

Family Matters

By Pat Irwin



Elsie was born in interesting times. Growing up in a working-class family in England, she experienced firsthand the hardships of the Depression, then 'did her bit' in the Women's Land Army during WW II. She was the embodiment of the ethics of that time - 'make do and mend', 'mustn't grumble', 'you've made your bed, now you must lie in it', and a firm believer in stoicism, making the best of things and never, ever making a fuss. She had a firm church connection and a

deep faith, that sustained her through two marriages, seven children (most as a single parent), a long career at Bell Canada, heart failure and diabetes, the premature death of her son, only brother and two husbands. Surely, this was enough to test the mettle of any woman.

Margaret's Top Tips for Palliative Caregiving

- 1.** Do the paperwork - be sure the Powers of Attorney for Property and Personal Care are complete, as well as the Will and banking arrangements.
- 2.** Respect your patient's wishes, even if you personally disagree. I recently lost an aunt, for whom I was executor. During her illness, she wanted to make a change in her Will, but I said, no, you're getting better, don't think about your Will right now! In hindsight, she was right, and I should have listened.
- 3.** Sometimes you have to ignore your own sensibilities, and understand that we are all different, with different beliefs and commitments...for example, Mum was very involved in volunteering and her church. She seemed to be spending a lot of money on both - but she was mentally competent, it was her money. So let it go.
- 4.** Don't be afraid to say goodbye. Mum was at peace with her decision, but each of us had to come to terms with it, and allow ourselves to let her go without guilt, resentment, or anger. We were so lucky that we had the time to do it.

However, there was more to come. Within two years of her second husband's death, she was diagnosed with bladder cancer. Chemotherapy shrank the tumour and eased the pain for awhile, but after a few months of treatment and a hospital stay, she was back home with full palliative support including regular nursing visits and pain medication. The stiff upper lip never wavered - Elsie announced she was tired and was ready to die.

Thus began a journey for Elsie and her family - a journey that tested the very fabric of themselves and their relationships - and ultimately, demonstrated their inner strengths.

Elsie's daughter Margaret says, 'We took our cue from Mum. Her attitude was total acceptance, so we went straight into planning mode. Each of us took a role - most of which mirrored our roles growing up. Mom had always been the Rock of Gibraltar - now some of us created that rock together.'

"As the primary caregiver, I moved into Mum's home. During the last 4 months of her life, we spent our time talking, doing crossword puzzles, and watching British sitcoms. Mum learned to laugh for the sake of laughing - she said I taught her that! During the last week of her life the palliative care workers came in from 11pm-7am, so I was able to get some rest. There were so many things about Mum I had never known, that she had just blocked out in order to survive. In losing my Mum, I got

to know her - in saying goodbye, I learned about who she was, but that enlightenment was only possible with the support of my brothers and sisters."

What the Professionals Say

HomeStead CareProviders specializes in providing palliative care services to clients in their homes. Their president, Ofra Garmaise, explains:

We recognize that the approach to death and dying has evolved. Rather than denying that death is imminent, we now embrace it as part of life. We have come to better understand the grieving process and to see the end of life as a time to validate and celebrate our loved one's life, to say our goodbyes, to bond in a special way, and to have closure. As home care providers, we have been inspired by families' undying love for those who could no longer reciprocate. Helping them fulfill the wish to end a life at home, with those they love the most, has been a privilege.

One daughter, whose mother lost her battle with cancer, wrote: *"Thank you for your kind words and all the support provided by your wonderful staff. Her wishes could not have been fulfilled without you."*

Another daughter, whom we had helped care for her dad in the final stages of diabetes, wrote: *"What a wonderful job your caregivers provided. We will be forever grateful for the manner in which my father was cared for in his final days."*

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Is it Caregiver Burnout?

Caregivers are always prone to burnout; even more so given the additional emotions of a palliative situation. Take this quiz developed by Veteran's Affairs Canada and check the Palliative Care Support Services box pg 17 to find the help that you need.

- I am always tired
- I don't sleep well
- I often get sick
- I have gained / lost weight without trying
- I often feel depressed
- I have given up favourite hobbies & spending time with friends
- I have become short-tempered
- I cry easily / often
- I feel unqualified to give the care
- I must provide
- I resent my role as a caregiver
- I feel hopeless about the future

If any of the above statements are true, you are at risk for caregiver burnout - please seek the help you deserve.

What is palliative care?

Palliative care describes the programs and services available to treat the symptoms, but not the disease, of someone with a life-threatening or terminal illness. It views dying as an inevitable part of life; neither brings on nor delays death; provides relief from pain; provides support to both the patient and the family; respects personal, cultural, and religious values and beliefs. The goal is not to cure, but to maintain the highest possible quality of life for the patient and their family.

Designate a sibling as the 'project manager'

There's always one sibling who assumes this role fairly early in the process. This may be due to proximity, profession or the wishes of the patient, but it's usually based on family dynamics.

Let everyone participate in their own way

As in childhood, your parent has a unique relationship with each of you. In Elsie's case, each of the siblings took turns spending time alone with her (as schedules allowed). One daughter took on Elsie's physical and material needs; another spent time playing games and reading the Bible to her; one of her sons' was the self-appointed handyman. The timeworn dynamics persisted - some siblings were totally reliable while others begged off or disagreed with the plans.

Keep everyone in the loop

Margaret relied on broadcast e-mails to keep everyone informed. 'It was consistent, time-effective and flexible - I could send messages at 3 a.m., if I needed to, and everyone received the same information.'

Talk early and often

Although she knew her mother's basic wishes, Margaret realized she needed to constantly revisit and confirm the plans with her Mum, the family and the palliative care professionals. ■

Palliative Care Support Services

The Palliative Care movement offers a wealth of support services and information

Care Services

Hospices provide a full range of end-of-life care in a homelike setting; many also provide outreach services for people dying at home; see pg 61. In-home Care is available from the various sources listed below. The first step is to contact the Community Care Access Centre (CCAC) (listed on pg 39 of this issue of Help's Here), which will make an assessment and assign a maximum number of care hours. To supplement this, families may hire care from non-profit agencies such as Saint Elizabeth Homecare, or from private agencies (see pg 24 in this issue).

Family Support

The Hospice Association of Ontario - www.hospicelifeline.com / 800-349-3111 - can provide all the information needed; where to get care, dealing with emergencies, what to expect; caregiver relief and respite care; emotional support; homemaking and care services; volunteer visiting; telephone advice.

Financial Information

Caregiving costs may range from a subsidized rate of \$12/hour to \$25/hour for a personal support worker; a visiting nurse may cost \$65/visit. Most families obtain whatever is available from the CCAC and supplement it with private care as needed, or handle the caregiving themselves. Many care costs are tax-deductible; visit Revenue Canada's website at www.cra-arc.gc.ca for details

and be sure to keep all receipts for caregiving services and supplies.

The federal government's Compassionate Care Leave program entitles any employee up to 8 weeks of compassionate care leave to provide care and support to a gravely ill family member. A certificate is required from a qualified medical practitioner, stating that the family member has a serious medical condition with a significant risk of death within 26 weeks - www.sdc.gc.ca.

Getting Started

Anyone may make a referral to any hospice or palliative care agency; the staff will guide you through whatever supporting information and procedures are required, or click on 'services' for detailed information. But please -make the call - help is available, and you're not alone.

Useful Links

- www.virtualhospice.ca - an interactive network for people dealing with life-threatening illness and loss
- www.hospice.on.ca - Canada's largest volunteer hospice organization providing high-quality, compassionate end-of-life care for individuals living with a life-threatening illness, and those who care for them.
- www.dyingwithdignity.ca - directory of hospice palliative care services throughout Canada; source for Living Wills kit.