Compassionate Communities:
A Public Health Approach to End of Life Care

In October 2018, I had the privilege of attending the 22nd International Congress on Palliative Care in Montreal where I presented a poster about Death Café and a poster about end-of-life doulas (EOLDs). I met many wonderful people from all over the world who are care providers, researchers and teachers related to the field of palliative care. I am attending the Congress again in October, 2020 and presenting my research findings about end-of-life doula pioneers in four countries.

Presentations at the 22nd Congress ranged from the latest in pain management, to the use of cannabinoids for serious illness, to palliative care in war-torn countries, for the homeless and for the incarcerated. The biggest buzz centered on the public health approach to creating "compassionate communities" for end of life. I was immediately interested because I can see how doulas fit into this worldwide initiative; however, those who are promoting and developing the concept do not yet know that EOLDs exist. We have our work cut out for us!

According to sociologist Allan Kellehear, Professor of Health Studies at the University of Bradford in the U.K., every major sector of the community should be involved in promoting the concepts of palliative or compassionate care at the end of life because "health and wellbeing is everyone's business" (Kellehear, 2015). Kellehear has initiated a Compassionate Cities approach whereby government entities, health services, schools, businesses, volunteer organizations and civic bodies partner to change policies and practices about serious illness, dying, death and bereavement. Like public health initiatives on smoking cessation, domestic and sexual abuse, human trafficking and opioid addiction, the compassionate communities approach encourages a collaborative network of community stakeholders to strengthen and expand services.

Awareness is raised in the effort to ensure that no one who needs compassionate care falls through the cracks. The basic premise is that most of our time spent dying, caring and grieving is at home, work and play, not at the doctor's office. Health promotion and death education is not a part of typical clinical bedside care (Kellehear, 2013). Therefore, services for the aging, the dying and the bereaved should be everywhere we live and spend our time—and they should be abundant, accessible and affordable.

How can EOLDs contribute to the creation of Compassionate Communities for folks at the end of life? EOLDs are educated about and experienced in supporting dying individuals and their families, emotionally, spiritually, physically and practically. EOLDs live and work as integral members of their communities. As such, they are ideally situated to provide education and resources about services at end of life. Because they are known and trusted *within* their communities, EOLDs can be the eyes and ears of public health initiatives designed to identify those in need of social services, palliative care, hospice or bereavement support and can, in turn, serve as ambassadors to spread the word about available services.

We know that many individuals do not seek palliative or hospice care until a very late stage of illness. We shouldn't wait until we are dying to begin to plan and access services that could help us prepare for the challenges unique to this stage of life. Doulas raise awareness in an informal way as they go about their daily activities—attending work, faith-based organizations, school functions, civic events and neighborhood gatherings. Like community health promoters in developing countries who are a bridge to health services, EOLDs come from many backgrounds. They can be quickly trained and will help transform our communities into places where every person who is suffering through illness, dying or bereavement can get the compassionate services they need and deserve.

At one time, families were accustomed to living in multi-generational households and caring for each other in birth, sickness and death. Extended family members, neighbors, co-worshippers and friends gathered 'round and supported the infirm and their caregivers. Today, many of us are aging while living in large cities made up of transient populations; in addition families are widely scattered. Too many of us are coping alone, for years, with serious illness. We *must* strive to recreate these caring communities—enlightened health care professionals alone cannot do it. A top-down approach is insufficient to reach all individuals in their daily lives. Only by working together in all sectors of a community to raise awareness and provide services can we bring compassionate end-of-life care to everyone who needs it. End-of-life doulas are among the many professionals who are needed to enhance health and wellbeing for the sick, the dying and the bereaved.

References:

Kellehear, Allan (2015). The Compassionate City Charter. Fourth International Public Health and Palliative Care Conference, Bristol, England. https://www.youtube.com/watch?v=AhiNY5_ub7E

Kellehear, A. (2013). Compassionate communities: end-of-life care as everyone's responsibility. *QJM: An International Journal of Medicine*, *106*(12), 1071-1075.