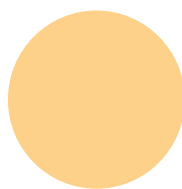
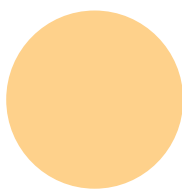
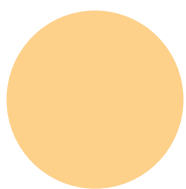


The Pan-Canadian Gold Standard for Palliative Home Care

Toward Equitable Access to High Quality Hospice Palliative and End-of-Life Care at Home



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Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs



Canadian Home Care Association
Association canadienne de soins et services à domicile

The Gold Standard for Nursing Care in Hospice Palliative and End of Life Care at Home

Nurses play an important role on home care hospice palliative care teams. They often serve as the main professional contact and primary liaison with the client/patient and family, the physician and other team members, monitoring the client's/patient's health and providing information to the physician, providing nursing assessment and care, and often managing and coordinating other services, such as personal care. They work closely with other team members to promote quality of living and quality of dying. Nurses are often responsible for providing education for family caregivers.

As more jurisdictions move to establish palliative home care programs, home care organizations must ensure they have an adequate number of nurses with the knowledge, skills and attitudes to support people who choose to spend their final days at home. The pan-Canadian Gold Standard for Nursing Care in Hospice Palliative and End-of-Life Care at Home sets out the expectations for nursing services that must be available to ensure high quality hospice palliative care for Canadians who choose to die at home. The Gold Standard is based on the Norms of Practice for Hospice Palliative Care in Canada⁷ as well as hospice palliative care nursing standards⁸. It recognizes that most nursing in palliative home care is currently provided by generalist nurses; it also acknowledges the important role played by the growing number of hospice palliative care nurses who bring specialized knowledge, skills and attitudes to nursing care at end-of-life.

1. Canadians receiving palliative home care have access to skilled, compassionate nursing knowledge and care, 24 hours a day, seven days a week.

Canadians who choose to spend their final days at home typically receive a significant amount of their care from family caregivers supported by members of the interdisciplinary health care team (e.g., personal support workers, nurses, physicians, pharmacists, volunteers) depending on their

Dimensions of Nursing in Hospice palliative Care

- **Valuing** – believing in the intrinsic value of others, the value of life and that death is a natural process.
- **Connecting** – establishing a therapeutic connection (relationship) with the person and their family through making, sustaining and closing the relationship.
- **Empowering** – providing care in a manner that is empowering for the person and family.
- **Doing for** – providing care based on best practice in pain and symptom management, coordination of care and advocacy.
- **Finding meaning** – helping the person and family find meaning in their life and their experience of illness.

hospice palliative care needs. People dying at home have access to compassionate and skilled nursing assessment, knowledge and care, 24 hours a day, seven days a week. Their families and other caregivers also have access to therapeutic nursing knowledge as required. This is crucial to address any fears or concerns, and to avoid unnecessary hospitalization. When individuals do not have family members who are able to provide care, the need for professional nursing assessment, support and care is even greater.

In some cases, skilled nursing support may be provided by phone or through the use of other technologies (e.g., telehealth, telehome care, Internet); however, technological support is not a substitute for hands-on care.

⁷ A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice. Canadian Hospice Palliative Care Association, 2002.

⁸ Hospice Palliative Care Nursing Standards of Practice. Canadian Hospice Palliative Care Association, 2002.

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2. Home care nurses providing palliative home care have the knowledge, competencies and attitudes to provide high quality hospice palliative care.

Providing supportive hospice palliative care is an integral part of every nurse's role; however, most home care nurses are generalists who will be providing care to a range of clients/patients with different health needs, including end-of-life care. To ensure generalist nurses have the knowledge, skills and attitudes to provide high quality hospice palliative care, all home care nurses providing hospice palliative care receive initial and ongoing education and training in essential hospice palliative care services including: pain and symptom management; practical support of clients/patients and family at home, including caregiver education and respite for caregivers; communication and conflict resolution; hospice palliative care for children; ethical issues at end of life; advanced care planning and decision support; psychosocial support; end stage disease management; and bereavement support.

All students in Canada's nursing schools receive consistent core education in hospice palliative and end-of-life care. This education is interdisciplinary in order to build and reinforce the skills required to work as part of a hospice palliative care team, and to foster a culture of trust and collaboration among health professions.

Employers ensure that both generalist and specialist home care nurses have access to appropriate ongoing education and resources to maintain and enhance their hospice palliative care knowledge and skills. Distance education programs are available for nurses working in rural and remote areas.

3. Generalist home care nurses providing palliative home care have timely access to an expert hospice palliative care team.

All generalist home care nurses providing hospice palliative care – regardless of whether they are working in urban, rural or remote communities – have timely access to an expert hospice palliative care team, including hospice palliative care nursing specialists and physicians with accredited postgraduate training in palliative care, who can provide support, advice and guidance as needed. They also have access to written and web-based resources. When nurses are providing palliative home care to children, they have access to experts in pediatrics and pediatric end-of-life care.

Jurisdictions explore the use of innovative technologies to provide equitable and timely (i.e., 24 hours a day, seven days a week) access to expert hospice palliative care knowledge and skills.

4. Home care nurses are part of a hospice palliative care team that works collaboratively to provide continuity of care for the dying person and his/her family.

Home care nurses work closely and collaboratively with other members of the hospice palliative care team – including the client/patient, family members, the family physician, the social worker, therapists, spiritual care providers, personal care providers, the pharmacist, volunteers and others – to ensure the client/patient receives high quality care through the course of a terminal illness and in the last days of life. All members of the team understand and respect their distinct roles, share common philosophies and goals of care, work to the full scope of their practice, and collaborate to ensure continuity of care.⁹

Tools to support and enhance communication and continuity of care, such as a common pain and symptom assessment tool, a common client/patient record, electronic information systems, laptop computers, and clinical rounds, are available and used by all team members in all settings (i.e., at home, in hospital, in an outpatient clinic).

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⁹ Enhancing Interdisciplinary Collaboration in Primary Health Care Initiative .

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5. Home care nurses use evidence-informed care pathways and guidelines to ensure high quality care.

Nurses collaborate with other members of the palliative home care team to develop care pathways that reflect evidence-informed provincial or national guidelines for high quality palliative home care. The pathways make optimal use of the skills and competencies of all team members. Home care nurses also have access to the training and support required to ensure they are able to implement pathways and guidelines consistently.

6. Home care organizations establish human resource plans that ensure continuity of care and make effective use of nursing knowledge and skills.

To provide high quality hospice palliative care, home care organizations have an adequate number and mix of nurses, with the appropriate skills and education. They have enough hospice palliative care nurse specialists to provide consultation, support and education for generalist nurses and other providers. They also have the appropriate mix of nurses and other providers on the interdisciplinary team to have the right provider in the home at the right time with the right skills.

One of the goals of hospice palliative care is to have the client/patient and family develop a therapeutic and trusting relationship with all members of the hospice palliative care team, and that is reflected in staffing plans. For example, to support that therapeutic relationship, organizations consider: assigning a primary nurse responsible for the client's/patient's end-of-life care, and working with all nursing staff and other providers on the team to ensure continuity and consistency of care. This will lead to an increase in client/patient and family satisfaction and confidence.

Jurisdictions and organizations provide enough nursing hours to meet the client/patient's hospice palliative care needs. Clients/patients should not have to be admitted to alternate care settings because of lack of nursing services or skills in the community or because of limitations on nursing hours of care. Organizations' human resource plans include appropriate strategies to recruit, retain and deploy nurses as well as other members of the hospice palliative care team (e.g., healthy work environments, autonomous practice, opportunities for leadership).

7. Canadians are aware of the option of hospice palliative care, including skilled compassionate nursing care, at home.

According to a 2003 Ipsos-Reid poll, 75% of Canadians were familiar with hospice palliative care and 25% of those surveyed reported that they or someone in their family had used hospice palliative care services. These results indicate that Canadians are becoming more aware of hospice palliative care services. As jurisdictions develop their palliative home care services, it is important for them to educate their citizens about the availability of these services and supports – including nursing care – so that more people will consider them as a viable end-of-life choice.

8. Jurisdictions continually monitor palliative home care services, and support nursing research to improve quality of care.

Jurisdictions establish performance indicators and other measures to assess the quality and effectiveness of their palliative home care services as well as systems to support data collection and analysis. They continually monitor and evaluate palliative home care services to determine how well they are meeting clients/patients' and families' needs, and make changes as required to provide high quality end-of-life care. Jurisdictions support both qualitative and quantitative research to improve nursing and other services in palliative home care.