Welcome to the second issue of the Ontario Palliative Care Network (OPCN) newsletter. We are also pleased to announce the launch of the OPCN website, now live at ontariopalliativecarenetwork.ca.

**Ontario Palliative Care Network capacity planning has real impact on patients’ and caregivers’ lives**

The OPCN has begun capacity planning to ensure that all Ontarians have access to the services and resources they need when and where they need them. The recommendations that resulted from this planning work are translating into system-level improvements that will, over time, lead to greater equity and better access to hospice palliative care services in Ontario.

The OPCN’s capacity planning strategy has focused initially on determining where and how many residential hospice beds are needed in the province and on making recommendations to the provincial government on how best to meet those needs.

The Ministry of Long-Term Care (MOHLTC) in its 2016 budget committed to funding 200 beds in Ontario. Consequently, the OPCN provided a recommendation to the MOHLTC as to where those 200 beds should be allocated.

Lisa Favell, Director of System and Infrastructure Planning at CCO, says the OPCN will continue to advise the MOHLTC about future residential hospice needs and is conducting a current state assessment of all the services patients currently receive in their last year of life in settings such as residential hospices and long-term care homes, as well as in community-based and acute care facilities. The goal, Favell explains, is to understand not only how and what services are being provided, but to identify what should be happening.
“We know a greater percentage of care currently provided in acute care settings should be shifted to the home, but the question is to what degree. It’s important to refocus the conversation so that palliative care is not just about end of life care; it’s also about providing the supports to improve the lives of those who are living with progressive life-limiting illness.” – Lisa Favell, Director of System and Infrastructure Planning, CCO

Those supports are crucial to people like Rob Oakes, who turned to Matthews House Hospice, located in South Simcoe, when his wife was diagnosed with a terminal illness.

“Before my wife got sick, I was only vaguely aware of hospices and the services they provide,” says Oakes. “To me, it was something that only older people needed. I could not have been more wrong. When we got the news that my wife’s illness was terminal, I did not know where to turn. That is when the community hospice came into my life. During my wife’s illness they provided support to my wife, which gave me the courage to grant her last wish, to die with dignity at home. This was the greatest thing I could have done for her. But my story does not end there. After her passing it was the lowest point in my life. Again, the community hospice was there for me. Through their grief counselling I have been able to understand the importance of my relationship with my wife and have found reason to carry on. Without the hospice, I really don’t know what I would have done.”

The conference followed national research conducted over the summer of 2016 to determine what Canadians think about the current state of palliative care and what they would like to see in the future.

The outcomes of this work will result in recommendations and policy options that will contribute to better access to and delivery of palliative care nationally. For example, the Conference Board of Canada is issuing a report based on the consensus statement to guide governments, healthcare organizations, professionals and other interested groups.

“The consensus statement has been developed through a collaborative process involving Canadian citizens, decision-makers and experts to address the public importance of improved access and equity in palliative and end-of-life care at home and in the community,” Boyd says. At the same time, the OPCN is working to achieve hospice palliative care improvements at a provincial level by partnering with community stakeholders, healthcare providers and health systems planners to develop a coordinated, standardized approach to delivering these services.

“As the principle advisor to the Ontario Ministry of Health and Long-Term Care on palliative care in Ontario, it is important for the OPCN to be active participants in these national initiatives,” Boyd says.

Dr. Jakda agrees, noting that in Ontario, the OPCN is taking a leadership role in supporting and building a better hospice palliative care system. “Our internal work plans align well with many of the principles in the consensus statement and we look forward to sharing and collaborating with our national partners,” he says.

The Ontario Palliative Care Network represents Ontario in national conversation about palliative care

Ontario has a provincial voice in a national conversation about palliative care in Canada.

In November, the OPCN Provincial Clinical Co-Leads Dr. Ahmed Jakda, a palliative care physician, and Melody Boyd, RN, attended the Palliative Care Matters: Building National Consensus Development Conference in Ottawa, where they participated in drafting a national consensus statement on palliative care that will form a road map for palliative care in Canada.
Ontario Renal Network Palliative Care Report focuses on six key recommendations

Advanced chronic kidney disease is a complex, life-limiting illness for which there is no cure. Every year at least 11,000 Ontarians with chronic kidney disease are treated with dialysis as a bridge to transplant, long-term maintenance, or to alleviate symptom burden. Dialysis patients face unique challenges, including high mortality with a 43 per cent five-year survival rate (CIHI, 2009), distressing symptoms, and low use of community palliative care services. An analysis of 5,507 Ontarians receiving dialysis between 2010 and 2012 found that only 9 per cent had one or more community palliative care visits in the last month of life (ICES, 2015).

In March 2016, the Ontario Renal Network launched the Ontario Renal Network Palliative Care report with six key recommendations to advance high-quality palliative care for people living with chronic kidney disease through an integrated and continuous approach earlier and across care settings in alignment with the Ontario Palliative Care Network.

Work is currently underway to realize these recommendations. Local champions have been identified to support partnerships between Regional Renal Programs and Regional Palliative Care Networks. LEAP Renal, an interdisciplinary palliative care education program, is being implemented within renal programs with strong community participation encouraged. Regional Palliative Care Networks are encouraged to reach out to their local renal program for more information.

Learn more about the recommendations here: www.renalnetwork.on.ca/palliativecare

Defining the Term Palliative Care

What does the term “palliative care” mean to you? In conversations with providers and healthcare administrators across the province, the OPCN has learned the term means different things to different people. To ensure that we all use consistent and provincially accepted terms related to palliative care, the OPCN has developed a Common Language Guide. Below is a small excerpt.

**Palliative:**

☑ Refers to an approach to, as well as a philosophy of, care. A palliative approach to care is appropriate for any individual and/or family member living with a life-limiting illness at any time.

☒ Should not be used as a label for nor as a category of patients. A person may have palliative care needs, or they may receive a palliative approach to care.

☒ Is not a phase or stage in the illness trajectory, nor a diagnosis.
Palliative Care News Across the Province

The OPCN is a network of partnerships, and as such, we would like to highlight a few examples of important recent advances in hospice palliative care in Ontario.

**North York General Hospital’s Freeman Centre for the Advancement of Palliative Care awarded Leading Practice designation**

In May 2016, Accreditation Canada awarded the Freeman Centre for the Advancement of Palliative Care, based at North York General Hospital, a Leading Practice designation. According to Accreditation Canada, Leading Practices are innovative and creative, client and family-centred, evaluated, able to demonstrate intended results, sustainable and adaptable.

The Freeman Centre is a patient- and family-centred program that supports patients with advanced serious illness, focusing on the seamless transition of patients through each care setting and consistent delivery of care by one integrated multidisciplinary team from referral to end of life.

**2016 Cancer Quality Council of Ontario honourable mentions for palliative care programs**

Congratulations to the Simcoe Muskoka Regional Cancer Program, Royal Victoria Regional Health Centre, and the Kirkland and District Hospital, on their great work! Both received honourable mentions in the Quality category at the 2016 Cancer Quality Council of Ontario Awards: the Simcoe Muskoka Regional Cancer Program for its efforts to collaborate with community partners to improve access to palliative care services in North Simcoe Muskoka; and Kirkland for collaborating with community partners to provide one central point for referral for all hospice palliative care, additional education on hospice and palliative care for clinical staff, a roster of family physicians who provide hospice palliative care, and increased support for patients and families, including for advance care planning. Visit the [Cancer Quality Council of Ontario Awards page](https://www.cancerqualitycouncil.on.ca/awards) for more information.

We would like to hear from you! Do you have a patient story, a story idea, an achievement to highlight or feedback on this newsletter that you would like to share? Please contact us: [info@ontariopalliativecarenetwork.ca](mailto:info@ontariopalliativecarenetwork.ca)

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