



Enabling Palliative Care at Home

Home Care is a vital and integral component of the health care system. In Ontario, health system stakeholders have committed to establishing a system of care with improved access to evidence-based palliative care that is largely offered in the community.

Home Care Ontario commends the government for committing to “greater choice for palliative and end-of-life care” as part of the 2015 “ten steps to strengthen home and community care”¹. Evidence has shown that when properly resourced, home-based palliative-care services result in higher patient and caregiver satisfaction with end-of-life care.

The paradigm within the health system must change and providers must fundamentally alter their attitude toward care at home. Providers must work together to not only shift care to the community, but to operate with the assumption that home is where care must be provided. Home Care Ontario believes that palliative care at home will be improved when the following key challenges are addressed.

Access

- Access to services, equipment, supplies and medication is equitable across the province and the health care continuum.
- Service Provider Organizations (SPOs) have greater latitude to use their staff's judgment in order to determine timing, length and frequency of visits that respond to the real-time needs of the patient.

Education

- SPOs receive funding and support to develop their palliative care expertise while continuing to meet their service delivery obligations.
- Providers are informed and provide patients and family with clear information about the nature of help through government, and the services available through charitable and private channels.

Awareness

- Stakeholders across government, social and employment sectors better understand the needs of family caregivers and provide effective supports.
- Providers supply honest expectations of family and fully disclose the resources available to support families emotionally, mentally and physically.

Provider Collaboration

- Team based care which permits and properly resources and remunerates house calls (virtual and in-person) by all members of the team is ubiquitous.
- Improved communication and shared documentation using standardized tools and point of care technologies is implemented.

¹ Ministry of Health and Long-Term Care 2015

Current State

Significant shifts in society and in the needs of individuals from the health care system are driving change. Social and medical advances mean that people live longer, even with diseases that only a few years ago would have been life limiting. Palliative care, which used to be considered end-of-life care where individuals did not receive any treatment, is now understood to be an approach directed at relieving suffering and improving the quality of living and dying. Palliative care is appropriate for any individual and/or family living with, or at risk of developing, a life-threatening illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and/or needs, and are prepared to accept care.

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Living longer with chronic and/or terminal conditions means a greater demand for care at home and in the community. Chronic disease represents an increasing burden, both for individuals and for the health care system. In Canada, advanced chronic illness is the underlying cause of most deaths.² Individuals with terminal illness spend the majority of time at their last months at home, regardless of where they ultimately die.³

Home Care

Home care services help people with acute, chronic, palliative or rehabilitative health care needs to independently live in their community and co-ordinate and manage an admission to facility care when living in the community is not a viable alternative.

Home care services include nursing, personal support/homemaker, therapy (including physiotherapy, occupational therapy, speech language pathology, social work, nutrition/dietetics), medical supplies and equipment, and case management. Home care is delivered by service provider organizations (SPOs) that meet high standards of excellence, many of which are reported publicly by Health Quality Ontario.⁴

Unique to home care service delivery is that it is provided in the patient's home and family and/or friends provide the majority of care. As guests in the patient's home, the SPO staff manages the delicate balance of creating a safe working environment and providing safe care for patients while respecting their individual rights within their own homes. SPO staff demonstrates flexibility, autonomy and excellent problem solving skills in working effectively in an unregulated environment that is controlled by others. They are also effective at teaching and supporting unregulated care providers, volunteers, families and friends to follow through on the established plan of care.

Palliative care at home will be improved when:

- Access to services, equipment, supplies and medication is equitable across the province and the health care continuum.
- SPOs have greater latitude to use their staff's judgment in order to determine timing, length and frequency of visits that respond the real-time needs of the patient.
- SPOs receive funding and support to develop their palliative care expertise while continuing to meet their service delivery obligations.

² Health Quality Ontario 2014, p 10

³ Gomes & Higginson 2013

⁴ See <http://www.hqontario.ca/public-reporting/home-care>

Palliative Care in Ontario

The 'Declaration of Partnership and Commitment to Action' (2011)⁵ is a framework to which all health system stakeholders have supported as the means to work strategically to optimize hospice palliative care in the province. The priority is to give patients more timely access to palliative-care services. The common purpose is to better support adults and children with life-limiting illness to improve their comfort, dignity and quality of life preceding death. This support extends to families and caregivers who are vital members of the care team and who are typically with individuals across all settings of care.

The goal of palliative care is to provide comfort and dignity for the person living with the illness as well as his or her family. An important objective of palliative care is relief of pain and other symptoms. Additionally, palliative care addresses the psychological, social, cultural, emotional and spiritual needs of each person and family.

Evidence suggests that most people would prefer to die in that familiarity of their home.⁶ However, about 60% of deaths in Ontario occur in hospital.⁷ High rates of hospitalizations and emergency room (ER) visits in last weeks of life, and deaths in hospital are indicators of poor quality end-of-life care.⁸ In 2007-2008, 80 percent of the 20,023 admissions of palliative patients to acute care beds in Ontario were via the emergency department. There are a number of reasons that patients at the end-of-life access the emergency room.

According to work by Taylor and Dudgeon, cancer patients in Ontario visiting the emergency room at the end-of-life cited abdominal pain, pain, dyspnea, malaise and fatigue, nausea, anemia and back pain among the top ten reasons for their visits.⁹

Issues relating to confidence in a sustainable discharge are often at the root of decisions to remain in the acute care setting.

Once admitted to hospital, discharge home is often difficult. MOHLTC data indicate that 10% of all Alternate Level of Care (ALC)¹⁰ days in Ontario in 2013/14 were due to patients waiting in hospital for palliative care

elsewhere.¹¹ With adequate resourcing and planning, many of these deaths could have occurred at home.

While cost-savings is a compelling driver for discharge¹², people generally want to be at home if at all possible. Discharge home may be thwarted by system issues, such as completion of planned tests or access to medications. However, issues relating to confidence in a sustainable discharge are often at the root of decisions to remain in the acute care setting. A recent qualitative analysis of discharge planning for palliative care patients in the US highlights important themes that need to be addressed.¹³

⁵ Local Health Integration Networks, Quality Hospice Palliative Care Coalition 2011

⁶ An Ontario study of 214 home care recipients and their caregivers, published in 2005, showed that 63% of patients and 88% of caregivers preferred a home death.

⁷ Auditor General of Ontario 2014, p264

⁸ Seow 2009

⁹ Barbera, Taylor, Dudgeon 2010

¹⁰ ALC is the designation made when a patient is occupying a bed in a hospital and does not require the intensity of resource/services provided in this care setting (Acute, Complex, Continuing Care, Mental Health or Rehabilitation).

¹¹ Auditor General of Ontario 2014, p 275

¹² Caring for terminally ill patients in an acute-care hospital is estimated to cost over 40% more than providing care in a hospital-based palliative-care unit, more than double the cost of providing care in a hospice bed, and over 10 times more than providing at-home care.

¹³ Benzar, Hansen, Kneitel, Fromme 2011

- **Prognosis:** Patients and families need honest information about prognosis and disease progression so they can prepare and be positioned to make informed decisions.
- **Symptom management:** Patients and families need help to recognize and manage symptoms. Providers need access to the latest evidence-based practice and the resources to provide best care in the community.
- **Access to support:** Patients, families and providers need to know that live telephone and/or in-person support is available 24x7.

Family / friend caregivers provide 80% of care at home, supplementing the government funded service. A successful death at home can occur when there is confidence that the resources and supports are available, responsive and supportive.

The paradigm within the health system must change and providers must fundamentally alter their attitude toward care at home. Providers must work together to not only shift care to the community, but to operate with the assumption that home is where care must be provided.

- Providers need to be informed and provide patients and family with clear information about the nature of help through government, and the services available through charitable and private channels.

Palliative Care at Home

“Providing palliative care at home is often not a conscious decision made by family but rather a situation that evolves as a result of a request by the patient, a lack of knowledge about the implications, an unrealistic sense of the expectations, a sense that there was no choice, pressure from the health system.”¹⁴ The requirement to provide care to a family member at home at end-of-life can have a profound effect on the family.

On average, Canadians estimate that 54 hours per week would be needed to care for a dying loved one at home.¹⁵

The involvement of families may depend on their availability, ability to financially supplement the home care program, the functional ability of the dying person and the ability to manage the physical symptoms in the home setting.¹⁶

“Family caregivers” provide care and assistance for spouses, children, parents and other extended family members and friends who are in need of support because of age, disabling medical conditions, chronic injury, long term illness or disability.

For people receiving palliative care at home and their caregivers, access to care around the clock is critically important to their comfort and ability to remain at home. This is particularly important in the last few days of life when patients require careful symptom management, and families need support and coaching as death approaches.¹⁷ If adequate palliative-care services, such as access to physicians and home care nurses, are not available when needed, patients will likely go to the emergency department to get the required care.¹⁸

¹⁴ Canadian Hospice Palliative Care Association 2013, p 10

¹⁵ Ipsos Reid 2004

¹⁶ Stajduhar & Davies 2005

¹⁷ Bailey 2015

¹⁸ Auditor General of Ontario 2014, p 261

Caregivers need respect and understanding and accordingly:

- Stakeholders across government, social and employment sectors must better understand the needs of family caregivers and provide effective supports.
- Providers shall supply honest expectations of family and fully disclose the resources available to support families emotionally, mentally and physically.

Interdisciplinary approach

A successful home care system appropriately utilizes and integrates all members of the team, enabling access to physicians, nursing, therapies, community pharmacists, and personal support. Each interdisciplinary member has a unique body of knowledge and scope of practice that is valued for the contribution to effective patient care. This team collaborates with the broader health system in order to provide patients with seamless coordinated care that enables patients to move easily among health-care providers to receive needed services on a timely basis. With the benefit of good communication and sharing of timely documentation, the team can ensure appropriate clinical management, and better quality discussions around the concerns and priorities as identified by the patient.

Health system collaboration will be enhanced through:

- Team based care which permits and properly resources and remunerates house calls (virtual and in-person) by all members of the team.
- Improved communication and shared documentation using standardized tools and point of care technologies.

To be truly effective and achieve improved care for patients, there must be genuine belief in the ability to support end-of-life care at home and authentic commitment to providing palliative care at home. This means that there is truly adequate resourcing to support care evidence-based care in the community so that hospital care is not the default when unexpected, and yet not unpredictable, events arise.

Conclusion

There is no dispute that too few Ontarians benefit from good palliative care at home and that most would prefer to die at home. A well-managed death at home is a gentle, natural experience. Home Care Ontario is pleased to be working as a partner to the Declaration. The recommendations offered in this report are offered as a complement to the important work underway. The Association will continue to work with all health system partners to ensure that Ontarians have access to high quality hospice palliative care across the continuum.

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