Caring at end-of-life

Canada’s Supreme Court strikes down the law prohibiting physician-assisted death. What does this mean for nurses?
Are you a Registered Nurse (RN) currently practicing or who aspires to practice in a primary care setting?

This two-semester, predominantly online program, is aligned with federal and provincial governments’ goals for establishing high performance health care teams, promoting a collaborative practice model that creates more efficient and effective client-centred primary care. This program educates RNs to practice to their full scope.

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Varied and intense views propel RNAO

DEATH IS A NATURAL PART OF LIFE.

We all know this. And yet it’s hard for many people to talk about it. Whether it happens unexpectedly, or it is on some level anticipated – even planned – it is a time charged with intense emotion.

In this issue of the Journal, there’s no shortage of emotion or intensity as we explore end-of-life care following the Supreme Court’s historic decision to strike down the ban on physician-assisted death (page 12).

The intensity that members bring to their conversations on this divisive and poignant issue does not surprise RNAO. In fact, the association has called for – and embraced – the varied and strong views of nurses for decades. Without the passionate energy and enthusiasm of members, RNAO would not be the force it is today, particularly at Queen’s Park.

Our recap of the association’s Queen’s Park Day (page 17) reflects the conviction of RNs, NPs and nursing students on other important health and nursing issues as well. Among those issues: medical tourism, RN prescribing, NP remuneration, environmental toxics, and the province’s minimum wage. Your energy at this event – and your knowledge of the issues – is what compels Ontario MPPs to attend in such great numbers (there were 52 who participated in breakfast meetings this year). Politicians know they want – and need – to hear what nurses have to say.

This tradition can be traced back to the early days of the association as well.

Check out our ongoing coverage of our 90th anniversary (page 24) for even more examples of the zeal past executive members brought to the issues of the 1960s, 70s, 80s and 90s. Regardless of the decade during which they represented the association at the local level, their eagerness and enthusiasm for advocacy shines through.

We’re looking for even more examples of your passion and involvement. Don’t forget to write to editor@RNAO.ca with your knowledge of the issues – your energy at this event – and your involvement. Don’t forget to write to editor@RNAO.ca with your story. It may be published on the pages of this Journal, and could mean $100 in Visa gift cards for three lucky members. RN

As a member, you are eligible to receive a digital copy of Registered Nurse Journal. You can choose to receive only an electronic version of the magazine by emailing info@RNAO.ca and stating your preference for a paperless version. If you haven’t received the magazine electronically, please let us know by contacting editor@RNAO.ca.
MPPs know nurses’ voices will not remain silent

In February, I had the pleasure of moderating RNAO’s Queen’s Park Day (see page 17). Listening to the speeches made by the premier, health minister and representatives of the two opposition parties, and to the Q&A sessions that followed, brought back memories of my time as provincial chief nursing officer. In that role, I edited briefing notes for the health minister’s office from which speeches for RNAO’s annual event would be prepared. I was responsible for anticipating the questions RNAO members might ask, and I was expected to provide the ingredients for the right answers. I must say, it is more fun – and much less stressful – to be on this side, as president of RNAO.

Queen’s Park Day is an impressive event. Nurses and students are a collective force – knowledgeable and prepared to tackle the key issues. This year was no exception. The swirl of activity this political advocacy event creates at the ministry and within MPP offices is a reflection of the clout RNAO has gained through effective interactions with politicians.

Nursing and health policy issues only become important when they achieve status on the political agenda. The key issues raised this year – RN prescribing, the replacement of RNs, equity in NP compensation, a ban on medical tourism, an increase in the minimum wage, the need for more affordable housing, and reducing toxics – were discussed at length with MPPs who attended the breakfast session.

During my morning meeting with David Orazietti, Liberal MPP for Sault Ste. Marie, the RNAO members I sat with talked about NP compensation. We know primary care NPs are leaving community health centres and family health teams because they can earn up to $20,000 more in acute care. This is a systemic wrong that has to be made right if we want how much we knew about each issue, and by the courage of our convictions. He asked us a number of questions to fully understand the issues from our vantage point, and what we offered as solutions. By setting out our expectations for action, it was clear we would be back to follow up. This is the kind of pressure MPPs try to avoid, but can’t because of the nature of Queen’s Park Day. The MPPs know nurses’ voices will not remain silent.

“THERE IS NO DOUBT THAT RNAO MEMBERS HELP SHAPE THE POLITICAL AGENDA AND DRIVE POLICY DEVELOPMENT. QUEEN’S PARK DAY IS ONE SIGNIFICANT WAY IN WHICH WE DO THIS.”

Following question period, several RNAO members commented that the experience was both interesting and entertaining. The opportunity to see MPPs debate in the moment provided insight into the manner in which public policy issues are challenged and countered in that formal environment. Some members commented that the repetitiveness of the questions – and responses – was tedious. I suggested that tenacity in securing answers is a lesson for RNAO members to take to their conversations with MPPs going forward. Remain consistent in your position on the issues and determined in seeking the right action.

During the keynote speeches and Q&A session in the afternoon, I was impressed by one RNAO member who used this approach to raise the issue of environmental toxics. What a proud moment when that member demonstrated a relentless pursuit for action on this critically important issue.

There is no doubt that RNAO members help shape the political agenda and drive policy development. Queen’s Park Day is one significant way in which we do this. Take Your MPP to Work is another, and it’s just around the corner. Now in its 15th year, the initiative begins each May, during Nursing Week. By getting involved, you can help RNAO build on our collective strength and voice.

If you haven’t already, I invite you to arrange a visit to your workplace by your local representative for an up-close look at the realities of your day-to-day practice. There’s no better way for your MPP to understand what needs to change, and how that change will positively impact patients and clients.

To find out more about Take Your MPP to Work 2015, visit www.RNAO.ca/MMP2015. Questions? Contact smartel@RNAO.ca

Vanessa Burkoski, RN, BScN, MScN, DHA, is President of RNAO.
Supreme Court decision awakens raw feelings, divergent views

OPOSSING VIEWS ON THE SUPREME Court’s decision regarding assisted dying are to be expected, but they should not be used to drive a wedge between nurses, or between nursing and the public. Differing personal values can be difficult to embrace, but we must all look beyond our own beliefs and respect those of others. The court’s ruling is not only a decision that will affect the journey of terminally ill patients under our care. It’s a decision that will affect our own personal journeys and those of our loved ones.

So, what’s next for nurses? In my view, it is critical for nurses – individually and collectively – to push for two top priorities. First, advocating for substantial funding improvements so we can ensure universal access to comprehensive palliative care in all regions of the province and country. Palliative care is not about going somewhere to die; it’s about living, as fully as possible, and without intolerable suffering. To enable this, more dedicated funding is needed.

The second priority is the establishment of a principled regulatory framework to translate the Supreme Court’s decision into policy. Such a framework should be national, but, if the federal government chooses to remain passive, an Ontario-made framework is vital. In the absence of such a framework, assisted dying will remain a private decision between a patient and physician. Private conversations of this nature – at one’s most vulnerable time in life – are, at best, troublesome. A protective framework – guided by firmly agreed-upon principles – is critical because it serves to ensure nobody is in a position to take advantage of vulnerable individuals at the end of their lives. And no health professional is obliged to participate in any activity or situation against their wishes or beliefs (see page 12 for details on RNAO’s proposed principles).

What is critical now is that governments need to get on with the task of engaging the public in a formal consultation to transform the Supreme Court’s decision into a policy and practice framework.

As your CEO, I am very proud of our courageous board of directors and consultation representatives at the 2014 annual general meeting, who brought forward a resolution and passed it (respectively), initiating a public discussion on this issue, which touches every one of us and everyone we know.

The court’s decision to strike down Canada’s law prohibiting medically assisted death has led to impassioned debate on multiple aspects and sides of this sensitive issue. Offering a platform for ongoing discussion is yet another example of RNAO’s courage when it comes to tackling difficult topics through a nursing lens. I’m proud that our association does not shy away from controversy, particularly when that controversy affects the lives of our patients and the public at large.

Over the past year, I have been asked several times to share my personal view. I won’t do that because it’s irrelevant. My role as your CEO is to represent the association and the views of members, and on this topic the views are varied. This conversation is far too important to focus on any single individual’s personal perspective. If we do that, we diminish the importance of the issue, and the varied views of the public. At the end of the day, this is not only an issue that affects health professions such as nursing and medicine. This is about larger societal beliefs, and how Canadians want to move forward.

The only personal view I have is that RNAO should never shy away from difficult questions and issues. Approval of the board’s resolution at last year’s AGM shows members’ support for a public conversation and for lending our expertise and voice to the ongoing discussions.

Whatever your view on assisted dying, it’s vital that each and every RN, NP and nursing student in Ontario be part of the dialogue; as a nurse and as a Canadian. It hasn’t been – and won’t be – easy to work our way through the many complexities of this fundamental issue. As the public dialogue continues with nurses’ full participation, RNAO will continue in its efforts to increase awareness of, and demand funding for, universal access to evidence-based palliative care.

We will also continue to engage with members, the public and other health professionals in shaping new mechanisms and regulations that, above all else, protect society and respect peoples’ wishes, as well as protect health providers.

As I often say: We all have a right to our own views, but it’s dangerous to disregard those who don’t share the same perspectives. We need to work together to ensure this process is respectful, and keeps the patient’s best interests and wishes at the forefront.

DORIS GRINSPUN, RN, MSN, PhD, LLD (HON), O.ONT, IS CHIEF EXECUTIVE OFFICER OF RNAO.

“OFFERING A PLATFORM FOR ONGOING DISCUSSION IS YET ANOTHER EXAMPLE OF RNAO’S COURAGE WHEN IT COMES TO TACKLING DIFFICULT TOPICS THROUGH A NURSING LENS.”
Cheryl Forchuk gets angry when she hears that people who are homeless and struggling with mental illness have been treated like “garbage.” As a renowned nursing researcher, she often hears the comment when she asks these individuals to tell her about their lives.

Society “...would really like to pretend these groups don’t exist, or blame the victim,” she says. “There’s a general discomfort in really acknowledging what’s actually happening.”

Forchuk is the assistant director at Lawson Health Research Institute in London, Ontario, and a distinguished professor at Western University. She works with mental illness survivors, health providers and community agencies to find out exactly what they need – and how to get it to them. Her research examining therapeutic relationships, transitional discharge, mental health, homelessness, and social inclusion has won many accolades, including RNAO’s Lifetime Achievement Award in 2012, and a Leadership in Nursing Research Award in 2014. She has been active in RNAO for three decades, helping to create the Establishing Therapeutic Relationships BPG and holding many executive positions in the Brant-Haldimand-Norfolk chapter.

“One of the fundamentals of my research is not just to look at what is, but what could be,” she says.

Building something better is what led Forchuk to nursing in the first place. As a high school student in Brantford, she volunteered at the local hospital. As a nursing student at the University of Windsor, she enjoyed community health. Her psychology courses also fascinated her because so much is unknown about the mind.

In 1976, Forchuk graduated with her baccalaureate as well as a BA in psychology. She completed her master’s degree in 1980. The demands of a young family and the absence of any Canadian doctorate programs in nursing made a PhD difficult. Then, Forchuk met nursing theorist Hildegard Peplau, who pressured her to go to the U.S. for a doctorate. Forchuk completed her PhD in 1992 at Detroit’s Wayne State University.

Through her work at the psychiatric hospital in Hamilton, Forchuk learned some psychiatric clients feared leaving the hospital because the staff and fellow clients were their only family and friends. A collaboration between staff and clients was launched with the goal of improving relationships between hospitals, community health providers, and peer support networks.

“She met with clients and tried to help them feel good about themselves,” Forchuk says. “Some studies have found as many as 43 per cent of suicides happen in the month after discharge,” she says. “As well, most re-admissions happen (then).

Yet this is the period when we have this huge gap between hospital and community.”

In January 2015, Forchuk released the results of a study that found supportive, therapeutic relationships decrease lengths of stay by nearly 10 days, saving the health system approximately $30 million. She says it’s frustrating that her research has not led to change across the health system, but she understands why. It takes time and resources to collaborate between the hospital and community sectors.

“The situation is more precarious for psychiatric clients without a home. Forchuk began working in London in 1994, around the same time she started to find psychiatric survivors living in shelters. It was the beginning of an era in Ontario that saw public housing costs transferred to municipalities, welfare rates slashed, and deinstitutionaliza-
Public health nurse worries about spread of measles

Measles has been spotted in Ontario, causing public health officials to worry about the reemergence of a disease once thought to be eradicated in North America. At least 19 cases of measles have been confirmed in the Greater Toronto Area, Niagara, and Hamilton regions since Jan. 25, 2015. “I’m sure it’s going to make its way here. It’s just a matter of time,” says Rose Huysge, program co-ordinator of school health at the Hal-dimand-Norfolk Health Unit. Measles can be transmitted even when an infected person isn’t showing symptoms – which are similar to the symptoms of a common cold, before the rash sets in, Huysge says. The confirmed cases in Ontario, along with more than 130 in Quebec and many more in the U.S. and Mexico, have prompted health-care professionals to reinforce the importance of vaccination. “People need to be aware that they need to be immunized,” says Huysge. Keeping up-to-date and accurate vaccination records is also crucial to prevention, she adds. “(We’re) trying to get that message out there, but it’s falling on deaf ears a lot of the time.” (Simcoe Reformer Feb. 10)

Mental health supports needed for preemie moms, RN says

More than four months after giving birth to preemie twin girls, Christine Kluczynski was finally able to take her daughters home. Maja and Alexis were born about 16 weeks early, and Kluczynski spent the first few months of their lives traveling back-and-forth to hospital as they suffered brain bleeds, underwent surgeries, and fought to survive. The RN, who returned to mental health nursing after her maternity leave, thought her struggles were over when she brought the girls home, but she was wrong. “People think that when you walk out the hospital doors, everything is fine. But it’s not,” she says. In fact, Kluczynski dealt with post-traumatic stress symptoms and worried about the future for her daughters, now two-years-old. “All those feelings don’t necessarily surface in the NICU (neonatal intensive care unit),” she says. “In the hospital, you’re on autopilot. You’re not thinking. You’re just surviving.” A 2014 report from the Canadian Premature Babies Foundation revealed the lack of emotional supports for parents after discharge is a major issue in the country. In recent months, Kluczynski has sent letters to politicians and health agencies, advocating for mental health services for parents of preemies, so no one has to go through what she did alone. She says there should be a mental health nurse in every NICU, counsellors to help parents transition their preemie babies into the home, and ongoing community supports, including home visits. (Toronto Star, Jan. 31)
NP says province should continue investing in family health teams

Pickering NP Claudia Mariano is concerned about a provincial shift away from family health teams (FHT), which she says have been improving access to care for Ontarians since their inception in 2005. Earlier this year, the Ontario government imposed sweeping changes to the way doctors are paid in the province. The changes limit the number of family physicians who can enter the payment structure used in Ontario’s 184 FHTs, and in effect, put a pause on the creation of new FHTs. Mariano discussed this issue as part of a panel on TVO’s The Agenda with Steve Paikin. These interprofessional teams have been providing same or next-day access to health care for many Ontarians who didn’t have primary care providers a decade ago, Mariano says, adding she rejects the notion that FHTs are too expensive. “(Too expensive) compared to what?” she asks. “We are doing something we haven’t done before...of course there’s additional cost.” Evidence shows that the healthiest societies deliver care in collaborative teams, and creating a healthier Ontario would save money long term, Mariano says. The province could also make health-care spending more efficient by ending NP remuneration problems in primary care, where NPs earn up to $20,000 less than their counterparts in acute care. This gap leads many NPs to look elsewhere for better wages, and is causing a “revolving door” at FHTs, Mariano says. (Feb. 25)

Province ignores study and puts seniors at risk

Insufficient staffing at Ontario long-term care homes is putting seniors in harm’s way. So say a number of health-care leaders, including RNAO CEO Doris Grinspun. “Hours of care (in long-term care homes) continue to be dangerously deficient,” she tells the London Free Press and St. Thomas Times-Journal (March 9 and 10). After problems surfaced at a pair of London-area nursing homes run by St. Joseph’s Health Care, a hospital executive called on the Liberal government to boost staffing levels in Ontario facilities to match those in other provinces. This call was echoed in a January 2015 report by the Ontario Association of Non-Profit Homes and Services for Seniors, which noted annual funding for long-term care is about $385 million short of what it should be. Seven years ago, the ministry of health tasked former RNAO President Shirley Sharkey, CEO for Saint Elizabeth, with investigating problems in the sector. Sharkey found seniors were barely getting three quarters of the care they needed, and sometimes as little as half. Critics say little has been done to remedy these issues. In early 2014, then Minister of Health Deb Matthews announced funding to hire 75 additional nurse practitioners in long-term care homes, a policy and funding priority pushed by RNAO. The government has yet to live up to its promise, Grinspun says.

Lois Barlow reminds readers to take good care of their lungs in this Feb. 12 letter to the Niagara-on-the-Lake Town Crier.

Take a deep breath, and protect your lungs

Breathing is something we often take for granted. Our lungs are amazing at doing their job but require us to take care of ourselves.

We can’t see our lungs or our breath, for that matter (unless it is really cold outside). If we were to lay out all the tubes, bubbles and bronchioles of our lungs, the surface area for oxygen exchange would fill one side of a tennis court. The air sacs that take in the air we breathe are tender and vulnerable like grapes on the vine. Anything we breathe in goes directly into arterial circulation and pulsates throughout our body and brain.

This winter has brought many viruses and bacteria with it. Staying as healthy as possible – good hand washing, and covering your cough – are tried-and-true, first-line measures to break the chain of infection. Especially vulnerable are those with underlying asthma, chronic obstructive lung disease or a chronic health condition, the very young, and the very old. Certainly there are medications that help control Airways such as inhalers and pills. Drinking enough fluids, eating healthy and getting some exercise always makes a difference. When you start to feel unwell, making sure to get enough sleep and cutting out some of the nonessential tasks and chores can help.

Take in a big breath to the depths of your diaphragm and breathe it out with new energy and resolve for a healthier future.
Raising minimum wage is good for the entire economy

When more than 130 RNs, nurse practitioners and nursing students met with Ontario politicians as part of RNAO’s Queen’s Park Day in February (see page 17), raising the minimum wage was on the agenda. After attending the event, Linda Holm wrote to the Woodstock Sentinel-Review about how an increase from $11 to $14/hour would benefit all of Ontario. “While the minimum wage increased to $11/hour as of June 2014 (and will go up to $11.25/hour in October 2015), this amount still leaves full-time workers 16 per cent below the poverty line,” Holm writes, adding that a $14 minimum wage will create a pathway out of poverty for low-income Ontarians. There is much debate, she acknowledges, about the impact of higher minimum wages on employers. Yet recent studies have found that upping wages leads to increased productivity and lower staff turnover. It can also create jobs and bolster the economy as lower-income workers get more spending power, she notes. “A minimum wage increase to $14 is seen by RNAO to benefit not only the minimum wage worker, but their employer and the economy as well.” (March 12) RN

RNAO INTRODUCES NINE NEW BPSOs

The newest cohort of RNAO Best Practice Spotlight Organizations (BPSO) was officially welcomed to the program on March 24 at an event in Toronto. Representatives from nine Ontario organizations (now referred to as BPSO candidates) met to show off their plans for best practice guideline implementation, and to network with and learn from designate (experienced) BPSOs. John Fraser, MPP for Ottawa South and parliamentary assistant to the Minister of Health and Long-Term Care, congratulated the group on behalf of the health minister. “I’m excited about how this will improve patient safety and patient outcomes,” Melissa Berquist, an RN and BPSO lead for Brockville General Hospital, told the Brockville Recorder. “These guidelines will set standards across our organization. This means improved, consistent care for all our patients.” (March 26)
RN Emeritus gets Order of Canada

When Susan French received a call from the Office of the Secretary to the Governor General, she thought it was about a letter of recommendation she wrote a few months prior for someone else nominated for the Order of Canada. She didn’t realize they were calling to tell her she herself had been nominated. “I had no idea,” French admits with a laugh, adding that she still doesn’t know who nominated her. French, who gained RN Emeritus status at RNAO in 2011, was invested as an officer of the order in February 2015. The now semi-retired RN was director of the School of Nursing at McMaster University when she spearheaded an innovative project with the Aga Khan University in Pakistan to help develop undergraduate nursing programs in that country. She worked on that project, funded by the Canadian International Development Agency, from 1983-2001, and says she is very proud of what they accomplished. “I think we really did help them (Pakistan) to become leaders in nursing…to develop education and practice, and to become leaders in research,” she says, adding that she believes it was this work that led to her nomination. During her decades-long career, French was also a nursing education and practice consultant in Bangladesh, the United Arab Emirates, Kuwait, East Africa, Japan and China.

Report on home, community care an important step, but more is needed

In March, the Ontario government’s Expert Group on Home and Community Care, chaired by former RNAO Executive Director Gail Donner (1984-89), released recommendations for change that it says will strengthen timely access to services for Ontarians. RNAO applauds the report, and fully endorses its call for an increased role for Local Health Integration Networks (LHINs), allowing them to work directly with primary care providers to improve system alignment. However, the association cautions against the use of integrated funding models rooted in hospitals, and insists home and community services be anchored in primary care. RNAO’s Enhancing Community Care for Ontarians (ECCO) model, released in 2012 and updated in 2014, is intended to streamline home and community care through system restructuring. It is designed to enable LHINs to perform whole-system regional planning, funding, service agreements and accountability functions.

ECCO calls for the elimination of Community Care Access Centres, which represent expensive structural duplication. “Ontario’s growing and aging population is set to become one of the defining health-care challenges of our time,” RNAO President Vanessa Burkoski says. “Nurses have proposed a bold approach (in ECCO), which would allow Ontario to tackle this challenge by supporting people to age at home as vibrant members of our communities, and advancing a person-centred health system, while at the same time improving health and financial outcomes.” Now, “It’s up to the government to act,” Burkoski says.

To find out more about ECCO, visit www.RNAO.ca/ECCO

Ontario campus health nurses form RNAO interest group

The Ontario Campus Health Nursing Association (OCHNA) was formally approved by RNAO’s board of directors as the latest provincial interest group in February, bringing the total number of affiliated groups at RNAO to 31. Members of OCHNA will come together from more than 30 educational institutions across Ontario. Campus health nurses are part of a unique interdisciplinary team and there is no other dedicated group in the province that represents our needs, OCHNA’s application to the board notes. “Together, we will work with RNAO and our surrounding communities to discuss current campus health-care trends, healthy community strategies, and provide professional growth and development opportunities for our membership,” OCHNA states. The group will collaborate with established post-secondary associations, such as the Ontario University and College Health Association and the Canadian Association of College and University Student Services, on common issues related to campus health trends, health promotion, and relevant policies and procedures. Members of OCHNA will be RNs in good standing with the College of Nurses of Ontario. They will be practising RNs in a campus health setting, but may also be students, new graduates or retired RNs. Membership is $25 for practising RNs, and $10 for students, new graduates or retired RNs. To find out more, visit www.RNAO.ca/OCHNA or email ochcnursing.RNAO@gmail.com RN
Four days before Christmas 2011, Tom woke up with a frozen shoulder. Having tumbled while hiking through the bush earlier that year, he shrugged it off. A few weeks later, he began struggling with everyday tasks, like using a fork, buttoning his shirt, and turning a key. Doctors thought Tom had a torn rotator cuff, but as his right arm continued to weaken, an orthopedic consultant sent him to see a neurosurgeon.

After five months, and a battery of tests and appointments, Tom was diagnosed in May 2012 with amyotrophic lateral sclerosis (ALS) disease, a progressive, fatal neurological illness also known as Lou Gehrig’s disease that attacks the nerve cells that control muscle action. Tom only had a handful of months to live.

By August 2012, his other arm began to grow frail. Two months later, he could no longer use his iPhone, raise a glass, or eat without assistance. His speech and breathing began to deteriorate. Within five months, Tom could no longer sit up. "The last four

Pseudonyms have been used to protect privacy.
In February, the Supreme Court of Canada unanimously struck down the law prohibiting physician-assisted death, directing Ottawa to rewrite relevant sections of the Criminal Code. Now, Parliament must decide how – or if – it will act. What does the ruling mean for nurses? **BY MELISSA DI COSTANZO**

months were quite unbearable for him,” recalls his wife, Margaret,* a retired RN who practised for more than 40 years.

Early in his diagnosis, when he began to lose control of his limbs, Tom made it clear “he just didn’t want to live any longer,” says Margaret. “Tom’s wishes were that, once he felt he had lost his dignity and a decent quality of life, when he was uncomfortable due to his medical condition (in his case, breathing and swallowing issues and pain), and when he had lost all mobility, he should have the right to die. He was a smart man, and he knew his disease was terminal.”

“My husband was not depressed or suicidal,” Margaret adds. “He had friends, family and a full life with lots to offer. He was trying to deal with a horrible illness with as much grace and dignity as possible.”

Tom’s health-care team advised him that there was no hope for improvement or recovery, and he would likely die from respiratory failure. Through many discussions with family and those providers, Tom was firm in his decision to decline interventions that may have prolonged his life, such as a
feeding tube, tracheotomy or ventilator. He signed a DNR order shortly after diagnosis. The team kept Tom comfortable, and reminded him that, should he change his mind, they would provide those interventions.

Tom was 71-years-old when he died peacefully in hospice, less than a year after his diagnosis.

“I was looking at a man I’d loved for 50 years, who was lying in a bed, unable to move, to speak, to swallow, with no mobility, and nothing left but eye movement,” Margaret says. “It was a long, hard journey, but ultimately, it was hardest for him.”

Tom believed he should have the right to die, Margaret says. He asked the health-care team to fulfill this wish, but was told providers aren’t permitted to do so.

Prior to the Supreme Court of Canada’s February decision to strike down the law on physician-assisted death, health providers would have risked their careers, and up to 14 years in prison, had they helped a patient die.

“Tom wanted to live every moment of his life to the fullest – so long as he had some quality of life,” says Margaret. “He was also very clear that the quality of his life was his to determine.”

She says she was always supportive of this view; Tom’s death only crystallized her perspective.

Margaret doesn’t want to be seen as a “poster child for dying with dignity,” which is why she wanted to remain anonymous for this feature. She acknowledges medically assisted death is a contentious topic, and says choosing how and when to die in the face of a terminal illness isn’t a decision people make lightly. It’s not for everyone, but it should be a patient’s right to decide, she says, adding Tom would have been pleased to learn of the Supreme Court’s decision.

And others share that view.

“If that’s truly what you want, and you’re of sound mind, I absolutely agree that people should be supported in that decision,” says Sue Thorne, an ER nurse at Sunnybrook Hospital, adding that strict directives must be in place to ensure only those in acute pain, and who are terminally ill, be permitted the option. Her perspective is informed by hundreds of patients she’s seen on ventilators for weeks on end, people experiencing pain, and ALS patients “who cannot communicate, who cannot even blink yes or no,” she says.

The February ruling can be traced back to 2011, when the British Columbia Civil Liberties Union (BCCLU) launched a lawsuit to challenge the Criminal Code on the issue of assisted suicide. The case opened up a national discussion on end-of-life care. And as that discussion began to heat up, RNAO was at the forefront of the conversation. In 2014, at RNAO’s annual general meeting (AGM), members passed – by a large majority – a resolution presented by the board of directors that, above all, urges a public dialogue on end-of-life issues.

The resolution contains a set of principles around which RNAO believes the discussion on assisted suicide and/or euthanasia should be framed. Personal autonomy and justice are fundamental; ensuring timely access to universal and evidence-based palliative care must remain a top priority; government must reject calls for involuntary euthanasia; assisted death must never be considered within the context of cost-savings; procedural safeguards must be enacted, including restricting assisted suicide to competent adults with terminal illness, and requiring that requests for assistance come directly from the person seeking the service, and be subject to a thorough review process; the practice must be restricted to professionals who have specialized education and training; no health professional or organization should be obliged to participate; and a provincial monitoring and reporting system must be developed.

The Supreme Court’s ruling included the principle that nothing should compel a physician to act against his/her conscious or religious beliefs. The declaration “simply renders the criminal prohibition invalid,” the ruling states. “What follows is in the hands of the physicians’ colleges, Parliament, and the provincial legislatures.” To date, the Conservative government has not indicated how it will proceed. The federal Liberals, meanwhile, have called for the creation of an all-party committee to lead national consultations on next steps.

**Improved palliative care remains a top priority**

While there are those who support the Supreme Court’s decision, there are others who staunchly oppose it, like RN Jean Echlin.

Echlin has dedicated the better part of her career – indeed, most of her life – to learning more about end-of-life challenges and contributing to conversations on palliative care, an approach she says improves quality of life. Even before the Supreme Court’s ruling, palliative-care providers (Echlin among them) were vocal about the need to improve and better fund palliative-care services. They argue that if people understand pain relief, counselling and spiritual services that help to usher patients and their families through their last chapter on Earth in peace, comfort and dignity, there’s no need for ongoing discussions on assisted death.

“I’ve never seen suffering that can’t be managed,” Echlin says, adding if a patient insists they would like to end their life, she has to “respect that they have every right.”

“But I’m not the one who could fulfill that need,” she remarks honestly.

**“Wanting to take your life is not a healthy state of mind… It’s usually out of distress.” LESLEY HIRST**

“I could not put to death somebody that I care about, and there’s not one of my patients I haven’t cared deeply for,” she adds.

A nurse consultant in palliative care and gerontology, and an adjunct associate professor at the University of Windsor, Echlin...
The Supreme Court of Canada, in a unanimous ruling, strikes down the ban on physician-assisted death, noting a request for help must be limited to a competent adult who “clearly consents to the termination of life,” and has a “grievous and irremediable medical condition...that causes enduring suffering that is intolerable.”

The court finds Canada’s ban “infringes the right to life, liberty and security of the person in a manner that is not in accordance with the principles of fundamental justice.”

It points out that the ban was designed to protect vulnerable people from being encouraged to commit suicide at a time of weakness. However, it catches people outside the class of protected persons, which infringes on their rights. This is, in at least some cases, not connected to the original objective, and the court ruled it is “thus overbroad.”

HOW DID WE GET HERE?

National debate on assisted dying dates back several decades, and is no less divisive now than it was in the early 90s. Here’s a look at some key milestones over the last 20+ years.

1992
Sue Rodriguez, who has amyotrophic lateral sclerosis (ALS), files a lawsuit with the B.C. Supreme Court that claims Canada’s Criminal Code, which prohibits physician-assisted death, is unconstitutional. She loses this decision, and appeals to the Supreme Court of Canada.

JUNE 2012
Canada’s law against physician-assisted death is declared unconstitutional by the Supreme Court of British Columbia as a result of a lawsuit brought forward in 2011 by the B.C. Civil Liberties Association (BCLA) and involving ALS patient Gloria Taylor. In July 2012, the federal government launches an appeal.

MAY 2014
RNAO passes a resolution that urges a public dialogue about assisted death. This comes shortly after two federal private members bills are introduced by Steven Fletcher, a Tory MP who is quadriplegic. The first bill would allow doctors to help people end their lives (with conditions). The second proposes a commission that will keep an eye on the proposed system.

FEBRUARY 1994
With the help of an anonymous physician, Sue Rodriguez dies at her Victoria home.

SEPTEMBER 1993
The Supreme Court of Canada dismisses Rodriguez’s appeal.

SEPTMBER 2013
Donald Low, a Toronto microbiologist well known for his work during Ontario’s 2003 SARS outbreak, issues a posthumous, passionate, videotaped plea for legislators to revisit the issue of assisted suicide, and take steps to change the Criminal Code.

OCTOBER 2012
Gloria Taylor dies from a perforated colon while holding an exemption that allows her to request a physician’s assistance to end her life.

OCTOBER 2013
The British Columbia Court of Appeal overturns the June 2012 decision of the Supreme Court of British Columbia, and upholds the law against medically assisted death. BCLA takes its case to the Supreme Court of Canada.

JUNE 2005
Blocquébécois MP Francine Lalonde introduces a private member’s bill that would allow a medical practitioner (or someone aided by a medical practitioner) to help a terminally ill person die if they are experiencing extreme physical and/or mental pain, and appear to be lucid. The bill does not pass. She introduces a private member’s bill again four years later, in May 2009. Again, it does not pass.

JUNE 2014
In a 94-22 vote, Bill 52, An Act respecting end-of-life care, passes in a free vote at the National Assembly in Quebec City. Quebec becomes the first Canadian province to establish a “dying with dignity” law.

RNAs CEO Doris Grinspun (left) and Immediate Past-President Rhonda Seidman-Carlson

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says: “As a nurse, I don’t feel that’s part of my ethics. It’s not part of my moral compass.”

“It’s their life,” she adds. “It’s not my place to take it.”

Lesley Hirst, president of RNAO’s Palliative Care Nurses Interest Group, holds the same view. “The fundamental issue, one that’s always puzzled me, is that if I expressed a wish to end my life right now, it would be considered a mental-health need, or suicidal ideation, and I would be able to access the appropriate resources,” she says. “Just because you’ve got a life-limiting, progressive illness shouldn’t remove the magnitude of that request to die.”

Hirst is wary about the Supreme Court’s decision. In her 20-year career in oncology and palliative care, this RN – who holds a master’s of science in palliative care, and has worked as an executive director of a community hospice – says three patients have asked her to help them end their lives. She responded to each of their pleas by pulling up a chair and saying: “That’s a pretty serious statement. Tell me what’s going on. How are you feeling? What are you feeling that makes you say that? How can I help?”

Hirst is not in favour of assisted dying, but acknowledges “...it’s something, sooner or later, we’re probably going to have to embrace.”

“Some people think it’s bad luck if you talk about death and dying,” she adds, noting this aversion is probably why some people don’t agree on the need for more dialogue on the subject. But, as Dean says, those people miss “wonderful opportunities to talk.” She speaks with teens about end-of-life, and says it isn’t a topic meant to be covered up. Funerals are celebrations, after all, and families should harness any opportunity they have – including the passing of a beloved pet – to discuss death. It needs to be taught in schools the same way sexual education is provided, Dean suggests.

We have to stop shyying away from it. “It’s just such a normal part of life,” she says, much like palliative care is a part of the health-care system. It, too, must be discussed with a wider audience, especially if we hope to get more funding and resources to meet demand.

“If we had better education in palliative care, we wouldn’t be going down this road at all.”

Anne-Marie Dean

“Palliative care is all about helping people live until they die,” she says, “Wanting to take your life is not a healthy state of mind, and when people say this, it’s often not a calculated, premeditated thought. It’s usually out of distress,” Hirst adds.

After expressing their anxieties and fears, these three patients never repeated their request to die. Hirst says. It’s up to the health-care provider to get to the bottom of the suffering, and devise a plan to address it, in tandem with the patient and their family, she suggests. “We have to try to do everything we can to support that person.”

Nurses should be equipped to counsel people who have expressed a wish to die. These skills need to be taught in school, she says.

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“At the end of life, patients need a consistent nurse to make it right,” she notes of having the chance, as an active proponent of proper pain management, and a vocal advocate for implementing palliative care into every health-care institution across the nation. He’s worked with people who are living with a life-limiting, progressive illness for more than 30 years, and holds two masters’ degrees in palliative care. He’s a volunteer consultant for the 10-bed Maison Vale Hospice in Sudbury. He, too, thinks providers need to wrap their heads around the power of appropriate medication when alleviating a patient’s mental and/or physical anguish.

Many health-care providers fear doling out medications, he says. “There’s a big myth in health care that you will have drug addicts if you give too much [medication],” Gauthier suggests. “If you don’t know how to prescribe, consult your colleagues, or transfer the patient to another [provider], for proper pain control. Don’t leave [patients] suffering.”

Changing the perception of death

Anne-Marie Dean has worked in palliative care for two decades. She has been executive director of Hill House Hospice in Richmond Hill for 16 years, and says helping Ontarians talk about death is a daily undertaking. She is not in favour of assisted dying, but acknowledges “it’s something, sooner or later, we’re probably going to have to embrace.”

“Some people think it’s bad luck if you talk about death and dying,” she adds, noting this aversion is probably why some people don’t agree on the need for more dialogue on the subject. But, as Dean says, those people miss “wonderful opportunities to talk.” She speaks with teens about end-of-life, and says it isn’t a topic meant to be covered up. Funerals are celebrations, after all, and families should harness any opportunity they have – including the passing of a beloved pet – to discuss death. It needs to be taught in schools the same way sexual education is provided, Dean suggests.

We have to stop shyying away from it. “It’s just such a normal part of life,” she says, much like palliative care is a part of the health-care system. It, too, must be discussed with a wider audience, especially if we hope to get more funding and resources to meet demand.

“If we had better education in palliative care, we wouldn’t be going down this road at all,” Dean says of the Supreme Court’s ruling.

“Palliative care is all about helping people live until they die,” she explains, which is why Hill House staff will prepare ice-cream sundaes at 3:00 a.m., pour a rye and coke for clients at breakfast, lunch and dinner (if that is their request), and take them out for a cigarette. Beds at Hill House are covered in duvets and there is no call system (residents, who arrive with four weeks or less to live, use hand-held bells in their rooms).
RNAO’s 15th Queen’s Park Day saw more than 130 RNs, NPs and nursing students meet with the province’s political leaders. They discussed a wide range of topics important to the health of Ontarians, and got some exciting news about their scope of practice.

BY DANIEL PUNCH
As RNAO members watched partisan fireworks erupt during question period at Queen’s Park on Feb. 26, it might have been difficult to imagine Ontario’s three political parties agreeing on anything. Yet all three sides came together later in the day in support of several RNAO priorities. And the Liberal government announced an important step forward on one of them: RN prescribing.

Health Minister Eric Hoskins, kicking off keynote addresses during the afternoon portion of the all-day event, announced the government will move forward with RN prescribing, and will begin consultations this spring in close partnership with RNAO. The news was met with a standing ovation by the more than 130 RNs, NPs and nursing students in attendance.

“RN prescribing is quite simply a perfect fit with our vision of a health-care system that puts patients first,” Hoskins said, with Premier Kathleen Wynne by his side.

RNAO articulated a vision for RN prescribing in Primary Solutions for Primary Care, a report released in 2012. RN prescribing will give patients enhanced access to our health system, says CEO Doris Grinspun, adding that “it is vital if the province wants to move to same-day access in primary care, and improved quality of care in long-term care. This change will also enable all sectors to deliver care in a more timely, effective and efficient way.”

Hoskins’ announcement may have been the highlight of the annual event, but it was preceded by several hours of spirited conversations between members and MPPs who started their day with breakfast meetings in the main legislative building. Members sat down with more than 50 MPPs in the morning and discussed a range of topics, including putting a stop to RN replacement, sector parity for NP compensation, raising the minimum wage to $14/hour, investing in affordable housing, and strengthening anti-toxics legislation.

Following breakfast, the group witnessed the partisan antics at question period, where opposition MPPs peppered the premier with questions about alleged misconduct in the Sudbury byelection. The barrage of questions prompted Liberal MPP Jim Bradley, acknowledging the scores of RNAO members in the public galleries, to repeatedly implore “where are the health-care questions?”

RNAO members made sure the health-care questions came in the afternoon, when Wynne, Hoskins, PC Interim Leader Jim Wilson, PC Health Critic Christine Elliott, and NDP Health Critic France Gélinas each offered an hour of their time to present a keynote address and answer questions from nurses.

Hoskins and Wynne were first to the podium, and wasted little time before their announcement to follow through with RN prescribing. Wynne first committed to expanding RNs’ scope of practice at RNAO’s 2013 annual general meeting, and officially made RN prescribing part of her election platform in May 2014 at RNAO’s Career Expo.

“When I spoke to you last spring, I made you a promise: I said we’d expand the scope of practice for RNs. (Now), we’re delivering on that promise.” Wynne told nurses, suggesting RNAO co-sponsor the spring consultations. “We need your advice, we need your expertise, (and) we need your support.”
When I spoke to you last spring, I made you a promise: I said we’d expand the scope of practice for RNs. (Now), we’re delivering on that promise.”

PREMIER KATHLEEN WYNNE
Support for RN prescribing also came from both opposition parties, with Elliott and Gélinas echoing its benefits for patient outcomes. And that wasn’t the only issue all parties agreed on.

Throughout the day, nurses reminded MPPs of the troubling disparity in NP remuneration. NPs working in primary care are paid up to $20,000 less annually than their counterparts in acute care and at CCACs, sparking recruitment and retention problems. About one in five primary care NP positions is currently vacant in the province, leaving a potential 250,000 Ontarians without a primary care practitioner. In her breakfast meeting with Elliott, RNAO board member Angela Cooper Brathwaite kept the issue front-and-centre. “We would like to see this discrepancy changed,” Cooper Brathwaite insisted.

During her keynote in the afternoon, Elliott announced the Conservatives would support an investment to increase sector parity for NPs. “If we want to encourage and expand the role of nurse practitioners in primary care, as we should, this must be addressed,” Elliott said.

Board member Aric Rankin, an NP, asked Hoskins about remuneration earlier in the afternoon and the minister insisted he is looking into the issue. “Rest assured that you and your colleagues have provided a compelling argument, I’ve listened and heard it, and now I’ve asked the ministry to look into how we can address it,” said Hoskins.

Gélinas echoed her support for parity in NP compensation, and said she’d repeatedly raised the issue with the minister of health.

RNAO President Vanessa Burkoski said she was pleased to hear that all three parties supported equity in NP remuneration, and promised that RNAO would continue to force funding for it to happen.

It was a similar story for medical tourism – a practice RNAO believes will destroy Ontario’s universal health system. In November, at RNAO’s insistence, Hoskins pushed the pause button on medical tourism in Ontario, asking hospitals to stop soliciting and treating international patients (except for humanitarian cases) and not to enter into new contracts to treat foreign patients in Ontario. While RNAO applauds this step, the association insists a full, legislated ban is the only way to protect Medicare.

Both opposition health critics reminded members of their ongoing support for a complete ban on medical tourism (Elliott made her stance official in a December press release, while Gélinas raised the issue in question period last October). “The proposition you’re putting forward (for a legislated ban) is bang-on,” Gélinas said. “Each and every one of us will have to continue to be vigilant.”

Nursing Students of Ontario (NSO) President Nathalie DiLabio told Hoskins she is worried about medical tourism. “My question is simple, but important. Will you legislatively ban medical tourism in the province of Ontario?” she asked.

Hoskins said that international patient contracts are being reviewed, and a framework is being established. “I think you will be satisfied with what comes out as part of this review process,” he said. Despite discrepancies in the details, all three parties agreed they want to reduce disparities in compensation for NPs, and eliminate medical tourism, Grinspun noted in her closing remarks. Given this all-party support, she said there should be no reason these initiatives can’t move forward – just as RN prescribing did.

“Nurses have raised these issues, and politicians have heard them,” Grinspun said. “Now it is time to walk the talk, and take these positive steps for the health of all Ontarians.” RN

The proposition you’re putting forward (for a legislated ban on medical tourism) is bang-on.”

NICKEL BELT NDP MPP AND HEALTH CRITIC FRANCE GÉLINAS (ABOVE)

Members attending RNAO’s 15th Queen’s Park Day received a set of detailed backgrounders on the issues for discussion with MPPs. These comprehensive policy documents include specifics on the association’s work as it relates to: environmental determinants of health; dignity and health for all Ontarians; health system structural reform; NP compensation; medical tourism; and RN prescribing. To access these resources, visit www.RNAO.ca/QPbackgrounders

DANIEL PUNCH IS STAFF WRITER AT RNAO.
Ontario’s Sergeant-at-Arms Dennis Clark shares a laugh with RNAO President Vanessa Burkoski during his keynote presentation about his role maintaining law and order in the House on behalf of the speaker, and overseeing security and property management at the Legislative Building.

Nursing students from across the province apply each year to participate in RNAO placements, including a visit to Ontario’s legislature during Queen’s Park Day. This year’s participants were: (front row, L to R) Patricia Cairns, Lhamo Dolkar, Austin White, Magen Brady, Bronwyn Lapp, and (back row, L to R) Paula Suciu, Anisha Garga, Natalia Kusendova, Holly Rogers, and Melissa Kim.

“If we want to encourage and expand the role of nurse practitioners in primary care, as we should, this must be addressed.”

CONSERVATIVE DEPUTY LEADER AND HEALTH CRITIC CHRISTINE ELLIOTT (FAR LEFT) (ON NP REMUNERATION)

Not just for politicians...

(This event) shows that nurses have a say in policy and that they’re respected by politicians and by governments. It’s very empowering as a future nurse to witness that, and to know that I do have a voice.”

NATALIA KUSENDOVA, NIPISSING UNIVERSITY (RIGHT)
On the ground in Sierra Leone

In November 2014, public health nurse Nancy Graham set out on a five-week mission to Sierra Leone to help that country deal with the Ebola outbreak. She was a volunteer with Médecins Sans Frontières (MSF)/Doctors Without Borders. The Toronto RN kept a diary, and offers this glimpse of life on the frontlines.
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he was quietly weeping, fat tears streaming down her face. For a moment, I hesitated to touch her, but it was OK as I was in full personal protective equipment (PPE). I reached for her shoulder with my double-gloved hand. She did not look up. And why should she? I was just another figure in a yellow plastic jumpsuit, white hood, plastic apron, mask, goggles and heavy boots. How can I connect with such a vulnerable person with these barriers?

High Risk Tent #3 has eight confirmed positive cases. She is one of them, and is sitting on a pink plastic chair just outside the tent. It’s only my second shift at the Kailahun Ebola Management Centre but I see her right away. She’s in her 20s, wearing a beautiful blue and yellow dress and flip-flops with plastic flowers. She clutches an oral rehydration solution (ORS) bottle, rocking back and forth, trembling while weeping. I check her patient ID bracelet. Number 1071. Kadiatu* is her name.

I call over to a colleague beyond the orange fencing. That’s where the low risk office tent is located, and where staff wear site scrubs, not PPE. “I think 1071 is in pain, does she have any pain meds prescribed?” Massimo*, the centre manager and my boss, checks her chart and replies. “Yes, Tramadol 50mg is ordered for 1071’s complaints of severe headaches and joint pain. Her last dose was 10 hours ago.”

He tosses over the mini plastic bag containing the pharmaceutical, which may provide some relief; some demonstration of care; some dignity.**

I always have a buddy with me, and our time suited up in the high risk zone is monitored. The supervising “dresser” helps me don the PPE before heading in, and writes my name on my hood, and entry time is on my left sleeve. Due to the unrelenting heat, we can only tolerate working in the high risk area for 45 to 60 minutes at a time.

The PPE makes a swooshing sound as I walk.

Clocks are on display in every sweltering tent. Jakob*, my national staff colleague, moves deliberately, doing temperature checks, pain assessments, repositioning, refilling of individual patient ORS bottles, and encouraging patients to drink while quietly speaking the Temne or Mende local languages.

Together we provide hygiene care, which includes changing and removing soiled diapers. Bio security is the priority, which means always washing our double-gloved hands in 0.05 per cent chlorine solution between patients. This is basic patient care, and all of us – nurses, aides, doctors and clinical officers – are providing this care.

When we’ve reached our limit, Jakob turns to me and nods. “OK, Mama Nancy, let’s go,” he says, and we walk slowly – exhausted – to the exit and undressing area. The hygienist barks instructions. “Turn around, arms outstretched.” He sprays my back. “Outside gloves off. Put in brown bin. Now, apron off. NO, NOT LIKE THAT. OVER YOUR HEAD. Now, goggles off. Bend forward. NO, LOOK AT ME. LIKE THIS. Put them in the green bin and rinse three times. Now, put in the other bin.”

Ten minutes pass and I am down to my scrubs. While I balance on one foot, then the other, he sprays the bottom of my white boots. I say with a smile: “Do you talk to your wife like that? I bet she does exactly as you say.” He bursts out laughing. I then thank him for keeping me safe.

I glance in the mirror on the way out of the restricted area and my face is transformed; scarlet red, short hair soaked to my head, no make-up. But standing under the full tropical sun, I feel relief. I can actually physically do this.

Massimo smiles at me as I head back to the low risk zone office tent. “You are looking good. How do you feel? Are you OK to go in again in about one hour?” he asks. I nod. I have so much more to learn about how to manage patient care and my own safety, one careful step at a time. Care in this context includes limiting our time in the high risk zone and being careful about patient identification, hence the numbers.

I feel so honoured to be here. To participate. To witness. And to remember. RN

** A bit of good news amid so much tragedy. Kadiatu recovered after three weeks at the health centre. Before leaving, she received psycho-social and public health counselling (including contraceptives), and parted with a discharge kit that included clothing, shoes, toiletries, money and food. She shared a celebratory dance with staff, and was transported home in a waiting MSF land cruiser.

* A pseudonym has been used to protect privacy.
Bargaining rights and education for RNs
Elizabeth Kauffmann was president of RNAO’s Kingston chapter from 1968 to 1970. “The opportunity to be an executive member of the chapter came when I was nominated for the position of president and ‘elected’ by acclamation,” she recalls. During her tenure, the big issues were collective bargaining and nursing education. “I remember there was much debate for and against (collective bargaining) and the issue certainly caught nurses’ attention.”

Debate was also raging over hospital schools of nursing “training” nurses when other professional health-care workers were “educated” in a college or university, Kauffmann recalls. “The closure of Ontario schools of nursing in hospitals was imminent,” she says, adding that, as chapter president, she spoke to media in Kingston about “…the role of the College of Nurses of Ontario and the registration exams. Not everyone was aware that when a nursing student graduated from a hospital school of nursing, they didn’t graduate as an RN. they qualified to write the registration exams.” Fast-forward four decades to 2005 and a baccalaureate degree would become mandatory to practise nursing in Ontario, thanks primarily to the advocacy efforts of RNAO.

RNAO welcomes ONA members back to the fold
Helen Schumacher-Tucker was president of the Lakehead chapter of RNAO in 1983, then Region 12 board representative from 1985-87. The decade leading up to her involvement was one of significant change in terms of the association’s membership base. In 1974, RNAO transferred all activities related to collective bargaining to the newly formed Ontario Nurses Association (ONA). This meant a decline in RNAO membership that Schumacher-Tucker remembers well. As chapter president, she remembers visiting other chapters such as Sioux Lookout and Dryden to talk to nurses about why their RNAO membership was still important. “I’m a strong believer in RNAO and that was one of the things I was pushing,” she recalls of raising awareness of the value of being part of both organizations. “I was adamant that ONA represented the workplace, but RNAO represented nurses,” she says. Almost a decade after ONA was formed, and during Schumacher-Tucker’s term on the executive (1983), ONA group memberships in RNAO took effect, and almost 30,000 unionized nursing colleagues were welcomed back to RNAO.

Memories of
In celebration of RNAO’s 90th anniversary, one-time chapter presidents and interest group chairs reflect on their time as advocates for the association.

By Kimberley Kearey

‘60s
Then Health Minister Matthew Dymond speaks to nurses on the front steps of Queen’s Park in 1965 during a rally about collective bargaining for RNs.

‘70s
Nursing students in this undated historical photo appear in caps and uniforms as they hit the books.
in celebration of RNAO’s 90th anniversary, one-time chapter presidents and interest group chairs reflect on their time as advocates for the association.

BY KIMBERLEY KEARSEY

RNAO finds its political voice and power
Janice McCallum joined RNAO as a master’s student in 1979. She says she held “all” positions on the local executive of the Middlesex North chapter (now Middlesex-Elgin) between 1980 and 1987. The chapter was very active, she recalls, “…putting forward resolutions to the AGM, holding active meetings, and hosting very successful all-candidates meetings.

I enjoyed this opportunity to have a voice, to meet with others at the assemblies or at the AGM…and learn from other incredible role models at these meetings.” McCallum joined the board of directors in 1982 and was on the executive of the Provincial Nursing Administrators interest Group (now the Nursing Leadership Network) for four years starting in 1985. She was chair for two of those years. “RNAO was really finding its voice in policy influence at that time,” she recalls. “I was young and quite new in my nursing career and it solidified my identity as a nurse and a professional. Being on the chapter and provincial boards gave me tremendous learning opportunities and helped me to develop skills that I would not have otherwise developed.”

Networking and mentorship opportunities a priceless perk for members
Marianne Cochrane attended her first AGM in the early 1990s and became membership officer for her local executive (Durham/Northumberland) shortly thereafter. “The mentoring and support I received from those on the chapter executive in those beginning years was invaluable and they set the example for me to strive towards,” Cochrane, the one-time chair of the Provincial Nurse Educators interest Group and four-term board member, says. “There is a sense of camaraderie that you experience when you are with others of like mindedness. Even though we may be working in different domains of nursing, we are each better when we come together and share our experiences and knowledge.” The networking opportunities are priceless, along with the friendships that develop, Cochrane adds. “There is nothing that can replace your fellow ‘sisters and brothers’ who work with you in the ‘trenches’ of health care. They understand what you experience and support you through the challenging days, and celebrate with you during the good times.”

Visit www.RNAO.ca/ninety to browse more historical photos in the photo gallery, check out the timeline for some of the association’s milestone moments over the last nine decades, or to submit your own story about memorable RNAO moments of the past.
It’s rare to see an empty bed at this residential hospice. In fact, Dean says they could use several more to meet local needs.

Province-wide, there are only 271 hospice beds. Ontario’s auditor general estimates the province needs between 500 and 800 more to keep up with demand. We also need more front-line staff, Dean charges. Added resources are crucial in communities to help people die at home, which, according to a number of studies, is what many Canadians want. Yet most of us (70 per cent) will die in hospitals, according to the Canadian Hospice Palliative Care Association.

Sandra* has worked in home care for 22 years, and says patients at the end of their lives often have no idea what to expect when they’re sent home. Neither do their caregivers. They’re not told that most visiting physicians have a two-week wait list, and that nurses come once a day; PSWs for 14 hours per week.

Embarrassed, humiliated and heartbroken, caregivers may not admit to struggling, Sandra contends. “They continue to care, and try the best they can,” she says, “...and I watch them erode psycho-socially, spiritually and physically.” Government must provide more resources to help nurses and other providers properly support their patients who want to die at home, she adds. It’s a “lovely idea,” she says of familiar comforts in your final days. “But if you don’t have a health-care system that will support what’s needed for that, then we are doing a great injustice.”

With a federal election slated for October 2015, it is possible assisted dying – a political hot potato – may not be addressed by Parliament until much later in the year. It’s even possible regulations won’t be crafted in the next 12 months – a timeframe granted by the Supreme Court, but not one the current government will necessarily adhere to. What lies ahead are likely consultations, debates and discussions mired in moral and ethical dilemmas. Nurses will offer important perspectives to those conversations, informed by their diverse views and by the ongoing discussions led by RNAO.

“The fact of the matter is that this is an extremely sensitive and, at times, divisive topic,” says RNAO CEO Doris Grinspun who, along with President Vanessa Burkoski, led webinars last fall and earlier this year with more than 500 RNs, NPs and nursing students to engage in the dialogue. “Nurses are well-positioned to guide and help to fashion this new law,” Grinspun says, adding that “end-of-life care is top-of-mind for nurses who work across the health system and in all sectors. As difficult as it might be – and it is – our voices must be part of the provincial and national conversations.”

Region 12 representative Pat Sevean introduced the board of directors’ resolution at last year’s AGM. She acknowledges many nurses don’t want to see assisted death legislated, “but if we don’t prepare ourselves to think about all the things that could happen...we’re going to make some dreadful mistakes.”

Thunder Bay member Michelle Spadoni stepped to the microphone when members were given a chance to respond to the resolution at the AGM. She’s participated in the dialogue to date, and suggests discussion on assisted death should be challenging. “We should struggle with (this topic); we shouldn’t be silent, and we need society to understand we’re struggling with this conversation, just as they are.”

**RN**

MELISSA DI COSTANZO IS STAFF WRITER AT RNAO.

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**90 years of influence & impact**

**APRIL 16–18 2015**

**Online registration for RNAO’s 2015 Annual General Meeting (AGM) is now open.**

Visit [www.RNAO.ca/AGM2015](http://www.RNAO.ca/AGM2015) to ensure you don’t miss this opportunity to connect with peers, and hear about the achievements of your professional association over the past year from President Vanessa Burkoski and CEO Doris Grinspun.

All RNAO members and student associates are invited to this three-day event. The AGM is your chance to see your association working for you. Hear an overview of the year’s achievements and help shape the priorities that lie ahead. Learn more about what’s to come in 2015 as a result of member-submitted resolutions. Watch peers – from every facet of our health-care system – receive their recognition awards; from those who work directly with patients, to nurses working in administration, as well as those working to shape the future of the nursing profession through education and research.

Visit [www.RNAO.ca](http://www.RNAO.ca) for more details.

*This year’s event will also feature a closing keynote panel of experts who will discuss the Supreme Court’s February ruling to overturn the ban on assisted suicide (see The end-of-life debate, page 12).*

**SATURDAY, APRIL 18, 11:30 AM–12:30 PM**

Closing Keynote Presentation: End of Life Care: Voices and Perspectives

Moderated by: Carol Goar, Toronto Star

**PANEL MEMBERS:**

Rahool Agarwal, Associate
Norton Rose Fulbright Canada LLP
Lesley Hirst, President
Palliative Care Nurses Interest Group
Michelle O’Rourke, Parish Nurses Interest Group
Maureen Taylor, CCPA, Widow of Dr. Donald Low
Professor Peter van Boegart
Antwerp University, Belgium
RNAO members play a role in deciding important governance issues that affect the current and future direction of RNAO. Members decide who gets to sit on the association’s board of directors, and also vote on the selection of RNAO’s auditors, and more. You do this by voting (electronically).

This year, members will vote for:

**PRESIDENT-ELECT**
Carmen James-Henry, RN, BScN, Med
Carol Timmings, RN, BScN, MEd/Admin

**MEMBER-AT-LARGE, NURSING EDUCATION**
Karimah Alidina, RN, BScN, MSc, CHPCN(C)
Salma Debs-Ivall, RN, MScN, PhD(c)
Elizabeth Edwards, RN, BScN, MSN
Shirley Marr, RN, BScN, MHEd, MHScN
(Other board members were acclaimed)

To be fully informed about your candidates, please visit www.myRNAO.ca to watch president-elect candidate videos, read candidate bios, and listen to candidate webinars.

One member, one vote will open online beginning at 12:00 noon (EST) on Tuesday, March 31. It closes at 12:00 (noon) on Wednesday, April 15. You can vote at any time during this voting period.

To find out more, visit www.RNAO.ca/AGM2015

Results of the voting will be announced at the annual general meeting (AGM) on April 17. The AGM will be divided into two sessions: the governance/business session will take place in the morning, and the membership consultation, to discuss the proposed resolutions, is scheduled for the afternoon. Consultation representatives will participate in the afternoon session.

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what makes you proud to be an RNAO member, and win $100 Visa gift card!

RNAO membership means many things to different people. Be it the professional development opportunities, our influential political advocacy, or being part of a network of outstanding nurses, something makes you renew with RNAO every year. We want to hear about it.

In honour of our 90th anniversary, we’re asking members to tell us their fondest memories of RNAO. Sending us your story automatically enters you into a draw for one of three $100 Visa gift cards.

Is there one moment that encapsulates what RNAO membership means to you? Is there an RNAO initiative that makes you particularly proud to be a member? Has RNAO helped you develop a long-lasting friendship with a nursing colleague?

Tell us about it in 500 words, and you’ll get the chance to win a great prize. Your story could be published on our website or in the July/August issue of Registered Nurse Journal.

Send us your story by emailing editor@RNAO.ca or visiting www.RNAO.ca/ninety/share-your-story
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When I began working as a nursing assistant at a children’s hospice, I felt a sense of pride in managing care for as many patients as possible. I was convinced that the busier I was, the better a nurse I could become. Emmy*, a passionate athlete and artist, was a 14-year-old patient who taught me otherwise.

Facing a relapse of cancer, Emmy spent most of her days sleeping. Her family, friends, and staff at the hospice cherished the moments she felt well enough to come out of her room.

Coincidentally, Emmy and I discovered we had both attended a camp for children living with cancer the previous summer. Our passion for camp, and the well-loved memories it provided, served as the foundation for many of our conversations. We longed to be back at camp, feel the heat of a campfire, and experience the freedom of dancing to crazy songs without a care in the world. As such, it came as no surprise to me when Emmy, out of her room on a good day, excitedly accepted my offer to create some traditional camp “bling” together.

As we decided what to create, worrying thoughts poked through my consciousness. What if the nurses needed my help? Was this a good use of my time? Could this even be considered nursing? With guilt, I pushed these thoughts aside. Something told me Emmy took priority.

We decided to create a keychain of her favourite word: fearless. However, her enthusiasm waned as she attempted to grasp the marker we would use to create her masterpiece. “I can’t use my hands,” she whispered, her eyes downcast and sad. “No problem, we’ll do it together,” I suggested.

We traced over each letter meticulously, Emmy holding the marker as I guided her hand. She drifted in and out of sleep, occasionally opening her eyes to supervise my work. “That’s not supposed to be coloured in,” she reminded me, and I frantically tried to undo my mistake. After nearly an hour, Emmy’s “bling” was complete; as unique, serene and fearless as the girl who had created it.

In nursing school, the gift of time is emphasized as the greatest thing we can share with our patients, yet I had overlooked its significance in my desire to develop practical skills that I believed would make me a good nurse. The children, families, and nurses I have the privilege of working with each day at the hospice consistently remind me that “making memories out of moments” is what end-of-life nursing is all about. Since this experience, I have learned that the act of being with our patients during their most difficult moments captures the essence of nursing.

Thank you Emmy, for teaching me to cherish the time we have, and for shaping me into the nurse I one day hope to become. RN

Mary Michalski is a third-year Bachelor of Science in Nursing student at the University of Ontario Institute of Technology (UOIT).

*A pseudonym has been used to protect privacy.
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