



# Guiding a peaceful end

RNs say the fine art and precise science of palliative care need support so more people have a dignified death.

**P**at Hickman is often present during one of the most emotionally charged chapters in families' lives: the time they spend saying their final goodbyes to a loved one who is dying. Keeping a terminally ill client comfortable while also giving families the privacy they need is a delicate dance Hickman has spent an entire career choreographing. Sometimes, the home care nurse needs to be at the patient's bedside to administer medication for pain, breathlessness or anxiety. At other times, she'll sit quietly in the corner of the room to finish paper work and give the family an opportunity for private conversations.

"You need to blend into the background of things so families have their time – their words, being with their loved one, their memory-sharing," she says. "It's an opportunity for them to mend some bridges. To say sorry. To say goodbye. They won't have that chance again."

Hickman, who is a member of Saint Elizabeth Health Care's palliative care team in Brampton, Ontario, says clients often teach her about the best way health-care providers can meet their needs. She recalls one man who was told by doctors last spring that he wouldn't live to see Christmas. He knew his heart condition was so severe that he was no longer a candidate for a defibrillator or a pacemaker, and that his renal failure was in the final stages. But he didn't want to know when the end would come. As Hickman talked to the man and his wife about

**BY JILL-MARIE BURKE • ILLUSTRATION BY SANDRA DIONISI**

his impending death, they told her that hearing about his failing organs hadn't upset them half as much as being given an expiry date.

Hickman says his story is a powerful reminder that bad news must be delivered in a way and at a pace that's appropriate for each individual. "Palliative care patients teach us about the emotional and psychological suffering and pain that we often miss in our efforts to manage their physical pain and symptoms," she explains. Hickman says if physicians had asked her client how much more he wanted to know, and had only given him the information he asked for and could handle at the time, he wouldn't have been haunted by the knowledge that he would be dead by 2010.

Hickman believes people could be spared any unnecessary suffering if all health providers truly understood the complexity of caring for the dying. Although the Canadian Nurses Association has recognized palliative care as a nursing specialty since 2004, Hickman still meets people who believe the job is as simple as "patients get into bed, we cover them all up cozy, and they just stop eating and drinking and then they die." Years in the field have taught her that it is an intense, complex specialty that requires her to think on her feet and use knowledge, assessment skills and state-of-the-art medical interventions to provide excellent nursing care at a critical time. She may provide sedation or manage symptoms related to shortness of breath, bowel obstruction or hemorrhaging. But Hickman says empowering patients to make choices related to their care and providing support to the entire family are equally important aspects of her job.

RNs who work in palliative care say they would be able to meet the needs of their clients more effectively if the provincial government recognized palliative care programs and resources in community, hospital and long-term care settings as specialties that need funding and support in their own right. While dying is a natural and expected part of the life cycle, the lack of government funding, the limited number of RNs with the education needed to provide specialized care, and a general lack of awareness among both health providers and the public mean that not all Ontarians can die on their own terms, in the place of their choosing, with the dignity they deserve. They're issues that will be top of mind for

## RNs HELP CHILDREN DEAL WITH DEATH

Adults aren't the only ones who grapple with issues and emotions related to mortality and loss. Children are also among the terminally ill and bereaved. Lisa Pearlman is a nurse practitioner and clinical lead of Pediatric Symptom Management and Supportive Care at London Health Sciences Centre. She works with infants, children and teenagers who have life limiting and life threatening illnesses. She meets most families when the child is still receiving treatment for the disease. That allows her to focus on quality of life and pain and symptom management so families have more quality time together. Pearlman says developing the year-old program was a dream come true.

"I wanted to develop a service that would enable families to talk about the most sensitive yet meaningful issues for them. Someone who would give them hope at the most difficult times, and assistance with making the most difficult decisions," she says.

Andrea Warnick also helps families grappling with the pain of death. As an RN and grief counsellor with Max and Beatrice Wolfe Children's Centre and the Dr. Jay Grief Program, located at Mount Sinai Hospital in Toronto, she teaches kids how to prepare for the death of a parent and then supports them as they grieve mom or dad's death.

Warnick says parents may think they're protecting their kids by not telling them what's happening. But when a parent is dying, children really need honest answers and accurate information. She says it's common for kids to believe that they caused the illness or to fear they'll catch it. They also tend to look at the situation in a very practical way. She recalls one four-year-old boy who asked his dying mother, "What's going to happen to me? I can't reach the light switch and I can't make scrambled eggs."

Warnick says teaching these children that their feelings and emotions are natural is the most rewarding aspect of her job.

"I'm not going to stop a child's mom from dying, and that's devastating," she says. "But I feel so empowered that I can shape that kid's entire story around the death." **RN**

RNAO's Palliative Care Nurses Interest Group as it begins its work in earnest this year. Hickman is part of the group which formed last fall, and says members want to ensure decision makers and the public understand that good palliative care begins well before the final days of life.

In the United Kingdom, where Hickman spent 20 years learning the art and science of palliative care, she was with patients when they received a diagnosis of lung cancer from their physician and followed them right through surgery to treatment and end-of-life care. She believes this philosophy of early nursing intervention needs to be adopted in Canada so people have more control over the final chapter of their lives. The earlier she is able to meet a client and his or her family, the sooner they can discuss medications, treatments, quality of life goals and symptom management. Being able to build trust and review wishes and plans early in a terminal illness makes it easier to talk about sensitive topics like resuscitation when the person is nearing death, she says. In Canada, however, Hickman's clients are referred to her by the Community Care Access Centre (CCAC), and she may only meet someone in the last

few months or weeks of life.

Lesley Hirst says supporting RNs like Hickman, and giving them a unified voice to lobby for changes to benefit the people they care for, is one of the main reasons she wanted to create the new interest group. Hirst says part of the problem with the current system is the level of government funding isn't sufficient to pay for more nurses such as Hickman. This means that people who need more home care must supplement publicly provided services with additional support covered by private insurance, if they have it. It also means that because 90 per cent of people want to die at home, providing care takes a financial, emotional and physical toll on loved ones who are expected to become nurses and personal support workers.

"People should be able to be a wife, a mother, a son, a brother, rather than being a nurse or a PSW. We ask a lot of them and they get burned out quickly," Hirst explains. Expecting families to be the primary caregivers for loved ones who want to die at home can lead to stress, exhaustion, job loss and even guilt if the responsibility becomes too overwhelming and the person ends up dying in the hospital when his wish

was to spend his final days at home.

Hirst says another issue affecting palliative care is the fact that community nursing agencies have difficulty recruiting and retaining the nurses needed because their salaries are significantly lower than those of their colleagues who work for hospitals or other organizations.

“I feel really strongly that nurses should be rewarded equally for the services and care they deliver, based on their education, preparation and their duties and not just where they’re based,” she says. RNAO agrees and identified equal remuneration for all RNs as a key policy recommendation in the association’s political platform document, which sets out priorities for candidates to adopt in the 2011 provincial election.

Given the challenges of offering comprehensive palliative care, Ildy Tettero feels lucky to be able to get involved with people who have cancer, amyotrophic lateral sclerosis (ALS), heart, or kidney disease early on in their illness. She’s sometimes present when they find out they have pancreatic cancer or another incurable disease. As a nurse practitioner on the outpatient palliative care team at Joseph Brant Memorial Hospital in Burlington, she can then help terminally ill patients navigate the health-care system and coordinate care with other members of her team, such as a social worker, dietitian and palliative care physician. She also works with family doctors, the Community Care Access Centre and home care nurses to help 83 per cent of her patients spend their final days at home.

If people are well enough to come to the clinic, Tettero will manage their pain and symptoms there. For others, she’ll make home visits and provide support over the telephone. While the outpatient palliative care team at Joseph Brant is meeting many of its patients’ needs, Tettero says there are a few changes that would further enhance care for the residents of Burlington. For example, as an NP, she isn’t able to prescribe narcotics or opioids to manage her patients’ pain.

“Nurses sometimes struggle to get hold of the physician to have medications changed because as people are dying their needs change fairly quickly. If I was able to prescribe more medications that are needed, I would be able to support patients’ symptom control better,” she says. She also wishes that her team could offer palliative care 24-hours a day, but there just aren’t

the resources to allow her or the physician to be on call during evenings or weekends.

But it will take more than just funds to find the staff to provide that kind of comprehensive care. Hirst hopes the new interest group will raise awareness of the special skills that are needed, because palliative care is a lot more than administering morphine.

“You have to coordinate the manage-

specialized like orthopedic surgery or plastics or burns. Dying is a part of living and it needs to be addressed.”

Palliative care is on the agenda at the School of Nursing at the University of Ottawa, which developed the Nursing Palliative Care Research Unit (NPCRU), the first of its kind in Canada, in 2009. But Ottawa professor Christine McPherson, an

**Hirst believes since most of us will die from a life-limiting, progressive illness and will need the care of nurses, it is surprising that most nursing schools in the province spend very little time teaching students about palliative care... “But death and dying are part of general life expectancy,” she counters. “It’s not specialized like orthopedic surgery or plastics or burns. Dying is a part of living and it needs to be addressed.”**

ment from a pharmacological perspective and you have to really look at disease progression and the effect it has on the body systems,” she says. “You have to be a detective and find out what has worked, what hasn’t, then figure out a new plan.”

Hirst says that by determining the best ways of keeping patients comfortable so they can enjoy the best quality of life possible, palliative care nurses enable them to focus on the important things in life, such as their relationships with family and friends, and clarifying their goals and objectives for the final phase of their lives.

That’s why Hirst says getting palliative care on the syllabus in nursing schools is one of the top items on the interest group’s to-do list. She believes that given the fact that most of us will die from a life-limiting, progressive illness and will need the care of nurses, it is surprising that most schools in the province spend very little time teaching students about palliative care, if it is discussed at all. She’s heard the argument that the goal of nursing education is to prepare generalists, so specialties aren’t on the curriculum.

“But death and dying are a part of general life expectancy,” she counters. “It’s not

RN and health psychologist who has been conducting research on the topic for the past 10 years, acknowledges that this is the exception and not the rule.

McPherson first became interested in palliative care when she nursed in acute care units and found that deaths often felt rushed because nurses were so busy and beds were in short supply. She realized that she was well prepared to care for people with heart disease or diabetes or those awaiting surgery, but felt unprepared to deal with death and dying. She says this lack of knowledge means that some nurses who don’t know how to speak to relatives of the dying may say nothing at all, and others grapple with ethical issues related to pain. The situation is further complicated by the fact that nurses working in acute medical settings are trained to keep people alive. “Death is often seen as a failure by health professionals,” McPherson says. “Yet, part of our role is to ensure patients who can no longer be actively treated die comfortably.”

Next year, a resource will finally be available to give nurses access to the best evidence related to caring for patients nearing the end of life. Last May, McPherson began leading an expert panel that is devel-

oping a clinical best practice guideline on end-of-life care. She says the guideline is intended for nurses who work in a variety of settings and will provide the information and skills they need to identify, assess, intervene and evaluate patients during the last days and hours of life. McPherson says much of the literature related to palliative care focuses on cancer, but RNAO's guideline will also discuss deaths from such diseases like organ failure and dementia. Topics such as recognizing, assessing and managing common symptoms such as delirium, pain and breathlessness are among the issues addressed in the guideline.

McPherson says it's important for nurses to ensure that families receive the support they need and the patient dies with dignity. She says family members will never forget what their loved one's final days were like. If they see that person in pain or experiencing delirium, they have to live with the trauma associated with watching them endure that.

Anne-Marie Dean believes all health

providers need to be more aware of the various types of care that are available to their patients during their last days. Dean is the executive director of Hill House Hospice in Richmond Hill, a three-bed facility that is one of 15 residential hospices in Ontario. Dean, an RN, and her staff of nurses and personal support workers care for people who are expected to live less than a month, and who have signed do not resuscitate orders. That means staff members don't give blood transfusions or perform CPR.

"Part of our job is to accompany them to a gentle death. We don't do anything to expedite death, but we don't do anything to prolong life either," she explains.

While some people choose to die in a hospice because their loved ones are no longer able to care for them at home, Dean says others don't want their family home to be associated with the end of their lives. That's especially true for young parents who don't want their children to live with

the memory that mommy or daddy died in the living room or in bed.

"Residential hospice is a wonderful alternative because it's a home-like setting and the family can be together. It's a calm environment. We don't have the bells and whistles of the hospital," Dean says.

Dean believes there would be more pressure on politicians and other decision makers to make palliative care a priority if more families were aware of the resources that are available for their dying loved ones. In fact, she says a little knowledge could go a long way to ending the conversation about legalizing euthanasia. She says families who don't know that hospices and nursing consultants can help with pain and symptom management have seen their loved ones struggle and wished they could put them out of their agony.

"People say: 'we put dogs to sleep, don't we?' But this is different," she says. "Good palliative care can help people live comfortably until it's time to die. We need to heighten the awareness of palliative care so more people will access it."

Dean also says more nurses would be interested in working in this area if they realized they would have the support of colleagues when losing so many patients becomes emotionally draining. She tells her staff it's OK to cry at work, they don't need to carry the emotions home. Every six weeks, all the nurses and PSWs get together to talk about the residents who have died during that time. For each patient Dean asks: how did we make a difference here? What would we do differently next time?

Hirst says debriefing sessions like the ones Dean holds for her team give nurses an opportunity to acknowledge their grief and address the emotional toll that caring for the dying can have on their spirit. But, she adds, while the job is intense and challenging, the rewards of joining people on their journey through the end of their lives make it worthwhile.

"This is an amazing area to work in," she says. "It's really a privilege to be sharing the deepest, innermost parts of people's spirituality at this time in their lives. And you can have some of the funniest days. Patients still have senses of humour, and there's still laughter and joking." **RN**

---

JILL-MARIE BURKE IS ACTING STAFF WRITER AT RNAO.

## PALLIATIVE CARE BEYOND PRISON WALLS

**M**ike had been an inmate at Bath federal institution near Kingston for 10 years when he was diagnosed with terminal lung and throat cancer and given seven months to live. He was allowed to leave the prison to receive chemotherapy treatments at a local cancer centre. But when he returned, he wasn't permitted to take his prescription medications and was locked in his cell from 6:00 p.m. to 6:00 a.m. The prison's health centre wasn't staffed overnight, so palliative care consisted of Tylenol for pain, Gravol and a bucket for nausea, and a bottle of water.

In July 2007, Mike had served all but a few months of his full sentence. He was given just six months to live, and entered a unique palliative care program for former inmates. New Beginnings Transition House, which is run by the Peterborough Community Chaplaincy, was featured in January in a TVOntario documentary that examined how ex-convicts adapt to life beyond prison walls. When Mike joined the program, a team of volunteers welcomed him, he received nursing care, and he reconnected with family members he'd been estranged from for years. Today, Mike is still living and looking forward to celebrating another birthday in June.

RNAO member Diane King is vice-president of the chaplaincy's board of directors, and played a key role in establishing the palliative program at New Beginnings. She says many men there also struggle with mental illness, drug and alcohol abuse, poor social skills and learning disabilities. Lack of trust is another common issue. "It takes us six months to convince these guys that we aren't going to abandon them," she says.

King, a recently retired instructor from Trent/Fleming School of Nursing, says Corrections Canada needs to change the way it treats and discharges those who are dying. She says compassionate parole does exist, but many inmates aren't aware it's an option. For those who do apply, it usually takes so long for applications to get through the system that most die while they're still in jail.

While the John Howard Society, the local hospice and hospital have been supportive of the program, King says the reality is that most people don't want to associate with ex-cons. "They are the most marginalized population I can imagine," she says, adding the men at New Beginnings have served their full sentences and have no intention of re-offending. "There's no reason for these people not to have palliative care." **RN**