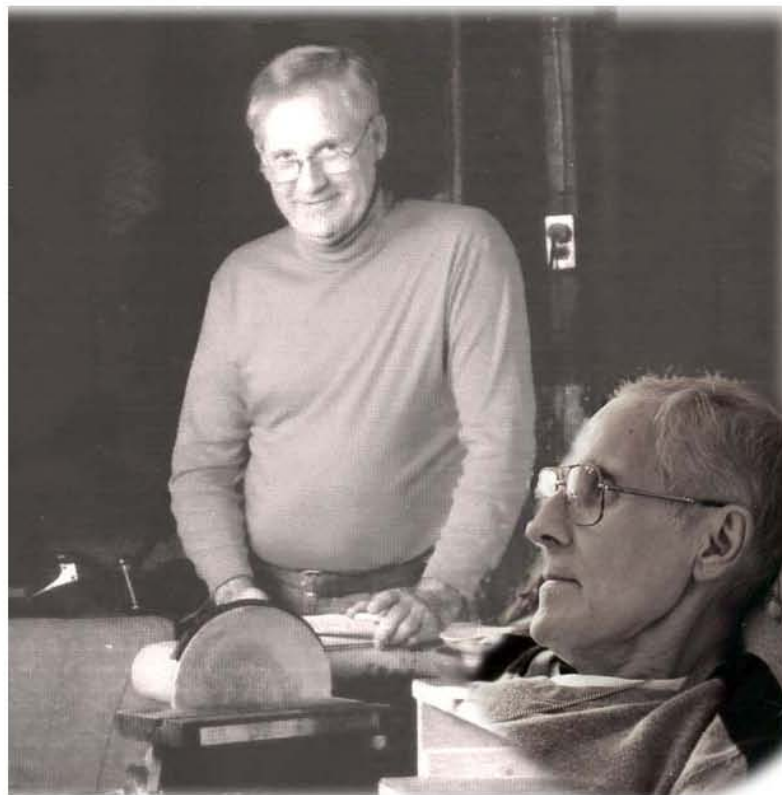


PASSING ON THE BLESSING:

STORIES, TIPS AND TOOLS OF A FAMILY CAREGIVER



KATHLEEN M. BANCHOFF

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***PASSING ON THE BLESSING:
STORIES, TIPS AND TOOLS
OF A FAMILY CAREGIVER***

KATHLEEN M. BANCHOFF

***SERIES EDITOR, ELLEN B. RYAN
THE McMASTER CENTRE FOR GERONTOLOGICAL STUDIES
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OF A FAMILY CAREGIVER**

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FOREWORD:
Knots, Memories, and Bouquets

by E. Mary Buzzell

There were many blessings to be had in that company and time, and finding the stories to tell about us returns me to the laughter and joy of it. It seemed like the hardest thing I've ever done effortlessly, and that is the grace I want to pass on. This is the book I promised Skip I would write.

Kathleen M. Banchoff

These 59 words by Kathleen M. Banchoff (KMB) are profound, especially her description of caregiving as “the hardest thing I’ve ever done *effortlessly*.”

Blessings are not often experienced, but Kathleen’s caregiving stories illustrate how to be on the watch for them even at times of loss. Blessings are unexpected gifts, surprises, sources of wonderment – emotional, physical and spiritual. Blessings need not be huge, need not be expressed verbally but are deeply felt. They can be recalled at will, reminding caregivers of the privilege of caring for a loved one who is suffering.

The late Father Henri Nouwen reminds us that suffering can lead to heightened intimate relationships, which can evoke joy as Kathleen so beautifully describes. Joy, not often associated with pending loss, helps the caregiver soldier on, and helps the person in care (like Skip, Kathleen’s father, and her other relatives) enjoy special moments. Joy often creates laughter which energizes and connects people to each other.

Kathleen's honesty enables her to share her knotty dilemmas and to reach out to others as she comes face-to-face with Skip's terminal illness and her acceptance of it. The tips and tools based on her caregiving experiences provide bouquets of concrete suggestions for caregiving readers to reflect upon and alter for their own particular circumstances.

Time, time, time! We caregivers often feel prisoner to it, even desperate in its clutches. In her frequent prayer "Thank you God for one more day with Skip", however, Kathleen helps us see time as a very precious commodity – the peace that passeth.



E. Mary Buzzell is a veteran nurse having practiced and taught in Canada and internationally for 51 years. Mary taught in the School of Nursing at McMaster University for 16 years. In 2001 she was awarded an Honorary Doctorate of Laws from McMaster and the Order of Ontario in 2002 for her contributions to education about aging and health. She has been especially dedicated to teaching how to foster personhood in long-term care.

A highlight of Mary's career was working for VON [The Victorian Order of Nurses] both at the National and Hamilton, Halton branches in Ontario. Seven years ago she developed an education series for Family Caregivers and continues to teach this for VON in her retirement. She was the main family member caring for her mother Helen for 7 years. Helen taught family and friends many treasured lessons - courage, hope, joy and love.

ACKNOWLEDGMENTS

Thanks to the **Victorian Order of Nurses** and to Anne Vallentin, director of their caregiver services in Hamilton, Ontario, for successive opportunities to work for the family caregivers in her practice.

Thanks to Ann Anas and the **McMaster Centre for Gerontological Studies**, for making this workbook a reality.

Thanks to Sophie Blistein, Frank Farris, Diana Jackson, and Robin Margolis for reading my stories and talking back to me.

For Ellen Ryan, my appreciation for your encouragement and support, particularly in the early days when your vision was clear, and mine, dim.

For Felicia McCarthy, my heartfelt gratitude for your tender-hearted spirit and for working with the clay of my words to shape my experience into story.

For Tom Banchoff, my continuing wonder and my deepest thanks for your love.

INTRODUCTION

Who would believe that the work and the care in living with frailty, illness, and nearing death could be anything like a blessing? And how in the world could there be a way to tell stories about it?

Taking care of my husband Skip at home as we lived with the debilitating effects of pancreatic cancer was not my first opportunity for caregiving, nor has it been my last. Skip and I accomplished that monumental and simple task in the company of family, friends, and neighbors over what seemed like an endless period of time. Yet it was only 10½ weeks.

There were many blessings to be had in that company and time, and finding the stories to tell about us returns me to the laughter and joy of it. It seemed like the hardest thing I've ever done effortlessly. That is the grace I want to pass on, and this is the book I promised Skip I would write.

"PASSING ON THE BLESSING" is a catalog of the gifts that have come to my family in caregiving. In the large Irish, Catholic family into which I was born, there is a long caregiving tradition, and an even longer storytelling tradition. Using both, I've put together this "workbook." My purpose is to help you see us, and to see your own place in the stories I tell. Stories like these happen in your own life.

Each story describes an opportunity for savoring the life that is present every day, especially as we face loss. Each tool or tip is a means we found for living gracefully with limitations – my own, those of my loved ones and my friends. I offer them to you who find yourselves awash in troubles, taking care of a loved one, and to you who stand by us. I wish to leave you with a sense of refreshment and renewal, and to inspire you to find your own stories.

AUTHOR'S NOTE: To respect the privacy of my family and friends, I have made up names for everyone in these stories except for mine and Skip's. The people are real; the stories reflect reality as I live it.

An Invitation



Will you join me?

I want to collect your stories about family caregiving, and the tips and tools you have for handling that enormous task.

Consider this an invitation to look for the stories and the lessons in your own family caregiving. Identify your moments of challenge and the ways you've invented to manage those moments, and write to me. We will find a way to craft it for sharing.

You may learn, as I have, that writing about your experience helps you. Others will identify with you and appreciate your personal words.

Your story can make the difference...

Kathleen M. Banchoff



Our intention at the Centre for Gerontological Studies is to publish this unique collection edited by Kathleen Banchoff under the title, ***This Little Light of Mine***. Please contact us to confirm your interest in participating in this exciting project. We will send you submission guidelines and the necessary forms (i.e., authorization and permission for publication). We will accept submissions for the first collection until **June 30, 2007**.

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September, 2006

CAREGIVING STORIES

SKIP

Bless Me

“How was I going to get through this? Now I needed a story not of survival but of transformation. ... a map of the unlighted journey I was about to take.

– Michael Chorost (2005), Rebuilt: How becoming a computer made me more human. New York: Houghton Mifflin.

Hearing the doctor say to Skip, “It’s stage 4 of 4, and the cure rate is zip” dumped me into the rapids of the river that would take me too quickly to the end of our years together. How was I going to get through this? In those first moments, as we drove home, it was Skip who said quietly to me, “*We have been broken open, my love, and your job is to say, ‘yes.’*” What else could I do? I had to find a way to live into that “yes.”

In the meantime, while we waited for his children to come to the house, he called several friends and shared the news, straight up. To one, he added: “*I don’t want you standing at my coffin telling someone else you thought I was a nice guy! If you’ve got something to say, get over here!*” That made me laugh.

We went on together to face those who responded to his invitation. I moved easy chairs from the den into the bedroom so the friends and family who often came together in clumps could be comfortable. And when we ran out of seats, I told the last one coming through the door to get into the bed next to Skip. That made everybody laugh.

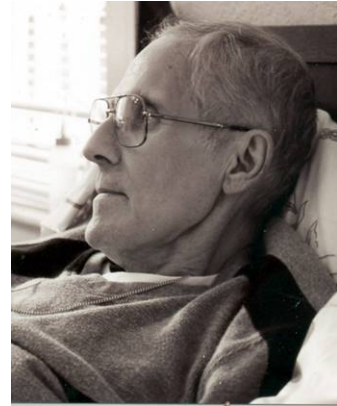
And so, our life went on for a while. I began wearing my athletic shoes because putting them on in the morning made me feel more sure-footed. Often during the day, one of the laces would come untied and I had to go down on one knee to tie up the loose end. I started saying to myself while I was down there, “*Thank you, God, for one more day with Skip.*”

I did that in front of Skip one day, and he asked me what I was doing on my knees. When I told him, he touched my hair, “*You’ll have to write a book about all this, so you can pass on the blessing!*” I still carry the smile.

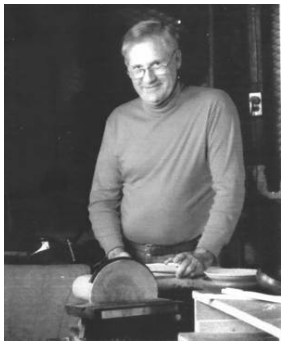
Significant Lesson: “Compassion lives in the here and now,” Beth Witrogen McLeod (2000) says, “and faces outward.” Pass it on.

A Picture Speaks a Thousand Words

As my husband Skip moved into the last stages of pancreatic cancer, his appearance changed dramatically. I myself never saw the change, but I saw the effect of those changes on the faces of the people who treated him. I wanted to remind the professional caregivers who assisted us of the person Skipper continued to be, even in his physical decline.



I took my favorite picture of Skip in his workshop to a copy shop. I asked someone there to enlarge it and print it on a plain, regular-sized sheet of paper. In my office, I found a 3-ring binder with plastic pockets large enough to accommodate a sheet of paper on the outside covers. I put Skip's picture on the outside front, and slid a list of contact numbers (see "House Calls").



That's what I carried into medical appointments: the binder hugged to my chest, Skip's twinkling eyes facing outward. I loved the smiles the picture evoked when people noticed, and Skip loved the conversations it started about his woodworking.

Significant Lesson: *Let the moment symbolized by a favorite snapshot stand up for you when you need it.*

Letting Somebody Else In



“What can I do to help?” people asked me when Skip was at home living his last days with me. They called or came to the door and Skip welcomed them, inviting them in to sit with him. But when they asked me what to do, I felt helpless in the face of the enormity of the question.

My gut reaction was, *“Man! (or Woman!) Make my husband well again! If you can’t do that, then go away!”* Of course, aloud I said, *“There’s nothing you can do. Thank you for your concern.”*

As the days passed, people continued to respond to Skip’s invitations. Neighbors brought meals to the door. A friend stopped by with ice cream in a flavor Skipper liked. My next-door neighbor went to the drugstore for prescription refills. In these small, simple ways, I began to let go of the small things. I came to appreciate the practical people who knew how *not* to ask the question – they just *did* something – usually sensible tasks they accomplished easily, such as grocery-shopping for me when they were going to the supermarket, or bringing computer supplies on their way home from the office. Doing an errand for us made them feel useful.

Some friends talked to us on the phone frequently. My best friend, who lived out of town, called me every morning at 8 a.m. without fail, even when it was only for a moment. That phone call was a quiet constant in the roar of changes in my life.

Other callers gave us a thousand reasons they couldn’t come to see us. But, they asked, was there something they could do? That huge question again, and the terrible stop it gave me! Gradually, I came to see these were people we loved who also felt helpless in the face of impending loss, and they needed to be told there was *something*... They really wanted an assignment.

I am a teacher at heart, and I made something up. I took the copy board I used at my computer, and put it on a small table in the entryway, where it could be seen from the street when the front door was open. Then I got a couple of pads of Post-It® notes in fluorescent colours and placed them around the house: in the kitchen, on Skip's bedside table, next to the couch.

The next time someone asked me THE QUESTION, I replied, *"Whenever I think of something we need, I'll put a note by the front door, and leave it open. Look through the door the next time you're in the neighborhood."*

Later, when I used the last of the milk on Skip's cereal, I printed "2% milk, half-gallon for Skip" on a lime-green Post-It® pad in the kitchen. Later, on a second Day-glo® orange pad in our bedroom, I wrote "1 bar, dark chocolate for me." I put them both on the copy board, making sure they could be seen through the open front door.

In the afternoon, I went to pick up the day's mail. There, on the tiles at the entryway, I found a chocolate bar festooned with the orange Post-It® and a paper bag wearing the green one. Each Post-It® was signed, below my block-letter request, by the friend who had called the day before. The note added on the chocolate bar read, *"I can't come in. Tell Skip I love him, and thank you."*

Significant Lesson: *There's a place for everyone in the life you lead now. Help them find it.*

An Artist's Eye

I knew the key to managing Skip's pain was to keep the doses precise and to administer them on exactly the right schedule. And there were other medications for other symptoms. So many bottles, so many rules: *"Take twice a day with food."* *"Take two tablets one hour before eating."* Sometimes, I just couldn't remember.

I asked our neighborhood pharmacist for ideas about how to manage. She gave me a big plastic container with rows of boxes labeled with the days of the week, and sections for four different times of the day. But the sections were too small to hold all of the pills he had to take, and it took me too much time to sort them all out. As tired as I was, I was also easily confused. I told Skip I was afraid I was going to kill him first by giving him the wrong medicine!

Frank and Josie, artist friends of Skip's from New Orleans, came to our rescue. When they stopped to see Skip one afternoon before supper, Josie watched me trying to sort through the prescription bottles for the proper dosage on the medicine he needed before eating. The next time they visited, she brought a gift: the medication schedule she'd put together when they were responsible for her dad's care.

"It's very simple," she said, as she handed me the sheet she'd used. She took out a notepad, and labeled a page for that day. She explained. *"When I could think straight, usually after Dad went to sleep at night, I would fix the next day's schedule. When I could, I fixed several days' grids at a time."*

For me, she drew a column for each medication, and then rows for every hour. *"When you need it, you just draw the grid on a blank page of note paper and for each medication, fill in the time block with the dosage."* (see "Skip's Medication Schedule" in the Tools section). That did seem simple enough.

Josie helped me fill in a grid for Skip's drugs for the next day. We filled in the columns for Skip's medications: *"For Roxicet, write in '1 tab' – or whatever the dose is – in the box at 8 a.m., 12 noon, 4 p.m., 8 p.m. and midnight."* In this way, the page was filled with prescribed doses for each med in the proper time squares.

Then she surprised me with a stylish additional suggestion. *"What made the system work for me is that I could colour-code the bottles. Josie handed me a packet of Avery© coloured dots in different sizes. "These were left over from pricing things for my garage sale."*

She put a different colour on the medicine bottles while she explained her coding system: green for morning medications, yellow for afternoon meds, and blue for ones that had to be taken at night. *"And I put a small red dot on any medicine that has to be taken with food."*

Simple was right. I could keep colours straight, better than having to read the labels every time. I used Josie's system successfully although it was easier for me to put together a grid on the computer, and then print one out when I needed it.

I used Josie's coloured dots to solve another racking problem with Skip's medications. When I gave Skip a dose of medicine, I put an appropriately-coloured dot in the corresponding box on the schedule sheet. That way, I could see at a glance what he'd already been given.

I also put together a similar chart to keep track of the food Skip took. But I didn't need colours to keep that one straight.

Significant Lesson: *Other caregivers are often the best sources of "tips" and "tricks" for managing the routines of caregiving.*

A Moveable Feast

Robert, the gastroenterologist who discovered Skip's cancer, took great care with us when he broke the news. Several months before, Skip had nicknamed Robert "the professor" for the lengthy explanations Robert gave about what Skip *might* have. He even gave us a book, "*so you can follow me better.*"

This morning, Robert was direct, blunt even, yet compassionate. He gave us privacy by turning away for a moment. When he turned back, he listened, and answered our questions in short sentences. He called another clinic to arrange a referral and walked with us to the appointments desk. "*I want you to come back after seeing the oncologist,*" he told Skip, "*just to see how you're getting along.*"

As the time approached for that appointment, Skip decided to cancel it. He didn't want to go to another doctor's office, even "the professor's." I called the office, and wrote Robert a note.

"*We won't be coming back to your office as patients,*" I wrote, telling him Skip's choice. I thanked him for the time and attention he'd given us over the many months he'd investigated Skip's symptoms, and I closed: "*Our front door is open to a steady stream of friends and family these days, and you are welcome to join the parade.*" Days later, I found Robert on our doorstep. "*You asked!*" he said, grinning broadly.



In the days that followed that, his wife Louise came as well. Together one evening, they cooked a gourmet meal for four, filling the house with inviting smells and happy sounds. When Skip said he wasn't up to coming to the dining room, where they're laid a beautiful table, Robert and Louise moved it to the bedroom. Across our bed, they arranged the feast – bright tablecloth, fancy glasses, tempting small bites on pretty plates. Good cooking, great friendship, and even better, good medicine.

Significant Lesson: *There is great power in the words, "Thank you." Say them often.*

Wrestling with an Angel



“At the end of the struggle [with the angel], Jacob is injured and limping, but the Bible nonetheless describes him as ‘shalem,’ a Hebrew word with connotations of wholeness, integrity, being at peace with oneself. ... In a sense, Jacob won by losing.”

*—Rabbi Kushner (2002), Living a Life That Matters.
New York: Anchor Books.*

I don’t remember the pharmacist’s name, only what marked me in our connection.

During the day, Skip had taken a turn. About 8:30 p.m., his physician called in a prescription for injectable insulin to the chain drugstore we usually used. But it was Sunday evening and the neighborhood store, where we were well-known, was already closed. Our neighbor Phyllis volunteered to pick it up for me at another store in the chain with a 24-hour pharmacy service.

Less than half an hour later, Phyllis called from the drugstore. She didn’t have our insurance card, nor did she have \$110 the pharmacist wanted for the full prescription. I asked to speak to the pharmacist and made a quiet plea. I explained that it was an emergency, and the medication was essential for my husband’s immediate treatment. Our insurance information was in the chain’s computer. Could I provide whatever identifying information she needed to find our records, and Phyllis would come back with the card ...

“Ma’am,” the pharmacist interrupted, “I don’t care if your husband is DYING. I will NOT hand over this prescription without \$110 or the insurance card!” With a sharp intake of breath, I realized she didn’t know what she was saying. *“My husband IS dying.”* I replied, and broke the connection.

Phyllis told me later that, when the pharmacist put the phone down, she handed Phyllis one dose of the medication. At the same time, she told Phyllis she would fill the rest of the prescription when she saw the insurance card. Then she turned away from the window.

After Skip received the insulin, he settled but sleep eluded me. While he slept, I thought endlessly about what happened in the crisis: the assistance that came to us with those who were quick to step in, and the offense I took with the pharmacist who hesitated. I knew she was simply conducting business-as-usual, and her remark was thoughtless but I struggled with the prospect of having to face her in the morning. What could I say? I alternated between wanting to knock some sense into her head, and begging her for an apology. I felt exposed and helpless. At the same time, I was angry.

In the early hours of the morning, I came to see my struggle in a different light. Having to speak plainly and quickly to the pharmacist of Skip's nearing death wrestled me momentarily and solidly into the present, facing the truth. The defensiveness and anger the pharmacist's remark evoked had no place at the pharmacy, where all I needed was a medication. I turned over and slept next to Skip until daylight.

Significant Lesson: Anger is a part of living with loss. It moved me to another level of recognition and acceptance.

Speaking Up

I was frightened. All day, Skip's mood had been swinging wildly from lethargy to agitated excitement. In the morning, I had trouble waking him for his morning meds and within an hour I had to struggle to keep him in the bed. Then, in the afternoon, for the first time in the illness that had befallen us, Skip got angry with me, berating me for some small mistake. That was totally out of character. I called the doctor.

Skip's internist, Lon, had worked with Skip for half a dozen years on half a dozen problems, and they liked each other. Skip trusted Lon's judgment because, as Skip often pointed out, *"he knows how to say, 'I don't know' and he laughs at my jokes."* Chief petty officer on aircraft maintenance crew in the navy, Skip knew well the responsibility that comes with giving advice and directions that keep people alive; he also knew the value of a well-placed joke. For Skip, being able to admit limitation defined Lon's character and his ability to laugh with us was part of Lon's charm.

Lon had also been my stalwart support in keeping Skip at home, assisting us with the connection to hospice care and handling my questions from time to time about what was best for Skip's comfort. He came to the house as soon as he got my message.

After examining Skip, Lon called in a prescription. To me, he said, *"I'd like to get him admitted to the hospital so that I can run some tests."*

In my mind's eye, I could see us spending hours waiting in the emergency room for admission, then being moved into a hospital room where I could not rest comfortably beside Skip. Our practiced ways for caring for each other would have to yield to hospital rules and routines.

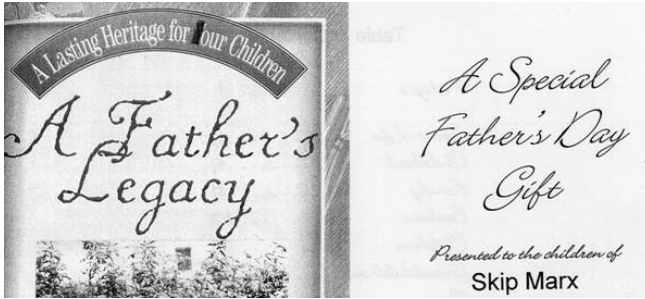
I asked Lon what the testing would accomplish. He replied, *"I would understand better what's going on, and why Skip's insulin levels are so far out of whack."* I thought about what he was saying for only a moment.

I asked, *"Will understanding more about what's going on make you or any of his other doctors treat Skip differently?"* Lon shook his head. *"Probably not."* he said.

"Well, then," I added, in an effort to lighten the moment. *"It's just as well. I don't think the hospital has any double beds."* In the laughter that followed, we agreed to keep both Skip and me at home.

Significant Lesson: *Be clear on what medicine can do, and what it can't. It's okay to ask questions.*

Road Tripping



"I want to finish my book," Skip told me after his various pain medications began their work.

He was talking about the book of questions his youngest daughter had given him for a birthday.

We'd taken it with us on several long driving trips and, while Skip drove, I'd open the book randomly and ask him the question on that page.

"Did you have a nickname? How did you get it?" I read from the book. While Skip watched the road and talked, I took down what he said, as best I could. He answered, *"I was nicknamed 'Skipper' by the nurse in the maternity ward who was a friend of my parents. My father was in the navy during World War I and when she heard me crying in the nursery at mealtime, she said to my mother, 'I guess I'd better go get the skipper.' My father laughed, and picked up the name. That's all he ever called me."*

The miles flew by as he talked, I wrote, and we laughed together at the things he remembered. The tales he told brought out the storyteller in him and listening, I learned about the person he was. By the time we took the second road trip with the book, I was making up questions to catch the stories he told *after* he answered the question in the book, and adding them in.

Now we were on a different journey – Skip playfully teased me about leaving the road part and just doing the stories. And so we traveled in the night, when we were both awake, and in the daylight when we had a moment alone. I looked for a page in the book that was still blank and read him the question, and he told a story or two in response. Together we finished his book.

In the weeks immediately after Skip died, I was lost in the now-quiet house and needed something to do. Telling a friend about Skip's book, I realized there were pictures to go with some of the stories he told.

I copied the book and took the pages apart, pasted up pictures with stories where they belonged, and put them back in an order that fit Skip as I knew him. I bound copies of the newly-made book and presented them to his children for Father's Day. Then I left for the beach.

Afterward: Several years later, I had lunch with Sean, one of Skip's grandsons. Sean was 12 when Skip died, and he particularly felt the loss. Sean had plans that year for a solo trip with Skip, as his older brother and sister had done in a previous year.

Over dessert, I started to tell Sean something about Skip when he interrupted me. "*I know, Grandma,*" Sean said. "*I've read **Skip's Legacy** so many times that I can tell you the story!*"

Significant Lesson: *Journal through your caregiving. Find ways to hear the stories, and recount them. You'll never guess who may be listening.*

OTHER FAMILY MEMBERS

Level With Me

My brother Tommy took the walls out of a new single-level house he bought when he and his wife Joan were facing the prospect of a long-term illness which would confine Joan to her bed. He put large expanses of glass in the walls which faced the back garden and the side patio, and placed Joan's hospital bed in a corner of the living space between them. He also moved interior walls so that from her place in the living room, Joan could survey her household. In the middle of everything, she could see the breakfast bar in the kitchen where their kids ate meals, and down a corridor to the bedrooms to call them awake or send them to sleep.

Tommy's was an incredibly insightful redesign of the house. But he didn't change any of the furniture. Soon after they moved into the house, Joan's bed was changed to an "air bed." It had high metal sides and underneath, an air compressor which generated a cushion of air on which Joan "floated."

Sitting up higher made it easier for Joan to oversee her domain, but harder for people to carry on an extended conversation with her. Seated in the nearby chairs in the living room, visitors were too far away for quiet conversation. The alternative – standing close by the bed – was tiring. Tommy didn't seem to notice that anyone talking with Joan for more than a few minutes pulled up an armchair, turned it to the side and perched on an arm—very uncomfortable after awhile.

I came to the house as often as I could arrange business travel that would take me there on my way home to Memphis. Over several visits, I didn't see any change in the furniture.

At Christmastime that year, I bought bar stools "*for the new breakfast bar in the kitchen,*" I told Tommy and Joan when I brought them into the house. After Tommy took the ribbons off, I took one of them to Joan's bedside and sat down.

I heard Tommy telling one of my nieces later, "Your aunt has been hanging around Grandma too much. She listens, and she just doesn't ask anymore!" I took that as a fine compliment.

Significant Lesson: *Every caregiver accomplishes extraordinary things. The rest of us must use our ordinary eyes to see what they can't, and fill in.*

Making Peace



Emma claims that her husband Bart, who was my oldest brother, “*lived as if he were going to be the first cure*” for metastatic prostate cancer. That was actually a line his friend Mike used in the eulogy he spoke at Bart’s funeral.

All my life, Bart was the one in charge. Growing up, I certainly chafed at his “winning is everything” attitude. In the eighteen months between Bart’s diagnosis and his death, the upside of that stance was mostly joy in being with him. He was upbeat, talkative, even funny in ways he usually wasn’t when fully occupied with the work of managing a sizeable business.

But Bart chose not to talk openly about his illness, or the treatments for it which took more and more of his energy. Nor did he acknowledge the prognosis. “*I do what the doctor tells me,*” he would say. “*I’m just following orders.*” This, from the man in charge!

Spending time with Bart was the only way he allowed me to take care of him, and time was what I had in the months following my husband’s death. So Bart and I hung out together at his place on the lake, as often as I could get there. We took “road trips” to nearby places for lunch or dinner, on the way to or from his treatments. I cooked for him and Emma, and sometimes a friend or two.

I wanted Bart to open up, to talk with friends and family as Skip had done, giving and receiving the gifts that people exchange when time is precious and we know it. Several times, I tried to broach the subject by talking about Skip and our good times in those last days. In exasperation one day, he said, “*I’m not Skip! I’m not going to die!*”

I fled for the patio facing the lake, waiting for the sun to set and breath to come back into my body. As I stood there, watching the globe of orange move relentlessly toward the blue-grey line at the horizon, several thoughts came to me.

Each of us makes our own choices about the way we live, and the way we die. Mostly, we are not transformed by the prospect of endings; we simply do our best to go on.

I wanted Bart to open up for my sake, to give me the permissions I sought as a girl from my big brother when I needed to face and claim my own way of living in the scramble of competing claims in our family. *Then* I had wanted his attention and respect. *Now* he wanted my attention and, I realized, his choices deserved my respect.

In the gathering twilight, at the beginning of what Bart called “the lavender hour” after the sun has set, I rejoined him in the family room. As I pulled the screen door closed, I said, “*There is an exhibition of Monet’s lily pond paintings at the art museum in Buffalo.*” He replied, “*And I know a place along the way, just off Route 90, that has the best ice cream in the world.*”

Significant Lesson: “*Remember what peace there may be in silence*” –
from Desiderata

Less is More

Born with Down's syndrome, Carrie was the last in our stair-step family of five boys and five girls. My sister Jackie and her husband John *Martin* (nicknamed "J&J" by their children) took Carrie into their family of three grade-schoolers and a pre-schooler when our mother's occupation became the full-time care of our dad as he faded into Alzheimer's.

Carrie was 32 when she "transferred" into the sheltered workshop program in Fairmont County and began sharing a bedroom with Ellie, J&J's youngest. Like many people with Down's, Carrie spoke with a speech impediment. But Carrie and Jackie were very clear to each other.

Once, I heard Carrie introduce herself to a parishioner at their church as "*Carrie McCarthy Martin*," I expressed my surprise to Jackie. "*How did she get that?*" Jackie replied, "*She didn't have to. Carrie just knows it saves having to explain what nobody else is going to understand anyway.*"

Carrie's increasingly limited mobility in her last years made it impossible to climb the stairs to her bedroom, so Jackie and John put Carrie's bed in the living room. J&J, and their now-grown children simply carried on their everyday lives with Carrie in the middle, as always.

J&J's children put on the party to celebrate Carrie's 50th birthday, and over a hundred people came. Their friends were Carrie's friends, and Carrie treated them all as her own. They wrote an obituary for Carrie that described all the ways she functioned fully in their family, church and school communities: beloved auntie, communicant, sports fan and dance teacher. This was the person they knew.

When they stood together to speak a eulogy at her funeral, they thanked their parents for giving them the gift of Carrie.

Significant Lesson: *Children learn what they live with, and they don't have to rely on language to tell you.*

A Cousin's Counsel



Roseanne was my favorite older cousin. Our dads were the brothers in a family of five, and they brought their children together from time to time throughout our childhoods to eat, fight, laugh, and otherwise take care of each other. Growing up, Roseanne and I developed our own firm friendship.

Now I was the favorite “once-removed” cousin for another, younger generation. Four of Roseanne’s children sat with me that Sunday morning around her dining room table. Ted, Roseanne’s second husband, was sitting beside her in the living room, watching birds in their wooded backyard. They were peaceful with Roseanne’s decision to die at home. Her children weren’t.

When I was a teenaged babysitter, they had been my favorite assignment. It was hard to resist Claire’s kindergarten giggle, Chandler’s open, first-grade smile, Amy’s impish nursery-school grin, and Jonathan’s boundless toddler energy. Now their grim, adult expressions reflected the reality of their impending losses.

These grown-up people with their tired, careworn faces were anything but peaceful. “*Do something about Claire!*” Amy had pleaded the night before, in the lobby of the hospice unit where I had spent the afternoon with Roseanne. “*Claire is determined that when Mom comes home tomorrow, we will be the only ones to take care of her because we’re the nurses! What about the boys? They want to help. They need to help, and Claire won’t let them.*” She finished, “*Please, Cousin! She’ll listen to you.*”

As a child, Claire had been passionate and intense, quick to judgment. She was so stubborn when she thought she was right that I sometimes had to guard my face lest I break into laughter as I carried her away from one more neighborhood fight. Leading her away from her convictions in this battle would not be so easy.

But we accomplished it. The siblings devised rules and roles which honored each one's wishes as well as the limitations which they could voice. And somehow, we made those admissions possible.

It was a "family council." They showed up. They talked. I refereed and took notes. As a beloved outsider, I could set the playground rules, and hold an honorable place for each one to take and leave as needed.

As a result, everyone got an assignment. Chandler took charge of scheduling siblings, family and friends to provide for his mom's care 24/7. Jonathan, by contrast, asked for a share of the caregiving, and agreed to be trained by Claire. Amy wanted shifts that would allow her to be home when her kids got back from school. And Claire – who stormed out of the room only once that morning and then came back – agreed to be bound by the caregiving "guidelines" we put together.

The result was a family plan to take care of their mom that the siblings themselves could sustain for more than a day or a week at a time. It was workable, flexible, and inclusive, and they owned it.

After a noisy, crowded family celebration held around her that Thanksgiving, Roseanne died peacefully in the night. Claire was the family caregiver with her at the time.

Significant Lesson:

"Caregiving is a temporary stage in a relationship which will take you to a level of compassion that you have never before experienced. ... It's not the disease; it's the level of giving that changes your life."

-- Beth Witrogen McLeod (2000).

HAMILTON
FAMILY CAREGIVERS

Filling Up

My sister Constance and her partner came to stay with us in Skip's last days and, when I wasn't looking, she posted a note on my computer screen. In big block letters, it read, "***You cannot give from an empty cup.***" After they returned home, I left it there where I would see it. Especially at that time, I needed the reminder to put myself on my own to-do list. I needed sustenance.

This awareness was reinforced when I began working with Ellen Ryan. In 2004, The Centre for Gerontological Studies at McMaster University hosted a workshop for professional caregivers (nurses, professors, case managers). Ellen intended to provide the afternoon's experience as a respite, a professional "thank you," to those who contribute frequently and greatly to the community and to the Centre. We wanted to listen to their answers to the question, "*What is the spirituality of caregiving?*"

Before the workshop, those invited sent us by email "*any image, poetry, story, or verse which lifted their spirits, or inspired them when their spirits flagged.*" I compiled the material, added things from my own files, and bound a sufficient number of copies for us to use to open the discussion. [See Ryan & Banchoff, 2005, *Gathering Inspiration: Lifting Our Spirits*, the booklet we compiled for broader distribution after that workshop.]

Ellen and I didn't need an opening. Instead, we had all we could do to harness instead the incredible energy that participants themselves generated through the stories they told. Opening the workshop, I instructed them: "*First, introduce yourself to one other person by telling a story about something significant in your life* (choices: a person, a place, or a date). *Then, introduce your partner* (in combinations of pairs, and then foursomes) *by telling their story.*" In less than 30 minutes, the room practically crackled with energy!

In the context created by those story-introductions, participants talked, in small groups, about what constitutes the *spirituality* of caregiving. Their answers were pure poetry [see "*The Spirituality of Caregiving is*" Workshop, TOOLS section].

Over time, Ellen and I have tried to explain to each other what happened. We've come to this: *Two important characteristics* distinguish caregivers' workshops from others.

- First, each caregiver walks into the room with a great big cup she or he is pouring out every waking or working moment as they attend to the people in their care or case load. ***Their need for refreshment is great.***
- Secondly, every caregiver is full of stories and short on experience with attentive audiences. Caregivers, whether professionals or family members, have limited options. ***Being heard is the key to their renewal.***

Significant Lesson: Creative endeavors – making images, reading poetry, posting quotes for encouragement, and telling stories – refill the cup.

Story Boats

“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*.
New York: Harper Prism.

In 2003, when Ellen Ryan and I first offered a Caregivers’ Workshop for the Victorian Order of Nurses (VON), we did not anticipate how profoundly *we* would be affected by the process.

Before each workshop, we paid careful attention to selecting the right material – definitions and principles, background and references – we did our homework. And each year, we were surprised by the power of the lesson that family caregivers taught us: **storytelling is the heart of the matter.**

- Each workshop begins with a “performance:” I tell half of a story from my own experiences in family caregiving, thus creating a “dilemma” for participants to work on. They share ideas from their own experience, and we work together on resolving the dilemma [see “Assertive Communication Illustrated” in the Workshop TOOLS section].
- As the dilemma resolves, the rhythm of storytelling takes over. A participant usually interrupts the workflow with, “*But what about ...?*” Almost always, it is an equally compelling story.

For instance, we were working on the “physical appearance” dilemma (read the story, “*A Picture Speaks a Thousand Words*”). There were several creative solutions on the table when a woman spoke up. “*But what about me?*” She – let’s call her Josie – explained a somewhat different problem.

“My husband hates the way he looks now!” “He’s asked me to put away all the good-looking pictures of him we had around the house because he doesn’t want to see them,” she finished plaintively. “But I need those pictures.”

Participants worked with us on some ideas for Josie, and together we settled on this: *“Take the pictures he’s asked you to remove from sight, and put them in a scrapbook **you** can look through when you need the trip down Memory Lane.”*

Another woman sent us an email the day after the workshop. *“As I was leaving yesterday,”* she wrote. *“I felt respected as a caregiver, and successful because we focused on caregiving ways that work.”* She believed that we heard her story, and listened.

With each event, Ellen and I got better at arranging an audience (small groups – *“not more than four”* one respondent requested, *“so that each of us has enough time to talk”*) and making more time for participants to tell their stories. (less demonstrating, more small groupings).

Most importantly, we learned, there is a rhythm that flows between teller and listeners, and the process is most powerful when those roles are interchangeable.

We are learning to go with the flow.

Significant Lesson: *Caregivers know the rapids and shallows, and when we listen to them and tell their stories, we teach the art and craft of building story-boats.*

CAREGIVING TIPS AND TOOLS

TOOLS FROM SKIP

Skip's Binder

First Things First



When a loved one is sick, and you are a caregiver, it is easy to lose sight of the picture of health and vitality he may once have been in your lives together. Further, the medical people who help you look after him now may never have ever seen that face.

So, when you are organizing a notebook or basket for keeping together all of the paper related to taking good care of him, copy your favorite snapshot large enough to be seen at a glance, and put it on the cover of your notebook. Or laminate it, punch holes in it, and tie it on the front of a basket. Then put the basket on a shelf where you can see it easily.

Organizing Important Documents

Organize all the paper related to your caregiving in one place: a binder with tabs or folders clearly labeled with HEADINGS which can be easily read at a glance.

On the top folder, or on the outside of the binder (the back cover is what I used), or on a bulletin board or family message center, POST a **contacts sheet**.

Put the FOLDERS in a basket, or TAB SECTIONS in the binder. Set aside, nearby, a roll of tape, a hole-punch, a stapler, and a pen just for your use. (p.s., I used a hair ribbon to tie a pen onto the ring in the binder, so that I wouldn't have to search for one.)

The sections I used in Skip's binder included:

- **Schedules**
 - calendar
 - doctor's / clinic appointments
 - meal journal
 - daily medications sheets
 - plan for Emergencies:

e.g., "Step 1: Call _____. Step 2: _____."

- **Medical Papers** (*Lab Reports, Bills and Drugstore Receipts*)
 - list of medications – updated **weekly**, if necessary
 - large, clear plastic envelope to hold prescriptions
 - pages on which to tape Rx receipts and bills [*making them easy to copy for insurance / reimbursements*]
 - laboratory reports and correspondence with medical people
 - Dated journal pages of symptoms; dated pages of questions for doctors / nurses / pharmacists, and dated pages with the answers, including names.
- **Legal Documents**
 - **copies** of living will, healthcare power of attorney, hospice papers, home health care orders or authorizations
 - **note:** Make sure that **lawyer's phone number** is on your contact list.
 - insurance paperwork, including Medicare / Medicaid.
 - Social Security disability paperwork
- **Personal Journals**
 - Caregiver's Journal
 - Visitors' Journal
 - *SEE SPRING 2005 WORKSHOP SUMMARY*

Lists of Contact Names and Numbers

On the binder (the back cover is what I used), or in the basket as well as on a bulletin board, POST a **contacts sheet** (see for example, on the following page, "*Housecalls for Skip*")

Copy one of the sheets we've included, fill it in and laminate it before you post it. Or, if you need to update the numbers from time to time, copy the document, laminate it, and *then* write in names and numbers with an erasable marker.

House Calls for Skip



Address: _____

Nearest Intersection: _____

Phone(s): _____

NAME

PHONE #

Physician _____

DAY: _____

Primary

EVE: _____

Physician _____

DAY: _____

Specialist

EVE: _____

Nursing _____

DAY: _____

EVE: _____

Clinic _____

EVE: _____

PHARMACY: _____ **location:** _____ **phone:** _____

Pharmacist's name (preferred): _____ *Pharmacist's name:* _____

EQUIPMENT Supplier _____

ELECTRIC Company _____ **EMERGENCY #** _____

CHAPLAIN / Parish Priest: _____

Church / Temple / Mosque _____

LAW FIRM: _____ **phone:** _____

Lawyer / Legal Assistant's name: _____

INSURANCE: _____ **Group / ID #** _____

Medical Case Manager: _____

FAMILY / FRIENDS: _____

Sharing Errands

Materials: *brightly-colored notepaper
markers or broad-tipped pens
board and tacks or tape to put notes up
place which can be seen from the street*

alternative: *e-mail list of friends / family AND
friend /family member willing to post “to-do” items daily*

Graces you’ll need:

- *the generosity to forgive friends and family who can’t live as you do.*
- *the willingness to let go*
- *an ability to break down the big job into small tasks that make life easier to manage.*



Skip's Medications

DAY: _____ DATE: _____

[WRITE IN]

MEDICATION	MEDICATION	MEDICATION	READING	READING

morning

5:00 am										
6:00 am										
7:00 am										
8:00 am										
9:00 am										
10:00 am										
11:00 am										
12 NOON										

afternoon

1:00 pm										
2:00 pm										
3:00 pm										
4:00 pm										
5:00 pm										
6:00 pm										
7:00 pm										
8:00 pm										
9:00 pm										
10:00 pm										
11:00 pm										

overnight

12 midnight										
1:00 am										
2:00 am										
3:00 am										
4:00 am										



Skip's Meal Journal

[WRITE IN]

DAY	Date

meal

TIME	FOOD / Beverage

DAY	Date

TIME	FOOD / Beverage

snack

TIME	FOOD / Beverage

TIME	FOOD / Beverage

meal

TIME	FOOD / Beverage

TIME	FOOD / Beverage

snack

TIME	FOOD / Beverage

TIME	FOOD / Beverage

meal

TIME	FOOD / Beverage

TIME	FOOD / Beverage

snack

TIME	FOOD / Beverage

TIME	FOOD / Beverage

***TOOLS FROM
OTHER FAMILY MEMBERS***

Roseanne's Family Guidelines
-- page 1 --

You are providing care for Roseanne in an ongoing way. Keep your main focus on her:

- If Roseanne seems anxious or agitated, get her attention by making eye contact or taking her hand, ask “What is it, Roseanne?” or “Tell me, Roseanne...” Wait quietly, minutes if necessary, until she responds.

When you are the primary or secondary family caregiver in the house, you have agreed to take on the responsibility for “directing traffic” primarily with phone calls and visitors.

- Make sure visitors recognize the need to **share Roseanne's good time**, which is limited. If someone stays too long, thank them for stopping by, help them into their coat or hand them their purse and walk them to the door.
- Leave the kitchen door open (there's a storm door there) when Roseanne has the energy to see visitors; close it when she needs rest.
- That way, people coming by to visit can see, just driving or walking by, whether to stop for a visit.

Roseanne's Family Guidelines

-- POST ON FRIDGE --

E-MAIL BULLETIN BOARD: Find someone among family or friends who knows how to construct a ***"listserv"*** (list of email addresses for family and friends) and will post news updates and acknowledgements, visiting times and other restrictions ***on a regular basis***.

Fill in the blanks on the next page and keep it posted in the kitchen, along with contact numbers.

* **OBJECTIVE:** **Keep someone present in the house 24/7** *in addition to* [WRITE IN NAME] _____ so that *1 person* is free to stay and go as needs be.

* **One caregiver** at a time takes ***primary responsibility*** for physical care-taking (bathing, toileting, lifting / assisting into and out of bed and chair). **Sign up for regular "shifts" on a master schedule** (*to be kept at the house*); *let 1 person be responsible for keeping schedule.*

-- **Family** able to do this include:

[WRITE IN NAMES] _____, _____.

-- **Volunteers/aides** include:

[WRITE IN NAMES] _____, _____.

* A **second caregiver** may be present/required ***to assist*** for transition times, including:

- wake-up (personal clean-up, meds, changing clothes, toileting)
- afternoon (daylight into darkness, meds)
- bedtime (personal clean-up, meds, changing clothes, toileting)
- meal preparation, room-cleaning, changing linens, providing quiet / music

Family/Friends able to do this include:

[WRITE IN NAMES] _____, _____.

Volunteers/aides include

[WRITE IN NAMES] _____, _____.

* **Regular Visitors** -- most importantly:

[WRITE IN NAMES] _____, _____.

Others expected? [WRITE IN NAMES] _____, _____, _____.

* **Daytime shifts**, for the primary person, should be about 8 hours – **night shift** is about 12 hours; overlaps can be worked out so that work and family commitments can get met. The idea is to keep each of you able to do 2-3 long shifts a week, and fill-ins (secondary person) as often as you like.

* **Aides / Volunteers** can fill in hours that family can't cover.

"Rules of Thumb":

1. Best that Primary signs up for **no more than** two days in a row. Secondaries can schedule more than two days running *if they choose*; aides will fill gaps.
2. Remember that **visitors must share** Roseanne's limited good time.
3. When necessary to help / keep Roseanne's energy, post a notice on the doors saying "**She's sleeping**" (like "Baby's sleeping").
4. Leave a notepad or book (like **an autograph book**) or something outside hanging on the door so that people who stop by – and don't / can't come in – can leave a message.

If someone needs to change their commitment (primaries only!), call [WRITE IN NAME] _____ [WRITE IN PHONE] _____ or e-mail [WRITE IN EMAIL] _____ @ _____ with the change/ substitution and we'll work it into the schedule.

Alternately, call [WRITE IN NAMES] _____ OR _____

[WRITE IN PHONE] _____ or e-mail

[WRITE IN E-MAIL ADDRESS] _____ @ _____.



Family Caregivers Schedule

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Nov 12	13	14	15	16	17	18
6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____
Nov 19	20	21	22	23	24	25
6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____
Nov 26	27	28	29	30	Dec 1	2
6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____
Dec 3	4	5	6	7	8	9
6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____
Dec 10	11	12	13	14	15	16
6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____	6am-10 ____ 10am-4 ____ 4pm-9 ____ 9pm-9am ____

Helping Hands Contact Numbers



24-hour number: [WRITE IN NAME] _____
 (WRITE IN #) _____

Doctor's office: [WRITE IN NAME] _____
 [WRITE IN #] _____

Nurse(s): [WRITE IN NAME] _____ **or** _____ [WRITE IN #] _____

Social Worker: [WRITE IN NAME] _____ [WRITE IN #] _____

Minister/Rabbi/Imam: [WRITE IN NAME] _____ [WRITE IN #] _____

Neighbor: [WRITE IN NAME] _____ **or** _____ [WRITE IN #] _____

Relatives:

[WRITE IN NAME] _____	[WRITE IN #] _____
[WRITE IN NAME] _____	[WRITE IN #] _____
[WRITE IN NAME] _____	[WRITE IN #] _____
[WRITE IN NAME] _____	[WRITE IN #] _____
[WRITE IN NAME] _____	[WRITE IN #] _____

Aides: [WRITE IN NAME] _____ [WRITE IN #] _____
 [WRITE IN NAME] _____ [WRITE IN #] _____
 [WRITE IN NAME] _____ [WRITE IN #] _____

[nights] [WRITE IN NAME] _____ [WRITE IN #] _____

Agency for filling in with volunteers / aides:
 [WRITE IN NAME] _____ [WRITE IN #] _____

Scheduling:

[WRITE IN NAME] _____ [WRITE IN #] _____

***TOOLS FROM
HAMILTON
FAMILY CAREGIVERS
WORKSHOPS***

Finding the Smile: Asking for Help Through Story

Caregiving is a gift, and not everyone has it. The experience of caregiving is so absorbing we may forget what our life looks like to those outside it. We may be disappointed with other family members who can't see what needs to be done or don't offer to help. Often, we may not know what to ask for.

By contrast, everyone knows how to listen to a story, once you have their attention. I've learned from family caregivers in our workshops that storytelling provides an opening for powerful connections, and that it can generate renewing and renewable energy for the caregiver. I treasure the perspective that caregiving gives me by telling stories about me as a caregiver, and the experiences that way of living has handed me.

CONSIDER THIS: Storytelling is a skill you can develop. Telling a story about your life – e.g., an incident, even a struggle or a disappointment – opens the door for listeners to see into your life. It engages them as an audience.

Think about a story you can tell about the work of your life as a caregiver. Create one that draws the listener into your world. Invite people in. We need them as companions on this journey.

The stories which follow illustrate particular storytelling tips. Each has a point, a target, and focuses on some limitation. The tips that accompany the story may help you see something in your own experience which you can make into a story.

Pearls

Targets: those who are impatient; family members who think that Grandma just babbles.



Finding the smile: Be open to the unexpected insight. It may provide a surprising glimpse of the person you thought was no longer present.

My mother took care of one of my grandmothers after she had a stroke and was no longer able to take care of herself or even to speak clearly. I remember watching Mom change my toddler brother's diaper on one couch in the playroom, and then Grandma's on the other.

Mom herself told the story that one day, as she was changing the baby, who was gurgling and laughing, she heard Grandma say, "*That baby is as happy as if her granny made sense.*"

Lesson in Storytelling: Don't include all the details. This story started out with lots of additional information. e.g.

- The grandmother in this story is my father's first wife's mother – a small, significant detail with implications about another, *different* story. It's a detail that *might* be distracting.
- My mother actually had *two* babies' diapers to change in addition to Grandma's (the toddler was about 2, and the baby, about 6 months). It's a detail that isn't essential.

Alzheimer-speak

Targets: those who are afraid of people with dementia; family members who think they can't deal with Dad anymore.



Finding the Smile: Alzheimer's speech is often metaphor. Tune in.

Lesson in Storytelling: Recognize the "good line" around which to build a story. In this case, it's Dad's unexpectedly funny remark.

- Choose words that are descriptive but not overly dramatic (e.g., "fading into").
- Use details that set up the punch line, without giving it away. (e.g., "he went on ahead")

Then tell the story several times to different people, adding and dropping details until the story suits your way of telling it, and your audience laughs in the right places.

When Dad was fading into Alzheimer's and living at home in Mom's care, I took them to church one Saturday evening.

As had been their habit for some years, we went afterward to their favorite restaurant for dinner. In the small town where they raised us, many of my parents' friends were dining at the same place. So, as we left, friends at several tables stopped us to say hello as we passed.

However, once headed for the door, Dad was restless to leave. He went on ahead of us to the coat rack in the entryway and, when I came up behind him, he was putting on a trench coat.

"Dad," I said, "You didn't wear a coat tonight." And he replied, "Good. 'Cause this one doesn't fit!"

A Little Zen

Targets: those who think that people with different mental capacities cannot teach us anything; family members with lots of reasons why they can't stop by.



Finding the Smile: The simple lessons for a happy life are: “*Show up. Listen. Try to laugh.*” – Anna Quindlen (2000), *A Short Guide to A Happy Life*. New York: Random House.

“*Carrie was my guru,*” Jackie told me one afternoon, and then went on to explain.

“*I was giving her a bath one day, and thinking about all the things I had to do at the same time I was talking to Carrie and washing her back.*” (Jackie is well-known for doing that.)

“*Carrie reminded me I had better things to do when she said, over her shoulder, ‘What’s your hurry?’*”

Lesson in Storytelling: Consider everyday things that happen in your life as a caregiver, and make it a story. It doesn't have to be long (in this case, three sentences), and keep it simple.

“So You Forgot the Milk!”

Targets: The caregiving family member too often “wounded” by the unwitting remarks of a loved one; friends and family members with sharp tongues.

Finding the Smile: Turn a criticism around if you can, so that your laughter gives the person who spoke the chance to retreat, reconsider or move on.

At first, I was offended when Martha said, as I unloaded the grocery bags, “*So you forgot the milk!*” She had been watching an old movie when I walked in, and she followed me into the kitchen.

I brought Martha groceries every week after she had her hip replaced. I was always careful to bring her *exactly* what was on her list. Martha had been a short-order cook for more than 50 years, and was particular. Also, living on a tight budget, she was careful.

But sometimes the way she spoke to me was just hard. What I wanted to hear her say was “*thank you!*” What I wanted to say to her was, “*But Martha! It wasn’t on the list!*” I turned to face her and I saw that pain had etched deep lines around her mouth.

I gave her a sideways hug, and replied, “*And you forgot to smile when you said that, pardner!*”

Lesson in Storytelling: If you can **laugh instead of crying**, it will free you up to see the gifts in the moment. The *least* you can get out of it is a good story.

Managing Communication Workshops for Family Caregivers

In April, 2004, 2005, and 2006, the Victorian Order of Nurses (VON) in Hamilton, Ontario invited people they serve to participate in a workshop on “*Assertive Communication Skills*.”

Year to year, the workshop used a simple design, devised by Kathleen Banchoff and Ellen Ryan. Our purpose was to teach a few principles of assertiveness and effective communication to family caregivers whose strong communication practices can ease the difficult situations they often encounter.

In each workshop, Kathleen told stories from her own caregiving experience to create “communication dilemmas.” Participants then worked together to resolve the dilemma. As someone related a solution, others anticipated the likely outcomes of each proposed course of action.

Here are some sample dilemmas (story titles included in this book are in *italics*). Use the handout included on the following pages to assess your own solutions to these dilemmas.

- **PHYSICAL APPEARANCE: “A Picture Speaks 1,000 Words”**. Skip’s increasing frailty is obvious to others in the dramatic change in his appearance. How do I keep myself – and those who help me care for Skip – reminded of the person he continues to be?
- **SHARING THE RESPONSIBILITIES: “A Cousin’s Counsel”**. One of Roseanne’s grown children starts telling the others what they can do and not do, and everybody’s feelings are hurt. One of the “directed” siblings begs you to tell Claire to get off her high horse.
- **RUNNING THE BUREAUCRATIC ROADBLOCKS: *Wrestling with an Angel***. On a Sunday night, Skip has a setback and the doctor prescribes injectable insulin. A neighbor runs to the pharmacy to pick up the prescription which the doctor called in. You forget to give her your insurance card. The pharmacist calls you.

Assertive Communication Illustrated

	Passive	Assertive	<i>AGGRESSIVE</i>
Choice	Defer	Choose	<i>IMPOSE</i>
	"Whatever you say ..."	"I can only keep caring if..."	<i>"YOU SHOULD HELP ME..."</i>
Attitude	Avoid	Consider	<i>CONFRONT</i>
	"I don't know"	"Let me think about that"	<i>"YOU'RE WRONG" OR "YOU'RE NOT LISTENING TO ME"</i>
Manner	Weak	Poised	<i>PUSHY</i>
Emotions	<u>Resigned,</u> Withdrawn	<u>Calm</u> Confident	<i>ANGRY,</i> <i>FRUSTRATED,</i> <i>RESENTFUL</i>
	"It happened..." language	"I want/need..." language"	<i>"YOU MADE ME..." LANGUAGE</i>
Perceived Benefits	<u>Avoid Risk;</u> stay out of the crossfire	<u>Accomplish</u> objectives	<i>ATTAIN GOALS NO MATTER WHAT</i>
Actual Outcomes	<u>Helplessness,</u> guilt	<u>Accomplishment,</u> Self Respect	<i>FRUSTRATION,</i> <i>RESENTMENT</i>

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Assertive Communication Illustrated (2 of 3)

◀.....

Passive	Assertive	<i>AGGRESSIVE</i>
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LANGUAGE

Indirect, <u>wordy</u>	Concrete, <u>specific</u>, descriptive words	<i>ATTACKING/ <u>DEFENSIVE</u> WORDS</i>
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"I know you must be tired but when you get a chance, would you think about giving me a minute of your time?"

"I can see that Mom is losing weight. Is there a good tasting nutritional supplement I can give her? She's always been a picky eater.."

"WHY DIDN'T YOU TELL ME SOONER WHEN I COULD HAVE DONE SOMETHING?"

<u>Overly-polite</u> (watch conditional verbs and conjunctions)	<u>Clear message</u>, direct request	<i><u>ACCUSING TONE</u> (WATCH "LOADED" ADJECTIVES/ ADVERBS)</i>
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"I don't know anything about nutrition and I'm not sure what I could do if I did understand it, but I'd like to help..."

"I need to understand Mom's weight loss. I am the main family cook. Can you help me?"

*"IF YOU'D JUST EXPLAINED IT BETTER, I MIGHT HAVE GOTTEN IT. YOU REALLY COULD HAVE HELPED ME!
(SOUNDS LIKE, "YOU DID THIS ON PURPOSE")*

.....▶

Assertive Communication Illustrated (3 of 3)

←.....

Passive	Assertive	<i>AGGRESSIVE</i>
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PARA-VERBAL BEHAVIOUR

Voice	Soft and flat	Expressive	<i>LOUD AND HIGH-PITCHED</i>
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NONVERBAL BEHAVIOUR

Posture	Closed, hunched, fidgeting or fluttering hands	<u>Relaxed Smooth and fluid motions, open hands</u>	<i><u>STIFF, UPRIGHT OR LEANING FORWARD; POINTING FINGERS, CLENCHED FISTS, OR WAVING ARMS</u></i>
Eye Contact	<u>No eye contact</u> – looking down or away	<u>Frequent</u>	<i><u>STARING OR GLARING</u></i>
Face	<u>Lack of expression</u>	<u>Open expression</u>	<i><u>HIGH COLOUR</u></i>

“The Spirituality of Caregiving is ...”

*Participants’ Responses in a Hamilton Caregivers’ Workshop,
Spring, 2004*

- | | |
|------------------------------------|--|
| ... Being mindful | ... Real, the reality of you [you are God] |
| ... Talking | ... Being quiet |
| ... A little bit of hope | ... A sense of something bigger |
| ... The Golden Rule | ... Listening |
| ... The smallest gesture | ... Touch |
| ... Perspective | ... A paradox |
| ... A bright idea | ... Memory box |
| ... Acceptance | ... Being close |
| ... A clear space | ... Life |
| ... Music | ... Laughter |
| ... Connections | ... Holding in love |
| ... Being open | ... Healing |
| ... Remembering | ... Self-awareness |
| ... A loving presence | ... Being present |
| ... Being touched | ... Transcendence |
| ... Affirming | ... Walking with |
| ... Crying | ... For the living |
| ... Help naming feelings and goals | ... Being positive |
| ... Support | ... Heartful |
| ... Belonging | ... Development for the soul |
| | ... Giving voice to the voiceless |

RESOURCE LIST
FOR
FAMILY CAREGIVERS

Books for Caregivers

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WEB SITES:

- Alzheimer's Association: <http://www.alz.org>
- American Association of Retired Persons: www.aarp.org/internetresources
- American Cancer Society: <http://www.cancer.org>
- Caregivers.com: <http://www.caregivers.com/>
- Caregiver Network, Inc.: <http://www.caregiver.on.ca/>
- Elder Care Online: <http://www.ec-online.net/>
- Family Care Research Program: <http://www.cancercare.msu.edu>
- Michigan State University Caregiver Resources <http://www.healthteam.msu.edu/fcrp/patients-caregivers/issues/caregiverresources.htm>
- National Cancer Institute: <http://www.nci.nih.gov/>
- National Family Caregivers Association: <http://www.nfcacares.org/>
- National Institute on Aging: <http://www.nia.nih.gov>
- National Organization for Empowering Caregivers: <http://www.care-givers.com/>
- Rosalyn Carter Institute for Human Development: <http://rci.gsw.edu/care-net.htm>
- Empowering Caregivers: <http://www.care-givers.com/community/chat/chat.htm>
- Elder Care: <http://www.ec-online.net/>

ABOUT THE AUTHOR

Kathleen M. Banchoff



Kathleen McCarthy Marx Banchoff is currently retired from teaching at Christian Brothers University, Memphis, TN and from managing market research projects and the marketing information function for several major corporations. She continues to work with academic and community organizations, and not-for-profits, on communication skills development projects.

This writing project, along with the book of stories she hopes to edit next year, arises out of the journaling she started at age 12, when her mother gave her a blank book and a glimpse at the journals she had begun keeping as a teenager.

In addition to her work with Ellen Ryan and the Victorian Order of Nurses for the past three years, Kathleen is also working on several evaluation projects in teaching technologies for math education. She lives with her husband in Providence RI, when they are not traveling around the country and the world.



About the Series Editor

Ellen Bouchard Ryan

Ellen Bouchard Ryan is Professor at McMaster University and former Director of the McMaster Centre for Gerontological Studies. She focuses her psychological research on the roles of empowering communication in fostering personhood and successful aging. She has created the *Writing Down Our Years* Series of publications to highlight the many ways in which writing life stories can assist older adults – the writers themselves as well as those with whom they share their writings.



Ellen lives with her husband in Ancaster, Ontario, and is looking forward to the birth of her first grandchild this year.

There were many blessings to be had in that company and time, and finding the stories to tell about us returns me to the laughter and joy of it. It seemed like the hardest thing I've ever done effortlessly, and that is the grace I want to pass on. This is the book I promised Skip I would write.

--- Kathleen M. Banchoff

"Kathleen's honesty enables her to share her knotty dilemmas and to reach out to others as she comes face-to-face with Skip's terminal illness and her acceptance of it. The tips and tools based on her caregiving experiences provide bouquets of concrete suggestions for caregiving readers to reflect upon and alter for their own particular circumstances."

--- E. Mary Buzzell, Foreword

WRITING DOWN OUR YEARS SERIES

**FROM
MCMASTER CENTRE FOR GERONTOLOGICAL STUDIES**

ELLEN B. RYAN, SERIES EDITOR



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