

Hospice Palliative Care:
Key Component of Comprehensive Elder Care

SSAO recently interviewed Dipti Purbhoo and Sue Lantz about Hospice and Palliative Care as a key component of elder care.

Dipti Purbhoo is the executive director of the Dorothy Ley Hospice in Etobicoke. Sue Lantz is the managing director of Collaborative Aging.

SSAO - How would you describe the essence of palliative care and hospice?

Dipti Purbhoo - Palliative care is the umbrella term that most people know. And hospice is generally associated with more end of life when people have very few months to live. We consider the two together. *Hospice palliative care is an approach to care* for people with serious illness or people with a life limiting illness. The goal is to support them with a focus on comfort, symptom management, quality of life, and support for their loved ones.

Palliative care is aimed at relieving suffering not only from a physical perspective but also from an emotional and a spiritual perspective, and not just for the individual but also for their family, however defined. And it is for the entire journey; that is one of the things that differentiates hospice palliative care from other types of care.

Not a lot of people understand hospice palliative care until they directly experience it. Many working in the healthcare system (who are not in palliative care) who are caring for older adults with complex or serious illnesses, don't understand what palliative care is and how it can benefit people much earlier in their illness. This is because they still associate hospice palliative care with just

easing suffering before death, but they don't understand the breadth of this approach to care. It's not just caring for people at the end of life. For example, some oncologists may only offer palliative care to their patients when cure is no longer possible. This is often too late for the person and their family to truly benefit from hospice palliative care. Why does this happen? It might be because hospice palliative care may be seen as a failure or last resort. However, you can have a focus on cure or interventions, and multidimensional *comfort at the same time*, which is what Hospice Palliative Care offers. It breaks my heart when we ignore people's holistic needs. Our whole system is organized that way.

If you start palliative care early enough, people would be more supported in their journey towards end of life. I think we have a hard time in our elder care system, wrapping our minds around prevention, supportive, earlier care, because we're so reactive. Our elder care system is designed to react to cure and to fix. The entire elder care system needs to change its perspective to be more holistic with an emphasis not just on cure but also on support and quality of life.

Sue Lantz - Ultimately, aging (and living) itself can be life-limiting. With medical innovations, we are living longer with more health conditions. This extended time is a gift and an opportunity to build a hospice palliative approach to the process of aging and the acquisition of serious or progressive health issues.

These two contrasting approaches to front-line care— fix, cure, intervene versus holistic supports, comfort, and quality of life — shows how hospice palliative care is distinct. Nevertheless, it is possible to have those two approaches occurring at the same time. When you recognize this, it allows you (and the clinicians and caregivers) to find a different and a better balance between these two approaches.

SSAO - It sounds like the work you are doing is focussed on a social model, not just the medical model. This is what SSAO has been promoting for the entire elder care system.

Dipti – Yes, hospice palliative care has got social components and personal components, not just medical. The pandemic has helped people to grasp the notion that we should be operating from the perspective of the social determinants of health. We need to recognize that health is not just the absence of illness, it is influenced by your social situation. I love the fact that hospice palliative care is not just for the individual, but for the entire family, whoever that family is. The approach is there for the entire journey until death, even after death for bereavement, with families. *We don't have that in our system for older adults.* They don't experience continuity of their journey. People should feel they are being continuously supported in an effective elder care system.

Sue – I feel we are at a crossroads, and we need to re-define what aging-in-place means and re-design what an elder care system should look like. A fundamental part of eldercare re-design starts with an understanding that life will come to an end at some point. Our mortality is a predictable aspect of life. If we can come to accept the idea that death is part of later life, and later life and longevity involve having multiple health concerns, then one can design a range of supports more effectively, based on this acceptance. And families, communities and other societal and health systems can work with people as they become comfortable with this fact, and even begin to proactively prepare for this reality. *The beauty of the hospice palliative care approach is that it offers a way of providing help that is holistic, which means that older adults and caregivers may accept help more readily.* It is an empowering, adaptive, and even preventative approach.

The kinds of supports that hospice palliative offers, allow you to take a holistic look at your life. Looking at your life and what is meaningful helps to shape and ensure that the people and experiences have the most meaning to you, will be woven into the later parts of your life journey. It also creates room for family and friends to consider how they can support the people they love in this phase of life. So, the focus is on finding the types of supports that allow you to transition yourself, along with the others around you whom you love.

Given that 97% of older Canadians say they want to age in the community, we must put those two concepts together -- *aging in the community with the right supports*, along with *aging in a way that is empowered, holistic, and realistic*. The hospice palliative care approach offers an answer to achieving this balance. It starts with holistically assessing and understanding a person's needs, directions, and situation and then building a holistic care map to guide their transitions from there.

SSAO – There are important insights here that the overall elder care system could be learning from hospice palliative care.

Dipti – For me, there are two things that I think a hospice palliative care perspective could contribute to the overall elder care system. One is the philosophy and approach to care. And then at the integration level, bringing hospice palliative care earlier for older adults. That's the model that we're trying to test and there's a huge opportunity there. It's about hospice palliative care partnering, bringing the best expertise, helping build capacity, and doing that much earlier in the trajectory for people who are working with older adults with complex needs.

Some people struggle with the terminology of hospice palliative care because they associate it only with dying. But while death is an event, dying is a process which occurs over time. I'm okay to change the label to compassionate care or

supportive care. For me, it doesn't matter what we call it - it's the philosophy and approach to offering care that's most important. And, when you describe the hospice palliative and holistic approach to people, they do want that service and support. The approach could apply to all areas of elder care.

I see one of the most valuable aspects of the hospice palliative approach relates to how well caregivers are supported. This certainly is needed in the elder care field generally. Much more can be done to support the natural networks of caregivers - the loved ones, friends, family, neighbors who surround a person. These individuals need equal amounts of support. Yet, our system isn't designed around this idea, and our long-term care institutions primarily serve people in their last two years of life, separated from their friends and families.

It is also a question of how you bring the two worlds of medical and social together to support the individual and their family. What I see in the current system is that we have health, and we have social care, but they're not connected. And in fact, seeing people beyond their illness, as whole persons not just patients, is key to enhancing the social aspects. Hospice palliative care recognizes both worlds and their connection.

Sue - We also need to learn from hospice palliative care that *the focus needs to be on quality of life*. Our system for elder care needs to be designed around the quality-of-life goals of the older person, with supportive options and pathways that allow the achievement of their goals. Elder care will need to be transformed if we are to develop a holistic approach that genuinely focuses on quality of life. It is a paradigm shift.

SSAO: Many thanks to both of you. You have given us food for thought about how we could learn from hospice palliative care, and why we need to advocate for better funding for this important part of the elder care system.