

A woman with short, layered blonde hair and black-rimmed glasses is smiling warmly at the camera. She is wearing a bright red blazer over a black top. The background is a blurred residential street with several houses, including one with a prominent red brick facade and a dark roof. The overall scene is bright and pleasant.

Palliative Care at the End of Life

| Report Update 2019

Following up on the Palliative Care at the End of Life report

In 2016, Health Quality Ontario released a specialized report, *Palliative Care at the End of Life*, to look at the care and services people receive near the end of their life. This 2019 report update renews the 2016 report, with new data and a new way of looking at the data.

The previous report looked at data related to people in Ontario – including adults, children and infants – who had received palliative care services during their last year of life. This report update examines palliative care data related to all people who died in Ontario,* not just those who received a palliative care service. This aligns with current reporting methods that have evolved since the 2016 report.

The evolving landscape of palliative care in Ontario

Since the release of the previous report, there has been a lot of activity to support improvement in palliative care across the province, including the establishment of the Ontario Palliative Care Network in March of 2016.

The Ontario Palliative Care Network has supported the evolution of Regional Palliative Care Networks and worked to ensure the establishment of administrative and clinical leadership at the regional level, as well as the alignment of regional work plans with system priorities. It has aided the development of provincial performance indicators, enabled capacity planning, and created the [Ontario Palliative Care Network Action Plan](#) with local partners.

The Action Plan outlines how the networks and their partners will work together to ensure that quality palliative care services are readily available and easy to access for people with life-limiting illness and their loved ones.



**Health Quality
Ontario**

Let's make our health system healthier

**Ontario
Palliative Care
Network**

On the cover: Anna Slawski, director of resident care at a long-term care home.

*People who died of major trauma, injury or poisoning, or who had a sudden death in an emergency department, were excluded from the analysis. See the technical appendix for more details.

Palliative care relieves suffering and improves the quality of living and dying, using a holistic approach.

It helps people with a progressive, life-limiting illness, as well as their families, to prepare for and manage end-of-life choices and the process of dying, and to cope with loss and grief. It does so by addressing their physical, psychological, social, spiritual, and practical needs.

Palliative care (also known as “hospice palliative care” regardless of where it takes place) can begin immediately after a patient is diagnosed with a life-limiting illness, and does not require that treatments to slow the progress of that illness be stopped. Earlier palliative care has been shown to contribute to a better quality of life throughout the course of a life-limiting illness.¹

There is a significant intersection between palliative care and medical assistance in dying, however this report update does not discuss medical assistance in dying.*

*Medical assistance in dying is the administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death. The vast majority of patients who are considering or requesting medical assistance in dying have palliative care needs. These patients and their families should receive the full complement of palliative care services that are required to meet those needs throughout the course of their illness. The Ontario Palliative Care Network promotes early and equitable access to hospice palliative care for all patients with a life-limiting illness, including individuals who have requested medical assistance in dying.

More Ontarians are receiving palliative care, but often not soon enough

There has been a substantial increase in the proportion of people who receive palliative care near the end of life.

- Of the 103,213 people who died in Ontario in 2017/18, 61.4% had a record of having received palliative care in their final year, compared to 58.6% in 2014/15 and 51.6% in 2010/11

This indicator measures palliative care received in any part of the health system, including in hospital, long-term care, or home care.

Nearly half of people who receive palliative care only receive it in their final month of life. (Figure 1)

- Among the 63,380 people who had a record of having received palliative care in their final year of life in 2017/18, nearly half - 46.8% - began receiving it during their final 30 days
- Another 12.0% began receiving it during their second-to-last month of life

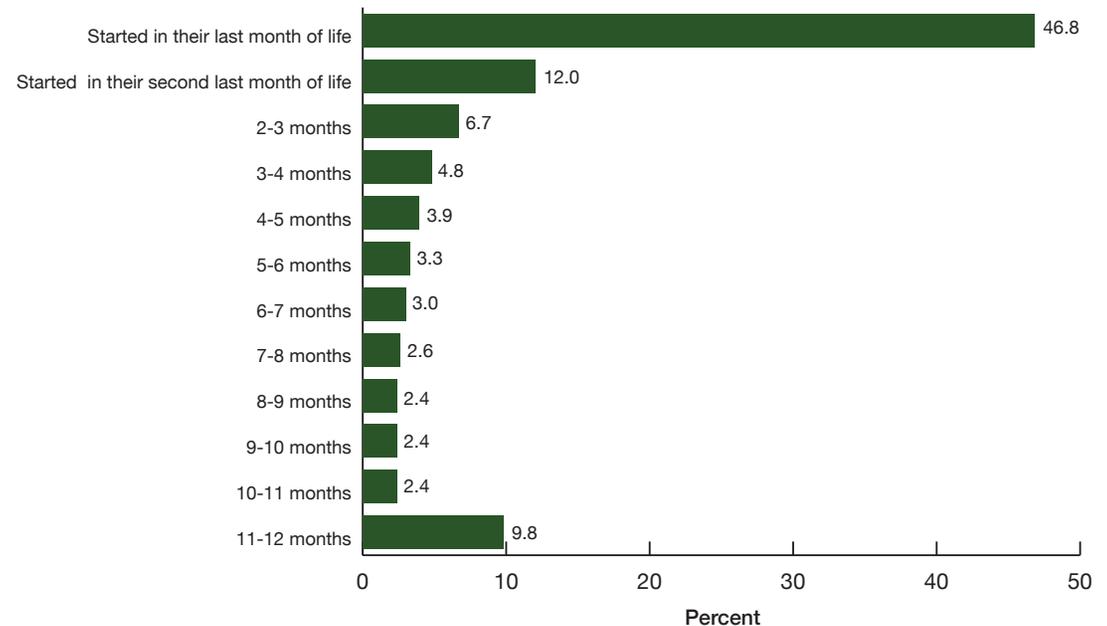
Health Quality Ontario's [quality standard for palliative care](#) states that people with a progressive, life-limiting illness should have their palliative care needs identified early through a comprehensive and holistic assessment, and that palliative care can begin as early as the time of diagnosis.²

Receiving palliative care earlier can lead to better quality of life at all stages as illness progresses.¹ It also increases the likelihood the patient will die at home,³ as most wish to do.^{4,5}

Encouraging early identification of patients who would benefit from palliative care has become a focus for quality improvement.

Out of 1,022 Quality Improvement Plans submitted to Health Quality Ontario in 2019 by primary care providers, hospitals, long-term care homes, and home and community care providers, 623 (61%) committed to prioritizing early identification of patients for palliative care.

FIGURE 1 Percentage of people who began receiving palliative care in each of the 12 months before their deaths, among people who died in Ontario and received palliative care during their last year of life, 2017/18



Data sources: Registered Persons Database, Ontario Health Insurance Plan Claims History Database, Discharge Abstract Database, Home Care Database, National Ambulatory Care Reporting System, Ontario Mental Health Reporting System, National Rehabilitation Reporting System and Continuing Care Reporting System, provided by Cancer Care Ontario



Assessing patients early for palliative care needs

Anna Slawski, director of resident care at a long-term care home, Toronto

“We started conversations about end-of-life with family members earlier on. We did work with medication, pain management, and a lot of education for the nursing team and for the physicians. We also covered the psycho-social aspects of palliative care, based on cultural background.

“With symptom management, we noticed a lack of standardized assessments, so we implemented an electronic assessment tool specific to a person who is experiencing a decline in their health status – not just physical symptoms but also social supports, spiritual and psychological needs, focusing on the whole person. The tool is also driven by clinical guidelines and best practices. The assessment has huge advantages, not just to the nursing and physician teams, but for the residents, families, and our home.”

Addressing the spiritual needs of patients and their families

Donna Mann, registered psychotherapist and spiritual care provider, Waterloo Region

“I support patients who have received a life-limiting diagnosis at any stage of their illness when their spiritual needs are identified. This may be early on, or when they’re facing the end of life and are experiencing existential suffering. We explore together the areas that are most distressing to them, which may include death anxiety, questions around life after death, or the grief of eventual separation from their family members. Their suffering may also involve a functional decline, loss of autonomy or their sense of dignity. Any number of concerns can impact their spiritual health.

“Family members who are coping with their loved one’s illness have emotional and spiritual needs as well. Sometimes I meet family members together, especially couples. At other times I meet with caregivers individually. They may have a need to express what they consider ‘forbidden thoughts’ such as ‘how long is this going to go on?’, and are often reluctant to openly acknowledge their own needs.”



Improvement in access to home-based palliative care has stalled

Following a period of modest but steady improvement, there has been little change over recent years in the proportions of people who receive publicly funded palliative-specific or any home care in their last month of life.

- 25.3% of people who lived in the community* during their final month of life in 2017/18 received palliative-specific home care during that month, compared to 24.5% in 2014/15, and 21.8% in 2010/11 (Figure 2)
- 51.7% of people who lived in the community during their final month of life in 2017/18 received any home care – which could have included palliative-specific care – in that month, compared to 51.6% in 2014/15, and 45.7% in 2010/11

Publicly funded home care services in Ontario include nursing, personal support, occupational and physical therapy, counselling, and other services, as well as home visits from doctors and nurse practitioners. The amount and type of care that people receive varies according to the nature and severity of their illness.

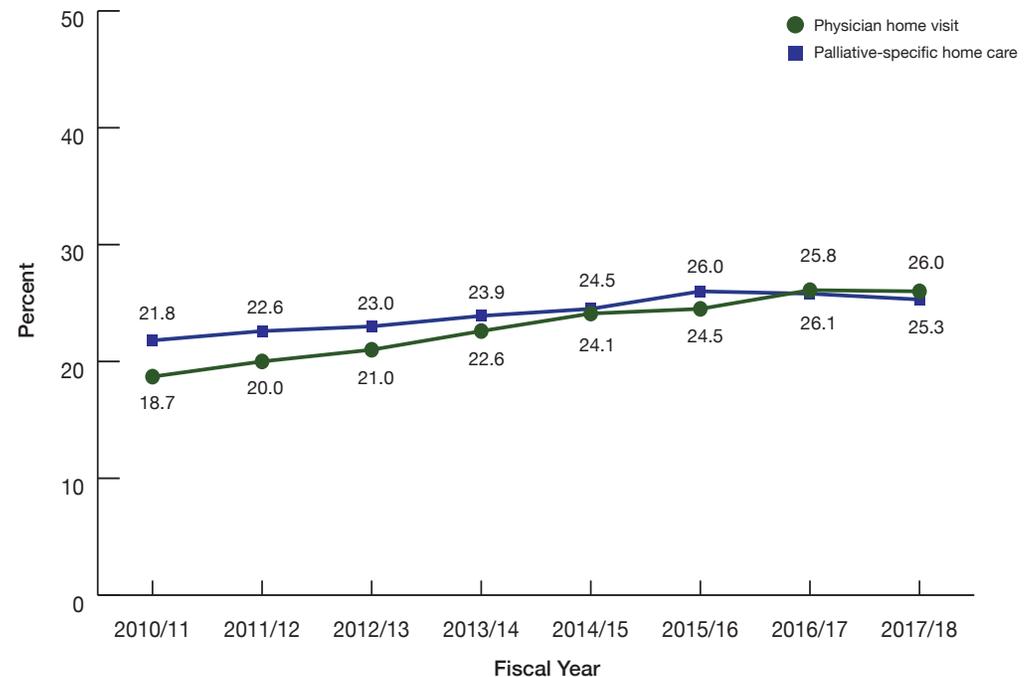
Palliative-specific home care often includes significantly more hours of service, after-hours service, and care by specialized palliative care staff. It is designed to relieve pain and suffering and improve quality of life by addressing the particular needs of patients with a progressive, life-limiting illness.

When patients are nearing the end of their life, publicly funded home care services can help to ease the burden on family and provide care that could increase the opportunity for patients to die at home if they wish. However, in 2017/18, about half of people who lived in the community during their final month of life did not receive any home care during that month, and three-quarters did not receive palliative-specific home care.

Improvement in the rate of home visits from a doctor in the last month of life has slowed.

- 26.0% of people who lived in the community during their final 30 days of life in 2017/18 received a home visit from a doctor during that period, compared to 24.1% in 2014/15 and 18.7% in 2010/11 (Figure 2)

FIGURE 2 Percentage of people who had at least one home visit from a doctor, and percentage who had at least one palliative-specific home care service, during their last 30 days of life, among people who lived in the community* during that period, in Ontario, 2010/11 to 2017/18



Data sources: Ontario Health Insurance Plan, Registered Persons Database, Discharge Abstract Database, Ontario Mental Health Reporting System, National Rehabilitation Reporting System, Continuing Care Reporting System, and, Home Care Database, provided by Cancer Care Ontario

Doctor home visits may help prevent unplanned trips to the emergency department, which can be disruptive and distressing for people nearing the end of life.⁶

Receiving a doctor home visit or palliative-specific home care decreases the likelihood of dying in hospital by about 50%, and getting both decreases it by 73%.⁶ Research shows most people would prefer to die at home rather than in hospital.^{4,5}

*People in the community included those who lived in their own home, a hospice, or an assisted-living facility, and excluded those who were in the hospital, a long-term care home or a complex continuing care facility during their last 30 days of life.

Sally and Wendy's story: The focus of all care



Photo of Wendy

When Sally was first diagnosed with chronic obstructive pulmonary disease and heart failure 10 years ago, she was able to manage them fairly well, her daughter Wendy says. But as the diseases progressed, Sally often had to be rushed to the emergency department of the nearby hospital in north Toronto. She was sick enough that she usually had to be admitted to the hospital.

“Her cycle at that time was emergency department, hospital admission, discharge to rehab, and home, but within a week she was back at the emergency and that cycle perpetuated,” Wendy says. “We were trying to manage it through her family doctor, but that was a challenge because he was a single practitioner and the clinic was not always open.”

During one of her hospital stays in 2017, Sally was offered palliative support through the hospital team. They gave her information about pain management and ways to cope with her deteriorating health. About a year later, Sally's health took another turn for the worse after she had radiation treatment for a cancerous growth on her leg. Wendy took a leave of absence from work to take care of her mother.

Back at home in north Toronto, Sally received home visits from a palliative nurse practitioner, which Wendy says reduced the need to go to the hospital. She also received home care visits for wound care, and visits from personal support workers to help her with day-to-day tasks. “Her care was excellent at home,” Wendy says.

But a couple of months later, Sally had breathing problems and had to go back to the emergency

department. After she was admitted to the hospital, her cardiologist said Sally was at end-stage heart failure. “In consultation with the hospital staff, a social worker, and our family, it was decided that Sally would come to my home in Caledon for as long as possible – we thought until the end,” Wendy says.

The regional health authorities helped with Sally's move to Wendy's home. “The palliative care physician and palliative nurse practitioner were a godsend,” says Wendy. Personal support worker services were offered, but this proved challenging to coordinate in rural Caledon, so the family paid for private personal support worker care.

Sally's condition continued to deteriorate, especially after she suffered an infection that contributed to delirium. After much discussion, the family and the palliative care team decided it would be best for Sally to move into a nearby hospice.

“At that point about 95% of the responsibility was on my shoulders,” Wendy says. “The nurse practitioner was available by phone, but it was too much for me. It got to the point where I was spent. I just felt like I was her service provider. I said I just want to be her daughter.”

On February 26, 2019, Sally died peacefully at the hospice. “I was blessed to be with her,” Wendy says. “Mom was the focus of all care. My family and I are so grateful for all the care we all received. I have taken advantage of the support available for family members as they grieve. Mom was a wonderful woman. The whole world loved her.”

Where people live may affect whether they receive palliative care

People near the end of life who are living in higher-income neighbourhoods are more likely to receive a home visit from a doctor.

- Among Ontarians who lived in the community* during their final 30 days of life in 2017/18, 32.1% of those who lived in the wealthiest fifth of neighbourhoods⁷ received a doctor home visit during their final month of life, compared to 20.8% in the poorest fifth (Figure 3)

People living in higher-income neighbourhoods are also more likely to receive any home care or palliative-specific home care to help them remain comfortable and address their needs.

- Among Ontarians who lived in the community during their final 30 days of life in 2017/18, 55.8% of those who lived in the wealthiest fifth of neighbourhoods received any home care (which could have included palliative-specific home care) during their final month of life, compared to 47.2% in the poorest fifth
- 29.2% of those who lived in the wealthiest fifth of neighbourhoods received palliative-specific home care in their final month of life, compared to 21.2% in the poorest fifth



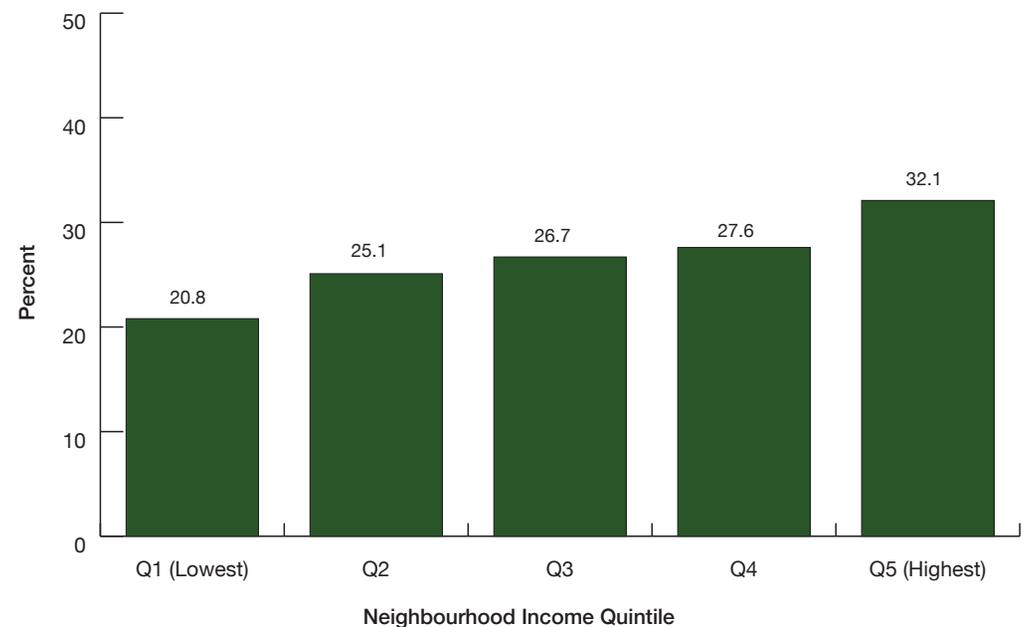
The challenge of providing palliative care services in rural areas

Nikita Matichuk, nurse practitioner, Rainy River District

“Being so rural we don’t have the availability of a lot of services or the frequency of services that they do in urban centres. My nurses are only able to visit end-of-life, actively dying patients in-home once a day, to set up the medications and provide teaching. Because of this, it is very much a family-centred cast to keep someone at home at end-of-life.

“Same with PSWs – they could maybe go in three times a day to check in, if we’re lucky, but there is no one available overnight or for longer than absolutely necessary. So some people do end up in hospital at end-of-life because they just need more care than the family can provide at home.”

FIGURE 3 Percentage of people, among those who lived in the community during their last 30 days of life, who had at least one physician home visit during that period, in Ontario, by neighbourhood income quintile, 2017/18



Data sources: Ontario Health Insurance Plan, Registered Persons Database, Discharge Abstract Database, Ontario Mental Health Reporting System, National Rehabilitation Reporting System, and Continuing Care Reporting System, provided by Cancer Care Ontario

*People in the community included those who lived in their own home, a hospice, or an assisted-living facility, and excluded those who were in the hospital, a long-term care home or a complex continuing care facility during their last 30 days of life.

Visits to emergency near the end of life have decreased slightly

More than half of people have an unplanned visit to the emergency department in their final month of life.

- Among all those who died in Ontario in 2017/18 and did not spend all their final 30 days in hospital, 54.1% made an unplanned* visit to the emergency department during their final month of life. That was down slightly from 56.6% in 2010/11 (Figure 4)

Unplanned visits to the emergency department are considered to be potentially avoidable. They can be disruptive and distressing for patients receiving palliative care, and may indicate needed care was not received in the community.^{6,9}



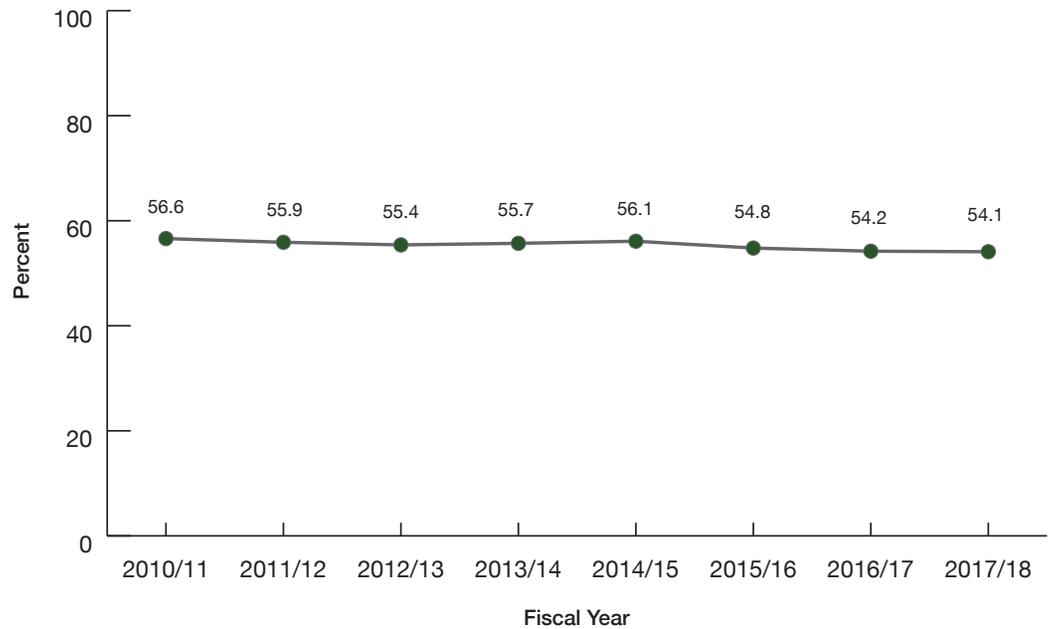
Volunteering to 'be there' for patients at a very difficult time

Brendan Devlin, volunteer, Ottawa

"I meet up with the clients I have been carefully matched with by hospice staff, usually once a week. I go into their home or hospice or hospital and provide companionship for them for 2-3 hours a week. We talk, we play games or simply sit together – depending on their interests and needs – and hopefully get their mind off their care or situation for a time at least.

"It can be a challenge to support someone in palliative care. Although I can't possibly know what the client is experiencing, I do try to imagine how I would feel if I were in their situation. When you see someone weekly, for years sometimes, you form a bond with them. I have good experiences with all of my clients. I learn from them and want to be there for them, and am privileged to do so."

FIGURE 4 Percentage of people, among all those who died, who had an unplanned emergency department visit in their last 30 days of life, in Ontario, 2010/11 to 2017/18



Data sources: Registered Persons Database, National Ambulatory Care Reporting System, and Discharge Abstract Database, provided by Cancer Care Ontario

*The type of planned visit excluded from this indicator would be, for example, an appointment in the emergency department for scheduled treatment or consultation when clinic or day surgery areas are unavailable.

Trev and Joan's story: Home, hospice and hospital

Joan's husband, Trev, lay in a Kanata hospital bed in a coma. She was told he would likely never wake up. Joan and her son and daughter left Trev's hospital room briefly to get some food, and when they walked back in, they heard a familiar voice: "I'm hungry." It was Trev.

Joan was shocked. "I was told you were in a coma!"

"I was but now I'm not, and I'm hungry," Trev said, matter-of-factly.

This was one of the many ups and downs that Joan says she experienced as a caregiver during her husband's palliative care journey. She was thankful to have the help of a support team along the way to help her and Trev manage their care and other needs.

Trev had diabetes, Parkinson's, depression, and arthritis. In 2014, after several falls because of his Parkinson's, Trev went to the hospital for surgery on his wrist. That's when doctors discovered he had cirrhosis of the liver caused not by alcohol, but likely by a pain medication. Doctors were not able to do surgery as they discovered Trev had a previously undiagnosed heart condition – he only had two chambers in his heart.

Trev was discharged from the hospital back home with Joan in Kemptville to receive home care services. But Joan says Trev was stubborn and refused all home care services. "He wasn't interested," Joan says, "so I was fighting the battle all by myself." But Trev did agree to go to a day hospice in Kemptville, a one-day-a-week program. "For me it was a blessing," Joan says. "It was

that one day, a few hours a week, where I didn't have to take care of him."

One day, Joan received a call from a woman who worked at the hospice, who suggested she come in for a chat. When Joan arrived, "she took one look at my face and said, 'She needs our help.'" The woman turned out to be the hospice's executive director. From then on, Joan said she had complete support from the hospice, as a family caregiver. "I didn't have a question that they didn't have an answer for," she says. "Somewhere along the way, I went for grief counselling because someone told me about anticipatory grief."

There weren't enough beds for Trev to be admitted to the hospice, but they had volunteers to help Trev and Joan as part of their day program. "They would tell me what would happen next, what might happen, and what would likely happen at the end," Joan says. "They gave me so much."

Trev was attending the day program at the hospice when he fell unconscious and was taken to a nearby hospital, where he went into a coma. After he awoke from the coma, the hospital planned to discharge him back home, but the thought of trying to care for Trev on her own terrified Joan. "He had a walker he was supposed to use when he was up, but he wouldn't use it. He would get up, walk out to the kitchen for a snack and he'd fall. He was too big, too heavy for me to pick him up." A home care assessment recommended that Trev stay in hospital. He died peacefully in the Kanata hospital six weeks later.

More than half of Ontarians die in a hospital

The majority of people who die in Ontario die in hospital, though research indicates most people would prefer to die at home.^{4,5}

However, the proportion who die in hospital has decreased in recent years.

- 52.2% of deaths in Ontario occurred in hospital in 2017/18 (Figure 5), compared to 58.2% in 2010/11
- Over the same period, the proportion of deaths that occurred in the community increased to 29.9% from 24.2%
- Deaths in long-term care homes remained essentially unchanged at 17.9%, compared to 17.6% seven years earlier

Deaths in the community include those in people's homes, in assisted-living facilities such as retirement residences, and in hospices.

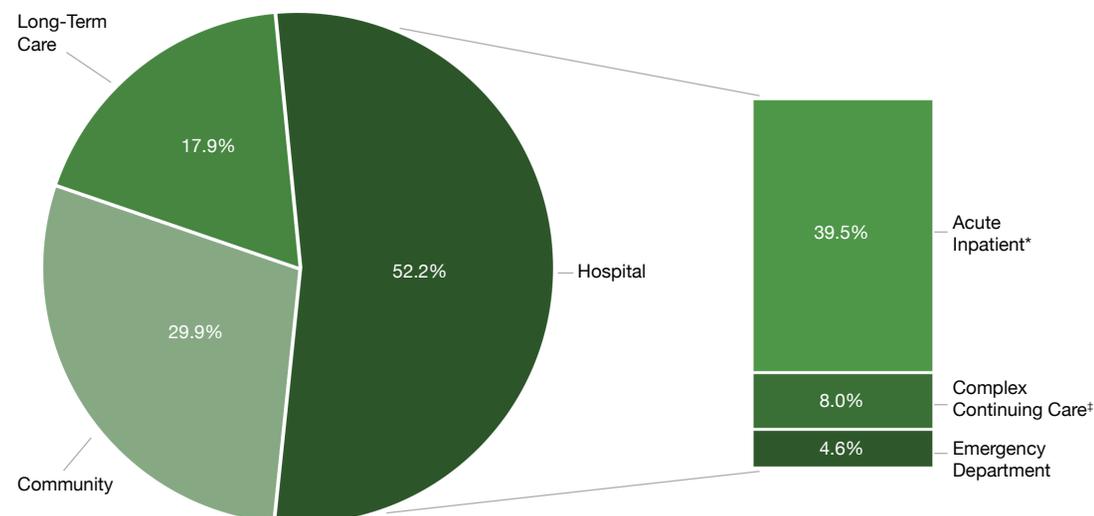
Some deaths occur appropriately in hospital if, for example, the patient's care needs are too complex to be met at their home or elsewhere in the community.

People who live in neighbourhoods with lower incomes or with more immigrants are more likely to die in hospital.

Among all people who died in Ontario in 2017/18:

- 53.3% of those who lived in the poorest fifth of neighbourhoods⁷ died in hospital, compared to 48.9% of those who lived in the wealthiest fifth of neighbourhoods
- 60.5% of those who lived in the third of neighbourhoods with the highest proportion of immigrants⁸ died in hospital, compared to 49.9% of those who lived in the third of neighbourhoods with the fewest immigrants

FIGURE 5 Percentage of deaths, by location, in Ontario, 2017/18



Data sources: Registered Persons Database, Discharge Abstract Database, National Ambulatory Care Reporting System, Ontario Mental Health Reporting System, National Rehabilitation Reporting System and Continuing Care Reporting System, provided by Cancer Care Ontario

Notes: *Acute inpatient beds are intended for the treatment of disease or severe episodes of illness, and include beds in rehabilitation centres and mental health hospitals. ‡Complex continuing care beds are intended to provide continuing, medically complex and specialized services for people with long-term illness or disabilities that require skilled or technology-based care not available in a home or a long-term care facility

Many Ontarians are having conversations about end-of-life care

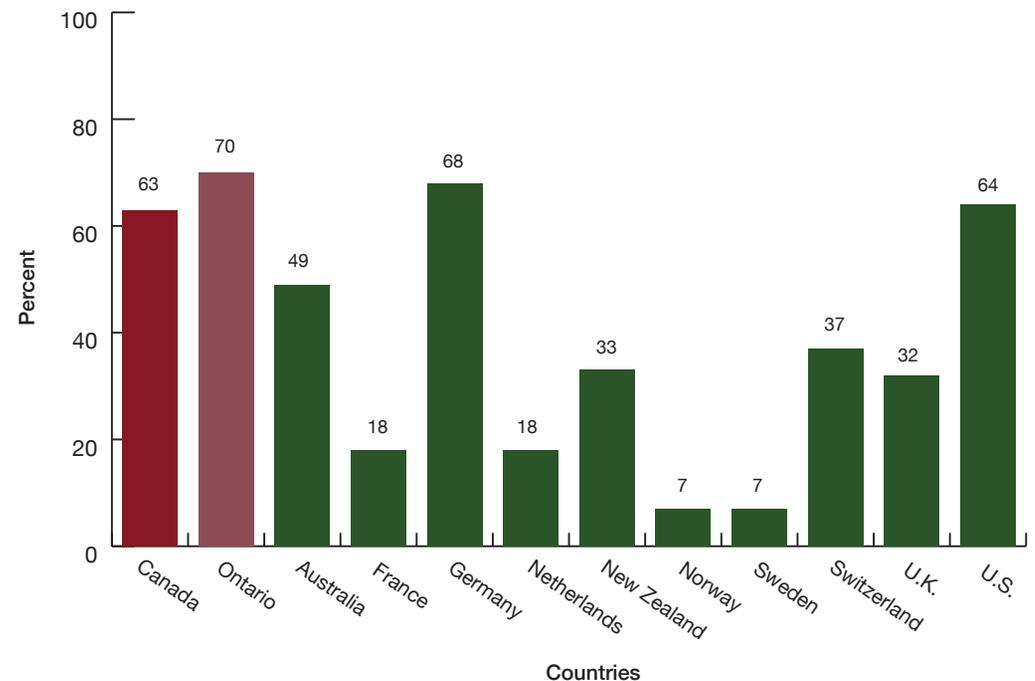
Compared internationally, a relatively high proportion of older people in Ontario are planning ahead for the care they want as they approach the end of life.

Effective palliative care depends to a large extent on patients discussing their wishes about the care they want with the doctors, nurses and other health professionals who will be providing it, as well as with the family members and others who might be assisting them during the course of a life-limiting illness.

According to the Commonwealth Fund 2017 International Health Policy Survey of Older Adults:

- 70% of people aged 65 or older in Ontario reported having a written document that named someone to make treatment decisions for them if they could not make decisions for themselves. That was one of the highest rates in the 11 socioeconomically similar countries surveyed, compared to 64% in the U.S., and 63% in Canada as a whole (Figure 6)
- 70% of Ontarians aged 65 or older reported having a discussion with family, a friend or a health care professional about what care or treatment they would want or not want if they became very ill or injured and could not make decisions for themselves. Among the countries surveyed, the proportion of older people who had had such a discussion was higher only in the U.S., at 76%

FIGURE 6 Percentage of people aged 65 or older who reported having a written document that named someone to make treatment decisions for them if they could not make decisions for themselves, 2017



Data source: Commonwealth Fund 2017 International Health Policy Survey of Older Adults



Identifying goals of care early to avoid stress and conflict later on

Alexis Peplinskie, nurse practitioner, Kenora

“The biggest challenge I find in palliative care is when patients and family members have different goals of care. A lot of times it comes down to who is the substitute decision maker, who is making the decisions, and are they aligned with what the patient expressed that they wanted?”

“How do we support family members and how do you educate people when they are in crisis about who can actually make the decisions? I try to get involved with patients early on to try to avoid some of that conflict.”

Just under a third of primary care doctors in Ontario routinely have end-of-life conversations with their patients.

The Commonwealth Fund 2019 International Health Policy Survey of Primary Care Physicians found that:

- 31% of primary care doctors in Ontario reported they “routinely” had “end-of-life conversations” with their patients about the patients’ preferences, wishes and goals for their care, in the event they became very ill, injured, or could not make decisions for themselves. Ontario’s rate was in the mid-range compared to results in the 11 socioeconomically similar countries surveyed, which ranged from 7% in Norway to 74% in the Netherlands. Rates in Canada’s other provinces ranged from 19% in Quebec to 49% in British Columbia
- 52% of Ontario primary care doctors reported they “occasionally” had “end-of-life conversations” with patients. Rates for this response ranged among the countries surveyed from 26% in the Netherlands to 71% in France, and among the provinces from 41% in British Columbia to 67% in Quebec

Helping doctors, patients and families navigate the palliative care system

Laura Harild, family doctor practicing in palliative care, Mississauga



“In the Mississauga-Halton region, we developed a palliative care education program for primary care doctors to be more confident with their palliative care. The tool includes a booklet along with an interactive discussion, and incorporates local resources. It walks the doctors through the phases of illness, and details who you should call and the forms you should fill out. We’ve reached about 140 doctors.

“I work in all settings and what’s most daunting is that palliative care is such a complex system to navigate. What I would love to see evolve is, no matter where you live in Ontario, the system is straightforward and simple.”

Considerations for patients and their families when dealing with a life-limiting condition

Advance Care Planning

- Patients need to be aware of who would automatically become their substitute decision-maker – usually their spouse, child or another relative – and if they want someone else, have a power of attorney document prepared that names their choice. Patients need to discuss their wishes, values and beliefs about future care with whoever their substitute decision-maker will be, to prepare the substitute decision-maker to make care decisions if it becomes necessary.

Goals of Care Discussion

- There needs to be discussion between patients, their families, and their health care professionals about the nature of the patient’s illness and what treatment or care options are available, so that patients and families can make decisions about care that align with their goals and values, and provide informed consent.

Health Care Consent

- In Ontario, the law requires all health care providers to get informed consent before providing a patient with any treatment or care. Health practitioners must tell the patient about their illness and what may be done to treat them. Patients or their substitute decision-makers have the right to agree to or refuse the treatments offered. Only in emergencies, to save a life or to reduce suffering, can people be treated without informed consent.

In Ontario, several organizations are helping to promote awareness and action on planning for end-of-life care. [Hospice Palliative Care Ontario](#) provides educational resources and tools on advance care planning, goals of care, and health care consent. [Speak Up Ontario](#), a partnership between Hospice Palliative Care Ontario and the Canadian Hospice Palliative Care Association, provides education as well as tools and resources that comply with Ontario laws. Health Quality Ontario and the [Ontario Palliative Care Network](#) have developed a [palliative care patient reference guide](#) that outlines best practices for quality palliative care and can help patients ask their health care providers informed questions. The quality standard and patient reference guide also include information about advance care planning and substitute decision-makers.

Current and future work to achieve high-quality palliative care

The data on palliative care in Ontario show us things have improved over the years, but patients with a life-limiting illness and their families continue to face a number of challenges to getting equitable, integrated access to quality palliative care.

Efforts to improve access to palliative and end-of-life care in Ontario have been ongoing for several years. For example, through the joint efforts of Health Quality Ontario and the Ontario Palliative Care Network Secretariat, palliative care indicators have been included in many health-sector Quality Improvement Plans since 2016, specifically indicators focused on discharging patients home with support (hospital sector) and on patients dying in their preferred place of death (home and community care sector).

Additionally, in April 2018, as a key partner in the Ontario Palliative Care Network, Health Quality Ontario produced a quality standard for palliative care, to serve as a resource for quality improvement. The quality standard's quality statements, related measures, and adoption supports are designed to help organizations determine where there are opportunities to focus their improvement efforts. To begin promoting implementation of this quality standard, an indicator focused on early identification of patients who would benefit from palliative care was added to the 2019/2020 Quality Improvement Plan program across all care settings.

To continue the momentum, more work is still needed. Some key areas to focus on include:

- Continuing support and development in Quality Improvement Plans for early identification of patients who would benefit from palliative care
- Increasing palliative care knowledge and competencies among primary care providers and within long-term care homes
- Working with system partners and clinicians to increase access to and equity in palliative care
- Using data to inform decision-making in health system and regional planning for palliative care
- Supporting access to palliative care through home care and community services
- Developing a strategy for public awareness and education around palliative care services, to help the general public better understand that palliative care focuses on improving quality of life regardless of prognosis and is not just end-of-life care
- Continuing investment in and development of processes and tools to enable coordination and connection between primary care and other providers for truly integrated palliative care

Tools & Resources

Health Services Delivery Framework – A model of care for adults with a life-limiting illness who are living at home or in community settings, and for their families and caregivers. It is designed to enable care to be delivered according to the quality standard for palliative care.

Tools to Support Earlier Identification for Palliative Care – To ensure that individual needs are addressed in a timely manner, this document provides preferred identification and assessment tools to help providers determine when palliative care should be introduced.

Ontario Palliative Care Competency Framework – This document clarifies competencies for each type of health care professional and volunteer providing palliative care. In addition to guiding future education and training for health care professionals, it will help ensure that patients receive palliative care from health care providers and volunteers who possess the appropriate knowledge and skills to deliver high-quality palliative care.

Quality Standard and Patient Guide for Palliative Care – These Health Quality Ontario tools guide health care providers in implementing effective palliative care plans to meet the needs of patients and their families, and help patients and families obtain the palliative care they need.

Palliative Care Implementation Support Group – This community-of-practice group on Health Quality Ontario's Quorum website is for quality improvement and clinical teams working on implementing the new Quality Improvement Plan indicator on early identification and assessment of palliative care needs. Members will find information on upcoming webinars and help sessions, and receive answers and support from the Ontario Palliative Care Network, Hospice Palliative Care Ontario and Health Quality Ontario team members.

The following **Goals of Care Resources** are for patients and providers to help support conversations that make sure treatment decisions align with patients' wishes, values, and beliefs:

- [Making Decisions About Your Care: Patient Resource](#)
- [Person-Centred Decision-Making: Resource for Health Care Providers](#)
- [Approaches to Goals of Care Discussions: Resource for Health Care Providers](#)
- [Advance Care Planning, Goals of Care, and Treatment Decisions & Informed Consent FAQs](#)

Resources for patients, caregivers and health care providers on advanced care planning and health care consent can be found at [Hospice Palliative Care Ontario](#) and in the [Speak Up Ontario Toolkit](#).

Acknowledgments

We thank our health system partners for providing Cancer Care Ontario and the Ontario Palliative Care Network permission to use their data in order to deliver this report update.

Institute for Clinical Evaluative Sciences: Parts of this report update are based on data and information provided by the Institute for Clinical Evaluative Sciences, which is funded by an annual grant from the Ontario Ministry of Health. The analyses, conclusions, opinions and statements expressed herein are those of the author, and not necessarily those of the Institute for Clinical Evaluative Sciences and funding sources. No endorsement by the Institute for Clinical Evaluative Sciences or the Ontario Ministry of Health is intended or should be inferred.

Canadian Institute for Health Information: Parts of this material are based on data and information compiled and provided by the Canadian Institute for Health Information. However, the analyses, conclusions, opinions and statements expressed herein are those of the author, and not necessarily those of the Canadian Institute for Health Information.

Ontario Ministry of Health: Parts of this material are based on data and information compiled and provided by the Ontario Ministry of Health. However, the analyses, conclusions, opinions and statements expressed herein are those of the author, and not necessarily those of the Ontario Ministry of Health.

Health Shared Services Ontario: Parts of this material are based on data and information compiled and provided by Health Shared Services Ontario. However, the analyses, conclusions, opinions and statements expressed herein are those of the author, and not necessarily those of Health Shared Services Ontario.

References

- [1] Zimmermann C, Swami N, Krzyzanowska M, Hannon B, Leigh N, Oza A, et al. Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. *The Lancet*. 2014;383:1721-30.
- [2] Health Quality Ontario, Palliative Care: Care for Adults With a Progressive, Life-Limiting Illness, Queen's Printer for Ontario, 2018, Available from: <https://www.hqontario.ca/portals/0/documents/evidence/quality-standards/qs-palliative-care-clinical-guide-en.pdf>
- [3] Costa V. The determinants of place of death: an evidence-based analysis. *Ont Health Technol Assess Ser [Internet]*. 2014 December;14 (16):1-78. Available from: <http://www.hqontario.ca/Portals/0/Documents/evidence/reports/eba-eol-determinants-pod-1411-en.pdf>
- [4] Brazil K, Howell D, Bedard M, Krueger P, Heidebrecht C. Preferences for place of care and place of death among informal caregivers of the terminally ill. *Palliative Medicine*. 2005;19(6):492-9.
- [5] Gomes B, Calanzani N, Gysels M, Hall S and Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliat Care*. 2013; 12(1). Available from: <https://doi.org/10.1186/1472-684X-12-7>
- [6] Tanuseputro P, Beach S, Chalifoux M, Wodchis WP, Hsu AT, Seow H, Manuel DG. Associations between physician home visits for the dying and place of death: A population-based retrospective cohort study. *PLoS ONE* 2018 13(2): e0191322. <https://doi.org/10.1371/journal.pone.0191322>
- [7] Average neighbourhood income (quintiles) is a proxy measure of personal or household income level, calculated by Statistics Canada when new census data become available. Average income estimates are first calculated for small geographic areas that have a population of 400-700 people. Based on these estimates, Ontario neighbourhoods are classified into five equal-sized groups, or quintiles, from poorest (Q1) to wealthiest (Q5). The postal code of a person's place of residence is used to assign them to one of the small geographic areas and then into one of the income quintiles.
- [8] This indicator divides dissemination areas into three categories according to the percentage of immigrants: low immigrant ($\leq 27\%$ immigrant population), moderate immigrant (27.1-51.8% immigrant population), and high immigrant ($\geq 51.9\%$ immigrant population). This is based on the immigrant (foreign-born) tercile (IMMTER) variable which divides the immigrant (and non-permanent resident) population (from the 2006 census) into three approximately equal parts.
- [9] Lawrenson R, Waetford J, Gibbons V, Kirk P, Haggart S, Reddy R. Palliative care patients' use of emergency departments. *The New Zealand Medical Journal*. 2013;126(1372):80-8

Health Quality Ontario
130 Bloor Street West
10th Floor
Toronto, ON M5S 1N5

Telephone: 416-323-6868
Toll-free: 1-866-623-6868
Email: info@hqontario.ca
www.hqontario.ca

ISBN 978-1-4868-3897-4 (PDF)

