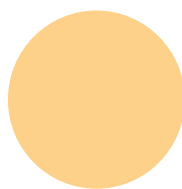
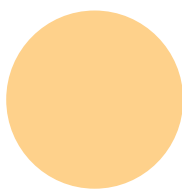
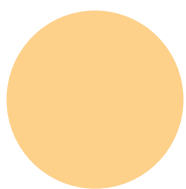


The Pan-Canadian Gold Standard for Palliative Home Care

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 Personal Care in Hospice Palliative and End-of-Life Care at Home

People who choose to die at home have a range of end-of-life needs. In addition to medical care, nursing care, pain management and psychosocial care, they may need:

- help with personal care, such as dressing, bathing, and eating
- help moving about the home
- comfort measures, such as massage or skin care
- help managing the equipment involved in their care (e.g., oxygen)
- assistance with food preparation and homemaking.

Clients/patients receiving hospice palliative care at home also need people with them who can notice and report any changes in their health to the health professionals on the hospice palliative care team. A great deal of this personal care is provided by family members, who may also have other family, home and work responsibilities.

Definitions

Personal Care – assistance with activities of daily living which may include help with dressing, bathing, grooming, feeding, toileting, mobilization and transferring.

Homemaking Service – essential housekeeping tasks necessary to enable the individual to remain at home in a safe and acceptable environment; may include cleaning, laundry, meal preparation, shopping, banking and transportation.

Home Support Services – personal care, homemaking services and/or respite to enable the individual to remain at home in a safe and acceptable environment.

Home care programs that provide hospice palliative care have a responsibility to help clients/patients and families with daily living, personal care and home management activities. This type of practical support is usually provided by personal care workers.¹⁰ Their role on the palliative home care team is to assist with activities that clients would be able to do themselves if they were well, and to provide some respite for family members. Their services are indispensable. Personal care workers play an integral role in end-of-life care, helping to enhance the client's/patient's and family's quality of life throughout the advanced illness, the process of dying, the last days of living, the event of death, and bereavement. Of all the members of the hospice palliative care team, they spend the most time in the home and have the greatest contact with the client/patient and family.

Role of Personal Care Workers in Palliative Home Care

- assist with the routine activities of care within the agreed-upon plan of care.
- work as a member of a team, observing and reporting their findings
- provide a range of services, including:
 - personal care, such as assisting with clothing, hygiene, mobility, eating and other routine activities of living
 - mouth care and skin care
 - comfort measures for clients experiencing pain or having respiratory problems
 - help managing equipment
 - help with moving about the home/transfers
 - home management, such as shopping, house cleaning and meal preparation/nutrition
 - assisting with other home/family responsibilities, such as routine child care

¹⁰ Generic term used in this document to reflect the unregulated home health care worker also known across Canada as Personal Care Attendant, Personal Support Aide, Home Support Aide, Home Care Attendant, Health Care Aide, Home Support Worker, Personal Support Worker

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At the current time, education requirements for personal care workers vary across the country, as do the expectations/scope of practice for people working in that role. As jurisdictions move to establish and/or strengthen their palliative home care programs, personal care must be recognized as an essential component of high quality hospice palliative care at home.

The pan-Canadian Gold Standard for Personal Care in Hospice Palliative and End-of- Life at Home sets out the expectations for personal care as part of a comprehensive palliative home care program. It is based on the Norms of Practice for Hospice Palliative Care¹¹ and on the Canadian Hospice Palliative Care Association Training Manual for Home Support Workers (2006). It recognizes that knowledgeable and competent personal care workers make a significant contribution to the palliative home care team.

1. Canadians receiving palliative home care have access to personal care 24 hours a day, seven days a week when needed.

People dying at home and their families have access to compassionate and skilled personal care services 24 hours a day, seven days a week, as required. Personal care workers focus on assisting clients/patients with activities of daily living as well as providing comfort measures that help enhance living and dying. The goal is to support and comfort the client/patient and the family. The resources allocated for palliative home care allow personal care workers trained in hospice palliative care to be available to the client and family around the clock, if necessary, in the more intense stages as death approaches.

When individuals do not have family members who are able to assist with their personal care needs (i.e., family member themselves are elderly or infirm) or when the family is not able to cope with impending death, the need for the services of personal care workers will be greater.

2. Families have access to flexible respite services that meet their needs as well as the needs of the client/patient.

The responsibility of caring for a family member dying at home can be exhausting and overwhelming. In addition to helping the dying client/patient, personal care workers also provide services that give family members some respite from their caregiving responsibilities and provide the support they need to be able to keep the dying client/patient at home. The number of hours of personal care allocated to the client takes into account both the client's/patient's personal care needs and the family's need for respite.

Organizations have in place the protocols and procedures to be able to safely delegate responsibilities to personal care workers to support respite services for families, such as giving medication.

3. Personal care workers providing services for people who are dying and their families have the knowledge, competencies, and judgment to provide high quality care at end of life.

Home care organizations use a selection process to identify personal care workers who are comfortable working with clients/patients who are dying and their families. Personal care workers who choose to work in palliative home care receive consistent core education in hospice palliative and end-of-life care.

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¹¹ Canadian Hospice Palliative Care Association, 2002 A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice. See also Nursing Gold Standard.

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To ensure personal care workers have the knowledge, skills and judgment to provide care at end-of-life, they receive – in addition to their regular training in personal care – specialized training in infection prevention and control, the nature of hospice palliative care, their organization’s approach to hospice palliative care, observation skills, how to make the client/patient more comfortable, how to communicate with clients, how to work with and communicate with family members, how to ease the anxiety that clients and families may experience related to some of the symptoms of dying (e.g., loss of appetite, respiratory problems), and the impact of culture on end-of-life needs.

Organizations employing personal care workers ensure that they have access to continuing education and training in hospice palliative care and in self-care in order to maintain and enhance their competency. Jurisdictions explore the potential of using technology to make education programs more accessible. Distance education programs are available for personal care workers in rural and remote areas.

4. Personal care workers are members of a hospice palliative care team that works collaboratively to provide comprehensive support for the client/patient and his/her family.

Personal care workers are part of the hospice palliative care team, and work closely with other team members – including the client/patient, family members, nurses, the family physician, the social worker, therapists, spiritual care providers, personal care providers, the pharmacist, volunteers and others – to ensure that the client/patient and family receive effective and high quality personal care throughout the 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 meet the client’s/patient’s and family’s needs, and ensure continuity of care.¹²

Home care programs establish consistent effective ways for personal care workers to communicate with other members of the team (e.g., charting on the interdisciplinary client/patient record, log books, team meetings, phone reports). Personal care workers know who they are to contact and what steps to take if there is a change in the client’s/patient’s or family’s situation.

5. Personal care workers have timely access to support and supervision.

All personal care workers in all settings (i.e., northern, rural, urban), have timely access to clinical support from an expert in hospice palliative care. They also have access to appropriate information and resources. When personal care workers are providing care to children who are dying, they have access to experts in 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.

Unlike other members of the hospice palliative care team, personal care workers are not members of a self-regulating profession, and the employing organization is responsible for providing timely appropriate supervision.

Personal care workers providing hospice palliative care are valued and encouraged to seek guidance and support in order to report observations and concerns or to receive instructions. Personal care workers who are new to hospice palliative care receive mentoring. They have the opportunity to debrief after a client’s/patient’s death, and receive support in their own grieving process.

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¹² <http://www.eicp-acis.ca/en/>.

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6. Personal care workers provide client centred end-of-life care that respects the client's and family's culture and personal beliefs.

Personal care workers receive the information, training and support they need to provide end-of-life care that is sensitive to diversity in culture, religion and sexuality. As the team member who will spend the most time in the client's/patient's home, personal care workers are aware of the client's/family's customs and beliefs, and are sensitive to different attitudes, expectations, rituals, and desires around dying and death.

7. Home care organizations establish human resource plans that ensure continuity of care and availability of personal care workers.

The development of a therapeutic and trusting relationship between the client/family and members of the hospice palliative care team is essential to quality hospice palliative care. Because the personal care worker spends more time with the client and family than other members of the hospice palliative care team, the relationship between the personal care worker(s) and the client/patient is one of the most important. To help clients/patients families and personal care workers develop therapeutic, trusting relationships, home care organizations ensure continuity of care and consistency of staff when assigning personal care workers.

To ensure high quality hospice palliative care, home care organizations have an adequate number of personal care workers with the appropriate skills and attitudes. They also have an adequate number of supervisors and access to hospice palliative care experts to provide support for the personal care workers.

Jurisdictions and organizations provide enough personal care hours to meet the client's/patient's personal care needs and the family's respite needs. Clients/patients should not have to be admitted to alternate care settings because of lack of personal care workers or limitations on hours of personal care.

Organizations' human resource plans include appropriate strategies to recruit, retain and deploy personal care workers for hospice palliative care (e.g., competitive compensation, healthy work environments, continuing education, opportunities for career development).

8. Canadians are knowledgeable about the personal care services that are part of palliative home care.

As jurisdictions develop their palliative home care services, they educate their citizens about the personal care services available through provincially/territorially funded home care programs as well as the role of the personal care worker, so more people will consider palliative home care as a viable end-of-life choice. Jurisdictions use a range of communication strategies to educate the public, including providing information to primary care providers.

9. Jurisdictions continually monitor palliative home care services and support research to understand the impact of personal care services on the end-of-life experience.

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 ensure they are meeting clients'/patients' and families' needs, and make changes as required in order to provide high quality end-of-life care. Jurisdictions support both qualitative and quantitative research to improve personal care at end of life and to support personal care workers. They also take into account international research on the role of personal care workers and the impact of personal care on hospice palliative care outcomes.