Hospice Palliative Home Care in Canada: A Progress Report

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Quality End-of-Life
Care Coalition of Canada
La Coalition pour des soins
de fin de vie de qualité de Canada

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Introduction

Most Canadians who are nearing end of life would prefer to die at home surrounded by family and friends. Yet almost 60% of Canadian deaths occur in a hospital. The gap between what Canadians want at the end of life and what they experience has been due, in part, to the variability in the hospice palliative care services provided at home in different jurisdictions.

In the 2004 10-Year Plan to Strengthen Health Care, 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".

In December 2006, the Canadian Hospice Palliative Care Association (CHPCA) in partnership with the Canadian Home Care Association (CHCA) published *The Pan-Canadian Gold Standard for Palliative Home Care*. The purpose of the document was to help jurisdictions develop high quality hospice palliative home care by defining best practices for each of the four hospice palliative home care services to be funded by government: case management, nursing, personal care and pharmaceuticals.

The Survey

The CHPCA also made a commitment to report on the progress in providing end-of-life care at home. To that end, the CHPCA took the issue to the Quality End-of-Life Care Coalition of Canada (QELCCC), a network of national organizations committed to quality end-of-life care for all Canadians. The QELCCC asked the federal, provincial and territorial governments to complete a survey based on the Pan-Canadian Gold Standard for Palliative Home Care (see Appendix A). Responses were received from 12 provinces and territories (Quebec did not participate) and one federal government program (Veterans Affairs Canada).

Data Limitations

The survey was sent to federal, provincial and territorial ministries of health. In some jurisdictions, the responsibility for some policies, procedures and service tracking has been devolved to regional health authorities. In jurisdictions with regional authorities, the provincial governments did not necessarily have the information to complete all survey questions. As a result, the survey responses and this report may not reflect the complete picture of hospice palliative home care in Canada.

About this Report

This report is a snapshot of hospice palliative home care services available to Canadians in 2008. The information refers only to hospice palliative care services provided in the home. Other settings where Canadians die – in hospital, long-term care homes and hospices, and on the street – are equally important but were not covered in this survey.

The QELCCC would like to thank the Canadian Hospice Palliative Care Association, Wyeth Canada and The GlaxoSmithKline Foundation for their support in developing this progress report.

Executive Summary

Over the past few years, jurisdictions across Canada have made some significant progress in improving access to hospice palliative home care services and the breadth of services available. Provincial and territorial governments have made considerable progress in improving access to pharmaceuticals, pharmacists, medical supplies and equipment. They also appear to have established processes that have made home care programs more effective in assessing and identifying people who would benefit from hospice palliative care, promoting a team-based approach to care, and improving case management services. Of the 12 provinces and territories and one federal government department that completed the QELCCC survey:

- all have a standard process to assess clients' hospice palliative care needs as well as eligibility criteria for hospice palliative home care
- all report that clients receiving hospice palliative home care and their families have access to advice from pharmacists
- 12 of 13 report covering the cost of some medical supplies and equipment or providing an equipment lending service, and educating the public about the hospice palliative care services available in their province or territory
- 11 of 13 provide coverage for a wide range of pharmaceuticals for people receiving end-of-life care at home; and the two that do not cover the cost of medications for hospice palliative home care are moving to do so
- 11 of 13 promote a team-based approach to care and eight of 13 provide some form of interprofessional education and training on hospice palliative care
- nine of 13 have policies on the distribution, storage, handling and disposal of pharmaceuticals administered in the home, and 11 of 13 educate families on how to administer medications and monitor equipment
- only four of 13 have explicit policies about ensuring access to case management, and six of 13 have policies about providing nursing and personal care services 24 hours a day, seven days a week; however, 11 of 13 have or are developing an information system to support case management, 10 of 13 report having methods in place to give people equitable access to case management services regardless of where they live in the jurisdiction, and six of 11 have protocols to ensure timely referrals
- seven of 13 support hospice palliative care research
- only four jurisdictions report tracking wait times for hospice palliative home care.

Most jurisdictions were not able to estimate what proportion of people dying at home have access to skilled nursing care, round-the-clock personal care or flexible respite care services; those that did provide estimates tended to report the proportion eligible for these services as opposed to those who actually were able to access them.

Table 1 summarizes the hospice palliative home care policies, procedures, programs and tools in place in different jurisdictions across Canada.

Table 1: Hospice Palliative Home Care in Canada at a Glance

Gold Standard	BC	AB	SK	MB	ON
Process to assess clients' hospice palliative care needs	X	X	X	X	X
Eligibility criteria for palliative home care	X	X	X	X	X
Tracking/managing wait times for palliative home care					X
Policies for 24/7 access to hospice palliative care case management services			X		X
Methods to ensure equitable access to case management services	X	X		X	X
Protocols to ensure timely referrals			X	X	X
Information systems/tools to support case management	X		X	X	X
Public education about hospice palliative care services	X	X	X	X	X
Policies for 24/7 access to nursing and personal care	X	X		X	X
% of people dying at home and families with access to: - nursing care - personal care - respite services	100% 100%			100% 100% 100%	100% 100% 100%
Policies to promote a team-based approach to care	X	X	X	X	
Interprofessional education and training		X		X	X
Support for research in palliative home care	X	X	X	X	X
Access to pharmaceuticals	X	X	X	X	X
Access to pharmacists	X	X	X	X	X
Policies on distribution, storage, handling, disposal of pharmaceuticals in the home	X	X	X	X	X
Education/advice for families on administering medications and monitoring equipment	X	X	X	X	X
Access to medical supplies and equipment	X	X	X	X	X

* Based on client needs and involves coordination of formal and informal supports

NB	NS	PE	NL	NU	NT	YT	VAC**
X	X	X	X	X	X	X	X
X	X	X	X	X	X	X	X
X				X		X	
X			X				
X	X	X		X		X	X
X		X		X	X		X
X	X	X	X	X		X	X
X	X	X	X	X		X	X
X	X						
100% 100% 100%		100% 100% 100%	80% 60% 80%	100%			100% 100% 100%
X		X	X	X		X	X
		X	X	X		X	X
X							X
X			X	X	X	X	X
X	X	X	X	X	X	X	X
X			X	X	X	X	n/a
X		X	X	X	X	X	X
X	X		X	X	X	X	X

**Veterans Affairs Canada

Executive Summary

Conclusions and Recommendations

While all jurisdictions have made progress and more Canadians are now able to receive hospice palliative home care, there is still much more to be done. Although many of the right policies and procedures are in place, the number of people who actually receive high quality hospice palliative home care services is still limited by lack of training – particularly for personal support workers, lack of resources, geography (i.e., people living in urban centres are more likely to receive comprehensive hospice palliative home care than those in rural or remote communities), and restrictive eligibility criteria.

To ensure that Canadians have access to "quality end-of-life care that allows them to die with dignity, free of pain, surrounded by their loved ones, in a setting of their choice" (as stated in the QELCCC Mission Statement) , provinces and territories should take the following steps to enhance hospice palliative home care and align their programs with the Gold Standard:

Case Management

1. Make consistent use of a valid assessment tool within and across provinces.
2. Ensure that eligibility for hospice palliative home care is based on need and not on an arbitrary time limit.
3. Ensure clients and families are referred to hospice palliative home care in a timely manner, maintain records of wait lists and times, and use this information to plan/fund services.
4. Gather information on the number of Canadians receiving hospice palliative care or dying in hospitals, long-term care homes, respite beds and other settings whose needs could have been met through hospice palliative home care.
5. Continue to develop active outreach programs to educate the public and providers about hospice palliative home care, rather than relying on passive strategies such as web sites.

Nursing Care/Personal Care

6. Identify creative and effective ways to ensure that Canadians dying at home and their families have access to case management, nursing and personal support service 24 hours a day, seven days a week.
7. Ensure that all members of the hospice palliative home care team receive appropriate ongoing education and training, and have access to support from specialized hospice palliative care teams.

Pharmaceuticals

8. Work with schools of pharmacy and pharmacy associations and colleges to develop education programs for pharmacists who provide consulting services for hospice palliative home care.
9. Ensure that all Canadians receiving hospice 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 end-of-life.
10. Ensure that access to pharmaceuticals for hospice palliative home care is based on need and not restricted by arbitrarily imposed time limits or cumbersome processes for requesting drugs or uses not covered by provincial/territorial formularies.

Despite the advances that have been made, at best, no more than 37% of Canadians who are dying have access to adequate hospice palliative care. There is still an urgent need to make sure that all Canadians dying at home have access to high quality hospice palliative home care services consistent with the Gold Standard.

At the provincial level, there is also an urgent need to develop high quality hospice palliative care services in other settings where Canadians die, including in hospital, long-term care homes and hospices, and on the street. These settings must be fully integrated, to allow for better efficiency in working together.

At the federal level, the same high quality hospice palliative home care now provided by Veterans Affairs for veterans should be extended to Aboriginal/indigenous communities across the country, as well as all other populations whose health care is under the overview of the federal government.

About the Quality End-of-Life Care Coalition of Canada (QELCCC)

The QELCCC is a network of 30 national organizations that believe all Canadians have the right to quality end-of-life care that allows them to die with dignity, free of pain, surrounded by their loved ones, in a setting of their choice. QELCCC members believe that achieving quality end-of-life care for all Canadians requires a collaborative, well-funded and sustainable national strategy for hospice palliative and end-of-life care. We must work together in partnership to achieve this goal. The QELCCC advocates for quality end-of-life care for all Canadians.

Some of its accomplishments include: preparing and submitting a brief for the Romanow Commission on the Future of Health Care in Canada (2002), producing *Dying for Care* – a status report on end-of-life care in Canada (2004), and advocating for changes to the Compassionate Care Benefits, resulting in expanded eligibility for the benefit (2006). For more information about the QELCCC, please visit www.qelccc.ca.

Accessing Hospice Palliative Home Care

Care at end-of-life is complex. When people are dying, their needs can change suddenly, and they and their family will have intense medical, psychological, spiritual and practical needs. To ensure that people are able to access the comprehensive, coordinated, compassionate care that can enhance quality of life, home care programs must be able to assess clients, identify those who would benefit from hospice palliative home care, and then provide appropriate services.

Are clients assessed to determine their hospice palliative care needs?

Yes. All the jurisdictions that completed the survey reported having a standard process that home care organizations use to assess whether clients need hospice palliative home care and to identify any changes in their health that would trigger a reassessment.

Some jurisdictions are using or implementing specific assessment tools. BC, Alberta, Ontario and the Yukon are using the InterRAI Home Care (HC) assessment tool. As the Yukon reports, "For clients who are already on the home care programs and whose needs require palliative care, the RAI-HC is used for ongoing assessment. This tool has the CHESS [Changes in Health, End-stage disease and Symptoms and Signs] scale embedded into it as well as an ADL [activities of daily living] measurement tool. It also tracks issues, such as pain, and supports the clinician's judgement in referring [clients] for more intense assessments as indicated. For clients referred to [hospice] palliative [home] care, the shorter Edmonton Symptom Assessment Scale (ESAS) assessment tool is used to assist in assessing pain and other symptoms."

Ontario's Community Care Access Centres (CCACs) are in the process of implementing a new Client Intake Assessment Tool (CIAT), which will be used to assess all adult clients and includes the InterRAI Contact Assessment Tool. In a recent survey, CCACs identified a palliative care assessment tool as a priority, and a number of are piloting the InterRAI Palliative Care tool.

Manitoba, PEI and some Ontario CCACs use the ESAS to assess a client's physical pain and emotional suffering and symptoms, and the Palliative Performance Scale (PPS) to assess the person's physical status. As PEI reports, "The PPS provides a framework for measuring progressive decline over the course of illness. The PPS is completed with every nursing visit to every [palliative care] client." Ontario notes that the ESAS "provides clinical information about the severity of symptoms over time … [and] the context within which symptoms can begin to be understood but is not a complete assessment tool in itself." Newfoundland and Labrador use the PPS and the Palliative Prognostic Index (PPI) to help determine whether someone is eligible for hospice palliative home care. New Brunswick uses provincial guidelines for its extra-mural palliative care services.

> New Brunswick, in consultation with front-line service providers, developed Palliative Care Guidelines for all its Extra Mural Programs (i.e., home care programs).

Using one or two specific tools ensures greater consistency in the way clients are assessed across the province. However, BC also noted that each regional health authority may also use other valid clinical tools to assess and reassess client needs (e.g., the Palliative Performance Scale).

In Saskatchewan, Nova Scotia and Nunavut, clients who are receiving hospice palliative home care are continually reassessed based on their condition, and reassessments are often triggered when someone – the client, a family member or a member of the care team – notices a change.

Although Veterans Affairs Canada (VAC) is not a home care organization, its staff work with families and the home care services provided by provinces and territories to ensure that eligible clients receive the services they need, including end-of-life care. Clients' needs are brought to VAC's attention by clients themselves or their families, or by referral from their care providers. VAC assesses all clients who are identified as needing palliative care and develops a comprehensive, individualized plan of care.

Who is eligible for hospice palliative home care?

All jurisdictions have some form of eligibility criteria for people to access home care services, and some have other specific criteria that people must meet to qualify for hospice palliative home care. At a minimum, the requirements include being a resident of the province or territory. Most jurisdictions also require people to be a Canadian citizen or permanent resident, have a valid health card, and have a home environment suitable for providing care. With VAC, clients must be veterans.

Some jurisdictions, such as BC, have different criteria for different services. For example, to be eligible for nursing services, clients must require care at home because of a terminal illness. To be eligible for personal care or palliative care services, clients must have a doctor's diagnosis of being in the end stages of an illness. The regional health authorities use these criteria as well as the principles and standards in the Provincial Framework for End-of-Life Care (May 2006) to determine whether clients are eligible for hospice palliative home care.

While diagnosis with an end-stage illness is a criterion for hospice palliative home care in at least six jurisdictions, only four make specific reference to life expectancy: Saskatchewan (weeks to months), Ontario (six months or less) and Nova Scotia (three months or less), and Veterans Affairs Canada (three months or less). Newfoundland and Labrador provides home palliative end-of-life care services for up to four weeks, and re-evaluates the client's needs if service exceeds this time period. This focus on end-stage and life expectancy may mean that clients who could benefit from hospice palliative home care in the early phases of a life-threatening illness do not have that option.

Some jurisdictions have processes in place to minimize the negative impact of the life expectancy criterion. For example, in the case of the VAC home care program, the three months or less life expectancy requirement does not disenfranchise anyone because clients receive the services and programming to meet their needs, whether or not they've been classified as palliative. In Ontario's system for classifying clients with a life expectancy of six months or less, many CCACs use the question, "Would you be surprised if the client were to die within the next six months" rather than trying to determine the person's life expectancy. Clients who are classified as "end-of-life" (Code 95) meet the criteria for hospice palliative home care; however, clients classified as "long-term supportive" (Code 94) are often expected to progress to the "end-of-life" category and, therefore, may be eligible to receive hospice palliative home care services.

In several jurisdictions, such as Alberta, Saskatchewan, and Nova Scotia, the focus of care and the person's informed consent are also criteria to qualify for hospice palliative home care (i.e., clients must be aware they are dying and that the goals of care have shifted from cure to comfort). As Nova Scotia notes, "the focus of care is on comfort and to improve the quality of living and dying at the end-of-life rather than curative treatment" and the person "requires active care to alleviate pain and symptoms". It is interesting to note that New Brunswick requires clients to be "referred by an attending physician … who has admitting privileges in the Regional Health Authority" and Nova Scotia also requires the client to "have an attending physician who is aware of the client's palliative status and has agreed to provide medical care for the client in the community".

How long do Canadians wait to receive hospice palliative home care?

Several jurisdictions noted that being eligible for hospice palliative home care does not necessarily mean that clients will immediately receive that level of care. Access is also affected by the availability of people and resources.

Only four jurisdictions – Nunavut, the Yukon, New Brunswick, and Ontario – report tracking wait times for hospice palliative home care.

- In the case of Nunavut, there is no wait time for service.
- The Yukon measures the time from referral to first contact and the time from referral to first service provision. At the current time, there is no wait list for hospice palliative home care, and clients are usually assessed within 24 hours of being referred to the program.
- New Brunswick did not provide any information on its wait times.
- In Ontario, wait times for individual services (e.g., nursing, personal care) are tracked and reported locally but wait times are not reported by client group at the provincial

Ontario's End-of-Life Care Strategy invested $115.5 million over three years to:

- Help shift care of people in the last stages of life from hospitals to home or another setting of their choice
- Enhance an interdisciplinary team approach to care in the community
- Work towards better coordination and integration of local services.
- Provide funding support for nursing and personal support services in residential hospices to over 30 communities

The funds made it possible to provide over 6,000 more Ontarians with compassionate, end-of-life care at home, improve the quality of end-of-life care, and strengthen the role of hospice volunteers who are trained to provide emotional, social and spiritual support for clients and families.

level, so information on wait times for hospice palliative home care is not available.

Some home care organizations in PEI track wait lists manually, and one of the province’s goals for 2008 is to establish a formal wait list. Several jurisdictions that have regional health authorities believe wait times for hospice palliative home care may be maintained at the regional level but this information is not reported provincially.

The policy in PEI is to respond to requests/referrals for hospice palliative home care with an assessment visit within 48 hours or sooner if a quick response is required. However, as noted above, the ability to provide hospice palliative home care depends on the client’s assessed need and the program’s available resources.

VAC maintains data on time to service for quality assurance purposes but reports that there would not normally be any wait for the services they fund once a plan of care has been developed. They have an efficient procedure to process requests and any cases that exceed the approval authority of local VAC offices are faxed to head office for immediate review. The average turnaround time for decisions in these cases is less than 24 hours. The only factor that might cause some delay would be the availability of services that are provided by other jurisdictions.

Wait times for hospice palliative home care are difficult to track because even when clients may not be receiving comprehensive hospice palliative care, they will likely be receiving other types of home care services that will attempt to meet their needs (e.g., speech language services to address a swallowing issue) until the more intensive, coordinated services can be provided, or they will be cared for in acute care hospitals, long-term care homes or volunteer hospices.

Ontario, Nova Scotia and Newfoundland and Labrador report that their home care programs give priority to clients requiring palliative care.

To help meet the needs of clients and families waiting for hospice palliative home care, the Northwest Territories reports that home care programs help the family connect with community resources or make arrangements for respite beds in regional centres.

Case Management Services

Effective case management is an essential part of care for all home care clients, but it is particularly important for people receiving hospice palliative home care because their needs are complex and may change suddenly. Effective case management strategies help connect the client, family and the hospice palliative home care team with other services in the community.

At end-of-life, do Canadians have access to timely, knowledgeable, compassionate case management services?

According to the Pan-Canadian Gold Standard for case management, people who are dying, their families and care teams should have access to case management services, 24 hours a day, seven days a week.

Although only four jurisdictions – Saskatchewan, Ontario, New Brunswick and Newfoundland and Labrador – have an explicit policy that states that hospice palliative home care clients and their families should have access to case management services 24/7, most are providing access to some level of ongoing case management services. For example:

- In BC, all residents who are eligible for home health services receive ongoing case management services to ensure they receive the appropriate range of services through to the end-of-life. Some areas in the province currently have access to case management services 24/7. The Victoria Hospice gives all residents registered with their service access to an on-call community-based hospice palliative care team. Fraser Health provides 24/7 access to case management services through an after hours hospice palliative service in partnership with BC NurseLine, and the province intends to make this service available to people receiving hospice palliative home care across BC.
- Under Alberta Continuing Care standards, "regional health authorities are responsible for establishing processes to coordinate continuing care health services and assist providers, clients, families and other service providers to work together in facilitating links across the continuum of care."
- New Brunswick has "liaison nurses" responsible for coordinating care between hospital, home and the community. Their role is essential to the success of the province's Extra-Mural Program.
- Through VAC's home care program, veterans have access to VAC case managers during normal working hours. However, if they need direct care (not case management services) 24 hours a day, seven days a week, the overall case plan would ensure access to these services.

In New Brunswick, the Liaison Nurse:

- engages in cooperative discharge planning between the hospital and home
- reduces inappropriate admissions by arranging for home and community services
- provides information to clients and their families
- arranges for necessary services and equipment.

How do jurisdictions provide equitable access to hospice palliative care case management services?

Jurisdictions across Canada use a number of different mechanisms in their efforts to provide equitable access to case management services, including:

- using a single entry access point where clients are assigned a care coordinator who will assess their needs, consult with the palliative care team and authorize services (Nova Scotia, Saskatchewan, Ontario)
- through use of a province-wide Integrated Palliative Care Program that provides case management services (PEI)
- using telehealth technology to give remote communities access to case management and palliative care teams/experts (Yukon, Saskatchewan)
- providing funding for a project that will give all health regions access to palliative care expertise (Alberta)
- case conferencing and "shuttle sheets" or patient-held medical records (Manitoba)
- using local health and social services (Nunavut, Newfoundland and Labrador)
- flying patients to access services (Nunavut)
- topping up provincial/territorial hospice palliative home care services or providing additional benefits that these programs do not offer.

Alberta Health and Wellness allocated $500,000 in its 2006/07 budget to enhance access to hospice palliative home care in rural regions. The goals of the program are to provide: shared 24-hour expert physician on-call palliative care services, training programs on palliative care for all regions, and initiatives to disseminate best practices on palliative care.

How do home care organizations track, evaluate and plan services?

In jurisdictions with regional health authorities, the authorities are responsible for tracking, evaluating and planning end-of-life services for their regions based on provincial standards. They, in turn, report information as required by the provincial ministries. As Newfoundland and Labrador noted, "The end-of-life program is relatively new in this province and the quarterly reports are useful in the evaluation process. The plan is to develop comprehensive palliative/end-of-life care services across sectors."

In Saskatchewan, home care directors meet with ministry officials regularly to discuss concerns and identify priorities. In the Yukon, the home care program is an active partner in the Yukon Palliative Care Advisory Committee, which includes palliative care providers from across the continuum of care.

In Ontario, CCACs are members of their local End-of-Life Care/Hospice Palliative Care Networks, which play a key role in systems planning and work with other community partners to plan and evaluate the delivery of service. The province's CCACs are also working together to develop common approaches to measure and report on service quality, efficiency and effectiveness, which would also apply to hospice palliative home care. Joint initiatives include a common provincial approach to measuring client, caregiver and stakeholder satisfaction, provincial performance indicators and benchmarks, and a CCAC scorecard.

In New Brunswick, the ministry holds palliative care forums with community agencies, front line providers and across government departments. Front line staff are involved in developing documents, including the Extra Mural Program Palliative Care Guidelines.

Currently, Nova Scotia does not track palliative care services but does respond to ad hoc requests for information on the number of palliative care clients, number of nursing visits and number of home support hours provided to clients receiving hospice palliative home care.

VAC case managers and members of the interdisciplinary team work with other jurisdictions and service providers to ensure veterans are able to access the services they require.

> Every regional health authority in Manitoba has a regional Palliative Care Coordinator, and the province has established a Provincial Palliative Care Network where members discuss palliative care issues and share best practices in service delivery to encourage consistency across the province. All regions report that palliative clients are spending less time in hospital, and more people are dying at home.

How do jurisdictions ensure timely referrals for clients whose needs can no longer be met at home?

Jurisdictions use a number of different mechanisms to ensure that clients who can no longer be cared for at home are referred in a timely manner, to other places for care, including:

- having family physicians with admitting privileges admit clients to acute care (Yukon)
- having the Integrated Palliative Care Program arrange referrals and continue to be involved in the care (PEI)
- having CCACs assess service needs and make referrals to residential hospices and long-term care homes, and using the ESAS and PPS to facilitate communication between care providers in different settings (Ontario)
- arranging for priority placements with personal care homes, long-term care homes and hospitals (Manitoba, Saskatchewan, VAC)
- using usual referral networks to hospitals (Newfoundland and Labrador, PEI)
- developing formal protocols as part of Phase II of its Palliative Care Initiative (Nova Scotia)
- referring clients to a long-term care home for a respite bed if appropriate (Yukon, Nunavut)
- providing support and respite services for spouses and primary caregivers (VAC).

Only one jurisdiction, Saskatchewan, described the procedure that is used when, for example, a long-term care bed is not available when required. In those cases, clients are offered options such as a personal care home (where the client must pay the costs) or an acute care bed.

Nova Scotia will be developing formal protocols as part of Phase II of its Palliative Care Initiative.

What information systems do jurisdictions use to support case management?

With the exception of Manitoba, Nunavut and the Northwest Territories, which use paper-based records, referrals and communication sheets, almost all jurisdictions have some form of electronic tool to track client care and support case management:

- Four of the five health authorities in BC used the Continuing Care Information Management System (CCIMS); the fifth uses its own software to provide the "minimum reporting requirements" to the provincial ministry. In the future, all authorities will use the minimum reporting requirements framework and plan to have client information management systems that can communicate with one another, such as MEDITECH and PARIS).
- Regional health authorities in Alberta use a number of tools, such as electronic health records, primary care networks and the interRAI assessment tools to track client care. Alberta Health and Wellness has also provided funding over the past two years to help the regional health authorities enhance their case management capacity and to provide case management training in all nine health regions.
- Saskatchewan uses MDS Home Care, an automated assessment and classification system, which provides quality indicators and outcome measurements that can be used to improve client care. The information can be used to identify client needs as well as areas for staff education. Regional health authorities are also using Procura, a software program that can be used by clinical staff at point-of-care and by administrative staff.
- Ontario is in the process of implementing a new provincial case management system (CHRIS), and some parts of the province are using or developing a common in-home record and common referral forms
- New Brunswick's Extra Mural Program has a provincial data collection system to monitor services provided to clients, and the province is developing an electronic health record.
- In PEI, programs use the Integrated Palliative Care Home Chart at most sites. The chart remains in the client's home and goes with the client to other settings (e.g., doctor's office, clinic). Some home care programs also maintain an electronic database of client

The Yukon's home care program uses a home chart that the client/family can take with them to physician appointments and to the hospital. The home chart, which was developed collaboratively by the home care program and the local hospital emergency department, has resulted in better communication between service providers in different parts of the health system, and better care for clients.

information, care plans and updates that can be accessed by the provincial medical palliative care consultant and provincial palliative care nurse.

- Nova Scotia uses SEAscape, an electronic case management system as well as the InterRAI tool.
- In the community sector, Newfoundland and Labrador use a Client Referral Management System (CRMS) to support case management.
- The Yukon has an electronic health record that is able to follow clients from the community into long-term care if needed.
- VAC staff use the Client Service Delivery Network (CSDN) electronic record, which includes fully automated client notes for documentation, assessments, optional tools and case planning instruments. Staff can also access electronic lists of all the equipment, medication, supplies and treatment benefit services provided by the Department.

By providing daily respite and home care nurse visits, Nunavut has now made it possible for people to die at home in remote fly-in communities.

Public Education

How do jurisdictions inform clients and families about services?

Clients and their families can play a key role in coordinating hospice palliative care services if they know the services are available. Nine of 10 jurisdictions report that they try to keep clients informed about the services available and who to contact. Communication/public education strategies include:

- a public education strategy and materials (e.g., brochures, posters, local radio announcements) about palliative care services (Yukon, Nunavut, Newfoundland and Labrador, PEI, Manitoba, BC)
- web sites – for both provincial and regional health authorities (BC, Alberta, Manitoba, Ontario)
- a web-based search tool that allows providers and the public to access information about services in their community and across the province (Ontario)
- displays during National Hospice Palliative Care Week, and having team members participate in the National Hike for Hospice and relay for life teams (PEI, Manitoba)
- ministerial announcement and press release (Nova Scotia)
- providing a toll-free, single entry access telephone number that will connect citizens to information and referrals (Ontario, Nova Scotia, VAC)
- evening education courses and sessions provided by Hospice Palliative Care Manitoba (HPCM)
- community visits (Nunavut)
- education provided by staff of the home care program (Yukon)
- routine information about the benefits available (VAC)
- presentations to service providers and district health authority staff (Nova Scotia, PEI)
- coordinators who are responsible for hospice palliative home care, who inform family physicians, social workers and other health care providers of the range of services available; they also ensure that the client's contact information is accurate and track who meets with the clients and their families (Newfoundland and Labrador)
- quality care coordinators who help clients navigate the health system (Saskatchewan)
- on-line supports, such as a virtual hospice (Yukon)
- through the provincial hospice palliative care association (New Brunswick).

Nursing and Personal Care Services

At end-of-life, do Canadians have access to nursing care and personal care 24 hours a day, seven days a week?

Six jurisdictions – BC, Alberta, Manitoba, Ontario, New Brunswick and Nova Scotia -- have explicit policies that people receiving end-of-life care at home should have 24/7 access to nursing and personal care.

- In BC, the Provincial End-of-Life Framework states that health authorities should deliver services that meet applicable hospice palliative care standards (CHPCA, CCHSA), including round-the-clock access to palliative care expertise, and pain and symptom management services from the beginning of end-of-life care through to and including bereavement services for the family. Each health authority is at different stages in achieving the vision of the framework. The number of hours of nursing and personal care provided to clients depends on their assessed need.
- In Alberta, the Coordinated Home Care Program Regulation Section 3(3)(b) exempts palliative care clients from the eligibility criteria for home care that states that clients should not require 24-hour care.
- Manitoba provides 24-hour access to health care aides.
- In Ontario, CCACs contract with nursing, personal care and other health care professions, and contracts include an expectation that services will be available 24 hours a day, seven days a week based on client needs. Although regulations under the Long-Term Care Act, 1994 establish the maximum number of hours of services an individual may receive through the CCAC (e.g., two hours of personal care a day), CCACs are able to provide up to 24 hours per day of care in the final days of life.

PEI notes that, "We believe in the importance of 24 hours access, however … access depends on assessed need and available resources at sites throughout the day and evening and on weekends. There presently is no access to 24-hour service."

VAC reports that its focus is on developing individual care plans that meet each veteran's needs rather than on the time when service is available.

Saskatchewan met the standards for short-term end-of-life home care before September 2004. The province invested an additional $300,000 annually to enhance end-of-life home care, giving people access to case management, nursing, personal care and palliative pharmaceuticals at no cost. By December 2006, Saskatchewan had met all the home care commitments in the First Ministers 10-Year Plan to Strengthen Health Care.

What proportion of people dying at home have access to skilled nursing assessments, knowledge and care, around-the-clock personal care and flexible respite services?

While all jurisdictions offer these services and try to meet the needs of their clients, most provinces and territories do not have the information to be able to answer these questions.

Ontario reports that some communities have specialized hospice palliative care nursing services, and the trend is for CCACs to have nurse practitioners or clinical nurse specialists on staff to provide consultation and support for the provision of end-of-life care.

Newfoundland and Labrador report that approximately 80 per cent of clients have access to nursing and respite care. Because of a shortage of health care workers, only about 60 per cent have access to personal care.

> In Nova Scotia, care coordinators identify resources to meet a family's needs, including home support workers who provide personal care, visiting nursing services, and volunteers. "Working together with the community, we can ensure people will spend their remaining days at home, surrounded by a family and a community that cares."

Even in jurisdictions such as BC, which has a policy that people dying at home should all have access to these services, the province acknowledges the ability to provide that level of service to 100 per cent of clients is often limited by the lack of human resources, particularly in rural and remote areas. New Brunswick also notes that access to these services is based on client needs and involves the coordination of both formal and informal supports.

PEI states that all clients in the Integrated Palliative Home Care Program have access to these services, based on assessed need and available resources. Resources are available primarily throughout the day and evening, and there are no round-the-clock services.

VAC reports that there are no funding impediments to veterans receiving nursing care, personal care or respite services, but their access may be influenced by "market-place conditions within the local community (e.g., availability of nurses or personal care workers, capacity to access respite services in supportive settings). Veterans Affairs works closely with external service providers, but may have restricted influence over timely access to services and benefits funded by other jurisdictions."

Do Canadians dying at home have access to team-based care?

Yes. 11 of 13 jurisdictions reported that they are actively working to provide team-based care; however, the nature of the teams is not clear. It is likely that most are generalist home care teams, rather than those who have received additional training and are designated to provide hospice palliative home care.

- In BC, the Provincial End-of-Life Framework is based on interdisciplinary hospice palliative care in the home, as described in the CHPCA Model to Guide Hospice Palliative Care (2002). Home and community care programs are required to provide nursing, rehabilitation, home support, day programs and caregiver relief/respite programs. At a minimum, each health authority implements team-based approaches to these services as part of end-of-life care. They may also offer additional services and providers, such as spiritual advisors and bereavement specialists.

- In Alberta, the Continuing Care Health Service Standards require that care be provided by an integrated, interdisciplinary care team.
- In Saskatchewan, nurses, physicians, medical social workers, pharmacists, dieticians, spiritual care staff, and palliative counsellors/assessors are involved in providing palliative care services.
- Manitoba uses a mix of home care case coordinators, pharmacists, palliative care coordinators, mental health services, occupational therapists, physiotherapists, RCMP, EMS, funeral homes, physicians, social workers and volunteers. However, there is limited availability of some professionals in some rural areas.
- Ontario does not have a specific policy on team-based care, but its End-of-Life Care Strategy supports interdisciplinary teams and the use of best practices. Where teams do exist, they include (depending on the client's needs) nursing, personal support, physiotherapy, occupational therapy, speech language pathology, dietician, social work, and spiritual counselling and bereavement services. CCACs are also working closely with Family Health Teams, palliative care physicians and community pharmacists to integrate delivery of end-of-life care.
- Guidelines for New Brunswick's program state that "to meet the identified needs of the client, service providers will recognize the contribution of other providers, establish effective communication and work together in partnership". Team members include: physicians, nursing, occupational therapy, physiotherapy, respiratory therapy, social work and dietetics.
- PEI has developed a small clinical resource team with training and expertise in complex

Prince Edward Island has developed Integrated Teams whose members are specially trained in palliative care. Everyone referred for palliative care receives an initial visit/assessment, and then the Integrated Team develops a care plan and assembles the care providers, who may include: a social worker to provide counselling to clients and families who are experiencing conflict, a physiotherapist to recommend treatment services to promote comfort, an occupational therapist to investigate and implement energy conservation techniques with the client and family, nursing and home support workers, community support workers and a pharmacist. Teams meet weekly to review clients receiving palliative care in all settings and share information with those providing direct care. The teams support the work of the front line, arrange timely referrals, and manage the client registry.

pain and symptom management, advanced care planning and grief counselling. Team members include physicians, nurses, pharmacists and social workers. The resource team provides support, leadership and guidance to the primary care teams that provide hospice palliative home care. The primary care teams include the family physician, nurses, chaplain, social worker, home support workers, community support workers, occupational therapist, physiotherapist, dietician, oncologist (if required) and community pharmacist.

- In Newfoundland and Labrador, generalist teams consist of nurses, pharmacists, social workers, physicians, pastoral care providers, occupational therapists, physiotherapists and nutritionists with a palliative end-of-life care regional coordinator. Not all allied professionals are available in all parts of the province.
- Although Nunavut does not have formal palliative care teams, clients can access the services of community health nurses, home care nurses, rehabilitation professionals, social workers, mental health providers, and physicians.
- Home care teams in the Yukon include social workers, nurses, physiotherapists, occupational therapists and personal care workers. Home care staff are generalists who provide palliative care as part of their work.
- VAC maintains full interdisciplinary teams at the district, regional and head office levels, which include case managers (who are often social workers), registered nurses, physicians, rehabilitation specialists, mental health specialists and occupational therapists. The interdisciplinary teams are supported by policy analysts, educators and other specialists.

Of the two jurisdictions that reported not having palliative home care teams, Nova Scotia intends to build an integrated team approach in the next phase (i.e., Phase III) of its Palliative Care Initiative.

How do jurisdictions ensure that all members of the team collaborate, respect one another, communicate and are able to access hospice palliative care specialists when needed?

Many of the strategies used to promote team-based care are developed at the level of regional health authorities. However, provinces and territories identified a number of different mechanisms to support team-based care, including:

- using common assessment tools, charts, electronic records, information systems and clinical guidelines (BC, Ontario, Newfoundland and Labrador, Yukon, VAC)
- using a secure service portal that providers can use to share information (Ontario)
- providing a 24-hour expert on-call service for palliative care (Alberta)
- establishing a case coordination and management structure (Manitoba)
- having regional or provincial palliative care coordinators/resource nurses who act as an expert resource for home care teams (Manitoba, Ontario, New Brunswick, PEI, Newfoundland and Labrador)
- having a resource team that reviews each client's file weekly (for clients in the Integrated Palliative Home Care Program) and stays current with the literature (PEI)

- holding regular interdisciplinary palliative care rounds or team meetings (PEI, Ontario, VAC)
- requiring external service providers to submit regular reports on the client's status and the well-being of primary caregivers to the case manager (VAC)
- having joint visits with experts and front line workers (PEI, Nunavut, Yukon)
- developing an Interprofessional Core Curriculum and providing education (PEI)
- developing operational guidelines that discuss the roles and contributions of all team members (New Brunswick, PEI, VAC)
- developing service definitions and expectations as part of service provider contracts (Ontario)
- evaluating collaboration and interdisciplinary team consultations as part of a quality assurance program (VAC)
- using telehealth/phone advice (Nunavut, Yukon)
- the BC Palliative Hotline, which gives 24-hour access to clinical support from a physician (BC, Yukon). However, the BC ministry does not fund this line; it is a BC Medical Association initiative that relies on physicians volunteering their time as well as donations from pharmaceutical companies.

Do teams have opportunities for interprofessional education and training?

The Pan-Canadian Gold Standards recommends that teams receive training in hospice palliative care, case management and cultural competency. This education is particularly important for home care staff who provide hospice palliative care as part of their work, and do not have any specialized training.

In BC, Saskatchewan, and Newfoundland and Labrador, ongoing professional education and training are the responsibility of regional health authorities. New Brunswick does not provide specific hospice palliative care training, but will provide funding for home care professionals who want to participate in professional development. In the eight jurisdictions that do provide education, the training consists of the following:

- Alberta Health and Wellness provides funding for training and knowledge transfer programs on palliative care in all regions, and has worked with SEARCH Canada to develop an internet-based tool – the Continuing Care Desktop – that provides resources, educational materials and best practices on continuing care, including palliative care. Alberta Health and Wellness also allocated $1.3 million to provide training materials and workshops on case management to all regional health authorities in 2008.
- Manitoba sponsors an annual hospice palliative care conference that includes workshops, volunteer training and support worker training. To help with cultural competency, the province also uses the Pallium Project's Aboriginal Training and Hospice Palliative Care Manitoba cultural presentations.
- Ontario funds agencies across the province to provide Community and Facility Palliative

Care Interdisciplinary Education Service and Pain and Symptom Management Consultation for providers. The education plan may include one-day courses, refresher days, mentoring programs and videoconferencing options. Ontario also funds education that targets family physicians as well as the Pallium program (Learning Essential Approaches to Palliative Care or LEAP) for interdisciplinary teams in communities around the province. Education programs include cultural competency.

- PEI provides education for occupational therapists, front-line staff, physicians, community service groups and volunteers on palliative care. Provincial palliative care experts have identified self-learning modules. The province uses the CHPCA National Hospice Palliative Care Course for Support Workers, and partnered with Cancer Care Nova Scotia to provide some interprofessional cancer education.
- Nova Scotia works with Cancer Care Nova Scotia to develop education programs designed to improve care for cancer patients and their families.
- Nunavut uses the Pallium Project training on palliative care, provides training on case management, and uses local Inuit to provide cultural competency training.
- The Yukon has developed training materials on hospice palliative care, provides training on case management as part of the home care orientation program, and takes advantage of courses provided by the government on cultural competency.
- Veterans Affairs offers ongoing professional training to department nurses, physicians and case managers. Education specific to end-of-life care includes pain management and, in the near future, the use of therapeutic surfaces to reduce or relieve pressure.

Do jurisdictions support research in hospice palliative home care?

Six jurisdictions actively support research into hospice palliative care.

- In BC, the Ministry of Health provided a grant to the Canadian Institute for Health Research (CIHI) to describe British Columbians' health care use and patterns in the last two years of life (to be published spring 2008). The ministry is also currently providing advisory support to three research projects:
  - Advance Care Planning: An Implementation Guide for Health Authorities, which is co-sponsored by Fraser Health (BC), Capital Health (Alberta) and Health Canada
  - A study on quality of care for the dying and their family members
  - Partnerships in Health System Improvements, a study to enhance timely access to hospice palliative care through improved end-of-life prognostication using routinely collected health data.
- Alberta Health and Wellness is currently supporting a project to provide access to palliative care expertise across the province. It has also partnered with SEARCH Canada to develop an internet-based tool, Continuing Care Desktop, which provides access to research in palliative care.
- In 2006, the Ministry of Health in Saskatchewan participated in and provided funding for an end-of-life study of care seeking patterns among clients at end-of-life in the four western provinces, led by the CIHI (2007). In 2005/06, the ministry also commissioned a review of the Home Care Program to assess the range and mix of services and their capacity to meet needs.

- Manitoba also participated in the CIHI study, Health Care Use at the End-of-Life in Western Canada (2007). The province also supports research done by Cancer Care Manitoba on palliative care.
- Ontario has established a Home Care Research and Knowledge Exchange Chair who is working to build capacity for research in home care. The province also funds the Seniors Health Research Transfer Network, which conducts research across the aging continuum of care, including palliative care, and the Institute for Clinical Evaluative Sciences, which has a "use of end-of-life care services in Ontario" study underway. In addition, CCACs are currently involved in several research projects, including:
    - A study with Queen's University, Cancer Care Ontario and Regional Cancer Centres to track outcomes related to the use of the ESAS and PPE assessment tools
    - A University of Ottawa study on decision support for clients deciding about place of care at end-of-life
    - A University of Waterloo study on caregiver burden related to end-of-life care
    - A University of Ottawa study on the pain experience of older patients with advanced cancer, pain management and the impact on caregivers
    - A project with three local palliative care networks and local hospices to examine story telling and structured narrative as a tool to help families work through the experience of dying and bereavement
    - A McMaster University study to examine the palliative care experience of patients with advanced heart failure.
- New Brunswick supports research in case management, nursing, personal care and interprofessional team care.
- Veterans Affairs reports that it collaborates with researchers who are exploring care and service delivery in the home, client outcomes and trends in utilization of available services. The program also maintains meticulous records on cases requiring supplementary funding or extensive services, and would welcome opportunities to work with researchers to investigate the efficacy of home care programming and services used by veterans.

At the end-of-life, Canadians need timely access to medications to manage pain and symptoms. One of the main reasons that people are hospitalized in the last few weeks of life is to be able to access additional medications needed and avoid or reduce the financial burden for their families.

Do Canadians dying at home have the same access to pharmaceuticals as those who die in a hospital?

Eleven of the 13 jurisdictions that responded to the survey now provide access to a wide range of pharmaceuticals for clients receiving hospice palliative home care (See Table 2). Most cover the cost of all pharmaceuticals recommended in the Pan-Canadian Gold Standard for Palliative-Specific Pharmaceuticals in Hospice Palliative and End-of-Life Care at Home.

Two jurisdictions do not cover the cost of pharmaceuticals: PEI and Nova Scotia. In PEI, clients receiving hospice palliative home care are responsible for paying for their medications – either directly or through their own insurance or company drug plans. In Nova Scotia, clients must use private insurance or – if they qualify – the Nova Scotia Pharmacare program. However, both provinces are planning to cover hospice palliative care pharmaceuticals, and Nova Scotia is currently evaluating a pilot in one district to identify the medications that its Palliative Care Initiative will eventually cover.

How do jurisdictions provide access to pharmaceuticals?

Jurisdictions use different mechanisms to provide access to pharmaceuticals for people receiving hospice palliative home care, including:

- the general provincial, territorial or departmental drug formulary (BC, Alberta, Saskatchewan, Manitoba, Ontario, New Brunswick, Newfoundland and Labrador, Nunavut, Northwest Territories, Yukon, VAC)
- a supplementary palliative care specific drug formulary or list (BC, Alberta, Manitoba, Ontario, New Brunswick, Newfoundland and Labrador, Yukon)
- an exceptional drug status program (Saskatchewan, Ontario)

The Veterans Affairs formulary is more comprehensive than any provincial or territorial formulary.

Who is eligible for pharmaceuticals?

- In BC, physicians determine whether clients are eligible for drug coverage. To qualify, individuals must be living at home, be diagnosed with a life-threatening condition, have a life expectancy of up to six months and consent to care focused on palliation rather than treatment aimed at cure. Individuals who are covered by other programs (e.g., Veterans Affairs Canada, the Non-Insured Health Benefits Program of Health Canada) are eligible only for medications not covered by these other programs. Members of the Canadian Forces and the RCMP are not eligible because their drug costs are covered by their employers.
- In Alberta, clients must be residents of the province, registered with the Alberta Health Care Insurance Plan, diagnosed by a physician as palliative and receiving care at home.
- In Saskatchewan, individuals must be designated palliative by a physician. Drug

coverage is not limited to the end-stage of life.

- In New Brunswick, eligibility is based on need, and the Extra Mural Program is the payor of last resort (i.e., clients who have private drug insurance must use that program first).
- In Nunavut, the drug program covers any medication prescribed by a physician.
- In the Yukon, physicians are required to complete a form that states the person is in the late stage of illness, has a life expectancy in months, and is receiving care designed to improve quality of life rather than a cure.
- In Manitoba and Newfoundland and Labrador, anyone enrolled in the palliative home care program or end-of-life program is eligible for drug coverage.
- For the Veterans Affairs program, eligibility is based on need.

It is interesting to note that only two jurisdictions put time restrictions (e.g., life expectancy of six months) on access to pharmaceuticals.

Who pays? When?

In most jurisdictions, pharmaceutical costs are billed directly to the provincial drug plan or to the home care program. However, in the Northwest Territories, families pay for the medications and then submit claims to be reimbursed. In Alberta, individuals/families pay a 30 per cent co-payment to a maximum of $25 per prescription up to $1,000 – after which, the province covers 100 per cent of the cost of eligible medications. Veterans Affairs reports that the normal process is for costs to be paid directly by the plan, but families can also purchase items on the formulary and submit claims for reimbursement.

How do clients access drugs not on the formulary lists?

Several jurisdictions – including BC, Saskatchewan, Manitoba, Ontario, Newfoundland and Labrador, Nunavut, the Yukon and Veterans Affairs – have mechanisms that allow hospice palliative home care clients to apply for coverage of drugs not on the general or palliative care formulary lists.

The time it takes to get approval for these special drug requests ranges from the same day (BC, Manitoba) to 3 to 4 days (Nunavut) to 7 to 10 working days (Newfoundland and Labrador).

BC asks physicians to indicate "for a palliative care registrant" on the request form so it will receive priority. Newfound and Labrador will also reduce the approval time for palliative care clients. Ontario processes palliative care Individual Clinical Review (ICR)/ Exceptional Access (EA) requests on an urgent basis. The Yukon noted that, to date, it has not had to use this special mechanism: all clients' pharmaceutical needs have been met through the general formulary and palliative-specific drug list.

In Newfoundland and Labrador, community health nurses provide palliative care in rural areas and one-nurse offices. They make home palliative care work by collaborating with other care providers locally or from a distance, by involving the family, and by anticipating care needs, solving problems and making themselves available to the client and family.

Veterans Affairs has a standard application process for non-formulary products (NFP). When clients bring a prescription to the pharmacy for a medication not on the formulary, the pharmacy will give the client/family a pamphlet telling them to write or call for approval for an NFP. When clients request pharmaceuticals that require special authorization, the pharmacist phones a 1-800 number and approved requests are usually completed within 20 minutes. VAC does not generally approve off-label use of medications.

Do home care teams have easy access to pharmacists?

All jurisdictions that completed the survey reported that hospice palliative home care teams have timely access to knowledgeable pharmacists who can provide advice on medications. Jurisdictions use a combination of strategies to access pharmacists, including:

- pharmacists on staff or contract with home care organizations (BC, Alberta, one county in PEI, VAC)
- hospital pharmacists (BC, Alberta, Manitoba, New Brunswick, PEI, Nova Scotia, Newfoundland and Labrador, Nunavut, NWT, Yukon)
- arrangements with a community pharmacist (BC, Alberta, Manitoba, Ontario, New Brunswick, PEI, Nova Scotia, Newfoundland and Labrador, Nunavut, NWT, Yukon, VAC)
- provincial phone consultation services (BC, Saskatchewan)

In BC, physicians and other care providers have access to a toll-free, after hours and weekend Palliative Care Consultation Line, staffed by palliative care physicians who offer immediate clinical advice and direct physicians to resources in their own community. The after hours confidential BC NurseLine Pharmacist Service is available to every BC resident or service provider.

PEI reports that access to pharmacists varies and is not consistent across the province. One home care team includes a pharmacist. The other counties depend on either hospital or community pharmacists, but there is no dedicated time from the hospital pharmacist allocated to home care clients.

Although all jurisdictions report that people dying at home have access to pharmacists, the Canadian Pharmacists Association has reported that its members require more education and training to be able to provide expert advice and support for people dying at home.

Pharmaceuticals

Table 2: Palliative Pharmaceuticals Available in Each Jurisdiction

Pharmaceuticals	BC	AB	SK	MB	ON	NB
Analgesics	√ No Tramadol/ acetaminophen, Ketorlac, Spinal/epidural opioids, Flecainide or Lidocaine - infusion	√ No Acetaminophen, Tramadol/ acetaminophen, Meloxicam, Spinal/epidural opioids, Sufentanil, Ketamine or Lidocaine - infusion	√ Clients are eligible for regular formulary and exception drug status drugs – but detailed list not provided	√	√ No Tramadol/ acetaminophen or spinal epidural opioids	√
Anticoagulants	Only Warfarin	√		√	√	√
Coagulants – antifibrinolytic agents	√	√		√	√	√
Anticonvulsants	√ No Lamotrigine, Pregabalin or Topiramate	√ No Pregabalin		√	√	√
Antidepressants	√	√		√	√	√
Antidiarrheals	√	√ No Bismuth subsalicylate or Loperamide		√	√ No Bismuth subsalicylate	√
Antiemetics	√ No Ondansetron, Granisetron, Marinol or Nabilone	√ No Marinol or Octreotide		√	√	√
Antifungal (oral/vaginal preparations)	√	√		√	√	√
Antimicrobials	√			√	√	√
Antipruritics	√	√		√	No	√

NS	PE	NL	NU	NT	YT	VAC
		√	√ No Flecainide	√ Clients are eligible for regular formulary and exception drug status drugs – but detailed list not provided	√	√
		√	√ No Tinzaparin		√	√
		√	√		√	√
		√	√		√	√
		√	√ No Venlafaxine		√	√
		√	√		√	√
		√	√ No Promethazine, Granisetron, Marinol or Nabilonee		√	√
		√	√		√	√
		√	No		√	√
		√	√		√	√

Table 2: Palliative Pharmaceuticals Available in Each Jurisdiction (continued)

Pharmaceuticals	BC	AB	SK	MB	ON	NB
Antipsychotics	√ No Olanzipine	√	√ Clients are eligible for regular formulary and exception drug status drugs – but detailed list not provided	√	√	√
Antispasmodics	√	√ No Hyoscyamine (Levsin) or Scopolamine		√	√	√
Antitussives	√	√ No Hydrocodone-phenyltoloxamine or Dextromethorphan		√	√	√
Antivirals	√ No Valacyclovir	√ No Famcyclovir		√	√	√
Anxiolytics/ Hypnotics	√ No Phenobarbital - parental	√		√	√	√
Bone Metabolism Regulators	√	√		√	√	√
CHF Therapy	√	√		√	√	√
Bronchodilators	Only Aminophylline tablets, Salbutamol – inhalers and nebules, and Ipratropium bromide – inhalers and nebules	√		√	√	√
CNS Stimulants	Only Methylphenidate	√ No Methamphetamine		√	√ No Methamphetamine	√
Diabetic Agents	√ No Gliclazide or Rosiglitazone	√		√	√	√

NS	PE	NL	NU	NT	YT	VAC
		√	√	√ Clients are eligible for regular formulary and exception drug status drugs – but detailed list not provided	√	√
		√	√		√	√
		√	√		√	√
		√	√		√	√
		√	√		√	√
		√	√ No Clodronate		√	√
		√	√		√	√
		√	√		√	√
		√	√		√	√
		√	√		√	√

Table 2: Palliative Pharmaceuticals Available in Each Jurisdiction (continued)

Pharmaceuticals	BC	AB	SK	MB	ON	NB
H2 Blockers and Proton Pump Inhibitors	Only Pantoprazole and Ranitidine	√ No Esomeprazole	√ Clients are eligible for regular formulary and exception drug status drugs – but detailed list not provided	√	√ No Esomeprazole	√
Diuretics	√	√ No Ethacrynic acid		√	√	√
Laxatives	√ No Docusate calcium, Miralax, Sodium phosphate/ sodium acid phosphate enema, or Sodium citrate/ Sorbitol/Sodium lauryl sulfoacetate enema	√		√	√ No fleet enema, Magnesium Hydroxide, MOM or microlax enema	√
Hemorrhoid Therapy – ointment and suppositories	√	√		√	√ Only zinc sulfate with and without hydrocortisone	√
Steroids	√	√		√	√	√
Wound Care	√ No Flamazine cream	√		√	√	√
Other Pharmaceuticals	Only Glycopyrrolate	Only Glycopyrrolate, Lidocaine and Megestrol Acetate		√	√ Only Glycopyrro-late Lidocaine and Megestrol Acetate	√

NS	PE	NL	NU	NT	YT	VAC
		√	√	√ Clients are eligible for regular formulary and exception drug status drugs – but detailed list not provided	√	√
		√	√		√	√
		√	√		√	√
		√	√		√	√
		√	√		√	√
		√	√		√	√
EMLA cream		√	√ No Ametop, Ropivicaine or Phlojel		√	√

Pharmaceuticals

Do jurisdictions have procedures to help families manage medications and equipment?

Families have identified the managing and administration of medications as one of the stresses in caring for someone at end of life. They also report that education and support from the rest of the care team is extremely helpful.

According to the survey, 10 of 13 jurisdictions have policies on the distribution, storage, handling and disposal of pharmaceuticals in the home, and 12 provide education and/or support for families on how to administer medication and monitor equipment. For example:

- BC has developed Personal Assistance Guidelines (PAG) that clarify the roles of both regulated and unregulated providers. With some exceptions, nurses can delegate tasks such as administering medications to unregulated care providers. Each health authority provides client/family teaching as a component of home care, developing strategies based on the population's need and cultural diversity.

- Alberta's Continuing Care Health Service Standards require regional health authorities and their contracted agencies to have policies and processes related to medication management.

- Manitoba has Clinical Service Protocols that set out expectations for medication management, and the palliative care programs have put in additional safeguards. Education is provided in the form of written materials, nurse training, discussions with pharmacists and a support phone line. The home care case coordinator and palliative care coordinator identify risk situations and plan to meet client needs.

- Regional health authorities in New Brunswick follow their own pharmacy standards as well as the standards and practice set out by the Pharmacy Association.

- Although PEI doesn't cover the cost of pharmaceuticals, the province does provide education for families on the safe use of medications through written materials, home care nurses, the dispensing pharmacist, and phone support from the home care offices.

- New Brunswick, Newfoundland and Labrador, and the NWT use similar education strategies: written materials, nurses and pharmacists.

- Nunavut relies on nurses to educate families.

- The Yukon has established some policies on medication management. For example, home care nurses are not allowed to transport medications, and families are responsible for keeping dugs secure. Local pharmacists teach families how to manage medications, and home care nurses reinforce this education. Families return unused medication to the pharmacy.

- Nurses engaged by Veterans Affairs to complete assessments must collect information about medications being used and the client's knowledge of and compliance with medication. They must also provide teaching on the storage and use of medication.

Medical Supplies and Equipment

Twelve of the 13 jurisdictions that completed the survey provide a range of medical supplies and equipment for people dying at home. The types of items covered and consistently available varies between jurisdictions and, in some cases, within jurisdictions (see Table 3). For example, Veterans Affairs provides more items than those listed in the Gold Standard and will consider requests for additional items on a case-by-case basis. On the other hand, the Northwest Territories reports that "most supplies are available only in larger centres". Clients in PEI pay for any supplies and equipment necessary for care. The only exceptions are some items available through some home care program, such as portable hospital beds, lift chairs, over bed tables, commode chairs, special care mattresses, walkers and wheelchairs.

Table 3 illustrates the types of supplies and equipment available in each jurisdiction. Relatively few jurisdictions provide diabetic supplies. In addition to the supplies listed below, some regional health authorities may provide other equipment – but that information was not available for the survey.

Supplies and equipment may be provided directly by the home care program or through other government programs, such as Aids to Daily Living or drug benefit programs. In New Brunswick equipment is available from the Extra Mural Program Equipment Loan Bank, the Red Cross and other agencies that lend equipment.

To be eligible to access supplies and equipment available through the home care programs, Canadians at end-of-life must be accepted or designated as a hospice palliative home care client or a client of the Veterans Affairs home care program. For some items, medical prescriptions are required.

To access supplies and equipment available through other programs, such as Aids to Daily Living, clients must meet the criteria for those programs, which usually include requiring assistance because of a disability, chronic illness or terminal illness.

To access supplies available through provincial drug benefit programs, clients must meet the criteria for those programs.

Medical Supplies and Equipment

Table 3: Equipment and Supplies Available in Each Jurisdiction

Gold Standard	BC	AB	SK	MB	ON	NB
Routine Dressing Supplies	√ No pressure dressings or disposal containers for needles and syringes	√		√	√	Equipment is available from the EMP Equipment Loan Bank, Red Cross and other agencies that may lend equipment
Intravenous Therapy Supplies	√	√	√	√	√	
Urinary Catheter Care Supplies	√ No pleurx catheters	√	√ No pleurx catheters	√	√	
Incontinence Supplies	√	√	√ No condom drainage sets	√	√	
Diabetic Supplies					No	
Ostomy Supplies		√		√	√ through the Assistive Devices Program	
Oxygen – with tubing and masks	√	√	√	√	√	
Wound Care Supplies		√	√ No sterile water, syringes, catheters, non-adherent dressings or exudry tapes	√ No catheters	√	
Equipment	√ No personal care equipment (e.g., raised toilet seat) or nebulizers	?	Only hypodermoclysis equipment and CADD pump equipmen	√	√	

NS	PE	NL	NU	NT	YT	VAC
√ No pressure dressings		√	√	√	√ No trays or solutions and ointments	√
√		√	√	√	√	√
√ No pleurx catheters		√	√ No pleurx catheters	√	√ No disposable gloves (non-sterile)	√
Only disposable gloves (non-sterile)		√	√	√	√ No disposable gloves (non-sterile)	√
		√	√	√	√	√
		√	√	√	√	√
		√	√	√	√	√
√ No composite dressings, foams or exudry tapes		√	√	√	√ No gloves or dressing trays	√
Only CADD pump equipment		√	√	√ No hypodermoclysis equipment, pressure relief equipment, personal care equipment, mechanical lift, nebulizers, mobility aids or electric hospital beds	√ No urinals, bed pans, kidney basins	√

Recommendations

Jurisdictions across Canada have made progress in providing hospice palliative home care services. However, there is still room for improvement. The June 2005 Senate progress report on quality end-of-life care, Still Not There, estimates that only 15 per cent of Canadians have access to high quality hospice palliative care. That means that only one out of every seven people who die in Canada receives care that takes into account their physical, emotional, psychosocial and spiritual needs and the needs of their families. Most Canadians are dying without much needed care and support.

The survey confirmed that access varies based on resources and geography, and that the problem of access to high quality, comprehensive end-of-life care at home is particularly severe in rural and remote communities.

Based on the survey findings, the Quality End-of-Life Care Coalition of Canada (QELCCC) recommends that all jurisdictions across Canada take the following steps to enhance hospice palliative home care and align their programs with the Gold Standard:

Case Management

1. Make consistent use of a valid assessment tool within and across provinces.
2. Ensure that eligibility for hospice palliative home care is based on need and not on an arbitrary time limit.
3. Ensure clients and families are referred to hospice palliative home care in a timely manner, maintain records of wait lists and times, and use this information to plan/fund services.
4. Gather information on the number of Canadians receiving hospice palliative care or dying in hospitals, long-term care homes, respite beds and other settings whose needs could have been met through hospice palliative home care.
5. Continue to develop active outreach programs to educate the public and providers about hospice palliative home care, rather than relying on passive strategies such as web sites.

Nursing Care/Personal Care

6. Identify creative and effective ways to ensure that Canadians dying at home and their families have access to case management, nursing and personal support service 24 hours a day, seven days a week.
7. Ensure that all members of the hospice palliative home care team receive appropriate ongoing education and training, and have access to support from specialized hospice palliative care teams.

Pharmaceuticals

8. Work with schools of pharmacy and pharmacy associations and colleges to develop education programs for pharmacists who provide consulting services for hospice palliative home care.
9. Ensure that all Canadians receiving hospice 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 end-of-life.
10. Ensure that access to pharmaceuticals for hospice palliative home care is based on need and not restricted by arbitrarily imposed time limits or cumbersome processes for requesting drugs or uses not covered by provincial/territorial formularies.

Based on the results of the survey, the QELCCC is considering surveying regional health authorities to get a clearer picture of the policies developed, the type/extent of services provided, and how they are monitoring/evaluating their services.

Conclusion

Jurisdictions across Canada have made significant progress in giving more people access to a range of palliative home care services (case management, nursing, personal care, pharmaceuticals), but there is still room for improvement. Timely access to comprehensive palliative home care services in most jurisdictions is still limited by lack of nurses and personal support workers (i.e., resources), lack of training in palliative care, and geography (i.e., it is more difficult to deliver high quality palliative home care in rural areas).

While progress has been made in home care settings, more must also be done to give Canadians access to palliative care in other settings where they may choose to die, such as hospitals, long-term care homes and hospices, and on the street. At best, no more than 37% of Canadians dying in all settings receive the kind of comprehensive, coordinated palliative care that improves quality of life at the end of life. We can and must do better.

At the provincial level, there is an urgent need to develop high quality hospice palliative care services in other settings where Canadians die, including in hospital, long-term care homes and hospices, and on the street. These settings must be fully integrated, to allow for better efficiency in working together.

At the federal level, the same high quality hospice palliative home care now provided by Veterans Affairs for veterans should be extended to Aboriginal/indigenous communities across the country, as well as all other populations whose health care is under the overview of the federal government.

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[1] Canadian Institute for Health Information, Health Care Use at the End of Life in Western Canada (Ottawa: CIHI, 2007), p. 22.

[2] Statistics Canada. Table 102-0509 - Deaths in hospital and elsewhere, Canada, provinces and territories, annual, CANSIM (database).http://cansim2.statcan.ca/cgi-win/cnsmcgi.exe?Lang=E&CANSIMFile=CII\CII_1_E.htm&RootDir=CII/ (accessed: April 18, 2008)

[3] Canadian Institute for Health Information, Health Care Use at the End of Life in Western Canada (Ottawa: CIHI, 2007)

[4] Canadian Institute for Health Information, Health Care Use at the End of Life in Western Canada (Ottawa: CIHI, 2007)

QELCCC Signatories

The Quality End-of-Life Care Coalition of Canada (QELCCC) is a network of 30 national organizations that believe all Canadians have the right to quality end-of-life care that allows them to die with dignity, free of pain, surrounded by their loved ones, in a setting of their choice. QELCCC members believe that achieving quality end-of-life care for all Canadians requires a collaborative, well-funded and sustainable national strategy for hospice palliative and end-of-life care. We must work together in partnership to achieve this goal. The QELCCC advocates for quality end-of-life care for all Canadians.

This document is endorsed by the following member organizations of the Quality End-of-Life Care Coalition of Canada:

ALS Society of Canada

Alzheimer Society of Canada

Canadian AIDS Society

Canadian Arthritis Patient Alliance

Canadian Association of the Deaf

Canadian Association of Occupational Therapists

Canadian Association fo Pastoral Practice and Education

Canadian Breast Cancer Network

Canadian Healthcare Association

Canadian Home Care Association

Canadian Hospice Palliative Care Association

Canadian Lung Association

Canadian Medical Association

Canadian Nurses Association

Canadian Pharmacists Association

Canadian Society of Palliative Care Physicianas

CARP: Canada’s Association for the Fifty-Plus

Catholic Health Association of Canada

Huntington Society of Canada

Long Term Care Planning Network

The GlaxoSmithKline Foundation

VON Canada