Unit) a girlfriend of mine who works in that hospital asked me what I was doing there. I explained everything to her. She gave me a big hug and we both cried. She told me that the cardiologist attending Mom was one of the very best and she was sorry they could do nothing more for her.

I told her that all of our small family in Canada was here to be with Mom except my daughter who lives in Texas. It upset me that I could not use my cell phone to call her so she could say goodbye to her Nana. The phone in the room was not hooked up. My friend said that she would have it hooked up shortly. I thanked her and we hugged

again. She left just as my boyfriend arrived with Mom's good friend.

The nurses had come into the room by this time to decrease the dopamine level a little and administer more morphine. The nurses decreased the dopamine level every 5 to 10 minutes and Mom was labouring harder with each breath.

I called my daughter and asked, "Do you want to say goodbye to Nana?"

She said "Yes", so I bent down to Mom and said, "Mom, your granddaughter is on the telephone and wants to talk to you, is that okay?" Mom said wearily, "Yes".

I placed the phone to Mom's ear. At this time the dopamine had been decreased past the halfway mark and I suddenly thought that perhaps I had been wrong. Mom's breathing was getting worse to the point that her body, from her neck to her feet, was lifting every time she struggled to breathe.

Oh, I said to myself, please forgive me God and please don't let Mom suffer.

My daughter said, "Hi Nana", into the phone and suddenly Mom's eyes opened wide for the first time in over 12 hours. A large breath came into her lungs and she started to have a conversation with her granddaughter.

Mom appeared as if she had just woken up from a deep and restful sleep. She remembers floating out of her body and holding onto a large pipe in the ceiling. She heard her own mother's voice telling her, "Hang on, it is not your time." Suddenly, she recalls, a large gust of air came at her body and filled her lungs, but not through her air channels. Then she heard her granddaughter's voice saying, "Hi Nana".

This was miraculous, for Mom had not been able to talk except for a word or two at a time, nor had she opened her eyes. The nurses, who had been crying and continued to snifle, were amazed. We all looked at Mom with such disbelief and wonderment. Mom was breathing on her own!

She stayed in CCU for two weeks and then went to the rehabilitation ward for physiotherapy and recovery for nine additional weeks. Tests later showed that she had minimal damage to her heart valves and that her heart was fine. Also she did not have severe brain damage but did have little moments here and there of forgetfulness. The staff at the hospital called her 'the miracle patient'.

I feel that 'protocol' is not always the best way and that many people might have a chance if the dopamine levels

were decreased slowly instead of suddenly. Not all people are the same inside and the medical journals are general.

My Mom tells everyone that I saved her life. But I say that it was not me, it was God who should get that praise and credit. I can only take the credit for listening and following my faith.

My Mom's health will always be poor but she is still alive. Some of her poetry has since been produced into songs. This has given her a huge sense of accomplishment.

After her heart attack I told my Mom that God must have a plan for her, that there is more for her to do before she goes home to Heaven.

—Vanessa A. Denny

*"I also realized that in order not to miss anything, I would have to remain calm and be in tune with this inner voice."*



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Spencer Creek (Spencer Gorge), Greenville ON, CA

## A Wandering We Shall Go

My mother started to wander in the month of May of 2003. As some of you who have dealt with Alzheimer's symptoms in loved ones will know, wandering in the evening is a form of restlessness. I believe that the causes are still unknown.

On May 26th around midnight my mother got dressed, left her bedroom and went downstairs. Fortunately for me I heard her go downstairs so I followed her. To my shock and horror mother went to the side door and turned the key. "I'm going home," she said, as she left.

I quickly got my wits together, ran upstairs to get dressed (I was still in my night gown) and then dashed after her. Thankfully, I was able to catch up to her. She had walked about three city blocks before I could convince her to return home. Alas, home again, all safe and sound and ready for bed. I felt overwrought, but thought nonetheless, the incident was over. To my great surprise, at three-thirty that same morning, my mother got up again and was eager to leave the house. This time however, I convinced her to stay. Excuses that I used included: it was too dark, something bad would happen to her, everybody was asleep at that hour and would not be able to greet her, the people she wanted to visit had moved. It's amazing what springs to your mind when it is necessary.

The morning finally arrived. I quickly leapt into action. Three things were on my agenda. First I arranged a visit to mother's gerontologist; then a visit to the Red Cross Society and last but not least, a visit to the Alzheimer's Society.

The gerontologist prescribed pills to calm mother down and make her less restless in the evenings. At the Red Cross I rented door exit alarms. These alarms were attached to exit doors which when opened would then activate the alarm system kept in my bedroom. The sound would awaken me and alert me to the fact that my mother had left the premises. At the Alzheimer's Society I picked up papers to register my mother with the Wandering Persons Registry with the local police department. I still keep these papers close at hand. In retrospect this was by all standards the smartest thing that I did. The registry is very thorough and you are given the connecting number to the police. The police are very amazing and wonderful people in these situations. They are too wonderful for words.

But I digress. My husband and I had a strategy in regards to the wandering episodes. It took us several midnight adventures to work out the kinks but in the end it was decided that my husband would remain at home while I would go and search for mother. Then, if she could not be located within 10 minutes or she did



not return home on her own accord, my husband was to phone the police and report her missing. So we thought we had everything under control. This procedure was followed for the next five months with success. But in the month of October all this was to change.

One night in October, mother left the house dressed only in her nightgown and slippers. That particular evening was extremely cold and she wandered not to her usual locale where she lived long ago but farther than ever before. Unable to find her, we phoned the police who eventually brought her back to the house wrapped in a silver “space blanket”. She was cold, wet, soiled and disoriented. I knew then that I was endangering her life by not wanting to deal with the restlessness at home. This was the last night my mother ever left the house at night.

For the next few months, the keys were removed from all doors of exit. We then spent time not chasing her, but listening to her rattle the doors for hours on end. In an attempt to distract her, we tried to use toys, like a mechanical dog that barked and jumped. This dog amused her for hours during the nights she remained up.

But then the strangest thing happened. The wandering stopped and my mother hasn’t wandered since that period in 2003. She still occasionally rattles the door, but as far as I’m concerned she can rattle any door she wants because she is still with us.

My mother wandered and we wandered with her, with more understanding and better insights we all wandered to a safer, warmer and loving place.

—Anna Piskorowski-Adams

## Caring for Grandmother

Have you noticed that when something you dread actually happens it is not bad at all? I used to hope I would never have to leave my home in a new subdivision, filled with young families, to live in my husband's mother's hundred-year-old, eleven-roomed house. When eventually she was unable to live alone, we sold our house and with three children moved in with her. The children enjoyed the novelty of front and back stairs, the attic with old treasures and the evenings we snuggled before a wood-burning fireplace, popping corn.

Grandma would have numerous naps during the day, but would call out several times in the night for my husband. She had a pleasant, non-critical personality and was easy to please. Not all care-givers are so blessed.

One day my husband and his brother took an old reel-type recorder into her room while they visited with her. They would ask, "Do you remember, Mother, when you and Father would take us on the train to visit your family in Uxbridge?" She would answer, "Oh, yes. Lottie was always glad to see us, and you boys used to love to jump in the haystack." Then they would

remind her of other happy times and she would reminisce with them. When I had to leave her to make the meals, do the laundry and care for the children, I would turn on the tape recorder. She felt she was not alone. She would answer her son's questions with the same answer she had given before.

In the final weeks a V.O.N. nurse came every day to bathe and care for her. One morning I was helping the nurse give her a bed-bath and change the sheets. All at once we discovered that Grandma had quietly slipped away. We looked at one another, shocked. The nurse asked, "What do we do now? I have never seen a dead person!" I hadn't either. I said, "The only thing I ever heard is that we should close her eyes."

Before we could remember to phone the doctor, my sister came. She was on her way to work but felt a strong need to stop in to see how I was managing. Then my father and mother came. My father was on his way to his office, but they too felt they should come in. They all took over, phoning my husband and the doctor.

I felt surrounded by love.

—Naomi Wingfield

## Working Family

I wanted to thank you all for something you may not expect—your indirect but good teachings! ... As I help my new mother-in-law and father-in-law adapt to her recovery from hip replacement surgery last week, I find I know how to help in ways they did not know they needed!

From Dad—I learned not to panic when someone has post-surgical anxiety. I learned that, if one person is calm and matter of fact, that makes it all seem better.

From Kathleen—I learned ... how to make medical dosage charts for people too dazed and exhausted to keep track—I did an Excel® spreadsheet for them ... and a checklist for her daily rehabilitative exercises.

From Mom—I made sure there were welcome-home flowers, vacuumed floors, done dishes, and a full fridge of ready to eat foods.

They are so grateful too. In a way my injured back has happened at a good time because I am really available to them. I have been able to run to the pharmacy for them, go to the home improvement store for accessibility tools etc. Greg and I removed interior doors for walkers to fit through, took down the tub's sliding glass doors and replaced them with a curtain, bought screen doors for her bedroom to let breeze in and keep dog out, and changed the shower heads to hand-held sprayers. I think all my remodeling experience has come in handy in ways I couldn't imagine.

It has been rewarding and reminds me of how we are all here on this planet to help each other. It's that simple.

Lots of love to you all.

—Mary Lynn Banchoff

## Things My Mother Taught Me

Her last five years were long and hard for my mom. She was almost immobilized after a very active life. Although she wouldn't say so, I felt she resented the limitations arthritis had put on her much loved walks the most.

She and a fellow resident of the care facility would start out right after lunch to walk the little hill up to a seating area near the restaurant at the top of the nearby park. Both wore their white hair proudly and dressed, as always, with an emphasis on clean and tidy but as fashionably as possible, given the limitations of curved spines and gimpy knees.

He was an old WWI veteran and my mom had been a nurse "all her life." She claimed to miss the starched white of a uniform but found she enjoyed the ease of dress slacks and a jacket that had lots of pockets, as long as they were clean, pressed and had a highlight of color or a pretty scarf.

The timing of the walk was orchestrated. Mom had struck up a friendship with the park gardeners and knew their schedule well. The fellows joined them for a little chat while they took a break from weeding and if mom wanted a coffee instead of the usual ice cream, one of them would help carry it outside from the restaurant. I often suggested that lunch in the park would be a nice treat but they both said it was more fun to "picnic" outside ... and "besides, there are so many nice people to talk to outside."

Later when the walks became too much for them, I would take them up by car on nice days, and let them off before I went to park. Much as I wanted to join their exclusive group, I found it worked best for them if I stayed back and watched. It was such a joy to see their faces light up with each cherished friend who stopped by their favorite bench to say hello.

And later, back at their residence (often with large bouquets of blossoms from the gardeners who always said they'd needed to "trim some back"), they would discuss and share the problems and joys of all these friends as if they were "family"—and indeed they were, in the truest sense of the word. Accepting and generous of time and talents, these folks provided the friendship that went missing when mom and Jack were no longer active within the working world.

We are told that we all need shelter, nourishment, affection and something positive to do in life but the walks provided much more than that to my mom. On walk days, she was a whole person again with a history, talents and joys and this opportunity to talk with old and new friends verified her personality.

At the park, she was no longer a "helpless old woman" but that "nice lady who always knows what to say to make you feel better." The smiles, given and received, were so precious to see.

I learned ways to handle my own aging and disabilities, from standing back and watching my mom handle her role as a kind, gracious mature lady. The things I learned from my mom have now become my way of life. I will never have her talents (or smile) but I do have tried and true, useable guidelines:

- You don't have to give up who you are when you age.
- A clean face and clothes make you feel better, and a smile is the perfect accessory. On days when you can't manage a smile, wear hot pink.
- Ask your friends how they really are. Maybe no one else has acknowledged them as an important individual all day.
- Always say thank you for a kindness—and treasure it.
- Plan something to look forward to every day.
- Share your joys with your friends and family.

—Mary Brown

*"On walk days, she was a whole person again with a history, talents and joys."*



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McCormack Pond, Dundas Valley ON, CA

## Your Keys

In the last year or two of your life,  
you were always asking for your keys.  
Every few minutes, it seemed: "Where are my keys?"  
Bewildered-looking, and not remembering  
you'd asked the same thing dozens of times that day,  
frightened-looking, a child's desperation  
shooting across your child's wide eyes.  
"You don't need them," we'd tell you.  
But we were wrong; you needed them all right.  
You wanted your life back,  
and were holding on with whatever delicate  
and near-miraculous, harried energy you still had  
to the days of house and apartment doors,  
and imagining locking and unlocking  
every minute left to you now  
while you paced and circled in the always-unlocked  
last room you'd live in, waiting to be taken out  
for hallway walks or downstairs meals,  
then impatient to come back again, and be there  
alone with her again, just the two of you,  
in the minutes you were still aware  
you'd forget almost as soon as they passed.  
And so when you were cremated, we had an old set  
put in your coffin with you in your shirt pocket.  
I remembered you years before –  
before strokes and memory loss and dementia:  
you and my grandmother  
in the Sears cafeteria in the mall  
having dishwater coffee and worse soup together.  
She'd gone to get serviettes,  
and you turned to me and said,  
"You know, this is all I want. It's funny."  
I thought not much about it then.  
I was twenty, maybe. But now, fifteen years or so later,  
I think that in your way you were handing me a key.  
And now I wish you your ring of keys back in your hand  
and all your memory safe, intact and shining,  
and more—if there is anything more.

—Russell Thornton

## Ties That Bind

### Wednesday, October 13, 2004.

It had been a busy day. My husband Bill and I had spent the morning helping Mom and Dad do their fall garden cleanup, then came home and tackled ours. The phone rang. Bill got it. "It's your Dad, Helen. He says your Mom fell and can't get up."

"Tell him we'll be right over," I said, my heart pounding. Luckily they lived only a fifteen minute drive away. We arrived to find Mom lying on the grass beside the driveway desperately trying to get up, and in a great deal of pain and shock. Dad and a neighbour were standing over her.

"Have you called an ambulance?" I asked. No, they were waiting for us. I rushed into the house and dialed 911. Scant details emerged about what had happened as we waited. Mom had slipped pruning a shrub. Dad as usual was inside dozing on the couch. The neighbour, bless him, saw what happened and roused Dad. In Emergency, X-rays confirmed that it was a fractured left hip, with surgery set for the next day. I called Dad and Bill with the news that would change our lives.

After years of living with Dad's alcoholism and subsequent dementia, hypertension and diabetes, I, an only child, was used to crisis phone calls, and doing damage control. But it was always Mom, not Dad who called. Without hes-

itation, we decided that my husband should stay at home with Dad until I could get back from the hospital.

Mom was very anxious about who would care for Dad. I assured her that I would take over as caregiver with Bill's support, as long as was necessary. What choice did I have? I had spent much of my adult life alternately trying to solve their problems and distancing myself from them in order to have a relatively calm, happy life of my own. I had a stable family, good friends, hobbies and volunteer work I enjoyed.

My relationship with my parents was a difficult and often frustrating one that hinged on trying to keep things 'normal' between crises. I did what needed doing, but it was always a relief to walk out the door and back to my own world. Now I was being thrown from the frying pan into the fire! How would I cope? How would Bill manage this new reality? Well, I'd read enough AA self help books to know that I would only cope if I took one day at a time and I did.

Bill and I decided that it would be best if I stayed with Dad where he was most comfortable. Fortunately, our two daughters were grown, happily married and self sufficient. Bill would take over the lion's share of caring for our house and garden as well as supporting his mother who was in long

term care. I knew I couldn't be in both places at once and visit my mother daily.

Mom had surgery and was moved to the rehab unit. She was one determined lady and we all prayed that there would be no complications. This respite from caring for Dad was just what she needed. For once she could focus on herself knowing that Dad was cared for.

Dad and I got on fairly well. Fortunately, circumstances had forced him to stop drinking by this point or things would have been quite different. He was docile and tried to be as sociable as he could. He thanked me often for anything I did for him. I tried to put the past behind me. I was determined to stay positive and upbeat. I kept things simple. Please, I prayed, let nothing happen to him. I worried about the stairs as he had the habit of going down to the basement for no reason. But nothing more serious than a badly stubbed toe occurred when he bumped into his bed frame.

I encouraged him to help out with small jobs around the house like making coffee, washing dishes, setting the table and sweeping the driveway. I baked cookies and made favourite meals every so often. I bought extra chips and we had them while watching TV. We even bet on the outcome of the U.S. presidential election; and he won!

His routine was different than mine but to avoid rocking the boat, I adjusted. However, I refused to give up all the things I had enjoyed before so I arranged for a volunteer visitor or other family members to sit with Dad so I could go out with friends. I walked daily and spent as much time as I could gardening or reading. My husband never complained. If he resented the time I spent away he kept it to himself. He saved me time and energy by arranging for the various handicapped aids needed when Mom came home.

The weeks passed in a daze of daily living and visiting Mom. As her discharge day approached, my uncle installed a sturdy railing by the basement stairs and I arranged for delivery of frozen ready meals and for a cleaning lady to come biweekly, something Mom had always resisted. The day Mom came home, I prepared a celebratory dinner and packed my belongings for the trip home. I knew I would still be spending a great deal of time there, but at least I would be back in my own bed and have a semblance of my old life back.

Would I do it again? I'm not sure. In some ways that time with my father was a blessing. It gave me a glimpse of the gentle, humorous and kind man he might have been had alcoholism and the resulting dementia not taken their toll. I came to forgive if not forget. I better understood my mother's coping mechanisms and her



daily stress. I accepted that she did the best she could, although I would have done things differently. I found a reserve of strength, patience and compassion I didn't know I possessed. I came to value my family and friends in ways I'd not done before.

**An update: June 20, 2007.**

Shortly after returning home I suffered the first of two retinal hemorrhages due to hypertension. After 13 laser treatments and two eye injections, I'm back to doing the things I love. I still have ups and downs,

side effects from medications, bouts with depression and my energy isn't what it was. But I'm content and feel very lucky to spend time with family and friends.

My father is in long term care after falling down the basement stairs. Mom is still in her own home with help from her family. So yes, I wish those weeks hadn't happened but I'm not altogether sorry that they did.

—Helen MacPherson

*"It gave me a glimpse of the gentle, humorous and kind man he might have been..."*



© Eleanore and Richard Kosydar

Cootes Paradise, Hamilton ON, CA

## Listening at the End of Life

For me, “End of Life Care” has a very special meaning. It represents the greatest learning experience of my life and of my long nursing career of 48 years. It involves my mother and me, and the six years plus during which I cared for her in my home. It also involves close friends.

Mum had always been a gentle person. Her feelings were seldom shown until she was nearing the end of her life. Never to be forgotten were three life episodes Mum shared, in reluctance at first, but later with great clarity.

Mum had been looking forward to having three elderly friends come for a formal tea. The day they were to join us Mum was not feeling well but insisted the event not be cancelled. She joined them for tea then asked to be taken to her room. When I checked on her, Mum asked to see each friend separately, saying she wanted to receive the benediction. It was clear that I was not to be present. The benediction was a way of engaging each in Mum’s special mission, that of asking good friends to take care of me when she was gone.

I will never forget Mum’s other two highly moving experiences. She awoke from her afternoon sleep with a radiant smile and a look of extreme peacefulness. It was so unusual, so obviously calming, so spiritual, as I learned later on that day.

We sat together in silence at first, her experience was only for herself. When I asked if what had happened was positive, a quiet “yes” was uttered. She said she was at peace, that I was not to worry. When I asked if she could share what had happened she said “no”. I respected her wish and told her if she ever wanted to relate what had happened it might help me in my old age or in my work with others.

That evening she was ready.

An angel had come and had taken her home to her early farm days, then to where my sister and brother-in-law live, miles and miles apart. Friends, family and the minister she had chosen for her funeral were all there. It was for her a magnificent reunion. She told me not to be afraid, that she was at peace, without any fear. I was reminded of the biblical words, “The peace that passeth all understanding”. To my knowledge the angel appeared only one more time, this time in everyday clothes. No further details were shared, if they occurred. They remained private.

What do these experiences mean to a daughter, a family and health professionals? For me they represent a very privileged and trusted relationship. They also represent rich and insightful learnings not experienced in 48 years of patient care.

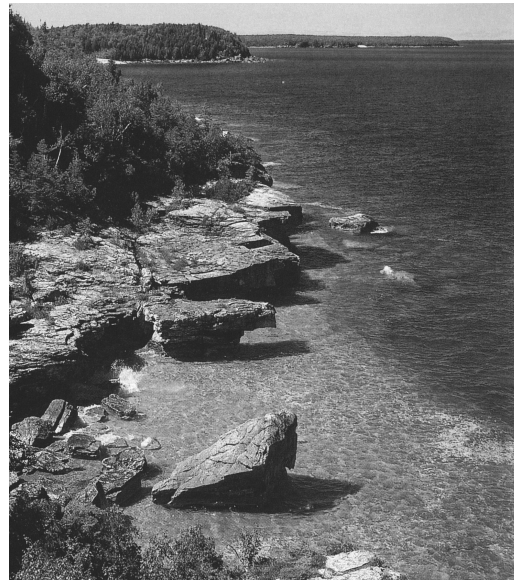
Clergy told me it is rare to witness such insights. They are shared only in relationships of trust. I regret that my family was not part of those moments and have tried to convey them as best I can, for they add a rare dimension to end of life care. I am left wondering how staff in

long term care can learn from my experience and find ways to be of help to elderly residents. It is easy to focus on tasks. However, preparation for the end of life comes from being open to learning from those whose life paths are ending.

—E. Mary Buzzell

*“Preparation for the end...comes from being open to learning from those whose life paths are ending.”*

© Eleanor and Richard Kosydar



Bruce Peninsula National Park, Georgian Bay ON, CA



## PERSPECTIVE

*All stories have a coda, 'a retrospective evaluation of what it all might mean, a feature that also returns the hearer or reader from the there and then of the narrative to the here and now of the telling.*

—Bruner (p. 20),

quoted by Anna Burack-Weiss, *The Caregiver's Tale*

Here is the last word, from one of the caregiver-writers of this collection (see her poem, "*The Caregiver*"). In this essay, Anna Jones' sensible streak and plain talk bring us around to see the end of our stories in just the right light.

Turning 89 this year and moving only recently out of her own home, Anna knows caregiving from many different angles. Learning the value of sharing in the first part of the last century, she returns her readers to the "here and now" of our own stories.

Anna peppers her comments with lots of advice and humor, and offers us directives and definitions, as well as thoughtful aphorisms.

- Look, for example, for the distinctions she draws between "fluffy care" and "intense care".
- Find out what she means when she advises us to "travel the road 'First Class'".
- Consider the ideas she offers for dealing with a difficult patient.



## Ideas, Thoughts and Concerns about Caregiving<sup>11</sup>

I was born and raised on a century-old farm in the rural Copetown area (in Ontario). In 1919, life-style was very primitive compared to our standards now. We had no telephone, radio or car. Families settled in this area were few in numbers. Neighbours were all white-skinned, of Anglo Saxon descent and mostly of the Protestant faith.

In order to survive, I learned we had to care for each other in our families and community. Money was very scarce, but we existed through exchange of care and services. We needed each other, making contacts by traveling with horse or by foot. Trading and sharing was part of our life-style: sharing with food, clothing, care of families and even care and exchange of farm animals. We shared the challenges of sickness, tragedy and life-style difficulties.

Doctors and professional people were few and at least five miles away. Many clever tricks of caring were devised under these circumstances. Being born into this era, it was common practice for women to be entirely responsible for home-life and caring for the family. This caring even spilled over to animals and their needs.

As soon as I could walk, I accompanied my parents when they cared for the chickens, horses, cows and pigs. Vividly, I remember

cuddling the runt of a litter of piglets. Wrapped in a piece of blanket, the small creature, more dead than alive, was brought to the house for special care to gain strength. With tender attention, this piglet would turn a pinky colour and start to wiggle.

The value of good care, with compassion, to people and animals was a big part of life. My concerns for care grew with me, as I was a mother to four children living on a farm. My husband was not a strong person, but this wonderful man survived to eighty years of age. Good care of himself was the canopy for his existence. Low stress levels, good food and positive thinking led to a worth-while life for him.

My mother had a major influence on my life, especially in the realm of care. For a quarter of my life, she was my major teacher. When she grew older, mother lived one mile from my farm home. She was a widow for 30 years living alone. She stayed in her own home until she was 96 years old.

During these years, my concerns for her well-being were my primary issues. Providing care at three levels, husband, family and aged mother is almost an impossible task. The caregiver risks the loss of their identity. Financially, caution has to be practiced. The caregiver has to con-

<sup>11</sup>AUTHOR'S NOTE: The challenge of writing down my ideas of caregiving has been an opportunity. These thoughts are entirely from my own experiences. I've been richly blessed throughout my life. Truly, I hope and pray I've been able to help others find the way.

tinually tell herself, “God never gives us burdens we can’t endure.”

### **Lessons Learned as a Caregiver**

Good health and the feeling of wellness are essential attributes to be a good caregiver. These gifts are attained by a diligent desire to keep yourself well, so you can serve others. Caregivers must have adequate rest to be able to care for another person. Giving care to others is very draining of one’s energies.

A good caregiver must radiate a feeling of well-being, give out cheerfulness and give the feeling to those around you that things will turn out for the best. A caregiver has to have her or his own well-being before it can be given to others. A caregiver can give out cheer by her own good grooming and appearance.

Lively positive conversation initiated by the caregiver can stimulate the patient. A good caregiver will make the patient aware of their own blessings. Preparing and eating nutritious food are “musts” for both caregiver and patient. As a caregiver going into another person’s home, you must be canny as you check out-dated medicines and food products. My own mother delighted in having adequate supplies. This intrusion into their privacy is difficult for everyone, but so necessary. Think well of yourself! You are doing a big job.

### **Defining a Caregiver**

Who am I as I face this enormous challenge to be a good caregiver? The care needed for the full span of family life falls into one of three categories. The first care involves one’s own children, secondly, your own generation including husband and siblings and thirdly, your parents or a senior family member. Each category has different needs, actions required, strategies and challenges.

During my 88 years of life, I’ve encountered care needed for all groups. Now I realize my candle is burning slowly. My next step will be a retirement home. I give thanks to the good Lord, who made us strong to cope with life at every stage.

A caregiver experiences many different joys, sorrows and challenges during a lifetime. As life evolves before a caregiver, one experiences changing anxieties and empathies. One has to be alert, to pay attention to activities, to heed and be aware what’s going on. As a good mother, you have to feel you are in charge to be able to guard and protect those under your care.

A caregiver’s day can be filled with profound anxiety and fretful worry. Decisions have to be made for loved ones as to what path to choose for the best. Coping with unexpected situations requires a great deal of energy and wisdom. It is not easy to be a caregiver.



## Strengths Caregivers Need

To be able to care for others, a caregiver must be strong mentally, physically and spiritually. I'll reveal my thoughts in the same order.

*Mental Strength.* You can't be an island unto yourself. Tap into abilities of family and friends. As for family help and advice, accept what's suggested in a gracious way. During each stage of your caregiving, try to be informed as much as possible. Libraries and the Internet provide information for many perplexing situations.

A great deal of diplomacy has to be used in troublesome situations. No one wins in an argument. You'll find you have to bite your tongue as you listen to your opponent. Humour is your best friend in rough times.

At all times, a caregiver must be honest. When you tell or repeat the truth, it does not need a cover-up. In caring for a child or a difficult patient, distraction helps to climb a big mountain, for example when giving a medication. Do not say "Your pill is crushed in this applesauce", but rather say "Do try this fresh applesauce".

When as a caregiver, you are involved with giving medication, be sure to know and understand what you are doing. Don't trust your memory, you must write down instructions. A good guide, especially with seniors, is to have duplicate copies of prescribed care. These instructions given by

professionals are for the patient's benefit and caregiver's protection. Care orders can be misinterpreted or neglected.

Persons receiving care should tell the caregiver of changes in their condition, feelings and problems. As a caregiver, keep yourself as bright and attractive as possible. It is difficult to find time for yourself, but it will pay off dividends.

The patient should be encouraged to cultivate good grooming. Help the patient to dress as attractively as possible. It's good policy for everyone's moral. Travel the road "First Class".

*Physical Strength.* A caregiver must have a healthy diet and adequate rest. To share wellness with others you must first have it yourself. Throughout all the aspects of caregiving, physical health and strength are important.

*Spiritual Strength.* As a caregiver, be your true self. When involved with a situation where a caregiver is needed, protect your own strength and energy. Take a survey for back-up support from family and friends. Your own spiritual meditation will help.

At first, you'll be tempted to always portray the perfect impression. Don't keep your own caregiving feelings and emotions "bottled up". Sometimes a caregiver has to sacrifice. You'll find sometimes you have to take a "back seat" and back off from your own suggestions, plans or

dreams. Inwardly, vote for yourself and silently ask for divine direction.

As a caregiver, you are a special person and your feelings should be respected also. Caregiving refines you to be a better person when you have to seek spiritual guidance. Strength does come in times of need, but you have to ask. Cultivate an open mind and be appreciative of other ideas. In crisis, be positive and say to yourself, "This too shall pass". Make the best of each day as you care for others. Love never dies, even though at times you may feel whipped and weary.

### **Different Types of Caregiving**

*Intense Care*, given with love, is the highest kind of care to be given. Caregiving motivated by true love is a rich experience for both the caregiver and recipient. This love affair is genuine service given to a person with shared empathy. Love and interest in each other bridges difficulties that arise.

Caregiving, especially involving a senior, starts off with the caregiver enthusiastic to truly help. Through continuous service and monotony of routine, the glow wears off. The caregiver starts to feel the burden and things getting out of control. This situation needs great diplomacy and awareness of yourself. As a caregiver, you have to realize what your own body will tolerate.

When energies break down, extra help must be solicited. If this exhaustion pre-

vails, you must recognize a change is essential. If you have been a caregiver for a long period of time, you'll understand.

Less intense care is what I call "fluffy care". It involves visitation, helpful contacts to shut-ins, buying groceries, driving to appointments or accompanying a person for a walk. This type of caregiving is very rewarding to the giver. You feel good about helping someone, but it doesn't drain your energy like intense care. It's voluntary service, as agreed by the giver and receiver.

One does not become involved in the trouble or poor health of the situation. Many caregivers find this service very stimulating to themselves and receive rich rewards in return.

The providers of medical care deserve much praise for their contributions. I find it almost unbelievable what a variety of services are offered to all of our people these days.

*Palliative care* is that higher level of comfort offered by a trained nurse. Comfort beyond the ordinary caregiver is needed when a "no recovery situation" arises. Specially trained personnel can offer so much support with the imminence of death. Advice for the family given by a palliative caregiver helps them so much.

*Respite care* has to be secured for the patient when the caregiver needs a break, a holiday or a good rest. Usually, it's the family doctor who takes action when

need arises. The patient is well cared for in other facilities while the caregiver has time to gain strength.

### Caregiving Over Time

During the past 100 years, tremendous advances have been made. The public must try to be knowledgeable about what changes occur.

Early in the 20th century, all seniors were cared for in the home until death. I remember grandparents having a couch in the farm kitchen. This was their bed, day and night. It was the only heated room during winter.

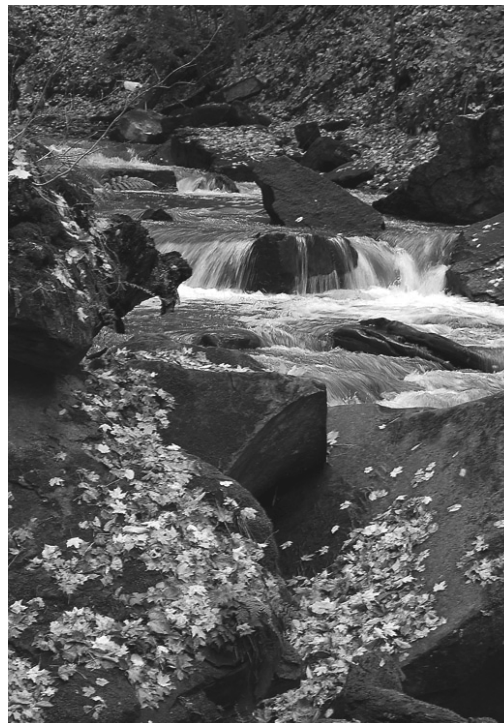
Caregivers had to resort entirely to home remedies. The proper equipment to handle the elderly was not available. Caregivers had to find ingenious ways to handle situations and work with what they had in the home.

### Caregiving in the Present Day

Modern life certainly has changed for the caregiver. Take, for example, walkers for seniors. Caregivers and families of those needing help must seek information and resources to get proper assistance. Medical help is available, but one has to be persistent in one's search.

—Anna L. Jones

*"In crisis, be positive and say this too shall pass."*



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Spencer Creek at Spencer Gorge,  
Greenville ON, CA

## List of Photographs

Photographs within the text are courtesy of © Richard and Eleanore Kosydar, who are passionate in their commitment to capturing what they describe as the “singular natural beauty” of parklands in Ontario, Canada, particularly the Dundas Valley. They have published two colour photographic books with accompanying text on the Valley’s ecology and history, most recently in *The Dundas Valley: Visions of Beauty* (2007), Dundas ON, Tierceron Press.

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## BIOGRAPHIES

### **Carole Abrams**

Carole Abrams is a retired school teacher. She began writing as a child when she kept a diary. She lives in the country outside of Dundas.

### **Patricia Aylott**

Patricia Aylott, aged 69, lives in Thunder Bay ON, CA and is very active volunteering for the Alzheimer Society and at the 55+ Centre in her community. She takes oil painting classes and creative writing classes seasonally, sings regularly in the 55+ choir and in her church choir, likes to walk regularly and work out at a local gym.

Serving the Alzheimer Society and those who care for loved ones with Alzheimer's disease is still Patricia's passion, and it keeps her busy. Her life is full.

### **Brenda Baker**

Brenda Baker is a writer-performer from Saskatoon SK, CA. Her work has been published in several journals and anthologies, and in 1999 her first book, *The Maleness of God*, won the Saskatchewan Book Award for Fiction. She has five CDs to her credit, the latest of which was short-listed for a Canadian Indie Award. She continues to perform, mostly for young audiences around Saskatchewan, and is the founding director of *Kids of Note*, a choir designed for the meaningful participation of children with cognitive disabilities. [www.brendabaker.com](http://www.brendabaker.com)

### **Lynore G. Banchoff**

Lynore Gause Banchoff is a retired social worker, mother and grandmother. who began writing poetry in 1980 while crossing the English Channel. She was born in So. California and returned to live in Menlo Park CA, USA three years ago.

Lynore's poetry has been published in books and magazines including the *Rhode Island Writers' Circle Anthology* which gave her a Second Prize.

### **Mary Lynn Banchoff**

Mary Lynn ("ML") Banchoff was born and raised in Providence RI, USA, and spent several years in the DC area before settling down with her husband in Texas. She currently paints portraits in pastel and is in training to lead workshops to end the battle of the sexes.

### **Mary Brown**

Mary Brown is a Surrey BC, CA writer whose work has appeared in *BC Parent* and *Chronically Canadian*. Brown has been a lifelong caregiver of family, friends and pets, and currently volunteers for the Chronic Disease Self Management Program in British Columbia. Now, using a wheel chair because of post-polio syndrome, she enjoys having time to write of life during the Depression and while 'living in the woods.' She still finds it fascinating to observe her own aging process.

### **E. Mary Buzzell**

E. Mary Buzzell is a veteran nurse having practiced and taught in Canada and internationally for more than 50 years. Mary taught in the School of Nursing at McMaster University for 16 years. As well she has taught family caregivers on topics such as stress, powerlessness, guilt and anger and community resources to help. She has been especially dedicated to teaching how to foster personhood in long-term care, and was the main family member caring for her mother Helen for seven years. Helen taught family and friends many treasured lessons in courage, hope, joy and love.

About herself, Mary writes:

“Nearing my mid seventies is a very insightful and reflective time of life for me. I am blessed to be surrounded by younger colleagues and friends who have become my teachers, support and strength. I enjoy teaching them too. For me the mystery of life is a precious gift.”

In 2001, Mary was honoured by McMaster University with an Honourary Doctor of Laws for her contributions over the years.

### **Peter Cameron**

Peter Cameron works as an educational researcher, after a career of nearly 30 years as a high school teacher working with disadvantaged children. He also works as a caregiving representative for several cancer voluntary organizations. Peter currently lives in England, and

hopes to visit as many places in the world as he can. He is particularly moved by the sheer power of storytelling where, he says, “narrative can be used to let others know about good as well as bad feelings.”

### **Gaiyle J. Connolly**

Gaiyle Connolly is a semi-retired art educator, and a Hamilton, Ontario resident of many years. She keeps busy volunteering, working as a guest artist, and indulging her passion for writing poetry and professional articles, and editing.

She has been published in several anthologies, and finds inspiration for art and print from her travels to exotic destinations.

### **Vanessa A. Denny**

Vanessa A. Denny lives in Hamilton ON, CA, is self-employed, a proud mother and grandmother. Enjoys renovating, restoring antiques, writing, music and training animals since she was 19 years of age.

“In my deepest moments of despair I turn to my spirituality as it has always helped me and I hope that this story will help to inspire others.”

### **Robert C. Dickson, M.D.**

Robert C. Dickson is a semi-retired family physician, practicing and living in Hamilton with his wife Mary Lou. He has been writing and publishing poetry for decades. His work has been included in issues of *Kairos*, *Hammered Out*, various medical journals including CMAJ and in hardcover anthologies *Pine's the Canadian Tree* and *This We Believe*.

**Wendy Edey**

Wendy Edey is a hope specialist, counselling psychologist and educator at the Hope Foundation of Alberta in Edmonton. Storytelling is a passion that enables her to find hope in happy and troubling life events. Her father-in-law Harry inspired her with his determination to be the best that he could be. This story is a gift of thanks to him.

**Jane Faraday**

*Jane Faraday* is a pseudonym created at the request of the author, who is a writer currently living in ON, CA. She began writing after her retirement as an audio-visual archivist. Her husband was diagnosed with Vascular Dementia/Alzheimer's Disease in the summer of 2003, and in October, 2007, the author and her husband celebrated their twenty-fifth anniversary—a second marriage for both of them. Between them, they have seven children and fourteen grandchildren.

**Linda Lee Geary**

Lin Geary, of Paris ON, CA, is a retired English teacher and freelance writer who won the Arts Hamilton Award 2005 for her short story *Mauve*, published in *Hammered Out*, a Hamilton literary journal. Geary more recently wrote and staged a one-act play on the life of Adelaide Hunter Hoodless at the 2007 Cobblestone Festival in Paris, ON. She is also a widely published poet who can frequently be heard at readings in coffee houses in Ontario.

**Steven J. Gottesman**

Steven J. Gottesman, originally from New York City, USA, currently works as an architect, living in Phoenix AZ since 2002. His architectural designs for various public and private clients have been published, winning awards over the past two decades. He began writing creatively as part of an ongoing personal spiritual journey and has seen some of his poetry published by several non-profit organizations.

**Tomas L. Griebing, M.D.**

Tomas Griebing is currently an Associate Professor and Vice-Chair of the Department of Urology, a Faculty Associate in The Landon Center on Aging, and an Assistant Dean for Student Affairs at the University of Kansas School of Medicine. His clinical practice and research focus on urinary incontinence, voiding dysfunction and other health-related quality-of-life issues in older adults.

A native of Mason City IA, USA, Tomas now lives in Shawnee, Kansas. His interest in creative writing and poetry are motivated by reflection on significant life events, and a desire to incorporate the arts in his daily life and work. An active musician, he is a Past-Chair of the Humanities and Arts Committee for the Gerontological Society of America, and a Lifetime Member of the National Flute Association.

### **Paula Grove**

Paula Grove is a Hamilton native who recently returned to care for a family member. She has worked in theatre, film and television for the last 17 years.

### **Dave Haskins**

Dave Haskins is returning to writing after a career Teaching English in Niagara secondary schools. He lives in Grimsby ON, CA.

A graduate of McMaster University and the University of Toronto, he currently writes poetry, short stories, and young adult fantasy. His published work includes a book of poetry, *Reclamation* (Borealis Press). Other works appear in literary journals, anthologies, and collections.

### **Tana Holland**

Tana Holland is a Master's level literacy and language specialist in Kelowna BC, CA She describes herself as an emerging writer and is currently co-writing a book called *Body of Purpose; A Healing Journey for Women*. She is also working on a book full of recipes and stories in homage to her Italian roots.

### **Marika Ince**

Marika Ince is an educator and life-long learner. Her writing is often inspired by the power of relationships, and her passion for social and environmental justice. She and her family live and garden in Flamborough Centre ON, CA.

### **I.B. Iskov**

I.B. (Bunny) Iskov is the mother of a young man who suffers from Pervasive Developmental Disorder & Schizophrenia. Bunny began writing poetry as a therapy, in order to help her cope as a caregiver for her son.

Her poems about her son have been published in numerous mental health publications, including *Open Minds Quarterly & Transition*. Her poems have been published in newsletters by 13 branches of the Canadian Mental Health Association. She is the founder of The Ontario Poetry Society.

### **Anna L. Jones**

Anna Jones, born in 1919, is an amateur writer with a rural Copetown (Ontario) background. Her thanks for the inspiration to continue writing go to: her family's positive influence, friends who gave her wings, the medical profession for their knowledge, her spiritual heritage, and continued support from the McMaster Centre for Gerontological Studies, in particular, Ellen Ryan. Anna writes:

"As seniors, we have experienced love, decisions, duty, joy, and exhaustion all mixed together. When life's frailties increase, any knowledge we can share is our privilege."

### **Bernard Klein**

Bernard Klein is a retired electrical engineer by profession, a still practising musician (violin) by avocation, currently living in a seniors' home in Hamilton,



Ontario. This is his debut as an author of published non-technical writing.

### **Barbara Knill**

Barbara Knill is a former realtor, married to the same man for fifty years, mother of three and grandmother of four. She and her husband are both retired and actively engaged in helping to rebuild their adopted “City of New Orleans”. Volunteering is now a way of life through their church, hospitals, politics and city planning. Visits to children and grandchildren are as frequent as possible as they are now the ones several hundred miles away.

### **John B. Lee**

John B. Lee is a writer who lives and works in Brantford ON, CA where he is Poet Laureate of the city. He has published well over forty books and his work has appeared in more than 500 publications. Lee has received many prestigious awards for his work, most recently, the *Winston Collins/Descant Award for Best Canadian Poem of 2007*. His most recent book is *How Beautiful We Are*, a winner of the Southwest Orion Award.

### **Magda Lenartowicz**

Magda Lenartowicz graduated from the McMaster University Gerontology Program in 2006, and currently lives in Ontario and works for the Department of Health, Aging, & Society at McMaster (she loves it so much she just cannot leave).

She is fascinated by the intricacy and interplay of language and cognitive

impairment, and is interested in learning more (and teaching others) about dementia, and the fact that cognitive impairment does not necessarily mean the loss of language, but its enrichment.

Her love of writing and poetry come from her great-grandmother, a teacher of Polish literature and history in Poland’s underground during the Nazi occupation, and a source of constant support and admonishment to speak and write well since, as she always told Magda, the soul lives in poetry.

### **Mark Leslie [Lefebvre]**

Mark Leslie is a Hamilton ON area writer and editor whose stories have appeared in a variety of magazines and anthologies. His collected stories appear in the book *One Hand Screaming* (Stark Publishing, 2004) and more recently, he edited the science fiction anthology *North of Infinity II* (Mosaic Press, 2006).

When he’s not writing, he tags “Lefebvre” back onto his name and works as Book Operations Manager at Titles, McMaster University’s bookstore, which recently celebrated 75 years of service to the McMaster community.

### **Gail Linklater**

Gail Linklater lives in Thunder Bay ON, CA and works as a social worker at AIDS Thunder Bay. She began writing as soon as she could hold a pencil and finds writing a means to sort her thoughts and release her feelings.

### **Helen MacPherson**

Helen MacPherson lives, writes and gardens in Ancaster ON, CA. About herself, she writes, "I've been retired from my job as a receptionist/assistant in an Optometrist's office since the year 2000. Having been interested in writing since my grade school days, I decided to pursue it more seriously as my own personal millennium project and enrolled in the Writing for Publication Certificate Program at Mohawk College." She completed that program in 2003.

### **Honey Novick**

Honey Novick is a Toronto singer/ songwriter/ voice teacher/ poet. She facilitates *Sing Your Way* for Sheena's Place which offers support services to people with eating disorders. and the *Spark of Brilliance*, a programme of the Canadian Association of Mental Health (CAMH), who use the arts to support their clients.

Writing is a way that she cares for herself.

Honey has been published both as a poet and songwriter, and can be reached by visiting [www.honeynovick.com](http://www.honeynovick.com)

### **Anne Philpot**

Anne Philpot is a semi-retired fundraising consultant who is currently doing some work for CUSO and United Way and volunteers with the Stephen Lewis Foundation *Grandmothers to Grandmothers* Campaign. She was born in Ottawa, loves to research and record the family genealogy, visit her grandchildren in Nova Scotia. She currently lives and works in Hamilton.

### **Anna Piskorowski-Adams**

Anna Piskorowski-Adams was born in Belgium, emigrated to Canada as a child, and currently lives in Ontario. She is a former elementary school teacher with degrees from universities in Canada and England and is now a full-time caregiver. She began creative writing when she was looking after her mother and needed an outlet to express her own insights into caregiving.

### **Margaret Pitkeathly**

Margaret Pitkeathly of Burlington ON, CA penned *One Moment in Time: An Alzheimer Love Story* in 1993, eight months before her husband's death. In this excerpt, Margaret speaks of keeping a journal exclusively devoted to *good* moments she and David continued to share. Those who find journaling therapeutic may see, in Margaret's approach, a powerful and effective coping strategy.

Retired from a career in corporate communications, Margaret has, since 1990, addressed diverse audiences on behalf of the Alzheimer Society. As a former caregiver, Margaret seeks to enlighten, encourage, and enable those responsible for the well-being of persons with dementia.

### **Stella Mazur Preda**

Stella Mazur Preda is a poet, whose book, *Butterfly Dreams*, was published in 2003. Stella began writing poetry in 1992 after the passing of her beloved father. She currently lives in Flamborough with her

husband and three cats. She retired from elementary teaching and is now owner and publisher of Serengeti Press.

Stella's poetry has been published in numerous books and magazines. Her poem, *My Mother's Kitchen*, was purchased by Penguin Books, New York and published in 2006 in an anthology entitled *In My Mother's Kitchen*.

### **Wendy Shade Reichental**

Wendy Reichental is a 46 year old living in Montreal, taking care of her feisty, independently-minded and independently-living, 86-year-old mom while trying to maintain a happy balance with her husband. When not writing short stories, Wendy works four days at McGill University as a secretary for the Dean of Continuing Education. Wendy earned a B.A. (1984) and Diploma in Human Relations and Family Life Education (1986) from McGill University.

### **Bernadette Rule**

Bernadette Rule is an Ontario teacher and writer, originally from Kentucky. She has had several collections of poetry published, most recently *The Literate Thief: Selected Poems* (Larkspur Press, 2006).

### **Ellen Bouchard Ryan**

Ellen Ryan is Professor Emerita at McMaster University and formerly, the Director of the McMaster Centre for Gerontological Studies. Her psychological research addresses the roles of empowering communication in fostering personhood and successful aging.

As Series Editor for *Writing Down Our Years*, she seeks to highlight the many benefits of writing life stories for older adults and those with whom they share their stories and poems.

She lives with her husband in Ancaster ON, CA and enjoys traveling to Sweden to spend time with her grandchild. She began writing poetry 7 years ago and makes use of poetry in her teaching and workshops.

### **Christy Santoro**

Christy Santoro served as the primary caregiver for her great Uncle Joe (who was essentially her grandfather) for the last 6 months of his life in 1996–97 in Norristown PA, USA.

This caregiving experience was the catalyst for her pursuing her calling as a midwife. It opened her eyes to the importance of a holistic approach to caregiving, and the similarities between working with women giving birth and working with people at the end of life.

Santoro is now a homebirth midwife based in Philadelphia PA, USA serving women and families in Pennsylvania, New Jersey, Delaware, and Maryland.

### **Grace Stewart**

Grace Stewart lives in Dundas and only recently began to write poetry.

THIS LITTLE LIGHT OF MINE:

### **Russell Thornton**

Russell Thornton is a North Vancouver BC, USA poet. Much of his work originates in his experience of his close family members as well as the west coast natural environment of his birthplace. His poems have won a number of awards, including First Prize in the League of Canadian Poets National Contest in 2000. His books are *The Fifth Window* (2000), *Thistledown*, *A Tunisian Notebook* (2002), *Seraphim*, *House Built of Rain* (2003), *Harbour*, and *The Human Shore* (2006), *Harbour*.

### **Naomi Wingfield**

Naomi Wingfield came to expressing herself through poetry in her early eighties. Now, at 95, recently moved into her own apartment in a retirement facility, she is still writing and anticipating the arrival of her first great-grandchild. Her collection of poems, *Light All Around Me* (2007), is available through Ellen Ryan at the McMaster Centre for Gerontological Studies.