

## DYING AT HOME – AN ALTERNATIVE

NOVEMBER, 1981

I make the decision; a philosophical, intellectual and emotional one which I keep to myself. I give little thought to its implementation. The decision is that my widowed mother, Ella, will come to live with me when she can no longer function in the Senior Citizens' Lodge where she makes her home. The surgery she had two years before, for cancer of the colon, has prolonged her life but has not arrested the cancer.

Ten years earlier I would not have made the same decision. But she and I have worked through our strong differences of opinion on child-rearing, religion and lifestyle to become friends. I watched her, at 77, fall in love with Duke, one of the residents at the Lodge, and we shared many woman-to-woman conversations about the hazards and joys of such relationships. I am her only daughter.

JANUARY, 1982

Ella celebrates her 80<sup>th</sup> birthday. Her two great-granddaughters, Devon, aged eight months and Emrys, fifteen months, compete for centre stage with the matriarch of this small family, all gathered for the celebration. It becomes apparent to all of us that her health is failing.

MARCH, 1982

An intense, but brief bout of illness precipitates action on the decision. My brother, Mike, and his wife, Jean, and I hold a conference. They are in agreement with my decision so we proceed to tell Mum, acknowledging that the date for moving is yet to be determined, and that it will be determined primarily by her. She tells me the knowledge she will not have to go to a nursing home or a hospital is a great relief to her. Now I wonder why we have not talked about that before. We have discussed, and she has written, a living will, instructing us and her physician not to use heroic measures to prolong her life if she is very ill.

I didn't talk to her about coming to live with me for two reasons: one, I didn't want to suggest

to this fiercely independent Yorkshire lass of 80 years that she was incompetent in any way, and two, the reality of having to change my lifestyle was hard to face. Periodically, mild panic would rise with the questions, "What if she lives for two years..... or five? What will I do? How will I cope" None of us expect her to see another Christmas but the questions came anyway.

APRIL, 1982

My itinerant daughter, Diane, and I have an important conversation. She and her friend, John, have plans for the summer which include a trip to Nova Scotia before settling in Vancouver in September. She agrees to help with the care of her Granny, although neither of us knows what that will mean at this point. We all anticipate that when Granny first moves in, she will be able to stay alone for most of the day; she may even have supper ready for me when I come home from work.

The room is readied. I have fun painting, buying curtains and new light fixture, getting ready for my new housemate. That's right, housemate. For she insists she will pay her way – half the rent, half the groceries. Her appetite is so small, that doesn't seem fair.

MAY, 1982

Mum comes to visit and "try-on" her room. She loves it. She is still strong enough to walk to the corner and back. We visit the Muttart Conservatory one afternoon and go to the movie, Chariots of Fire, on another. During Mum's third short visit, Diane arrives early in the morning to give Granny her breakfast before she goes to her own job at 10am. I come home by 2:00, cutting my day short. This is the pattern I anticipate will continue for some time. How mistaken I am! Moving day is May 30. She has her cable TV and her own phone installed; the phone so she can keep in daily contact with her dear Duke, who remains at the Lodge.

JUNE 2, 1982

Diane also moves in! I am startled when she quits her job in order to be here full time, although it is already clear that Mum should not be left alone for long. My once quiet home is suddenly hopping. People are coming and going all the time. Mum's friends, Diane's friends

and mine are buzzing around. Where yesterday there was me, today there are three of us. I am invaded. Where is my freedom? Where is my privacy? Help!

JUNE 7, 1982

My call for help goes out first to my kin and a family meeting is called. My brother, his wife and most of the 7 grandchildren attend. Granny chooses not to come but she is extremely interested in the outcome, which is a guaranteed offer of assistance at a moment's notice. Diane and I are urged to call on them not just if we have to go out, but also if we want to go out. And we do. They make good the offer which results in some precious time sharing for Mum with her son and all the family.

Beyond the family, a community of support surrounds us. Old friends and new come to share time with Ella so that Diane will have some free daytime hours. They do the same for me in the evenings. My need for privacy is partially met by those who give me the keys to their homes and an invitation to use them whenever I want. People bring flowers and fruit, and some of her old friends, including Duke, drop in for short but sweet visits. Meetings which I am obliged to attend are held at my house for my convenience. Diane receives long distance support from John in Nova Scotia. My second daughter, Lindsay, offers to be Granny's hairdresser, and a music lover makes tape recordings of music which seem to bring Mum pleasure as she drifts off to sleep. Mum and I develop an evening ritual of Mexican coffee and conversation which we share with any and all who come. People offer to help and we accept all offers.

JUNE 17

At the cancer hospital we visit the doctor whom Mother adores. In answer to my question, he informs us that should Mum require hospitalization, she would be admitted to a different hospital under her family physician. This is, I suppose, because she is not receiving active treatment for her cancer. Her family doctor has already told us that he is reluctant to act without direction from the physicians at the cancer hospital. A dilemma! In any case, it is our hope she will not require hospitalization, or if she does that it will be temporary, and she will

die in her own bed at home.

JUNE 18

I reach out into the community and visit the Palliative Care Unit in the Edmonton General Hospital. I am greeted warmly by a colleague who serves with me on the fledgling board of Hospice Care Edmonton, a volunteer organization dedicated to the promotion of excellent care for dying persons and their families. The philosophy of the Unit fits with ours so Mum's doctor makes the necessary referral. Their prompt, caring attention is reassuring to all of us, though no alarming problems have arisen. Ella is delighted by the informality and warmth of the physician's visits at home.

JUNE 22

Mum has been here three weeks now, and while we have supper at the picnic table, the three of us women, ages 22, 47 and 80, discuss our living together and what it's been like for each of us. It's not an easy conversation. Diane is feeling some unjust criticism from her grandmother and Ella is afraid we are going to leave her alone sometime. With love and cooperation, the misunderstandings are resolved. Our own network is strengthened and the bonds deepened by this rare opportunity for sharing.

JULY 2

This day is the beginning of the end, though we do not know it at the time. Today, she cannot get out of the bath unassisted. Tomorrow she will be unable to climb the stairs.

JULY 3

Her newest great-granddaughter, Sarah, five days old, is brought to visit and Granny holds the baby, at the same time carrying on a private conversation with her cherished grandson, Tom, the infant's father. They both know it is their last conversation. Mum is ready to die and has said so for some time. She treats the matter with a mixture of common sense, wisdom and humour which many of us would do well to copy. She is impatient with my tears which come

unbidden sometimes.

#### JULY 5

Diane drives to Southern Alberta for a day or two, everyone encouraging her to go. Before leaving, she sadly reports that today, Granny needs help with walking and toileting. It is the final indignity for this English lady and I believe Ella made the decision then, to “run the rest of the way home”. There was nothing more that needed her attention. She had no unfinished business and was free to go.

The events of the next two days are something of a muddle, even now. Lindsay comes to help care for her Granny; she and her toddler sleeping here when she senses my uneasiness at being here alone with Mum overnight. The nurse and doctor are contacted when the vomiting starts, and once again we receive prompt and solicitous care. New medications are prescribed, and later, an oxygen unit is brought to keep her comfortable. As each crisis occurs over those two days, the option of admitting Mum to the hospital is discussed, but each time we decide we can cope at home, with their support.

I still think Mum will rally; that this is temporary.

#### JULY 7

Lindsay and I watch as Mum's physical systems slowly wind down. She is peaceful and in no pain. I am shocked, when in conversation with the nurse, I realize my mother is dying – NOW. Utter disbelief is followed immediately by action. Mike must be called. He must come now if he wants to make contact with his mother again.

Diane returns mid-afternoon refreshed from her 48-hour junket, and is shocked and unbelieving to find her Granny just able to welcome her back with a smile and a whispered greeting. Mike and Jean arrive and shortly after, Ella drifts into sleep.

She dies peacefully at 11:45pm with her son keeping the vigil, holding her hand and stroking her back.

#### NOVEMBER 1982

What did I learn?

If I had known she was only going to live with me for 6 weeks, I would have taken leave of absence from my work. At the very least, I would have stayed home a lot more. An answering voice within says, "Oh yes, and have done it all yourself? Don't you know how important it was for all those others who loved her to share in her care? You would have deprived them of something special. And don't you know how important it was for you to ask for help and take it when offered?"

I learned the wisdom of not making my circle of support too small. Somehow I knew that limiting my circle to one or two people was not a good idea. Building a support group takes time and it's worth it.

I learned too that death can be friendly and peaceful, albeit sad, and it need not be frightening and cold. I treasure the message written by my sister-in-law the morning after Mum's death. It says, in part, "... you broke with tradition and nursed Mum to the end." It goes on, "... you have shown me that death can be warm, dignified and without great sorrow."

Diane and I could not have broken with tradition without the support of our loyal and loving family, our wonderful friends and the professionals at the Palliative Care Unit. I want to share our experience so that others might also choose to care for someone who is dying at home. I recognize that each family situation is different and that personal and community resources will vary. Gifts of time and energy will be forthcoming from expected and unexpected sources. The events of the last year surrounding my mother's physical deterioration and death constitute for me a religious experience. I am a Unitarian; a Unitarian who does not believe in a personal god. In times of trouble, I turn to people: a person, a woman or man who cares for me and who expresses that caring in tangible and intangible ways. The love demonstrated to me and around me throughout this whole experience is the very essence of life itself.

*In 1981, the hospice movement was in its infancy and dying at home was not common. The Palliative Care Unit at the Edmonton General Hospital was the first in the city.*



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