

Bridging the worlds: Palliative care with a difference

For the deaf,
dying in a
hearing world
can be as difficult
as living in it

BY KYLE BUCKLIN

Father Campbell will never forget the cancer patient who inspired her quest for better palliative care within the deaf community.

Several years ago, she received a request from an Ottawa hospital to facilitate communication between a terminally ill cancer patient and her family. The cancer had caused the patient to lose her voice but, hearing her trying desperately to communicate by paper and pen, the family needed help to talk with her during her final hours.

"I was very hesitant at first," said Ms. Campbell, whose own father had recently died of cancer.

She would eventually spend five hours at the hospital, interpreting the words that the patient would mouth to her family, an experience that proved fortuitous.

"Those five hours of my life changed me," she said. "I came away a different person."

Since then, the 47-year-old, who was born deaf, has made it her mission to improve the quality of care for deaf palliative care patients.

She said she had noticed terminally ill clients from the deaf community suffering as a result of not being able to express their needs to hospital staff.

She then decided to dedicate herself to learning about this type of care and to make a difference by enrolling in the Palliative Care Medical/Literacy Program at Algonquin College in 2000.

At the time then, she realized no others from the deaf community had signed up for the program, an opportunity that would be the college's history.

She had shared her concerns with her deaf peers, discussing palliative care, and what they needed to do to break down the institutional, cultural, and communication barriers that deaf people's access to quality care, she said.

"The 11 deaf students had access to sign language interpreters and could hear the lectures, receiving the same information as everyone else. It was a wonderful experience," she said. "They were very excited to learn us."

"We didn't get special treatment, and we didn't want that."

Ms. Campbell has two courses to complete before she receives her certificate. Because of a long-term disability, she has been taking her courses part-time.

While her physical stamina may be limited, her inner strength is vibrant.

She is an outspoken advocate for the deaf community who does not view being deaf as a disability, but a confirmed way of life, with its own language — American Sign Language.

Her special eloquence and passion about her drive to help the deaf community.

In February of this year, she was named a co-recipient of



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Elaine Campbell says the terminally ill within the deaf community often suffer as a result of not being able to express their needs to hospital staff. She wants to make a difference in their lives and in care hearing about this type of care is a special program of Algonquin College.

the Dr. John Davis Burton Award, given to a student with disabilities and a strong sense of community spirit, which surprised and delighted her.

But, she said, she wouldn't have been able to do any of it without the support and help of the deaf community.

"It was humbling and completely surprising," she said. "Why me? It wasn't really me, it's the deaf community," she said. "They encouraged me to continue on with the course."

She doesn't want attention or accolades — she is fighting for the voice of the deaf community to be heard, she said.

She wants to see culturally sensitive training for palliative care staff, along with basic sign language training, so deaf patients will no longer struggle to communicate their basic needs only to be met with confusion by staff that don't understand American Sign Language.

There also needs to be a better understanding of how vital ASL interpreters can be to the do of, she said. From her own hospital experiences, she knows how frustrating it is to

be left to communicate with out one.

"If they don't have access to interpretation services, they are really stuck, and it's not because of their intelligence," she said. "It's because of communication barriers. Communication is the main key to creating a world for the dying," she said.

Basic signs for stomach illness and different levels of pain are easy to learn, she said.

Ms. Campbell, who was born and raised in Prince Edward Island and moved to Ottawa in 1988, was not raised within the deaf community.

She didn't learn to communicate using sign language until about age 10, when a virus disease caused her to lose her job as a classification monitoring officer at the federal Public Works Department, so long-term disability.

"I was angry" she said. "I had to give up the losses I experienced from the illness."

After she finally thought her anger she finally realized that she was not a broken person who needed to be fixed.

"I was struggling so hard to

keep up with the hearing world," she said.

"I didn't know ASL, or have any exposure to the culture of deaf world."

"I didn't have any sense of belonging. I had fractured back and forth between the two worlds."

When she began taking sign language courses, she found a new sense of self-identity, she said.

"These experiences helped me to accept me, a broken being who happens to be deaf," she said. "I'm no longer ashamed to ask people to repeat if I don't understand. I feel comfortable to use sign language."

She said she has also gained a better understanding of deaf culture.

"They don't consider deafness a disability," she said. "They don't mind if they have deaf children, because it's part of the culture."

She said she wants to understand the deaf community, the loss of hearing, and the loss of culture and be of support in any way she can.

"There was a lot of personal

and spiritual growth through all of the courses I have taken," she said. "I came to know myself better, and what I can do through the course."

The goal is to help set up a training program geared to the needs of the deaf to train others to become personal support workers.

"Missouri has a deaf hospital," she said. "They're doing a lot of homework to educate the public. We'd like to do the same here in Canada."

"You can't ignore or deny the cultural gap people with disabilities face."

She said being involved in palliative care has given her a new positive perspective.

"I have more appreciation for life and living," she said.

"In palliative care, you help the dying to live their final days as fully as possible."

She said those who are dying have much to teach others about the joy of living, and it is vital to ensure their needs are being met.

"Even though they are slowly dying, they are still living," she said.