"Thanks...for teaching me that": Reflections on my experiences as a palliative care nurse

By Sue Ness

Abstract

In the field of cancer nursing we are privileged to work with patients who impact our lives forever! They teach us "life lessons" that change our perspective, heighten our awareness, and some even sadden us. The true value of these lessons, however, emerges when we use them to enhance the care we give others. "Thanks...for teaching me that" reflects on some of the lessons one palliative care nurse learned.

The management and care of the patient with cancer has undergone major changes in the last decade. To each of us working in the field of oncology those changes have a different and special meaning. There are, though, common threads that prevail as our points of intervention criss-cross.

Some of us help people through the initial assessment and diagnosis. It means being with the patient when he/she is told "It's cancer"; helping them deal with the realistic hope that "They got it all"; and with the realistic fear that they didn't get it all. Still others work in the area of treatment, where patients must be guided physically and psychologically through chemotherapy and radiation. This involves teaching, sharing information and just being there. Much of my work has been with cancer patients who have not responded to treatment, but who must patiently be supported through their disease to a peaceful and dignified death.

Little did I know six short years ago, when I was hired by the New Brunswick Extra-Mural Hospital as a palliative care nurse for the community, that it would not be my knowledge of death and dying that would increase, it would be my insight into life and living.

I entered this unfamiliar territory of palliative care armed with a wide experience in a traditional hospital, a sound knowledge base and a sincere caring attitude. "There", I thought, "this will get me started, and I'll learn as I go along". And I did! Let me share with you some of the lessons I've learned, sharing with you, at the same time, a little of myself and a little of the people who taught me these lessons.

Sue Ness

Miracles of the human spirit occur every day

Jason was a tall, handsome boy, known best in his town as a great hockey player. He was diagnosed with an osteosarcoma at 15 years of age. I met him when he was 17, now with widespread metastatic disease. He was spending his last days at home among friends and family. Like most 17-year-olds, his friends were a very important part of his life, especially his hockey team. The night of the play-off game, the coach and team stopped in to see Jason on their way to the rink.

Giving them a smile and thumbs-up sign he said "I'll have the best seat in the house tonight." The team knew by these words that Jason would die soon. They made their pact: "We'll win this one for Jason". And they did.

Isn't it wonderful to realize that we humans have the capacity to bridge the physical plain and the spiritual plain, to link heaven and earth?

"Thanks, Jason, for teaching me that".

Good care makes me feel so good

Betts died four years ago with cancer of the breast that had metastasized to her lung. Along with her husband and four children, I helped look after Betts at home. One day after rubbing her back and smoothing her sheets she said "Oh..., good care makes me feel so good".

Suffering, not death, is the real enemy. Therefore we must remember good symptom management is imperative. Because Betts had no pain, because her nausea was controlled, she had some energy left for pursuits like enjoying a drive to view autumn's splendour, holding her new grandchild and watching Golden Girls on TV right up until the day she died.

In her own special but quiet way she was asking two simple things of me. Be competent. Be caring.

Those of us working in oncology cannot afford to be complacent in the area of symptom control. Continuously we must question, search, report new findings, and demonstrate assertiveness in trying to apply these findings.

Only by combining these two skills can we ensure that our patients will enjoy a certain quality of life.

"Thanks, Betts, for teaching me that".

My cancer is only part of what I am

Al was a farmer, used to working long hours in the fields. A mole on his back that had "changed a little" was diagnosed as a level 4 malignant melanoma. In an instant, life had thrown him a curve with which he now had to deal.

Al felt betrayed by his body, but he wanted to make sure we remembered what made him special and unique. He was a good

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ABRÉGÉ

Nous avons la chance, dans le domaine des soins infirmiers oncologiques, de travailler avec des patients qui ont un impact durable sur notre vie! Ils nous donnent des "leçons" qui changent notre façon de voir la vie, nous font prendre conscience de bien des choses et il y en a même qui nous rendent tristes. Cependant, on découvre la vraie valeur de leurs leçons quand on fait appel à leurs services pour améliorer les soins que l'on dispense à d'autres malades. L'article "Thanks... For Teaching Me That" se penche sur quelques-unes des leçons apprises par une infirmière en soins palliatifs.

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husband and a wonderful father. He love nacho chips with salsa sauce, and the Blue Jays were his team!

It is important that we care for our patients holistically, taking into account all their physical, emotional and spiritual dimensions. Only then can we give them the reassurance that their value will not end with their death.

"Thanks, Al, for teaching me that".

Listen to me!

Ed was an 82-year-old man with cancer of the rectum. One day, after I had changed his colostomy appliance, auscultated his abdomen for bowel sounds, and checked his vital signs, I sat in an antique rocker close to his bed. We were admiring his garden and taking in the beauty of the river flowing by outside his window.

As I put on my coat to leave, a floodgate of questions opened "Why did this happen to me, Sue?" "Mary isn't capable of looking after herself." "How come my sex life isn't what it used to be?" "Will the pain get unbearable?"

Taking his hand, I replied "Ed, I don't know the answers to all those questions." He smiled, "I know" he said in his weak voice, "you don't have to know all the answers, but thanks for listening to the questions." I think of Ed each spring. He gave to me some of his beautiful flowers and they now grow in my garden! I learned that day that there is value in just "being", we don't always have to be doing.

"Thanks, Ed, for teaching me that".

People will face the crisis of cancer as they've faced other crises in their lives

Wayne had been an unhappy, angry teenager who had been a "trial" to his parents all his life. During his illness he was difficult, even abusive to his wife and child. When he died of Hodgkin's Disease at age 26, very little of his earlier difficulties had been resolved. He was still difficult and angry.

The ambivalent feelings one has towards a patient like this stir up strong emotions. It is very stressful and we often lose our perspective. What I came to realize, though, was that people choose how they act and react to their illness; and that we must respect their way of coping even if their judgment seems poor. We must also accept the fact that we don't grieve everyone's death. This was probably the most difficult lesson of all.

"Thanks, Wayne, for teaching me that".

We must care for the caretaker

I hope that in no way have I glorified my work. It's sad; it's taxing; it demands commitment. But do you know what I get in return for working in the field of oncology. I learn to take things one day at a time! I know nothing is for certain or forever, and that means I live my life as if every day might be my last; I don't make mountains out of molehills, and I appreciate that there is much around me that is good; I love life!

People often ask "How do you keep this work with terminally ill patients from overwhelming you?" My reply is that even though cancer has become a part of these peoples' lives, I can only hope that, through my involvement, I will help them deal with their circumstance more positively.

We must also learn to recognize our own needs. Try to be as honest, caring and supportive of one another as you are with your patients. Keep up with your other interests, whatever they might be. For me it is swimming, skiing and reading. A busy life outside your work rejuvenates your energies. Above all, recognize that it might be right for "time out", and feel no guilt about it.

In conclusion, each of us will bring our own uniqueness to handling these patients and situations. Know that caregiving is always special when it is laced with sincerity, honesty and true caring. Laugh! A sense of humour is always right.

"Thanks...for teaching me that".

What Cancer Can't Do

Cancer is so limited...

It cannot cripple love,
It cannot shatter hope,
It cannot corrode faith,
It cannot destroy confidence,
It cannot kill friendship,
It cannot shut out memories,
It cannot silence courage,
It cannot invade the soul,
It cannot reduce eternal life,
It cannot quench the spirit,
It cannot lessen the power of the resurrection.

*Reprinted with permission from "Our Daily Bread" Radio Bible Class Publications Vol. 33, No. 9, 10, 11
February 1988, Grand Rapids, Michigan, U.S.A.*

Cancer Drug Manual

- B.C. Cancer Agency

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