

# The Beacon

Spring/Summer 2020

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## Greetings from Caregivers Nova Scotia!

Greetings from Caregivers Nova Scotia! This is a dark time for many Nova Scotians as we deal with the outbreak of Covid-19. We know that many of our caregivers have been impacted by this pandemic in both good ways and bad.

In these challenging times, we are very pleased to be able to provide ongoing support to family and friend caregivers in Nova Scotia. While our programs look different as we are not able to provide in person support through our support groups and workshops, we are able to provide individual and group support over the phone. We are just a phone call away and we hope you continue to take advantage of this as you adjust to the many temporary changes.

You are hearing from me because our Executive Director, Angus Campbell is on extended sick leave and approaching retirement at the end of June. We are in the process of hiring his successor who will be in place by mid June at the latest. In the meantime, we have been pleased to appoint Jenny Theriault to the position of Acting Executive Director. Jenny and all our support coordinators would be happy to answer any of your questions and provide you with any information, direction and /or support you may require. Please also continue to access our website which has a wealth of information.

Saying farewell to Angus is difficult, given he has brought this organization forward in so many ways, he will be missed. At the same time, we wish him all the very best in his much-deserved retirement. With the addition of a new Executive Director and the growing recognition of the crucial place of family and friend caregivers in our health care system, we see an opportunity for growth and expansion in how we support caregivers in Nova Scotia.

I would like to take this opportunity to thank our team for their flexibility, dedication and hard work during this unprecedented time and on behalf of the CNS Board and team, I would like to wish you all good health, strength and calm as we make our way through this pandemic. Together we will come out the other side of this.

Patricia Murray  
President and Chair, Caregivers Nova Scotia Board



Thank you to the  
Department of Health  
& Wellness  
- Continuing Care Branch  
for their ongoing support.



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## Palliative and End-of-Life Care

At Caregivers Nova Scotia we have just put the finishing touches on a new section of our website that deals with palliative and end-of-life care.

This new section, *Palliative and End of Life Care*, comprises 12 sections, and is a deeper dive into many aspects of Palliative and End of Life care for caregivers.

We are very proud of this latest section and are dedicating this May Newsletter to focussing on this very important phase in everyone's journey, caring for loved ones at end-of life.

The thumbnail shows a webpage titled "Palliative and End of Life Care" with the Caregivers Nova Scotia logo. The page includes an introductory paragraph, a list of topics, and a circular icon of two hands holding a person. At the bottom, contact information is provided.

**Palliative and End of Life Care**


Palliative care is a method of patient and family-centered care that focuses on comfort, dignity and quality of life when a life-limiting illness is present.

This new section of our website is intended as a one-stop caregiver source of help to provide information that will help you anticipate, to whatever extent possible, what you might expect as your care recipients condition progresses. It will help you identify needs and where to find help and supports and give you a sense of control through an uncontrollable situation.

The outline below shows the different topic areas covered in Palliative and End of Life Care. Topics are arranged in order of increasing levels of intervention or service.

**Some of the topics included are:**

- Communication during chronic illness and end of life
- Getting prepared
- Palliative Care
- Living and dying at home
- Living and dying away from home
- When death is near
- The moment of death
- After death has occurred
- Funeral and Burials
- Other considerations
- Grief and Bereavement



Palliative and End of Life Care  
[www.caregiversNS.org/resources/people](http://www.caregiversNS.org/resources/people)

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## Four Personal Perspectives on End-of-Life Caregiving

Four Personal Perspectives on End-of-Life Caregiving is written by four of our own staff members and outlines their personal experiences with palliative and end-of-life caregiving. We will be sharing four different perspectives on end of life care. Caring for someone at end of life in long term care, caring for a loved one who dies at home, caring for a loved one who dies in palliative care and being present to a loved one who chooses MAID, Medical Assistance in Death. All four perspectives are important, and each highlight the deep care and love that is a part of every caregiver's journey.

### Dad's Last Days in Long Term Care

By Joan Parks-Hubley

Hurricane Juan was a turning point for our family on so many levels. My father had been living in Assisted Living and was due to move to a nursing home on that auspicious day. He was fragile and in late stage dementia. Within two months of moving to long term care, my Dad

had a partial fall out of bed and developed pneumonia. The home's physician, who knew Dad, visited. With support and compassion the physician made it clear that my father was dying. There would be no second chances this time. The nursing home moved us to a private room, and I set up vigil with Dad's favourite music. We formed a little cocoon around him. Staff was as supportive as they could be under the circumstances, checking in frequently.

A minister who knew our family came and said prayers with and for Dad, as we formed a huddle and held onto Dad tenderly. He seemed to respond on some level.

On the evening Dad died, I arrived with a thermos of Tim Horton's and a book, prepared to relieve my sister and stay the night. As I entered the room and Dad heard my voice, he opened his eyes for the first time in days. I was amazed and said "Hi Daddy. It's me, Joan!" As I moved in closer, his eyes turned and focussed on something behind us. We looked but there was nothing that was apparent to us. He took his last breath.

His death felt like a blessing, although a heartbreaking loss. The staff at the nursing home slipped in quietly after my father died and formed an honour guard around Dad's bed. It was a show of solidarity and respect that I have never forgotten it.

## **Palliative Care at Home**

**By Maggie Roach-Ganaway**

I would like to share with you my experience of caring for my husband at home during his terminal illness through to his death. I hope my story might open the door to important conversations around end of life care and death and dying at home.

No one should be told they have terminal brain cancer at the age of 49 and that they may only have a couple of years left to live. But that is what my husband of 24 years was told in 2007. At first it sent us into a tailspin as we had not talked about end of life before this. But rather quickly it became our main topic of conversation. My husband had worked at the hospital for over 30 years, and one of his main concerns was that he did not want to spend his final days there and he did not want to die in hospital. He wanted to die at home surrounded by his family. I promised him that I would make sure his wishes would be granted when that time came.

So, 4 years later, when that time did come, I couldn't have been more pleased with the cooperation and care we received from the palliative care team of doctors and nurses that helped make his final wish a reality. The team arranged for a hospital bed to be delivered to the house so that he could be as comfortable as possible. The nurses who came in daily from VON were all so kind and caring and even though they knew I had worked in health care as an LPN, they made sure that I was not over tasked with his care and that my emotional and physical wellbeing was also a priority. The doctors let me know that they were only a phone call away, and even made house calls when necessary.

The most important thing was that family and friends could come and visit with my husband and I and share a cup of tea or coffee in the comfort of our home.

This was important to my husband as he was a very family-oriented person. Most importantly, having my husband at home gave me the freedom to be a wife to him instead of his nurse. This helped to ensure that we were able to make his final days as happy as possible.

My husband was at home for two weeks before his passing, and although I wouldn't want anyone to go through what we had to, I couldn't have asked for a better understanding of how people should be treated when facing their final days. I am so grateful for the time I had to spend with my husband and our children in our own home before his death. With help and support the best was able to be made of losing my husband, my best friend and my first love.

## **The Hospital Environment**

**By Catherine Parent**

There are many opinions about which location and environment is "best" for the person who is palliative and at their end of their life. Some feel that a medical or hospital environment is not the ideal location, feeling that it lacks comfort and compassion in one's final days. This could not be farther from the truth in my experience. End of life care can be skillfully and lovingly provided in a hospital setting. This is my story.

My mother had been diagnosed with breast cancer a number of years earlier. When things went downhill, she entered the emergency department of her local hospital, where she spent less than twenty-four hours. During our short time in the ER conversations of my mother's wishes were discussed, and the emergency department provided us an area to be together as a family. It was decided that palliative care and end of life measures were to be initiated.

The following day, my mother was moved to a private room on the palliative unit of the hospital. After being settled into her room, I clearly remember the calmness in her demeanor. I knew my mother was at peace and that she felt safe. Shortly after being admitted to the unit, the Palliative Care Team approached our family. A meeting was scheduled for us and the hospital team to talk more in depth about the care and approaches

that my mother and family desired at this end of life stage. We met as a family with members of the hospital team, the physician, social worker, and unit nursing staff. This meeting was not rushed through in anyway, and I recall thinking during the meeting, “These guys are strongly advocating for my mother’s end of life wishes and thinking that, secondly, they are here to support the rest of us as well”. For an emotional meeting, it brought a smile to my soul. The plan of care was thoroughly discussed, everyone’s input was voiced and recognized, questions were answered, and reassurances of comfort were given.

The eleven day stay on the palliative unit was taken one day at a time. Our family was encouraged to be who we were, as we would “normally” be. The days consisted of steady conversations, numerous hours of singing spiritual hymns with our mother, and tearful moments of recalling past events. Early into the last days, a nurse assisting our mother spoke with a genuine smile and said to me these words that left a long lasting impression...she stated “This is your family’s time to be together, we will work around you and with you, as this is your mother’s schedule, not ours”. This was a powerful statement that has stayed with me all these years.

Each day the hospital staff continued to openly exhibit gentle and compassionate care, emotional and physical support to our family, continued ongoing communications, gave true quality care, and shared moments of laughter with us. They gave our family a sense of control in an uncontrollable disease process. The hospital staff and palliative team were present for us as our mother made her way to the end of her journey of life. We were not rushed out of this environment; rituals were respected, and time was spent with the nursing staff who had cared for our mother.

In the hospital environment, quality of life, dignity of people, respectfulness of individuals, and the compassion that we all need, were given freely and openly by the staff of the Palliative Care unit. I refer to this team as the Angels of Care. What an amazing and dedicated team of extended, temporary family.

## Medical Assistance in Dying

By Jennine Wilson

I was asked by my dear friend to be present on the day they chose to have medical assistance in dying (MAID). This is a journey I was honoured to take.

When my friend received the devastating news that their cancer had metastasized to other parts of the body, the previous optimistic plan for surgery had quickly changed to a plan for radiation of the newly affected part of the body. The prognosis after radiation was not good and so began their journey for MAID.

The process began with my being one of two witnesses on the paperwork to have all things in place if and when the choice for MAID was initiated. My heart swelled with great love at being asked about my willingness to sign the papers. There was such a mixed bag of emotions, love, trust and sadness. Tears in my eyes, I signed.

As my dear friend became more unsteady on their feet there was a fear that something would happen, and they would not be able to say yes to assistance with death. As this declaration of agreement is essential at the time of MAID a date was chosen.

It is very strange knowing when someone will die. Since my friend had made this decision just shortly after MAID became law, we were not talking about their choice to others. Our world was very small in the days leading up to the chosen date for MAID. Thankfully, it feels like there is more open dialogue in regard to MAID now.

I had many of my own internal philosophical dialogues going on. I wondered what choice I would make if the tables were turned. I knew my friend as fiercely independent, who’s duty was to protect those they loved, who loved to use their brain and learn new things and had a cutting, good sense of humour. I knew from other illnesses they endured that they loathed being taken care of and from this knowing their choice to die on their own terms made sense.

The VON came earlier in the day to put the portal in and my friend's loving partner went to the pharmacy to pick up the necessary medications. Four loved ones, as well as two doctors were present. I cannot express enough the compassion and respect the two doctors embodied as they moved through their chosen duty. My friend comfortable in their bed, in comfy clothes with their beloved partner cuddled up to them, said yes while their favourite music was playing. From my perspective it was very peaceful, and their partner told me later they felt like their loved one's spirit was released before all the medications were administered. My thoughts were how brave they were and how deeply I will miss them.

This was my personal experience. To me it was a great act of love finding the strength to follow through with a partner's wishes and bringing ease in any way they could at the expense of their own.



## Trickling Tears

### A Nine Year Old's Perspective on Death and Dying

Sarah

I braced myself before I walked into the room. Wondering what he would look like, how skinny he would be and how the cancer was progressing inside of him. I was finally ready; I pushed the heavy door open to see Donnie lying on his bed with my mom sitting right beside him.

"Hi Donnie, how are you doing?"

There was no reply to my simple question. I decided to sit down on the chair next to his bed, not knowing what else to do. We sat in silence for the first few minutes. A few minutes later me and my mom started to talk.

"How was the drive over here Sarah?"

I was just about to answer but then saw Donnie move his arm quickly to his stomach.

"Are you okay Donnie?" I asked uneasily.

"Sarah, how about you go wait in the kitchen I'll be out to see you in a second." My mom said with a sharp tone in her voice as I turned towards the door.

"Bye Donnie, I will see you later." I said as I was just about to turn the knob. I opened the heavy door once again but this time even slower. Trying not to disturb Donnie when he needed quiet. I walked to the kitchen wondering what was going on in the room, but I brushed it off and turned the TV on.

I heard some rustling out in the hallway so I turned to see what was going on. I then saw a nurse rush into Donnie's room with medication. I realized my mom sent me out at the perfect time as tears trickled down my cheek.

# You Are My Sunshine

Therese Henman-Philips

At 88, my Dad became ill and was diagnosed with dementia. Coming from a supportive family network, we rallied to provide the care he needed at home. Myself, my three siblings along with numerous grandchildren stepped in to support Mom as we looked at medical and community supports. The dementia appeared so quickly, struggling we tried to get a process in place to stabilize him. While getting to 88 years is a goal most would hope to achieve, I'd have to say we hoped and expected longer. Looking back, I think we thought he was invincible, that old age had eluded him, thinking his fate would be governed by something other than dementia! Something quick and painless.

After a hospital assessment and treatment for dementia, it became apparent that our goal of having him return home was going to be a challenge. Systems are not perfect. Navigating and getting the information we needed at the time we needed it, was not always possible. Having said that, as a family, we did the best we could with what we knew.

In the early months of his disease, we were introduced to many compassionate medical professionals and while they couldn't accurately predict his trajectory, I distinctly remember one doctor saying our job was to, "just love him". That resonated. So, as a family, we set out to make his experience as positive as it could be while we awaited placement in long term care. We set up a very committed family system ensuring as much as possible that he was a continued and valued part of the family while also making sure his needs in hospital were adequately addressed. Personally, there were costs, but not one regret.

While we all knew his death was a possibility, we were still not prepared to lose him, and the information given to us at times contradicted this eventuality. I don't think anyone, if I recall, used the word palliative or frailty to describe his medical condition in the way I understand these words now. For me, palliative care was something reserved for those in the final stages of cancer. The fact was that Dad

was palliative. I don't think I understood that at the time. I know that now. Palliative is about the living and the process leading to up to death. Frailty was his disease. Dad was moving through the stages of frailty towards the end of his life.

While Dad had addressed his advanced care directives from a legal sense many years before, we never really spoke about them at an emotional level. While I have no regrets about what we did as a family in the circumstances we were presented with, we never really had that conversation with him while he was an active agent of his own destiny. I don't know how he felt about the choices we made on his behalf. I can only hope he trusted us to do the best we could.



Dad was in hospital for fifteen months; he never did see long term care. His end of life came quickly and by way of pneumonia and a fall that robbed him of that physical strength we had always seen. It was at this time that I remember first hearing the word palliative. There is a reality attached to the word palliative, the decisions and needed support that comes with that understanding.

We had requested to bring Dad home to die on a Thursday but his deterioration over a weekend didn't allow for this planning. Dad died that Monday. The room in which he died however didn't matter. It was just a room. What mattered was that everyone who was significant was there in some form. Despite the event, his death, his end of life, it was a time marked by togetherness, sharing of memories, joy, faith, prayer and song. He was not alone. That mattered. That is what I remember most despite any decisions that I replay in my mind from the months and days preceding it. That is where I gain my comfort.

As we travel through our world's current circumstances, I have so much empathy for those who are unable to be with their loved one at the end of life. It truly was a gift to be with him on his journey. As a man of great faith, on his journey home.

## Caregiver Support Coordinators

Northern Region, Leanne Taylor



February 2020, I happily accepted the position as Caregiver Support Coordinator for Northern and Eastern Mainland. I am very excited to join the Caregivers Nova Scotia team and I have been busy learning how much work this

organization does to support unpaid caregivers in our province.

Caregiving has always been a part of my life; from the time I was a child up till the present. Being a caregiver has had positive and negative effects on my life, but it has made me a stronger person and fueled my passion to be in a helping profession. I understand the valuable role caregivers play and how demanding it can be.

I also have personal experience as a care provider working as a CCA and most recently I was the Senior Safety Coordinator for the Hants County Senior Safety Association. I am honoured to be able to help others.

As Caregiver Support Coordinator for the Northern Region, I will continue to learn, share knowledge and will strive to be a valuable team member to Caregivers Nova Scotia. If you are a caregiver, please contact Caregivers Nova Scotia, there is an amazing team there to help.

Western Region, Joan Parks-Hubley



I am a retired social worker who has worked in both non-profit organizations and government. While working at the NS Public Service Commission, I was able to help pilot workshops on caregiving and

the workplace for both employees and supervisors across government.

As a teenager, I supported a family member with mental illness. Later in life, I cared for family members and a close friend with cancer.

After retirement, my experience caring for my father, who had Alzheimer's disease, led me to work with the Alzheimer Society of NS where I was able to educate and support caregivers of persons with dementia. I found it rewarding to provide others who were starting on the caregiving journey with knowledge and practical strategies that I didn't have on mine but would have been most appreciative of.

It is a privilege to join Caregivers Nova Scotia and to support the wonderful work of this organization. I am enjoying speaking with the many dedicated caregivers in the South Shore Region and facilitating support groups. I am learning new things about caregiving and am inspired every day, thanks to those who are doing this important work on the frontlines.



### Got Feedback?

We're listening.

Give opinions and provide feedback on services, newsletter, programs, ... everything CNS.

Please contact us.

1.877.488.7390 or [www.CaregiversNS.org](http://www.CaregiversNS.org)

## May Is Caregiver Awareness Month

During the month of May, Caregivers Nova Scotia Association (CNS) recognize caregivers across the province for the unpaid support they provide to family and friends.

Never has recognition been more important than this year. COVID 19 has put tremendous pressure, stress and risk on everyone. We are inundated each day with news about the number of people infected, the businesses that are closing and losing money, the numbers of unemployed, and sadly, the number of deaths.

However, one constant through all of this is the devotion and care provided each and every day by the unpaid family and friend caregivers in our province and across the country. Statistics show that 1 in 3 Nova Scotians identify as an unpaid caregiver.

These unsung heroes continue to go about their days, during this pandemic, with little to no acknowledgement and most definitely no stimulus package. Where are the funds to help offset the lack of home care or respite care? With less respite care being provided caregivers are now forced to either bring along their care recipient with them when they go shopping for necessities or stay at home and rely on scant services for home delivery. If they do have to bring their care recipient along it potentially exposes this person as well as the caregiver to possible infection.

How are caregivers to gain access to those they care for living alone in apartment buildings where they are no longer permitted to enter due to visitor restrictions? There are so many stories that have gone unnoticed because this resilient population just do what they have to do without additional support from any level of government regardless of party stripe.

When will those who have the power to help step up to address their needs and concerns? The home first policies adopted by governments are great and most people want to remain at home for as long as is humanly possible, but at what cost and whose expense? We are all aware of the crisis in our long-term care facilities caused by the coronavirus but there is also a crisis looming in the homes of unpaid family and friend caregivers, some of whom are struggling to cope.

At CNS, we strive to support and advocate for caregivers, as well as provide information and resources. We realize the contribution caregivers are making in our province and want to recognize the impacts.

Join us this May 2020 in recognizing and supporting unpaid caregivers. Find us on Facebook (@CaregiversNS) and Twitter (@CaregiversNS) for daily updates.

**AGM**  
**Our Annual General Meeting**  
**will be held Saturday, June 27**  
**11:00 am**

This meeting will take place virtually.  
Please call 902.421.7390  
for more information  
and to register.



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