

Faces of Help

Resources
for Leading a
Digital Stories
Discussion



Transcripts
Faces of Help Digital Stories



Compassionate Ottawa
Compassion Ottawa

Introduction

Compassionate Ottawa is a community movement that works to change the way we think about living well, dying, death and grief, and to strengthen the capacity of people to care for each other in times of serious illness and loss.

To share their vision and message, in 2020, Compassionate Ottawa invited 7 storytellers to share a personal experience of giving or getting

help while dealing with caregiving, dying or grieving. The Faces of Help videos are their stories. The videos can be viewed online at <https://compassionateottawa.ca/resources/>

These transcripts provide viewers with the opportunity, either prior to or following watching the videos, to enhance their viewing. Enjoy the moving stories!

Last Wishes

by Ann Barkley

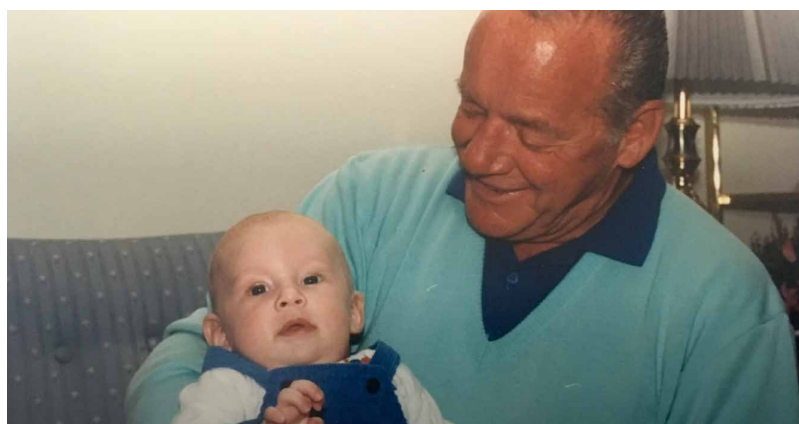
Sometimes it's hard to balance the wishes of your loved one who has died, and the needs of your loved ones who are left to grieve.

My dad fell and broke his hip. After surgery for a partial hip replacement he faced weeks of rehab to walk and climb stairs again so he could return to his home. As I look back, this time in rehab was a wonderful gift to me as I was able to spend many hours alone with him. It was just me and my dad, no distractions of everyday life.

He always loved the outdoors, so I would push his wheelchair out to the garden where I sat on the swing and we talked. He shared memories growing up in Ottawa, his four sisters, but especially his time in the Merchant Marines during World War II, as he travelled the world.

These were stories I hadn't heard growing up. We laughed together as he told me about getting his first tattoo. It was after crossing the equator. He and his shipmates went to a questionable parlour that certainly would never have passed inspection here!

He also had some pretty strong ideas about what should happen after he died: cremation and scatter the ashes on Frenchman Lake in Northern Ontario where our family camp was located. No casket, no visitation, no flowers, no funeral and no obituary in the paper.



Being with him in his last days and hearing how strongly he felt about his last wishes being followed, I had no problem carrying them through. What I didn't anticipate was the reaction of his grandchildren. They were upset there wasn't a funeral or gathering to remember their grandfather. It was like his life didn't happen - didn't matter.

They decided to meet in Sudbury for a weekend to celebrate his life, reminisce about their memories of his time with them, and say goodbye. I wasn't able to attend but that was okay - this was their time to grieve together in their own way.

I think my Dad would be proud of his children, who carried out his last wishes, and proud of his grandchildren, who needed time together to honour a man who had touched their lives.



Dancing with Lucy

By Marvin Bedward

*Images of boxes (opened and closed) Use
Dream Escape music*

My life has always been filled with projects. I open more boxes than I can close. Some of the projects succeeded, others were just work.

These projects relied on having what I felt was boundless energy. I was up before six each morning having worked until the wee hours of the night, either on my own or with a crew of collaborators - from software programmers to sound engineers and musicians. Weekends were spent travelling to the country to see my wife, dinners with friends and taking care of my Airbnb.

Twelve years ago, I was diagnosed with a brain tumour that took 4 years to recover from. Despite the tumour, I continued to open new boxes, starting a publicly traded company while recovering in bed. But then, two years ago, I lost my energy and almost my life due to sudden heart failure.

While waiting in the hospital for results regarding my heart condition, I was inspired to write a song, ***Dancing with Lucy***, to keep me and a young man who I had met on the ward, and who was also suffering from a serious heart condition, committed to life. To remind the two of us that life is filled with tosses and turns with never ending struggles.

Start of music from Dancing with Lucy

“I was dancing with Lucy last night, surrounded by all my friends, we were howling at the moon, the blood red moon... I turned to leave the crowded floor and she said, she said you’d better hold on; you better hold on, and keep dancing, just keep dancing.”



I have since curtailed many of my activities to spend more time with my wife, listening to audiobooks, watching Netflix, playing with the dog, and marveling at life. I’m more focused on **being** rather than **doing** – not trying to open boxes for the sake of keeping in the game.

Last year I wrote the young man from the hospital to share the song I wrote for us. I wonder if he’s still dancing with Lucy.

Dancing with Lucy

Verse 1

*I was dancing with Lucy last night
Surrounded by all my friends
We were howling at the moon, the blood red moon,
Dancing, just dancing
She curtsied left and I bowed to the right.
She circled to the left, I circled to the right
Dancing, just dancing
I turned to leave the crowded floor
and she said, she said
You better hold on; you better hold on, and
Keep dancing, just keep dancing*



The Dressing Room

By John Cosgrove

In 2001, my wife Geri, was diagnosed with cancer. We began a 7-year roller coaster ride of shock, ... hope, ... disappointments, ... hope again, ... then an awareness that no further treatment was possible.

At one point during that journey, we decided that I would return to playing hockey something I really enjoyed. So I went back to the arena.

As I walked toward the dressing room, apprehensive about meeting the players I hadn't seen for many months, I expected an awkward silence, unsure of what I would say, or what the men might say.

I entered the dressing room, and to my surprise, a guy at the end of the room shouted "Welcome back, John", and two others added "Yes, good to have you back".

Then the comedian of the group said "Sit down and tell us how many goals you are going to score today" ... and they all laughed (because I'm not a prolific scorer).

The tension I felt was gone, and I focussed on having fun on the ice.

I have been playing hockey for 70 years, and have been in many, many dressing rooms. I realized the room was more than just a place to get changed. So much more happens here.

The men supported me in a variety of ways ... some with a quiet nod, with concern on their faces, others with humour, ... and a couple of them privately, on the way out of the arena, with an offer to help Geri or I, if and when we needed it.

While playing with the same group of men for years, I saw them support others, individually and collectively. Four men, who had terminal illnesses, and could no longer play, periodically returned to the dressing room ... to visit teammates, ... to hear the banter ... and have a beer. They too were welcomed back.



Also, we once phoned a former player from the dressing room. He was to have life-threatening surgery the next day, and we offered best wishes ... hope ... and laughter.

As players, we spent 4 hours a week together in the dressing room. As the years passed, men began arriving earlier and earlier to play, and stayed longer afterwards.

We learned how we might support each other ... and were less awkward talking about difficult issues. And when the time came, the guys were all there for me.



Listening to the People Behind the Numbers

By Martha Fair

I was in my home office scanning the literature to aid in developing a caregiving proposal. In front of me was a recent report “*Restoring Trust: COVID-19 and the Future of Long-Term Care*”. A phone -in radio program was playing in the background. I heard that distinctive voice. Yes, it was Mary from our church - the lady that my husband and I visit with as she waits in her wheelchair for Para Transpo to arrive and deliver her to her long -term care facility. I turned the radio volume up. I just wanted to listen and hear what Mary had to say.

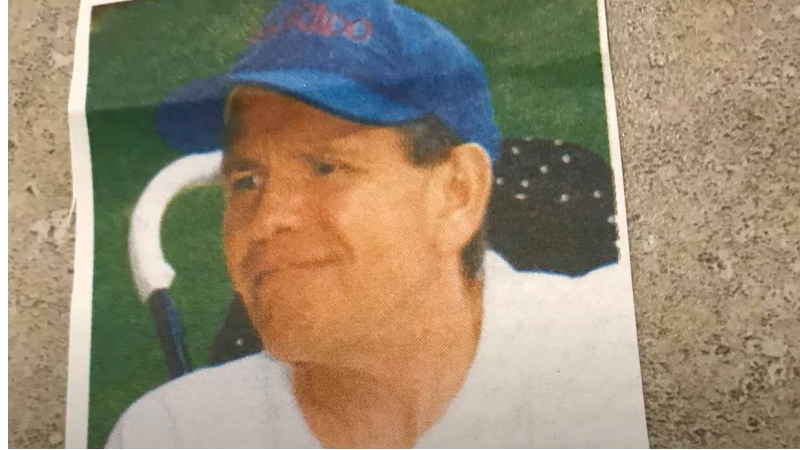
“I am thankful that there is no COVID-19 here”, she said. “But I am very lonely and sometimes even depressed. I am concerned about the mental health of people here because we are all so isolated in our rooms due to COVID. Where can I get help? I talk to my family and they say that you can go to the Champlain Local Health Integrated Network or else you can talk to your nurse. But the nurses are so busy and do not have enough time to listen to me. I do not have a computer and I find it difficult to talk on the phone for a long time”.

“In addition, the food they bring me – it seems that everything is mashed and cold. Mashed potatoes, mashed this, mashed that... I spend much of my day watching television and what do I see but chefs cooking up colorful exotic dishes”!

The news came on and Mary had to stop. I asked my husband to call her immediately. This lifted Mary’s spirits up and she was so encouraged to know that we cared and were listening.

Mary reminds me of all the help I received when my parents and nephew passed away, and how family, church and community were a great support and help to us.

What can I do for Mary, and the many people like her? What about helping the caregivers and the care receivers in my community?



As a volunteer I am interested in health research, both globally and locally, and evaluating its impact. In addition, as part of a team at our church, we provide church services at extended care homes. At other times it is a phone call, looking up information on the internet, providing spiritual care, making that special lemon loaf that can be enjoyed, helping in the garden, sending greeting cards, having conversation over coffee or providing clothing and food to those in need. The opportunities to help are endless.

“There are only four kinds of people in the world.

Those who have...BEEN Caregivers,

Those who...ARE Caregivers,

Those who...WILL BE Caregivers and

Those who...WILL NEED Caregivers.”

Rosalynn Carter



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LOST IN TRANSLATION

By Michelle de Courville Nicol

My husband, Jacques, like many people (dare I say men?) was never too concerned about his health. An entrepreneur at heart and a businessman by day, he had been active all his life in the francophone community and devoted much time and energy to various causes. He was one of the instigators of the Movement for a bilingual Ottawa, which led in 2017 to a provincial law recognizing the bilingual character of our nation's capital. He continued to work very hard towards this goal even while his health was deteriorating.

In early 2012 we were faced with quite a challenge when he developed serious health issues which rendered him paraplegic, a prisoner of his body and of his hospital bed set up in our family room. His life changed drastically, while I started a new phase of **mine**. I became his caregiver, responsible for his care 24/7, a period which lasted six and a half years.

Home care was essential, for him as well as for me. We needed personal support workers, or PSW's, who spoke French as he would have been very unhappy otherwise. At first, we obtained these services from the private sector. We were grateful to find PSW's that spoke French. They contributed greatly to his quality of life as well as to mine. However, his condition deteriorated over time, and our financial burden increased.

I turned to public home care services and discovered that the difficulty of obtaining services in French in the Ontario health system was very real. The preferred language of the patient was not always a consideration in the offer or delivery of services. I was never hesitant to request services in French, but the system of home care in Ontario is complicated, and it is not easy to get what you need.

I remember when the personal support worker we were assigned for a month could only speak English and my husband's reaction to this. I ended up having to be the go-between who had to explain to him, in English, everything to do with all aspects of his care. It is stressful enough to be the main caregiver without having to deal with language issues.



My husband needed to be able to develop a personal relationship and to talk freely with his PSWs. Patients feel very vulnerable when they are at the mercy of a caregiver who is essentially a stranger. The difficulty of speaking in another language adds to their stress and many important details can be lost in translation.

Jacques eventually died at home, surrounded by his children, grandchildren, and his life partner of 54 years, as he wished and as I had promised him.

I think we need to innovate and collaborate better to improve the cohesion of French language health and social services in Ontario.



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Dying is Part of Living

By Karin Scheerder-Tesser

When I was a little girl growing up in the Netherlands, dying was very much a part of living.

I experienced this first-hand in my own family because my aunt took care of my Oma and Opa at the end of their lives so they could die at home surrounded by loved ones.

My aunt instilled in me the feeling to help other people who needed to be cared for. I loved her very much.

We always felt comfortable talking about death and dying in my family. When my dad was dying of cancer he was cared for at home. I remember getting the call early in the morning that he had died. After taking care of our toddler and 4 year old I left them with my husband and drove 30 minutes to see my dad and help my mom.

The roads were very quiet this early and I thought: "Why did he have to die this young at 63? I remembered all the times he played with me and read me stories when I was very little. He was such a hands-on dad.

Dad was so disappointed when they told him that the cancer treatments weren't working anymore and that there was nothing more they could do. He had a difficult time expressing his feelings and wouldn't talk about it. So I didn't really have a chance to say goodbye.

Helping my mom washing him and dressing him in clean pyjamas was my chance to say goodbye and let him go. This is a ritual as old as time and even though I was only 27 then I felt so full of old wisdom. He looked very peaceful and we were all relieved he didn't have to suffer anymore.



Helping the elderly became part of my life. These days I volunteer for a local Hospice and offer companionship to palliative clients. We share stories about life and talk about dying. We also laugh a lot! I have become a very good listener and often that is all that is needed.



The Open Door

By Sue Simonsen

My Family Studies classroom was in a busy hallway of the high school, so at lunch break, I purposefully kept my door open so that students could drop in if they wanted.

Adolescence is a difficult time, with teenagers experimenting with new behaviors, often resulting in serious results. Also, they found it difficult to talk to their parents.

In my job, I fully understood that teachers can provide a role of counsellor — a role which can be a heavy responsibility, and not lightly assumed.

One day, Jeannie, a grade ten student in one of my classes came in, and plunked herself down on the chair opposite me. She announced that she wanted to talk.

She told me of a date she had with Eddie last Saturday night. They had been to a movie and the date had gone well. After, when he drove her home, he “came onto” her demanding a good night kiss and a more intimate time with her. She refused his advances, thanked him for the date and quickly got out of the car, slamming the door behind her, and running up the walk to her house. Eddie was furious, hit his fist against the steering wheel in a fit of anger, raced the motor, and tore off. As he carelessly turned onto the highway, he crashed with an oncoming car and in the collision, was seriously hurt.

Jeannie broke into tears. She could not tell her parents of her argument with Eddie, nor had the police questioned her about the accident, and she felt that none of her friends understood the situation at all. She felt guilty and alone.

I assured her that she had done nothing wrong and was not in any way responsible for the accident. She went on to talk about feeling unsure about what to say to her parents. I simply listened and continued to probe a bit more for information, but not offering any solutions.



In the end, she worked out her own solutions of where to go from here. She left my room having wiped away the tears, but now having a plan of what to do.

A week later in class, I caught her eye, and raised my eyebrows in a questioning way. She smiled at me and nodded. I felt assured she had followed through with her plan, and we left it at that.

