



Easing the final journey

Stajduhar, at
Victoria Hospice

Strengthening support for end-of-life caregivers benefits the entire health care system

by Peigi McGillivray

If you had a terminal illness, where would you choose to die? If you're like most Canadians, you would choose to be at home. But while a quiet, peaceful death at home is the gold standard for patients, it may not be so good for their family members.

"People want to care for their dying loved ones at home," says Dr. Kelli Stajduhar, a professor and researcher in the University of Victoria's School of Nursing and Centre on Aging. "But many of them don't have the skills, knowledge or support they need to provide this care without endangering their own health and well-being."

Stajduhar has recently completed a five-year study into what is becoming a critical issue in health care—family caregiving at the end of life. The study, funded by \$1.5 million from the Canadian Institutes of Health Research, involved a team of researchers from across Canada working together to gather data.

The goal was to better understand the experiences of families during caregiving, and to minimize the long-term health consequences for those who take on this responsibility.

"Most family caregivers are women," says

Stajduhar. "They take on the caregiving role in addition to their jobs and other family responsibilities. Doing so can compromise their health, can have a negative impact on family relationships and can sometimes create real financial hardship."

Family caregivers often have a steep learning curve—perhaps taking on additional household responsibilities as well as learning practical nursing skills and complex tasks. These include everything from how to turn someone over in bed without hurting them; to how to change bedding, clothing and diapers for someone who is incontinent; to assessing and providing pain-relieving medications.

Providing the right kinds of support is vital, says Stajduhar. "We have to focus not just on the needs of the patient," she says, "but also on the needs and abilities of the caregiver."

Stajduhar proposes several practical supports that can help family caregivers provide care without endangering their own physical, emotional or financial health.

These are: access to education and support on caregiving; practical support for household tasks and financial planning; access to hospice and palliative care resources; government support for caregiver health and well-being;

respite breaks for rest and renewal; and an improved and more accessible compassionate care benefit for those who have to stop working to provide care.

"If we don't provide the right supports, family caregivers may suffer economic or health consequences, or may be unwilling or unable to take on this role," says Stajduhar. "And that will have a long-term impact on individuals, families and our whole health care system."

This study is just one of Stajduhar's many research projects, which focus on identifying the elements needed for a comprehensive and coordinated system of health care for people at the end of their lives.

Study results are disseminated to health authorities and the provincial and federal governments, says Stajduhar. "Our audience is direct care providers, managers and policy-makers, so our findings are informing policy development and front-line practice."

As Canada's population ages and health resources become strained, family caregivers will play an increasingly important role. "With the right support," she says, "family members who choose to become caregivers can become key components of a strong, well-balanced health system."

EDGEwise

Almost one in four Canadians is caring for a seriously ill relative, according to a 2007 survey. Nearly six in 10 family caregivers are women. Forty-three per cent of caregivers are between the ages of 45 and 54, the age at which many Canadians still have children living at home. Nearly three out of four caregivers are married, and more than half are also employed.

If you are a caregiver and need advice or support, visit the Family Caregivers Network Society at www.fcns-caregiving.org, the Victoria Hospice Society at www.victoriahospice.org/ or VIHA Home and Community Care Services at www.viha.ca/hcc/.

Kelli Stajduhar brings her passion for research into the classroom. "I don't see any separation between teaching and research," she says. "I use my findings to develop curriculum and to capture students' attention, and their questions inspire new avenues of research."

UVic researchers were awarded nearly \$100 million in outside research grants and contracts in 2009/10—more than triple the amount achieved 10 years ago.



Supporting education in our community



We're going places.

University of Victoria Research