



# DEBATES OF THE SENATE

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## **FRAMEWORK ON PALLIATIVE CARE IN CANADA BILL**

SECOND READING—DEBATE CONTINUED

Speech by:

The Honourable Patricia Bovey

Monday, June 19, 2017

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### FRAMEWORK ON PALLIATIVE CARE IN CANADA BILL

#### SECOND READING—DEBATE CONTINUED

**Hon. Patricia Bovey:** Honourable senators, I rise in support of Bill C-277 and the eloquent comments of Senator Eaton, underlining the need to develop a framework on palliative care in Canada, to enhance palliative care across the country, and to do so with equal access from coast to coast to coast. Believe me, it is needed.

I also applaud the speech of Senator Cordy and her very significant research for her inquiry.

Our palliative care units in Canada's hospitals and hospices do a wonderful job, and I am pleased that home palliative care is increasing and I trust its profile is too. These critical services are relatively new.

According to the May 27 *Winnipeg Free Press*, the family of Karalee Grant only learned what Palliative Care Manitoba could have offered them almost a year after the 2010 passing of this honoured and courageous young woman. Her mother is now board president of Palliative Care Manitoba, whose vision is "that all Manitobans experiencing a life-threatening condition live well until the end of their life, and that those around them are cared for in the process." They begin offering support when an individual is diagnosed as having about six months to live.

Indeed, the hospice and palliative care system dates back to the 1960s in the U.K. and has since been implemented in Canada. In Winnipeg its first office was in 1986 and I have to commend the teams of researchers, doctors, health care professionals and academics who continue to do pioneering work in the field. We need that work, and we need palliative care services to be accessible across this country, both in health care organizations and at home.

Please allow me to be personal on this issue. I have lived it and did so over a number of months.

First, I want to challenge a major general misunderstanding. Palliative care is not, and should not, be just about the last days or weeks of a person's life, entered into when all other options have come to a close. Palliative care should be available to patients while there are still treatment options ahead. It should be about ensuring the highest quality of life possible for those with a terminal illness. It should not require a patient to sign off on, or agree to forgo, future treatments, thus denying themselves of new treatment opportunities if they become available.

I know my situation is one with which many have to deal every year, so I tell my tale in tribute to them and as a positive call for expanded programs, particularly in home palliative care, which has been demonstrated as being compassionate, less stressful and less expensive than long-term hospitalization.

Diagnosed just a few months after we were married, the last three and a half years of my husband's life, following his diagnosis, gave us wonderful times, as well as very tough ones. He faced those last three years, especially his last nine months, with courage, optimism and realism. When we learned he was facing the "one-way street," he made it very clear that he wanted to die at home. I was there to support in any way I could.

The psychological difficulty before us? In order for him to receive the benefits of home palliative care, he had to sign off on any new or experimental treatments. He did not want to do that as he was quite willing to be a "test" case for new medications. While accepting reality, he did not want to sign a document saying there was no hope — he lived with hope. He therefore did not sign the document for about six months after the point when it would have been most beneficial. I do want to stress, though, that his doctors were brilliant, honest about his situation, and compassionate, as were all the cancer care staff, and I thank and applaud them — much-needed, appreciated and difficult professions.

We reached the point of signing that dreaded piece of paper so we could get a hospital bed at home. Life became much easier after we had the bed, for him and for me. As an art curator, I could and did obviously lift art. As a mother and grandmother, I could and certainly do lift children. But I had no training in lifting patients, especially one larger than I, who had metastasized bone cancer. I learned, but I could not have done that if I had not been physically fit.

Once that piece of paper was signed we also got home palliative care help of 20 to 30 minutes a day in the morning. I had already learned to give injections, as the system could not commit that a nurse could come daily at the required time. I had to track all the medications — and there were many — at one point with the opioids reaching about \$13,500 worth a month. Some, but not all, were covered.

Finally, our level of help was expanded to two more sessions a week to cover my teaching commitments — the duration of my class plus 15 minutes on either side. That was almost impossible — driving to the university, parking, getting the computer set up and projects and all and be ready to go within 15 minutes. I'm glad I live close by.

[*Translation*]

My students were very accommodating when I had to ask them to come see me at home, and they were glad to do it. They also called me with their questions and concerns instead of asking for private meetings after class.

Snowstorms, of course, were another problem, as were the caregivers' sick days and vacation days. Every one of those professionals was wonderful. They were truly sorry when, for one reason or another, they couldn't come. Friends helped too, taking over so that I could go to the grocery store or the pharmacy or take care of various professional obligations.

[English]

Urgent cancer care was a blessing. We were also very fortunate that his GP still made house calls. What I would have done if he hadn't I honestly don't know. It was hard enough getting to cancer care several times a week and often daily. I had to leave him in a wheelchair in the lobby while I parked a number of blocks away. Handi-Transit finally approved him the day after he passed away. All this to say, it was hard, as it is for anyone in these situations, emotionally, physically and practically. We tried to keep life as normal as possible, and I am one who was long used to juggling and planning. I was also healthy and may I say, I hope, young enough. Also having been widowed once before, I knew what I was facing. My concern was his comfort, his dignity and his being able to do what he wanted, and could, as long as he was able. But I worry about others in similar circumstances.

What do those do whose work has to be done in offices or workplaces elsewhere and those with specific unalterable work times and shifts? How do people 10, 20 or more years older than I handle it? And what about partners who are not physically able to do the lifting, cooking, assisting with wheelchairs, getting in and out of the car and to appointments or, indeed, the myriad other care needs? What do those do who do not have friends and family who can help, or those who do not have financial flexibility to hire caregivers and other assistance? The 20 minutes of help a day was great, but honestly it did not cut it. The daily needs were larger.

I'm grateful that we were able to make it work fairly well, at least until his last 36 hours when a sudden shift made it impossible to cope at home, requiring pain medication I could not administer.

Honourable senators, I look forward to the day when palliative home care is not dependent on a partner whose employment, physical and mental ability and personal finances have the flexibility to enable their loved one to stay at home, if that is their wish. I look forward to the day when one can access home palliative care without having to agree to foregoing other or new experimental treatments.

Having spent as much time as I have working in St. Boniface Hospital in the public gallery I started 10 years ago, I do know the positive power of engaging in one's interests and activities. I also know the power of home and the power of being able to continue connecting with one's interests in the safety and comfort of one's own space.

Let us make sure we enable our palliative care system to develop across this country giving everyone, regardless of where they live, equal opportunity to live their lives the way they wish. I hope you will join me in supporting Bill C-277.

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