

A Hospice Story: Janet & Charles Edmunson

Reprinted from Parmneter's Perspectives

Ensuring that her husband's legacy lives on and sharing her hospice experience in order to help others, is what drives Janet Edmunson. In May of 2000, Charles, Edmunson's husband of 20 years, died at age 50 from a neurological disease called cortical basal ganglionic degeneration (CBGD). He had been cared for by Wayside Hospice for over a year in his Framingham home. Since then, she has been writing a book, tentatively titled, "Caring for Charles and Finding Meaning," which chronicles the progression of his dis-ease and their experience "walking that journey together" with hospice.

As his disease progressed, Charles lost his ability to walk and to talk, in addition to eye movement. After he endured two frustrating hospital stays over a three-month period, Edmunson realized they couldn't go through another hospital stay. She signed a DNR (do not resuscitate) order, but when telling Charles' home health aides about it she realized, "What are we going to do if something happens? I really felt vulnerable, like I didn't know what that would mean in practical terms."



Fortunately, however, a discussion with a Blue Cross / Blue Shield case manager regarding next steps, triggered something in Edmunson. "One of us mentioned hospice," she recalls. "My Dad had been in a Florida hospice before he died. Because I had such a wonderful memory of that, I knew I definitely wanted hospice in the end."

Transferring to Wayside Hospice was terrific says Edmunson. Charles' nurse, Dianne Oelberger, was "very smart and very caring. I felt like I had a safety net now that I had hospice ... now I have a plan when something goes wrong." It gave her "tremendous piece of mind knowing that hospice was there." Hospice also helped to get the necessary equipment for Charles such as a hospital bed. If something wasn't working for Charles, they could try different medications to treat various side effects.



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(cont.)

Throughout Charles' illness, Edmundson continued to work full-time as the Product Manager for Prevention and Wellness for Blue Cross/Blue Shield of Massachusetts. Coordination of care for Charles was difficult; there was a gap between when the morning aide left and the evening aide arrived. Sue Anderson, Volunteer Coordinator for Wayside Hospice, stepped in and arranged for hospice volunteers to fill in this block of time. The volunteers became Charles' friends at a time when some of his friends found it very difficult to visit. "Each of the hospice volunteers provided their special touch to the care they showed Charles," recalls Edmundson. Additional home health aides on the weekends also allowed her to get out for errands or a bit of respite.

Edmunson recalls that the hospice Social Worker was also very helpful when she suggested that they bring in their Spiritual Care Counselor. Although he had been a minister in his youth, Charles was an agnostic. However, Edmunson says, "I feel very sure that spiritual support was very helpful. I would not have thought to bring someone in like that."

"As things got closer," to the end says Edmunson, "I always wondered how he would die." While it scared her, she knew that she'd have Dianne to rely on. When Charles stopped eating, over a few days his body slowly began to shut down. "Dianne explained the process," says Edmunson, and "we let him wind down. It was obvious to me that morning that it was the last day. Dianne helped me get through the day. Once Charles died, I called her and she handled everything. It was just tremendous support."

Janet recalls that "it meant a lot to hear how Charles had had a positive impact" on the lives of various hospice staff. After his death, she found hospice's bereavement newsletters to be very helpful in conjunction with the books that she was reading. Wayside Hospice's social worker also continued to come for awhile to visit.

Because people have commented on her positive attitude, Edmunson was encouraged to know that she made it through this ordeal and had a lot to share about the caregiving experience. Fortunately, she had taken notes as she went along which aided the writing process. "The other thing that inspired me to write the book was Charles," she says. "He had never written a book prior to his disease but had wanted to. As his illness progressed and he lost his writing ability, I suggested it was time do so." People helped take dictation and Charles' book, "Paradoxes of Leadership" was published.

Edmunson has now switched to a more compressed work schedule in order to devote every other Friday to her writing. She also has taken writing courses and is in a writing group. She estimates that the first draft of the book is 90 percent complete and will be finished in the next couple of months.

Charles "was such a wonderful person in so many ways," says Edmunson. "To see his life get cut so short – I feel the book is a way that I can get his philosophies out. I really want to share my caregiving experience and I want to share Charles."



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