

Palliative Care | Building
Matters | National Consensus

L'importance des | Forger
soins palliatifs | un consensus national

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**What are the essential components
of quality palliative home care services
for all Canadians?**

1. Overview

Why home care?

Home care includes:

- Health services (e.g. nursing, physio and occupational therapy, etc)
- Practical services (e.g. Personal support, equipment.
- Palliative home care has end-of-life intent (death within a year)

Home care is important setting for palliative care

- Many people prefer to be cared for and die at home
- Hospital care is overcrowded and costly

Objectives

- Describe methods and data sources behind the review
- Review evidence for what are the essential components of quality palliative homecare services (Findings)
- Review considerations to support these components being implemented in home care services for all Canadians (Implications)

Data Sources and Methods

1. IPSOS survey
 - Present data a survey of Canadians
2. Studies on what patients, families, and providers value at end-of-life
 - Qualitative and survey research
3. Study on essential elements of palliative home-care programs
 - Review of systematic reviews that had positive outcomes

2. Findings

1. IPSOS Survey

Asked to rank 15 essential elements of a palliative home care program

1. 24/7 access to a nurse (91%),
2. Daily assistance with caregiving (91%),
3. Access to equipment as needed (91%),
4. Panic alerts/buttons for patients when left alone (91%),
5. Education and information for caregivers (91%),
6. Someone in the system to coordinate care (91%), and
7. A single access point (i.e., one number to call) for help (90%).

Major themes v1: IPSOS Survey

Timely and responsive

- 24/7 access to a nurse
- Panic alerts/buttons for patients when left alone

Managing Symptoms

- Daily assistance with caregiving
- Access to equipment as needed

Education & Preparedness (Pt & Family)

- Education and information for caregivers
- Someone in the system to coordinate care

Communication across settings

- A single access point (i.e., one number to call) for help

2. What Patients, Families, Providers feel

1. Accessibility when needed,
2. Good pain and system management,
3. Provision for non-physical needs,
4. Preparedness for family caregivers,
5. Control over the care process, and
6. Compassionate and respectful care.

Major themes v2: qualitative survey research

Timely and responsive

- Accessibility when needed,

Pain, symptoms non-physical

- Good pain and symptom management,
- Provision for non-physical needs,

Education & Preparedness (Pt & Family)

- Preparedness for family caregivers,

Communication across settings

Dignity, respect, control, personal, customization

- Control over the care process, and
- Compassionate and respectful care.

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3. Review of Positive Home care Studies

1. Homecare linkage with hospital, primary care, and other community agencies;
2. Presence of a multidisciplinary team;
3. Providers with palliative care expertise or training;
4. Pain and symptom management;
5. Management of non-physical symptoms;
6. On-call around the clock accessibility;
7. Needs-driven customized care plan.

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Major themes v3: Review of Positive Studies

Timely and responsive

- On-call around the clock accessibility;

Pain, symptoms non-physical

- Pain and symptom management;
- Management of non-physical symptoms;
- Providers with palliative care expertise or training;

Education & Preparedness (Pt & Family)

Communication across settings

- Homecare linked with hospital, primary care, community, etc.
- Presence of a multidisciplinary team;

Dignity, respect, control, personal, customization

- Needs-driven customized care plan.

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3. Implications

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Major themes v4: Implications

Timely and responsive

- Timely and responsive;

Pain, symptoms non-physical

- Pain and symptom management;
- Managing holistic, non-physical symptoms;

Education & Preparedness (Pt & Family)

- Patient and family preparedness;

Communication across settings

- All settings working as 1 team;

Dignity, respect, control, personal, customization

- Build on local strengths

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All settings working as one team

Communication across settings

- Good homecare inextricably linked to good care beyond settings
 - Linkages between different settings and providers
 - Leads to improved transitions, communication, collaboration
- Good homecare needs to build strong primary care capacity
 - Enable specialist providers to train and mentor generalists
- Requires dedicated resources for inter-professional team building
 - Need to foster mechanisms to build trusting relationships

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Manage Pain & Symptoms at home

Pain, symptoms
non-physical

- Need workforce where *all* providers have basic palliative care skills
 - some have specialized training
 - frontline workers can consult specialized providers as needed
 - work together in proactive planning
- Need avenues to facilitate mentorship & bedside training (↑ capacity)
- There is decent access to equipment in the home
- Barriers exist to accessing pain management medications readily
 - e.g. provincial drug coverage policies, access to physician to write prescriptions, lack of after-hours access or delivery, etc).

Manage Holistic, Non-Physical Symptoms

- Want to comprehensively address the social, mental, physical, and spiritual dimensions of dying.
- Requires building and supporting inter-professional teams
 - including nurses, social workers, pharmacists, psycho-spiritual counsellors, bereavement workers, etc.
 - team with diverse skills can customize care and address diverse needs
 - Leads to relieving all forms of suffering and improving quality of life.

Pain, symptoms
non-physical

Timely and Responsive

Timely and responsive

- Enable access to a member of the team when crisis occurs
 - alongside education and proactive symptom management
- 24/7 is ideal; but extended-hours (e.g. 7am-9pm) also effective
 - with clear instructions for families on what to do in off-hours
- Includes early identification

Patient and Family Preparedness

Education & Preparedness (Pt & Family)

- The patient and the family as one unit
- Requires education and guidance to the patients and families about what to expect as function declines and disease progresses
 - involves clarity on care expectations and service limitations.
- Includes caregiver respite and assistance with caregiving
- Includes coordination

Build on Local Strengths

Dignity, respect,
control, personal,
customization

- Context matters. A one-size-fits-all approach often fails.
- Requires building on local relationships and existing resources.
- Recommendations cannot be too rigid in structures and processes.
- Core elements should be standardized; how to achieve them should be flexible
 - E.g. Chart in home can improve communication, but is not the only solution
 - E.g. Panic button can support timely response, but is not the only solution
- Solutions need to be derived from the local context and local providers
- Relates to differences between rural-urban, First Nations communities, etc.

7 Patient Commitments

- We will provide dedicated expertise 24/7 so you never feel alone
- We will communicate and connect as providers so you don't have to repeat your story numerous times
- We will respond in a timely and effective manner so you experience minimal discomfort and distress
- We will attend proactively to the wellness of your mind, body and soul so all forms of suffering can be alleviated
- We will provide education and guidance so you can prepare for what lies ahead
- We will support you to resolve personal affairs and realize goals so you can feel fulfilled and at peace
- We will serve as advocates so you can achieve the type of care, and death, you desire

Conclusion

Timely and responsive

- Timely and responsive;

Pain, symptoms non-physical

- Pain and symptom management;
- Managing holistic, non-physical symptoms;

Education & Preparedness (Pt & Family)

- Patient and family preparedness;

Communication across settings

- All settings working as 1 multidisciplinary team;

Dignity, respect, control, personal, customization

- Build on local strengths

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**Questions?
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