Ontarians are talking about end-of-life care, yet for many, palliative care may begin too late or not at all, new report finds

Toronto, ON – June 28, 2016 – Almost 60% of people in Ontario who die receive palliative care services, according to *Palliative Care at the End of Life,* a new report by Health Quality Ontario, the provincial advisor on the quality of health care. And among those who have a record of receiving palliative care, about half begin to receive it in their last month of life.

Palliative care, the broad approach to providing comfort and dignity for patients and families who are living with, or at risk of developing, a life-threatening illness, can be started as early as the time of diagnosis. It includes managing pain and other symptoms so patients are comfortable, and helping them to cope with loss and grief.

According to a survey highlighted in the report, Ontarians are thinking about end-of-life care. Nearly two-thirds (64%) of older adults surveyed in Ontario say they've had discussions with family, friends or health care professionals about health care treatments in the event they become ill and cannot make decisions on their own – higher than the Canadian average and many countries around the world. But the report suggests there could be gaps in palliative care services.

"Everyone in Ontario who needs it should have access to palliative care," says Dr. Joshua Tepper, President and CEO of Health Quality Ontario. "This report reveals the challenges and opportunities for our health system in providing palliative care for all patients."

Key findings in the report:

In surveys of patients and caregivers in Ontario, most people say they would prefer to die at home, but the report found most patients in Ontario who receive palliative care die in hospital.

More than 95,000 people died in Ontario between April 2014 and the end of March 2015, and, based on the best available data, about 54,000 – or almost 60 per cent – of them had a record of receiving a palliative care service.

Among those who were determined to have received palliative care services:

- About half (47.9%) began receiving palliative care in their last month of life
- Nearly two-thirds (64.9%) died in hospital
- About one-quarter (25.8%) spent half or more of their last month of life in hospital
- Nearly two-thirds (62.7%) had unplanned emergency department visits in their last month of life

- Less than half (43.3%) received palliative home care services in their last month of life
- About one-third (34.4%) received a home visit by a doctor in their last month of life (this does not include visits from nurse practitioners)

"The new legislation on medical assistance in dying in Canada provides a potential choice for some patients who are facing intolerable suffering," adds Dr. Tepper. "But it does not at all change the underlying need for access to the best possible palliative care for all terminally ill patients when and where they need it, so they feel comfortable and supported."

Efforts to improve palliative care are underway. In 2016, the Ontario Palliative Care Network was established as a partnership between health care providers, planners, patients and caregivers, with a goal to transform palliative care in Ontario by addressing the gaps within the current system. In addition, the Ontario government's 2016 Budget included an investment of \$75 million over three years to provide patients with more options and access to community-based palliative care. The Ontario government also recently announced a 16% funding increase to hospices and has committed to funding an additional 200 hospice beds over the next three years.

To get a first-hand view of what Ontario's palliative care system looks and feels like right now, *Palliative Care at the End of Life* weaves in stories from patients, caregivers and providers of patients, who offer sometimes heart-wrenching experiences that cannot be captured in the numbers.

In one story, Jon describes what it was like helping to care for his mother Pat through her final weeks before she died from cancer complications at her home in Toronto: "My dad, my brother and I felt like we could write a book to guide people through this; what to expect, the highs and the lows and where to go for help, because there is no rulebook," Jon says. "There are so many important parts and every important part has the opportunity to go well or wrong."

To read the full report, visit www.hgontario.ca/palliativecare.

The report is based on the best data available: the 2014 Commonwealth Fund Survey of adults over the age of 55 years and administrative data for people who died in Ontario in 2014-15. Patients who received palliative care were identified based on having a palliative care service or end-of-life designation in their medical health records in their last year of life.

About Health Quality Ontario

Health Quality Ontario (HQO) is the provincial advisor on the quality of health care. HQO reports to the public on the quality of the health care system, evaluates the effectiveness of new health care technologies and services, and supports quality improvement throughout the system. Visit <u>www.hqontario.ca</u> for more information. For more information, or to book an interview, contact: Reena Kudhail, Senior Communications Advisor, Health Quality Ontario reena.kudhail@hqontario.ca O: 416 323-6868, ext. 694, C: 416-770-1898