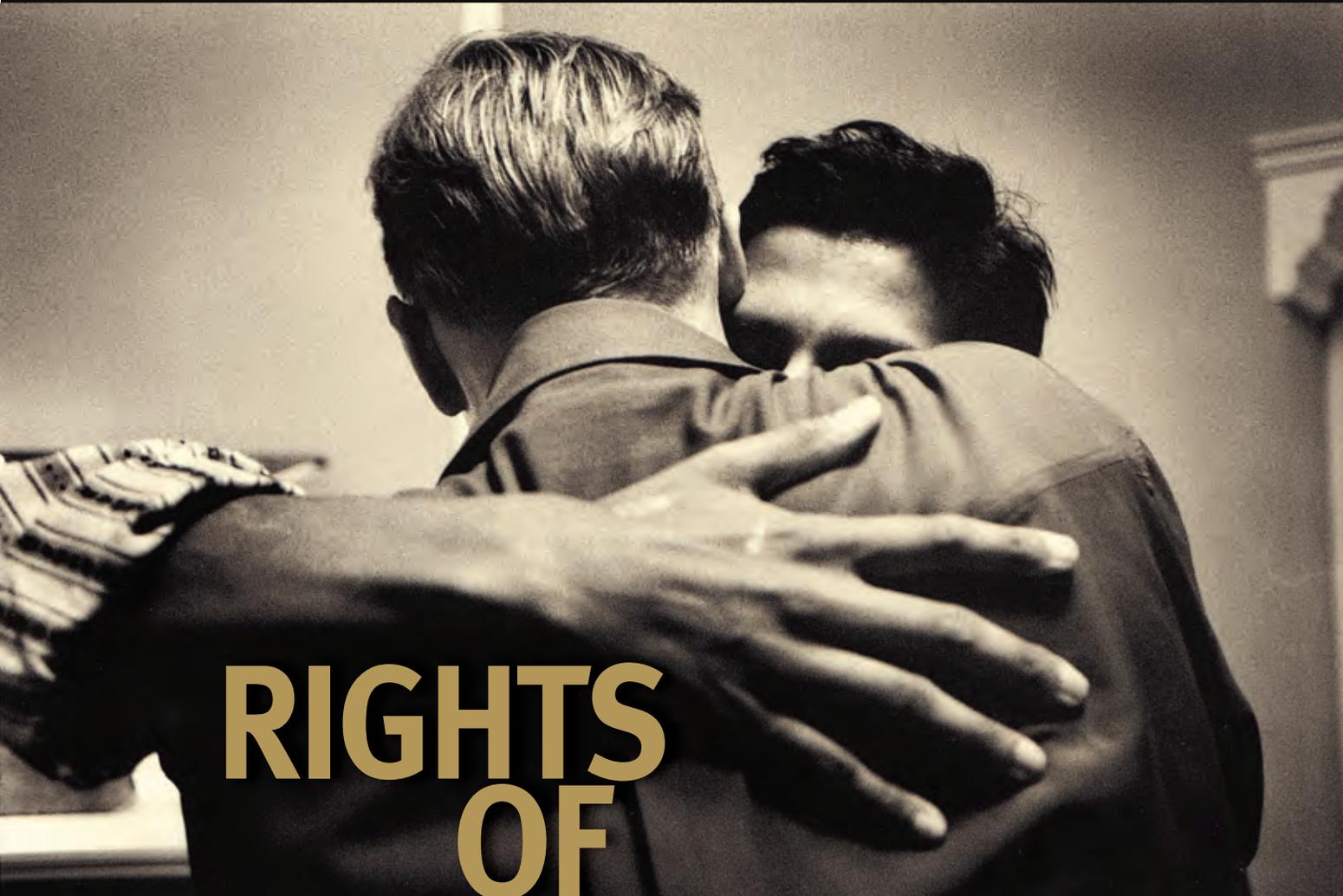


# CANADIAN NURSE



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TO PALLIATIVE CARE

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# RIGHTS OF PASSAGE

## INTEGRATING PALLIATIVE CARE

A new approach will help  
more Canadians with  
life-limiting diseases live well

The photos, of real people sharing their end-of-life experiences, are an integral component of the Living Lessons campaign. The goal of this national initiative, a partnership between the GlaxoSmithKline Foundation and the Canadian Hospice Palliative Care Association, is to raise awareness about the hospice palliative care resources and expertise that are — or should be — available in our communities.

Photos: Roger LeMoynes

By JANE LANGILLE

**PALLIATIVE CARE IN CANADA** has traditionally been offered only in the last weeks or months of life, when curative treatments are no longer possible. Care then shifts to keeping patients comfortable.

This model is ineffective. Only 16 to 30 per cent of Canadians have access to or receive hospice palliative and end-of-life care services. As well, in a system where funding for hospitals and physicians comes from medicare but most of the provinces and territories fund home care, moving patients between settings of care as their health needs change can create logistical or communication problems that can lead to additional hospitalizations. “People don’t necessarily get the best care, and often they get more extensive and therefore more expensive care than they actually need,” says Sharon Baxter, executive director of the Canadian Hospice Palliative Care Association (CHPCA).

In fact, only about 15 per cent of dying Canadians require the complex services that are provided in specialized units. Baxter explains that most needs can be met by integrating a palliative approach into the care patients are already receiving. In this approach, patients have access to palliative care earlier in their diagnosis and are cared for in the setting (if possible) where they currently reside, such as their home, a long-term care facility or a community hospital. Services are delivered in all areas — urban, rural and remote.

The integrated approach to care is patient centred. In addition to pain and symptom management, it includes

**“Hospice palliative care is aimed at relieving suffering and improving the quality of life for persons who are living with, or dying from, advanced illness or are bereaved”**

– CHPCA website



open communication between caregivers and patients and their families about the illness trajectory and advance care planning, and psychosocial and spiritual support for both patients and family members. It focuses on providing care and enhancing quality of life throughout the illness.

“In an integrated palliative approach to care, a person is assessed and then receives different services of care as needed,” says Baxter. “The primary care team is educated about the palliative approach and works closely with other health professionals

to provide seamless transitions for patients when they have to move from one setting of care to another.”

#### THE DEMAND FOR INTEGRATION

CHPCA estimates that demand for hospice palliative care services will continue to increase over the coming decades. One reason is the growing number of seniors. Currently representing about 14 per cent of the Canadian population, this group is projected to account for about 25 per cent by 2036 — an estimated 10.4 million people. “Even now, we don’t have enough dedicated pallia-

tive care units or staff in place to be able to care for every patient who is dying,” says Judy Simpson, president of the Canadian Hospice Palliative Care (CHPC) Nurses Group, a subgroup of CHPCA.

People are also living longer and are more likely to live with chronic diseases. By 2025, two-thirds of Canadians who die will have had two or more chronic illnesses and will have lived for months or years in a frail state of health. In the current system, where patients often are eligible to receive palliative care services only within a defined period of time before death is expected (typically six months), those who have complex health issues might suddenly deteriorate and die without ever receiving this support.

There is also the fact that it is difficult to predict time of death, even for those who are terminally ill. A study led by two researchers at the University of Chicago Medical Center asked 343 doctors to provide survival estimates for 468 terminally ill patients in outpatient hospice programs in Chicago. A comparison of the doctors’ predictions with actual survival times revealed that 63 per cent had overestimated



**When people receive palliative care services, they report fewer symptoms of their illness, a better quality of life and a greater level of satisfaction with their care**



These images were created by clients in Doane House Hospice's art therapy programs. The hospice, located in Newmarket, Ont., provides bereavement support and non-medical support for those affected by or caring for someone with a life-threatening illness.

survival time and 17 per cent had underestimated it. The researchers also found that the better the doctors knew their patients, the less accurate the predictions were.

#### THE CASE FOR INTEGRATION

Both research and anecdotal evidence show that when people receive palliative care services, they report fewer symptoms of their illness, a better quality of life and a greater level of satisfaction with their care.

A 2010 study at Massachusetts General Hospital in Boston involving 107 patients newly diagnosed with metastatic non-small-cell lung cancer found that those who received palliative care together with standard oncological care early on had a significantly higher quality of life and fewer symptoms of depression

than those who received only standard oncological care. In addition, the median survival rate was almost three months longer for the group that received early palliative care.

Currently, almost 70 per cent of Canadian deaths take place in hospital, despite the fact that most people say they would prefer to die at home. An integrated palliative approach focuses on helping people receive care in the setting of their choice. After her terminal diagnosis, Kath Murray's mother expressed her wish to die at home and made it clear she wanted no surgery or further tests. "She wanted her pain managed and was very grateful to those of us on her pain management team — her kids, her family doctor and the home care nurse — for supporting that goal," says Murray, who is the director



#### **Hope**

The underwater garden in this fingerpainting signalled the beginning of hope and the recognition of the woman's journey of self-healing through art following a loss.



#### **Fading Memories**

This silk painting was created by an elderly patient with Alzheimer's. She had struggled to remember how to use a paintbrush and paint but found peace in the process of working with water and silk.

## Resources



**Canadian Virtual Hospice.** Launched by a team of Canadian palliative care specialists in 2004, this website offers a wealth of up-to-date, evidence-based resources and tools about palliative care for health-care providers, patients and families. Site visitors can read materials online, watch educational videos or listen to audio clips. Nurses are welcome to download and print out materials to give to patients and families who do not have Internet access.

Ask a Professional, a signature tool of the site, allows providers, patients and family members to ask a team of palliative care experts confidential questions about terminal illness, end-of-life care, loss and grief. Brenda Hearson, one of four clinical nurse specialists on the team, explains that, to date, the interdisciplinary team has written over 50 evidence-based articles that address, in plain language, the most common concerns of patients and families. “The most downloaded article is ‘When Death is Near,’” says Hearson. “I share it with families in my day-to-day clinical practice, and they say it helps them understand what happens near the end of life and what to expect from quality care.”

**Speak Up Campaign.** This CHPCA website provides free, downloadable resources, including the Just Ask card, that health-care providers can use to help patients and families start the conversation about end-of-life care and advance care planning. Patients and families can use the *Advance Care Planning Workbook* and *Advance Care Planning Quick Guide* to explore their values and state their wishes.

**CHPC Nurses Group.** This group supports nurses by defining and advancing the body of knowledge for hospice palliative care nursing and supporting research, education, practice and administration. Members can access networking opportunities and a forum for exchanging questions and answers on a range of topics, from specific treatment protocols to nursing policies and procedures for new programs. “We have become the go-to group nationally and internationally for issues related to hospice palliative care nursing,” says Judy Simpson, the group’s president. Any nurse in Canada is welcome to join.

**Life and Death Matters.** This website provides helpful resources for teaching and learning, including the *Essentials in Hospice Palliative Care* manual, companion workbooks, teaching presentations, podcasts and online courses.

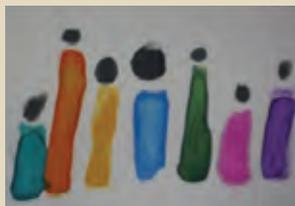
**iPANEL.** This group of nurse researchers, practitioners and administrators in B.C. is collaborating on research to advance the further integration of a palliative approach into the health-care system, particularly for people who live with chronic life-limiting conditions. The website features ongoing and completed research projects, publications and webinars.

**Quality Palliative Care in Long Term Care Alliance.** The alliance consists of 38 organizational partners and 27 researchers who are collaborating on a five-year research project to improve quality of life for people dying in long-term care homes by developing sustainable, person-focused palliative care programs. Four Ontario long-term care facilities are study sites for the project.



### **Difficult Pathways**

The young artist mixed coarse pumice gel into the paint, which hardened into rough lines that represent the roadblocks and changes she faced after her cancer diagnosis.



### **The Cancer Family**

Before his father died, the teen expressed his anxiety in this depiction of a strong yet divided family. Fears that his dad would be forgotten by others and a need for open discussion about cancer were on his mind.

## Advance care planning



An important part of integrating a palliative approach to care is engaging patients and their families in a discussion of the patient's prognosis, treatment options and preferences to determine what kind of care he or she wishes to receive at different stages of the illness.

Patients may want to put their wishes in writing. A written, signed statement — called an advance directive — has two important components: an instructional directive that provides instructions about care decisions, and a proxy directive that specifies who will make the decisions in the event that the patient is no longer able to do so.

Many provinces and territories now have materials on advance directives for the public, and these materials are also perfectly appropriate for nurses to use as a resource for assisting their patients, says Jocelyn Downie, a professor of law and medicine at Dalhousie University. "I recommend that all nurses complete an advance directive — they can tear it up afterward if they don't want to have one. By going through

the process, they'll find out how it feels from an emotional perspective and learn what kinds of questions are typically raised."

### EFFECTIVE DIRECTIVES

- **Keep informed.** Legislation varies across the country and changes over time. Downie advises that Canadians become familiar with all of the relevant legislation in their province/territory to ensure their advance directive is up to date and meets validity requirements. "It's important for two huge reasons — it increases the chances that their wishes will be followed and it's an enormous gift for their loved ones."
- **Be clear.** Advance directives should specify measures to be taken or not taken under different circumstances. Vagueness can lead to confusion and controversy, says Downie. "Instead of saying 'If my condition is hopeless, I do not wish any extraordinary measures,' say something more specific, like 'I do not wish to receive artificial hydration and nutrition if I am in a persistent vegetative state.'"
- **State priorities.** Because it isn't possible to anticipate all eventualities, it is helpful to state what matters most (e.g., the ability to communicate with loved ones, or mobility rather than length of life). Statements of priorities can help the substitute decision-maker and health-care providers determine what a patient would have wanted in unanticipated circumstances.

Downie's End-of-Life Law & Policy in Canada website provides links to province- and territory-specific information, along with other resources, for members of the public, health-care providers and policy-makers.

of Life and Death Matters, a company in Victoria that provides teaching resources for front-line caregivers and offers workshops and online education in hospice palliative care. "My mom died nine weeks after her diagnosis, at home where she wanted to be, cared for by her family and loved ones. She described that period as the richest in her life, with opportunities for closure, healing and loving."

"I strongly believe that the principles, practices and philosophy of hospice palliative care need to be integrated into the general system

of health care," says Simpson. "We need an interprofessional approach in which the family physician, a community-based nurse, a social worker and other care providers each have a good understanding about hospice palliative care and can help their patients in a variety of settings."

How close is this approach to becoming reality? "We're starting to move toward it, depending on who you talk to and what part of the country they're in," says Simpson. She points out that Cancer Care Ontario has a palliative care strategy and B.C. has a framework for end-of-life care,

while other provinces and territories are just thinking about it. "Whether or not a framework is in place, until the federal government provides funding, the provinces and territories are each going to make decisions separately, and the system will not become as integrated as it should be."

As a start, the federal government has provided one-time funding for a three-year initiative to better integrate the palliative approach to care across settings. The Way Forward initiative is identifying and sharing best practices and developing tools and resources, as well as creating a

**Most people say they would prefer to die at home. An integrated palliative approach focuses on helping people receive care in the setting of their choice**



national framework — a practical roadmap that will help system planners, policy-makers and service providers identify and remove barriers to integrating hospice palliative care in communities. The initiative is managed by CHPCA under the guidance of the Quality End-of-Life Care Coalition of Canada, a group of 37 national organizations.

Baxter sits on the advisory committee guiding *The Way Forward*. “We have a draft document now, and we’re waiting for feedback from stakeholders. The next step will be to seek support for the implementation of the framework across care and community settings.”

**PALLIATIVE CARE IN THE CURRICULUM**

The dissemination of national palliative care competencies and indicators to nursing schools in 2011 has paved the way for greater inclusion of palliative care learning in undergraduate programs. The competencies and indicators were developed by a Canadian Association of Schools of Nursing (CASN) advisory committee that included, among others, members from the CHPC Nurses Group. Stakeholders from across the country, including Simpson and other CHPCA members, were involved in reviewing the document. “While it’s up to the individual schools to decide the best way to integrate the competencies into their curriculum, students

cannot graduate now without learning about hospice palliative care,” says Simpson. “They won’t graduate as palliative care specialists, but they will have a beginning understanding of the care of individuals at the end of their life.”

Coby Tschanz, an assistant teaching professor at the University of Victoria, has taught a stand-alone elective on hospice palliative nursing for the past seven years. “I think newly graduated nurses are becoming increasingly well prepared for hospice palliative practice — thanks in part to the CASN competencies, which we have used since 2011 to refine the curriculum. I also hand out the competency document to my students, and they find it helpful in assessing their own learning needs and progress.”

**A SHARED-CARE MODEL**

The *Way Forward* framework proposes a shared-care model in which the patient’s primary care team, whose members have a generalist level of palliative care expertise, provides care over the course of the patient’s illness. A specialized hospice palliative care team supports the primary care team by educating, advising and relieving when necessary, depending on the expertise of the primary caregivers and the extent to which the palliative approach has been integrated into the particular community setting.

The specialized team takes the lead only in cases where there are complex, intensive or tertiary end-of-life needs. Nurses participate at all stages of the patient’s care as key members of these teams, which also include physicians, social workers, psychologists and spiritual advisors.

“Because nurses are involved throughout the process, they can identify changing conditions and help patients and families identify their fears, preferences and goals of care,” says Murray. “They can share information about the disease, symptom management and care options that assist patients and families in making informed decisions about treatment. Nurses can also advocate on behalf of patients and families — such as when care isn’t in line with a patient’s goals — by making referrals for specialist support or linking patients to other services.”

The integrated model of hospice palliative care is still in the planning stages, but the shift from the traditional approach to a more patient-focused approach has begun. “The success of our move to integrated hospice palliative care will be achieved with nurses on side as champions,” says Baxter, “so that more Canadians can experience a good quality of life while they’re dying.” ■

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