

## Life should be savoured until the very end; Death doula enhances dying experience

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### IMAGES

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Uncredited image

Levine (FPinfomart: Restricted,  
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A doula is traditionally someone who is trained to assist at the beginning of life, but a new breed of doula is emerging to help those at its end as well.

The director of a well-established program in New York City that trains and supervises volunteer doulas for the dying will speak for the first time in Canada this week about how to enhance the care people receive at the end of their lives.

Organizers of Edmonton's CapitalCare conference -- called Dying Well, Living through the End of Life -- hope volunteers and professionals in Alberta will be able to implement some elements of the New York program here.

"Illness can be so isolating," said **Amy Levine**, who runs the donation-funded Doula to Accompany and Comfort Program in New York. "The volunteer is trained and is able to listen and be available without an agenda. ... They are compassionate companions."

Levine will speak in Edmonton at sessions designed for health-care workers as well as for family and volunteers during the 24th People and Progress Continuing Care Conference on Thursday.

Nearly 400 professional and voluntary caregivers from across Western Canada are expected to attend the conference, organized by the charitable foundation that raises money for CapitalCare, the public long-term-care provider in the Edmonton area. Levine will also offer a two-day training workshop after the conference designed to help professionals implement a doula volunteer program.

The New York doula program has trained about 400 volunteers since it was established in 2000, and currently has about 60 active doulas comforting the dying. They provide emotional, spiritual and social support as well as companionship for people whose life expectancy is 18 months or less. They go to hospitals, nursing homes, assisted living facilities and private houses to visit seriously ill patients who have limited support from family and friends.

Volunteers come from a wide range of backgrounds and professions, but most have some level of comfort dealing with death, Levine said. "Most of society doesn't really want to talk about dying," she said. "The key is really being aware of our discomfort, our anxiety, that we want to fix it. In doing that, we become comfortable."

Doulas are trained in communications skills such as deep listening and taught to be present and fully available for the patient, Levine said. Sometimes the volunteer has a single, short visit with a patient and other times the volunteer visits a patient numerous times before they die.

Doulas are told to take time to recover after one of their patients dies. Volunteers receive ongoing support and gather every year for a memorial service to honour patients who have died. Certainly, it's hard to get to know this person and watch them die, so there is sadness."

Bernadette DeSantis, CapitalCare spokeswoman, said the New York program is promising. "It's proven and it has helped so many people (in New York) and that's really what our business is all about -- to help people have a beautiful end of life experience," DeSantis said.

"How can we create a beautiful death in the same way that we create a beautiful birth?"

Other speakers at the conference are Dr. Romyne Gallagher, a British Columbia palliative care expert, and Dr. Ira Byock, a longtime palliative care physician in the United States, advocate for improved end-of-life care and author of the book Dying Well.