

# The Pan-Canadian Gold Standard for Palliative Home Care

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

December 2006



Canadian Hospice Palliative Care Association  
Association canadienne de soins palliatifs



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

# The Pan-Canadian Gold Standard for Palliative Home Care

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

Production of this document has been made possible, in part, due to the support and collaboration of the following organizations: Canadian Home Care Association; Purdue Pharma.; and *Canada's Research-Based Pharmaceutical Companies (Rx&D)*

### Reproduction

Permission to reproduce and distribute this document for non-commercial educational purposes is granted when the attribution statement is displayed (as below). For any other uses, please contact the national office of the Canadian Hospice Palliative Care Association.

### Attribution/Citation Statement

Canadian Hospice Palliative Care Association. The Pan-Canadian Gold Standard for Palliative Home Care: Towards Equitable Access to High Quality Hospice Palliative and End-of-Life Care at Home. Ottawa, ON: Canadian Hospice Palliative Care Association, 2006.

Copyright © 2006, Canadian Hospice Palliative Care Association. All Rights Reserved.

# Table of Contents

Introduction.....	2
1. The Gold Standard for Case Management for Hospice Palliative and End of Life Care at Home .....	4
2. The Gold Standard for Nursing in Hospice Palliative and End of Life Care at Home .....	8
3. The Gold Standard for Palliative-Specific Pharmaceuticals in Hospice Palliative and End-of-Life Care at Home.....	11
Table 1: Minimum List of Palliative-Specific Pharmaceuticals .....	14
Table 2: Minimum List of Medical Supplies and Equipment .....	16
4. The Gold Standard for Personal Care in Hospice Palliative and End-of-Life Care at Home.....	17

# Introduction

## The Need

Most Canadians with life-threatening illnesses would prefer to die at home surrounded by family and friends, yet about 75% of deaths in Canada still occur in hospital or long-term facilities<sup>1</sup>. The gap between Canadians' preference and current practice in the health care system is due to a number of factors, including lack of awareness of hospice palliative care services<sup>2</sup> available to people in their homes and the wide variation in the type of hospice palliative care services provided by home care organizations in different jurisdictions.

**Our goal is to ensure all Canadians have equitable access to high quality end-of-life care at home.**

To develop the gold standards, the two associations consulted with experts in hospice palliative care, experts in home care, and a wide range of professionals who would be part of hospice palliative care teams, including physicians, nurses, pharmacists, personal care workers, social workers, case managers and home care administrators. Draft standards were reviewed by individuals across Canada with appropriate knowledge and expertise, and revised based on their feedback.

## The Commitment

In 2004, in the 10-Year Plan to Strengthen Health Care, governments recognized the need for hospice palliative care services in the home. In that plan, the federal, provincial and territorial First Ministers made a commitment to "provide first dollar coverage by 2006 for certain home care services ... [including] case management, nursing, palliative-specific pharmaceuticals and personal care at the end of life."<sup>3</sup>

The gold standards provide the benchmarks for high quality hospice palliative care at home. They are based on the National Principles and Norms of Practice for hospice palliative care, developed by hospice palliative care providers, organizations and consumers through a consensus building process led by the Canadian Hospice Palliative Care Association.<sup>4</sup>

## Why a Gold Standard?

To support provincial and territorial government efforts to fulfill their commitment, the Canadian Hospice Palliative Care Association in partnership with the Canadian Home Care Association has defined the "gold standard" for each of the four home care services to be funded by government: case management, nursing, palliative-specific pharmaceuticals and personal care at the end of life.

The gold standards establish the ideal level of care and support that all jurisdictions should strive to provide for people receiving hospice palliative care at home. They are designed to encourage and support a consistent approach across the country to hospice palliative care services at home.

<sup>1</sup> Carstairs. Quality End-Of-Life Care: The Right of Every Canadian. Final Report to the Senate. June 2000.

<sup>2</sup> This paper refers to hospice palliative care services and palliative home care services. The language used in the 2004 10-Year Plan to Strengthen Health Care refers to palliative home care; however the preferred term in the field is hospice palliative care.

<sup>3</sup> 10-Year Plan to Strengthen Health Care, Government of Canada, 2004, [http://www.hc-sc.gc.ca/hcs-sss/delivery-presentation/fptcollab/2004-fmm-rpm/index\\_ehtml](http://www.hc-sc.gc.ca/hcs-sss/delivery-presentation/fptcollab/2004-fmm-rpm/index_ehtml)

<sup>4</sup> Ferris FD et al. A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice. Canadian Hospice Palliative Care Association. March 2002.

# Introduction

## A Call to Action

The gold standards set out the desired practice and the vision for excellence for hospice palliative care at home. As government policy makers, home care leaders and clinicians implement the 10-Year Health Plan, we encourage them to use these gold standards to ensure their citizens have access to comprehensive high quality hospice palliative care at home. To achieve these standards, we recommend that all jurisdictions:

- Adopt strategies that will give their citizens timely access (i.e., 24 hours a day, seven days a week) to hospice palliative care at home – including appropriate pharmaceuticals and equipment – so they feel confident that they can choose to die at home
- Establish interdisciplinary hospice palliative care teams that make effective use of the skills of each member to support clients/patients and families/caregivers
- Support ongoing hospice palliative care education for members of the health care team and family caregivers
- Invest in home care case management and information systems that support the interdisciplinary teams and provide information that can be used to evaluate home care services at end of life
- Support ongoing research into best practices for hospice palliative care at home, including the cultural, ethical and spiritual aspects of care.

We recognize that provinces and territories are at different stages in developing home care services for clients and families requiring hospice palliative care. Some may already be delivering gold standard care; others may still be working to define or refine their services. While the gold standards encourage consistency, they do not imply uniformity. Jurisdictions may differ in the policies, procedures, strategies and staffing models they use to provide home care; however, their goal should be the same – to provide home care services that meets the gold standard in hospice palliative care in order to relieve suffering and improve the quality of living and dying for people at the end of life.

## Next Steps

Over the next few months, the hospice palliative care community will be contacting the federal, provincial and territorial governments to offer advice and support, and to ensure actions are taken to improve the availability, quality and consistency of hospice palliative care at home. In a year's time, we will publish a report on the progress made across Canada in providing end-of-life care at home.

# The Gold Standard for Case Management for Hospice Palliative and End-of-Life Care at Home

Palliative home care is provided by a number of different professionals, volunteers and family members who work together as a team to meet the client's physical, psychological, emotional, social, spiritual, practical, end-of-life care and grief needs as well as the family's needs. Team members collaborate to provide comprehensive, coordinated, compassionate care that can 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.

**Case management is “a collaborative client-driven strategy for the provision of quality health and support services through the effective and efficient use of resources in order to support the client’s achievement of goals.”**

**Canadian Home Care Association (CHCA)**

Team members work effectively together to coordinate care for the client/patient and family, and ensure they have access to the services they need when they need them. Effective case management strategies help link the client/patient, family and palliative home care team with other health and social services in the community, such as hospital services, hospice care, legal advice, and mental health services. Case management includes identifying and understanding the client/patient's and family's needs, communicating clearly with the client/patient, family and other service providers, identifying and coordinating

services for the client and family, educating clients/patients, families and other service providers about the services available, and advocating on behalf of the client/patient and family for timely access to services to meet their needs. It also includes making the most effective use of resources for the client and family, and for the health care system.<sup>5</sup>

Effective case management is an essential part of the care provided for all home care clients, but it is particularly important for people receiving palliative home care because:

- their health and needs may change often and suddenly
- their family is likely to have intense psychological, spiritual and practical needs.

Case management is part of the scope of practice of all health professionals. Organizations providing palliative home care may take a range of approaches to managing and coordinating care. Some will have designated or specialized case managers, whose only role is to provide case management services. Some will assign the case management responsibilities to one member of the palliative home care team, such as a nurse, social worker or personal care worker. In some cases, all members of the team are responsible for implementing case management strategies.

Regardless of how home care organizations provide case management, they should strive to meet the pan-Canadian Gold Standard for Case Management in Palliative Home Care, which is based on the Norms of Practice for Hospice Palliative Care in Canada.<sup>6</sup>

<sup>5</sup> Canadian Home Care Association, 2005, Case Management: A Strategy for Health Systems Integration

<sup>6</sup> 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.

# The Gold Standard for Case Management for Hospice Palliative and End-of-Life Care at Home

## 1. Home care organizations have a timely responsive process for designating clients/patients who need hospice palliative care.

Some clients will be referred to home care for hospice palliative care; others will develop hospice palliative care needs in the course of receiving home care. Home care organizations have the clinical skills to determine when clients with complex illnesses (e.g., Alzheimers Disease, multiple sclerosis, renal disease) require hospice palliative care.

Eligibility for palliative home care is not based solely on an arbitrary time limit (e.g., six months from death), but on the client's need for hospice palliative care. Even clients in the early phases of a life-threatening illness who are receiving curative treatment may benefit from hospice palliative care services, such as pain and symptom management and comfort care. Hospice palliative care is appropriate for clients whose goals include reducing suffering and improving or maintaining quality of living and dying. As their illness progresses, the clients' need for hospice palliative care will tend to increase, while interventions aimed at cure will decrease.

To ensure that clients who need and would benefit from palliative home care services receive them, organizations have a process to assess where a client is in the illness trajectory and to match services to client needs.

## 2. Clients/patients and their families have access to timely, knowledgeable, compassionate case management, 24 hours a day, seven days a week.

All clients/patients nearing end of life, regardless of diagnosis, race, religion, culture or sexual orientation have access to timely compassionate case management, 24 hours a day, seven days a week. Case management services are designed to address a client's or family's urgent needs as they arise, avoid inappropriate use of emergency and acute care facilities, and keep the client/patient at home as long as possible.

Home care staff work with the larger hospice palliative care team to help clients and families access the right service at the right time depending on their hospice palliative care needs. The mix of providers on the team is based on the client's needs and care plan. The team includes or has access to an on-call physician experienced in hospice palliative care who can adjust orders and medications to meet client needs.

Clients/patients and their families are informed about the range of services and resources – including spiritual and cultural supports – available in the community and how to access them (i.e., either directly or through the hospice palliative care team). They also know who to contact on the care team or at the home care organization with any questions or requests for services.

Jurisdictions explore the use of innovative approaches to provide equitable access to hospice palliative care case management in their regions, such as tele-homecare or using the expertise of other services in the community (e.g., social workers, on-call physicians).

## 3. Home care organizations that provide palliative home care services establish and maintain partnerships with other service providers required for effective case management.

Home care organizations are knowledgeable about the other services in their community, including spiritual and cultural services, and how they can be used to help palliative home care clients and their families.

Because the needs of someone who is dying at home can change suddenly, the home care program has in place the partnerships, protocols and mechanisms to support timely referrals to key services, such as hospitals, residential hospice programs and respite programs. It is particularly important to have established agreements in place for clients/patients with complex needs (e.g., renal disease, Alzheimers Disease) and those whose needs can no longer be met at home.

The home care team has access to advice and support from hospice palliative care specialists as needed.



# The Gold Standard for Case Management for Hospice Palliative and End-of-Life Care at Home

## **4. Home care providers identify effective case management strategies that reflect the client's/patient's needs and the family's needs and respect diverse cultural beliefs.**

Assessment of client and family needs is key to effective case management. Each client's disease management, physical, psychological, social, spiritual, practical, end-of-life and grief needs are identified initially and throughout the time they are receiving palliative home care – as are the family's physical, psychological, social, spiritual, practical and grief needs. Any cultural needs or expectations are also identified.

The needs assessment is used to guide case management and the process of providing care (see Figure 1: The Square of Care) both within the home care program and with other health and social services. Case management strategies are identified based on the client's goals of care.

The home care organization uses a standard needs assessment process and procedures, which include the events or situations that trigger a reassessment.

## **5. Case management is provided by professionals who have appropriate knowledge and skills.**

Palliative home care case management is provided by knowledgeable professionals who have: strong communication skills, advocacy skills, problem-solving skills, negotiation skills, interpersonal skills, cultural competency and experience. The professionals providing case management are also knowledgeable about the health care services in their community and the needs of people nearing end-of-life at home and their families.

To ensure that providers responsible for case management have the knowledge, skills and judgment to support the hospice palliative client and his or her family and to integrate services, the home care organization provides appropriate ongoing interprofessional education and training in hospice palliative care, case management and cultural competency, including distance education for those working in rural and remote areas. The home care organization also provides appropriate support and supervision, including a focus on care for the caregivers.

## **6. Members of the care team have the information systems and communication tools to support collaborative practice and effective case management/continuity of care.**

Communication among all members of the hospice palliative care team – including the client's family physician – is essential to collaborative practice and effective case management. The home care organization develops and maintains information systems and other tools to support effective case management, including assessment protocols, care plans, a common or interdisciplinary client/patient chart, case conferences, regular meetings with the family, service agreements and other mechanisms as required. Providers develop and use evidence-informed case management strategies that make optimal use of the skills and competencies of all providers and community services, and support continuity of care.

## **7. Canadians are aware of hospice palliative care options available to them, including palliative home care.**

As jurisdictions develop their palliative home care services, they educate their citizens about the services and supports provided through federally and provincially funded palliative home care programs. Case managers inform individuals and families of the full range of options, services and supports available to meet their needs so more people consider palliative home care as a viable end-of-life choice.



# The Gold Standard for Case Management for Hospice Palliative and End-of-Life Care at Home

## **8. Home care organizations in partnership with other parts of the health system track services available in their communities for people receiving end-of-life care at home, identify gaps and work collaboratively to meet needs.**

Home care organizations are in a strong position to identify the services required to support people who choose to die at home as well as their families, and to identify gaps in service in the community. In their role in hospice palliative care case management, they have a responsibility to track, evaluate and plan for services, and to work with other providers to develop a continuum of hospice palliative care services for their communities.

## **9. Jurisdictions monitor the quality and effectiveness of hospice palliative care case management strategies.**

As part of program evaluation and strategic planning, jurisdictions consistently assess the quality and impact of hospice palliative care case management strategies, using both quantitative and qualitative tools. Home care organizations use this information to refine and improve case management at end-of-life. This information is also used to determine how home care contributes to achieving system goals for hospice palliative care.

Jurisdictions consistently support research that leads to innovation in hospice palliative care case management and improves client and family outcomes.

# 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 Canada<sup>7</sup> as well as hospice palliative care nursing standards<sup>8</sup>. 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.

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

<sup>8</sup> Hospice Palliative Care Nursing Standards of Practice. Canadian Hospice Palliative Care Association, 2002.

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

## 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.<sup>9</sup>

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).

.....  
<sup>9</sup> Enhancing Interdisciplinary Collaboration in Primary Health Care Initiative .

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

## 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.

# The Gold Standard for Palliative-Specific Pharmaceuticals in Hospice Palliative and End-of-Life Care at Home

At the end of life, Canadians need timely access to medications to manage symptoms and pain. One of the main reasons that people are hospitalized in the last few weeks or months of life is the need for effective pain and symptom management. In some cases, the issue is financial: pharmaceuticals are paid for in the hospital and there is no financial burden for the family. In some cases the issue is access: certain drugs required for hospice palliative care may not be available through existing provincial drug formularies. In some cases, the issue is coordination of care: people dying at home need timely access to professionals who can adjust their medications and ensure pharmaceuticals are used appropriately.

The Gold Standard for Palliative-Specific Pharmaceuticals in Hospice Palliative and End-of-Life Care at Home sets out the mechanisms and services that must be in place to ensure high quality pain and symptom management for people who choose to die at home.

## **1. Canadians receiving palliative home care have access to the full range of prescription and over-the-counter pharmaceuticals required for pain and symptom management and comfort care at the end of life.**

People who have been assessed as being palliative and who are receiving home care have the same access to pharmaceuticals for hospice palliative and end-of-life care as people receiving hospice palliative care in an acute care hospital.

Provinces and territories are currently using three mechanisms to give people receiving palliative home care access to appropriate pharmaceuticals: access to the province's drug formulary, access to a specific palliative care formulary or list, or access to the province's drug formulary plus a supplementary palliative care drug list. The reason for a supplementary palliative care list is to ensure people have access to some over-the-counter medications or other drugs that are not included in provincial drug formularies.

The gold standard for pharmaceuticals in palliative home care is access to the full provincial formulary (provided the formulary is comprehensive) PLUS any additional prescription drugs and

over-the-counter medications required for end-of-life care. At a minimum, people receiving hospice palliative care at home should have access to the prescription and over-the counter pharmaceuticals listed in Table 1.

The formulary and/or palliative care drug list should be reviewed regularly to ensure it reflects clients'/patients' pharmaceutical needs, and jurisdictions should have a timely mechanism to add medications to the formulary or list based on evidence of their efficacy. Provinces and territories should also implement a mechanism for review and approval of access to case specific drugs.

## **2. Providers have a timely mechanism to access pharmaceuticals for palliative home care that are not on provincial formularies or palliative care drug lists.**

Individuals receiving palliative home care may require pharmaceuticals that are not on the approved formulary or a drug for a use that is not covered on the formulary (i.e., off-label use). In these cases, providers have access to a mechanism to apply to the provincial/territorial drug program for approval to cover the cost of the drug. The application process is fast and easy, and providers receive a timely response.

Requests for medications not on the formulary or palliative drug list are evidence based and consistent with current best practice in hospice palliative care. Part of the authorization for off-label use includes the requirement for evaluation, which is then used to determine whether the medication or use should be added to the formulary.

## **3. Canadians receiving palliative home care have access to the supplies and equipment required for their care.**

All jurisdictions provide access to the medical supplies and equipment – as well as maintenance and repairs – required to administer pharmaceuticals, manage pain and symptoms, and provide comfort care at end of life. At a minimum, people receiving palliative home care have access to the supplies and equipment listed in Table 2.

# The Gold Standard for Palliative-Specific Pharmaceuticals in Hospice Palliative and End-of-Life Care at Home

Providers are able to access supplies, equipment and repairs seven days a week, and obtain emergency access when required. Wherever possible, there is a system in place to deliver equipment and supplies to the home.

## **4. Eligibility for pharmaceuticals for hospice palliative care at home is based on the person's need for end-of-life care.**

The length of time that people require hospice palliative care can vary considerably, so eligibility for pharmaceuticals for hospice palliative care at home is not based solely on an arbitrary time limit (e.g., six months from death), but on the client's need for hospice palliative care (e.g., pain and symptom management, comfort care). Anyone whose care is aimed at improving or maintaining the quality of life at the end of life (rather than treatment or cure) is eligible for pharmaceuticals for hospice palliative care, regardless of age.

## **5. The process to apply/register for pharmaceuticals for palliative home care is timely and responsive.**

All jurisdictions have a mechanism in place for people to apply for coverage for hospice palliative care medications. The time it takes for applications to be approved may vary, but all jurisdictions work to ensure that the process is timely, responsive, and sensitive to urgent needs at end of life.

Once approved, coverage is backdated to the date of application or the date the client/patient was assessed as requiring hospice palliative care. Jurisdictions also have a timely efficient process to reimburse clients/patients and families for any drug costs incurred between the time they became eligible and the time their application was approved.

## **6. All jurisdictions will provide 100% first dollar coverage for pharmaceuticals required during hospice palliative and end-of-life care.**

All jurisdictions will provide 100% first dollar coverage for pharmaceuticals required during hospice palliative and end-of-life care as stated in the 2004 Health Accord. They also

establish payment mechanisms that ensure prescription and over-the-counter medication and supply costs are billed directly to the drug plan and/or home care program so families do not have to pay and then claim for reimbursements.

Jurisdictions ensure that dispensing fees and other related costs for pharmaceuticals required for hospice palliative care do not create an unreasonable financial burden for the client/patient or family.

## **7. Palliative home care teams have timely access to knowledgeable pharmacists who can advise on the use of pharmaceuticals in hospice palliative and end-of-life care.**

Canadians who receive end-of-life care in an acute care hospital have access to the services of clinical pharmacists with expertise in the administration of hospice palliative care pharmaceuticals. The same level of care is available to people receiving palliative home care.

The hospice palliative care team includes a physician, nurse, psychosocial support and a clinical pharmacist with expertise in hospice palliative care. In addition, community pharmacists are required to have education on the use and management of pharmaceuticals in hospice palliative care. They are also linked with a clinical pharmacist on a hospice palliative care team who can provide support and advice. Jurisdictions work with the pharmacy profession to establish a consulting service with clinical pharmacists to support end-of-life care in the home.



# The Gold Standard for Palliative-Specific Pharmaceuticals in Hospice Palliative and End-of-Life Care at Home

## 8. All jurisdictions have policies on the distribution, storage, safe administration and disposing of pharmaceuticals used for hospice palliative care in the home.

Provincial governments work with the federal government and regulatory colleges to develop policies on handling, accessing, storing, safe administration and disposing of controlled drugs (e.g., opioids) used in end-of-life care at home.

Providers work with local pharmacies to ensure easy access (i.e., 24 hours a day, seven days a week) to pharmaceuticals for hospice palliative care, particularly opioids, close to people's homes. Medications that would normally be stored securely in a hospital are also stored securely in the home. This reduces the risk of injury or theft.

When drug storage in a client's/patient's home is an issue, this does not limit the client's/patient's access to appropriate pain management: providers are responsible for finding another way to manage pharmaceuticals.

Providers administering drugs have the training, equipment and support to ensure that medications are administered safely.

Providers also have policies and procedures for disposing of medications after the client's/patient's death.

## 9. Family members receive the education and ongoing support they need to handle, store and administer medications, to monitor equipment, and to recognize adverse reactions.

Family members play an active role in palliative home care and may be required to monitor symptoms, administer medication, recognize adverse reactions or monitor equipment. If that is the case, they receive appropriate training and education, as well as ongoing support to fulfill their role. Clients/patients and family members are also educated about proper handling and storage and, if required, safe administration of medications.

To ensure that families are not asked to take on inappropriate tasks related to pharmaceutical management, jurisdictions develop policies about the types of monitoring and care families can safely and appropriately provide. Home care providers are also able to assess family members' capacity to monitor a client/patient or administer medications. If the family member is not capable or interested, providers make other arrangements to support the client/patient at home.



# Table 1: Minimum List of Palliative-Specific Pharmaceuticals

## Analgesics

### Non-Opioid

- Acetaminophen
- Tramadol/acetaminophen

### NSAIDs

- Celecoxib
- Diclofenac
- Ibuprofen
- Ketorolac
- Meloxicam
- Naproxen

### Opioids

- Codeine products including acetaminophen combinations
- Fentanyl
- Hydromorphone – po, iv, sc
- Methadone – po, iv, sc
- Morphine – po, iv, sc
- Oxycodone
- Spinal/epidural opioids
- Sufentanil

### Misc Analgesics

- Flecainide
- Ketamine
- Lidocaine – infusion
- Mexilitene

### Anticoagulants

- Dalteparin sodium
- Tinzaparin
- Warfarin

### Coagulants – antifibrinolytic agents

- Tranexamic acid

### Anticonvulsants

- Carbamazepine
- Clobazam
- Gabapentin
- Lamotrigine
- Phenytoin
- Phenobarbital—oral and parenteral
- Pregabalin
- Topiramate
- Valproic acid

### Antidepressants

- Amitriptyline

- Bupropion
- Citalopram
- Desipramine
- Doxepin
- Fluoxetine
- Fluvoxamine
- Imipramine
- Mirtazapine
- Nortriptyline
- Paroxetine
- Sertraline
- Trazodone
- Venlafaxine

### Antidiarrheals

- Bismuth subsalicylate
- Diphenoxylate
- Loperamide
- Octreotide<sup>1</sup>

### Antiemetics

- Dimenhydrinate
- Prochlorperazine—po, supp, IM
- Domperidone
- Metoclopramide—po, parenteral
- Haloperidol—po, parenteral
- Dexamethasone—po, parenteral
- Promethazine
- Ondansetron
- Granisetron
- Marinol (ΔTHC)
- Nabilone
- Octreotide

### Antifungal (oral/vaginal preparations)

- Clotrimazole
- Fluconazole
- Nystatin
- Ketoconazole

### Antimicrobials

- All antimicrobials normally covered by provincial drug formularies

### Antipruritics

- Hydroxyzine
- Diphenhydramine

### Antipsychotics

- Chlorpromazine
- Haloperidol – po, sc

- Loxapine
- Methotrimeprazine
- Olanzapine
- Risperidone

### Antispasmodics

- Atropine
- Baclofen
- Benzotropine
- Dantrolene
- Hyoscyamine (Levsin)
- Scopolamine – parenteral, patch
- Dicyclomine (Bentylol)
- Scopolamine (Buscopan)
- Oxybutynin
- Phenazopyridine

### Antitussives

- Codeine syrup
- Hydrocodone-phenyltoloxamine
- Dextromethorphan

### Antivirals

- Acyclovir
- Famcyclovir
- Valacyclovir

### Anxiolytics/Hypnotics

- Alprazolam
- Clonazepam
- Diazepam – po, parenteral, supp
- Lorazepam – po, sl, parenteral
- Midazolam
- Oxazepam
- Phenobarbital – parental

### Bone Metabolism Regulators

- Pamidronate
- Clodronate
- Zoledronic acid

### CHF Therapy

- All **ACE inhibitors** that are normally covered by provincial drug formularies
- All **Beta blockers** that are normally covered by provincial drug formularies
- Carvedilol
- All **antianginals** that are normally covered by provincial drug formularies

.....

1. As a last resort only (e.g., currently covered for profuse diarrhea in advanced AIDS not responsive to multiple constipating agents).

# Table 1: Minimum List of Palliative-Specific Pharmaceuticals

## **Bronchodilators**

- All bronchodilators that are normally covered by provincial drug formularies
- All inhaled corticosteroids
- Aminophylline tablets
- Ipratropium bromide – inhalers and nebulas
- Salbutamol – inhalers and nebulas
- Salmeterol
- Tiotropium

## **CNS Stimulants**

- Dextroamphetamine
- Methamphetamine
- Methylphenidate

## **Diabetic Agents**

- Insulin
- Gliclazide
- Metformin
- Rosiglitazone
- Glyburide

## **Diuretics**

- Amiloride
- Ethacrynic acid
- Furosemide
- Hydrochlorothiazide
- Metolazone
- Spironolactone
- Triamterene

## **H2 Blockers and Proton Pump Inhibitors**

- Cimetidine
- Esomeprazole
- Lansoprazole
- Omeprazole
- Pantoprazole
- Ranitidine

## **Laxatives**

- Bisacodyl
- Docusate calcium
- Docusate sodium
- Fleet enema
- Glycerin supp

- Lactulose
- Magnesium citrate
- Magnesium hydroxide –MOM
- Miralax
- Microlax enema
- Sennosides
- Sennosides/Docusate sodium
- Sodium phosphate/sodium acid phosphate enema
- Sodium citrate/Sorbitol/Sodium lauryl sulfoacetate enema

## **Hemorrhoid Therapy – ointment and suppositories**

- Anusol, Anusol HC or equivalent preparations
- Framycetin
- Zinc sulfate with and without hydrocortisone

## **Steroids**

- Dexamethasone
- Prednisone
- All topical steroids normally covered by provincial drug formularies

## **Wound care**

- Flamazine cream
- Fucidin cream, ointment
- Topical metronidazole

## **Other**

- Ametop
- EMLA cream
- Bupivacaine HCL
- Glycopyrrolate
- Ropivacaine
- Lidocaine – injection, gel, ointment, spray
- Megestrol Acetate
- Oxygen
- Parenteral fluid replacements – iv, sc (e.g., normal saline, D5W, D5 1/2NS)
- Phlojel (for compounding)

## Table 2: Minimum List of Medical Supplies and Equipment

### Medical Supplies

#### **Routine Dressing Supplies**

- sterile dressing supplies
- bandages, including elastic and adhesive, and tape
- pressure dressings
- trays (disposable or re-usable)
- solutions and ointments
- medication and administration supplies
- needles, syringes, swabs
- proper disposal containers for needles and syringes

#### **Intravenous Therapy Supplies**

- hydration solutions: normal saline, 2/3 & 1/3, D5W
- mini-bags, tubing, catheters, syringes, needles, heparin locks and caps

#### **Urinary Catheter Care Supplies**

- urinary catheter equipment including drainage tubing, drainage bags, connectors, leg bag drainage set
- pleurx catheters
- catheterization tray
- disposable gloves (non-sterile)

#### **Incontinence Supplies**

- incontinence briefs, pads and diapers
- condom drainage sets
- disposable gloves (non-sterile)

#### **Diabetic Supplies**

#### **Ostomy Supplies**

#### **Oxygen – with tubing and masks**

#### **Wound Care Supplies**

- gloves
- sterile water for irrigation
- syringes for irrigation
- catheters as needed for irrigation
- occlusive films
- hydrocolloids
- alginates
- composite dressings
- foams
- non-adherent dressings
- specialty absorptives
- exudry tapes
- anti-microbial dressings
- dressing trays
- special dressing materials e.g. hydrocolloid, foam and other dressings

### Equipment

- hypodermoclysis equipment
- computerized ambulatory drug delivery (CADD) pump equipment, including cassettes and other approved pain control delivery technologies
- pressure relief mattresses, bed cradles, foam wedges (to elevate head), sheepskins, rubber sheets, sheepskin heel and elbow protectors
- over bed table, raised toilet seat, hair washing tray, transfer belt, trapeze bar
- mechanical lift
- commodes, transfer boards, bath seats, bath poles, wheelchair shower chair
- urinals, bed pans, kidney basins
- nebulizers
- walkers, canes, crutches, standard wheelchairs, wheelchair ramps
- electric hospital beds (where necessary)

# 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.<sup>10</sup> 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

<sup>10</sup> 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

# The Gold Standard for Personal Care in Hospice Palliative and End-of-Life Care at Home

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 Care<sup>11</sup> 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.

.....  
<sup>11</sup> 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.

# The Gold Standard for Personal Care in Hospice Palliative and End-of-Life Care at Home

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.<sup>12</sup>

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.

.....  
<sup>12</sup> <http://www.eicp-acis.ca/en/>.

# The Gold Standard for Personal Care in Hospice Palliative and End-of-Life Care at Home

## 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.