Program Overview

Presentation #1

PEI Provincial Integrated Palliative Care Program





"You matter because of who you are. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die."



-Dame Cicely Saunders, nurse, physician and writer, and founder of hospice movement



What will you learn?

At the end of this presentation, you'll have an understanding of:

- 1. What is Palliative Care?
- 2. The Palliative Approach to Care
- 3. Palliative Care Framework and Shared-Care Model
- 4. Provincial Integrated Palliative Care Program (P-IPCP)
- 5. P-IPCP Roadmap and Key Priorities
- 6. Program Statistics
- 7. Where we have come
- 8. Referral Process



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What is Palliative Care?

Palliative Care is an approach that improves the quality of life of patients and their families facing the problem associated with life-limiting conditions, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." (World Health Organization, 2013)

Palliative Care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- □ Enhances quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications





Evolving - Palliative Approach to Care



Palliative Care used to be viewed as a specialty team or program that occurred only in a hospital or palliative/hospice setting and only offered in the last few days/weeks of life, and usually only to cancer patients.

We think of it as a philosophy or approach to care.

Can benefit people with any progressive and life-limiting illness, not just cancer

Should be integrated into all care settings

Offered by all health care providers who provide primary care

Focuses on relief of pain and other symptoms including physical, psychological, social and spiritual





Palliative Care is not about dying; it is about living well until the very end.



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Integration?

INTEGRATION

The act of bringing together smaller components into a single system that functions as one

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The Palliative Approach to Care

- This approach makes key aspects of palliative care available in the regular care patients receive from their primary care provider, at home, in long-term care, in the hospital or community settings
- It is s Shared-Care Model with Generalists, Local Palliative Care Teams and the Provincial Integrated Palliative Care Team
- Regardless of the setting of care (primary care, at home, in long-term care, in the hospital or in other community settings), the patient and family would receive:
 - Communication about prognosis and illness trajectory,
 - Advance care planning,
 - Psychosocial and spiritual support,
 - Symptom screening and management,
 - > A plan for emergencies, and
 - Referral to expert palliative care services

if required for more complex needs.

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The Palliative Approach to Care

The delivery of Palliative Care is based on the philosophy of the *palliative approach to care*. Essential components of the palliative approach to care include:

- □ Identify patients who would benefit from a palliative care approach **earlier** in their illness
- Discuss prognosis and goals of care with these patients and families at some point need to discuss meaning of "family"
- □ Initiate Advance Care Planning conversations
- Assessing and managing physical and psychological symptoms at a basic level
- Identifying social and spiritual needs
- Connecting patients with palliative care and end-of-life (EOL) resources as needed
- Consulting and referring to specialist level of palliative care clinicians and services if they need assistance because the complexity of patients' needs and circumstances

The palliative approach to care focuses on:

- Patient and family, and on their quality of life throughout the illness, not just at the EOL
- Person's autonomy and the right to be actively involved in his/her own care strives to give patients/families a greater sense of control
- □ Treating an illness, pain and other symptoms including those related to the treatments especially as the illness progresses and more complications occur
- Preserving the quality of the patient's life so that their suffering is minimized but their experience of life is not

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Framework - Integrated Palliative Approach



A palliative care approach is a Shared-Care Model where -

Generalist care providers such as primary care providers, home care nurses, long-term care staff, hospital staff and other health care workers will provide an integrated palliative care approach

Local Palliative Care Teams (coordinated by Home Care Palliative Care Coordinators in each of 5 regions) with specialized palliative care knowledge will provide support and consultation for generalist care providers as necessary within their local care setting

Provincial Integrated Palliative Care Team

(palliative care physicians, nurses, social worker, spiritual care adviser - located at the Provincial Palliative Care Centre) will provide expert palliative care knowledge to the Local Palliative Care Teams and to Generalist care providers as necessary

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Shared-Care Model

Decision-making is shared by Interdisciplinary Care Team, Patient/Family/ Substitute Decision Maker/Proxy and the Provincial Integrated Palliative Care Team, with the P-IPCP focusing on all palliative care needs and supporting the Interdisciplinary Care Team's capacity to provide care.



Shared-Care Model Levels of Expertise

Generalist

- Care providers have basic understanding of palliative care and core competencies and provide general care for patients with less complex needs
- Provide moderate level care for patients with increased needs





Shared-Care Model Levels of Expertise

Local Palliative Care Teams

Generalist care level care provided by clinicians who act as resource persons for palliative care in their setting of care, but for whom palliative care is not sole focus of their clinical practice



Shared-Care Model Levels of Expertise

Provincial Integrated Palliative Care Team

Specialist expert knowledge of palliative care

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- Professionals working solely in the field of palliative care and whose main activity is devoted to dealing with complex patient needs requiring specialized skills and competencies
- Provide consultation and support for Local Palliative Care Teams and Generalist Care providers for patients with more complex needs
- Support education of health care providers in all care settings



Provincial Integrated Palliative Care Program (P-IPCP)

- Established 2004 prior two completely independent initiatives rural palliative care project and 8-bed unit at the former Prince Edward Home
- Home Care is the single point of entry to the P-IPCP
- Vision:

All Islanders faced with a life-limiting illness can access integrated, informed, personcentred, quality palliative care in setting of their choice

- Guiding Principles:
 - Integrated across care sectors, disciplines and province-wide from diagnosis to bereavement

One Island Health System

- **Person-centred** and **inclusive** of family, as defined by the individual
- Flexible and culturally competent
- Inclusive of staff and caregiver support
- High quality care which meets accreditation standards
- Focus on preserving quality of the recipient's life so that suffering is minimized but their experience of life is not
- Supports a Shared-Care Model

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The Program

- Standardized Provincial community-based program, fully integrated in 5 regions
- Program is part of the Family & Community Medicine & Hospital Services West Division
- Managed by a Provincial Integrated Palliative Care Team Medical Consultant, Resource Nurse, Drug Program Manager/Social Worker, Spiritual Care Advisor (all located at Provincial Palliative Care Centre) and 7 Home Care Palliative Care Coordinators and district nurses who provide palliative care in five Home Care delivery sites – O'Leary/Alberton, Summerside, Charlottetown, Montague, Souris
- Pharmacists, physiotherapists, occupational therapists, dietitians, hospice volunteers, bereavement coordinators and other provide expertise to Team as required
- 2 full-time palliative care physicians as well as 7 GPs with interest support
- Program delivers services in a number of care settings Home Care, LTC, Provincial Palliative Care Centre (10 beds), PCH (6 beds), O'Leary (4 beds), designated palliative care beds located in the community hospitals (7 beds),

and the PEI Cancer Treatment Centre and PCH site

Program has had significant growth from 340 patients in 2010/11 to 647 patients in 2017/18

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Our Roadmap

In 2015, the Executive Leadership Team of Health PEI mandated the development of a palliative care action plan for PEI to guide the work of the Provincial Integrated Palliative Care Program for the next five years.

The Health PEI Palliative Care Framework and Action Plan 2105-2020 is our roadmap.

Our Goals

- Decrease hospitalizations and length of stay in acute care/increase in home death
- Significant reduction in the cost associated with EOL care
- ✓ Improve use of acute care resources
- Improve quality EOL care for patients and their families, by standardizing practices, providing continuity of care and seamless transitions
- Improve facilitation of EOL issues between patients and families
- Improve communication between patients, families and health care providers by a shared knowledge of the illness trajectory
- Provide a model fro collaborative practices in today's health care system



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Our Program Priorities

- Formalization & designation of beds
- Adoption of the level of care
- Clear intake & flow process
- Adoption of best practices & guidelines
- Clear reporting & governance structure
- Standardization
- Early integration of palliative care



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Palliative Care Statistics

- Fewer than 1 in 6 (15%) who died in 2016/17 received publicly funded palliative home care (CIHI, 2018)
- □ 75% of population wishes to die @ home/only 19/20% do (PEI, 2013)

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- □ PEI had 1,270 deaths (2015) with <30% receiving service from palliative care
- 94% of patients who died in hospital could potentially have benefitted from palliative care during their final stay (CIHI, 2018)
- No. of Specialists/Subspecialists in Palliative/Pediatric Palliative Medicine across Canada is 51 physicians (CSPCP, 2017)
- 26% of physicians are very comfortable discussing Advance Care Planning (ACP) with patients, and one quarter of physicians/nurses across Canada know little or next to nothing about ACP (CSPCP, 2017)
- Recent research from CIHI (2018) indicated that patients who received palliative care earlier, were less likely to visit emergency departments frequently or to receive aggressive treatment at the end of life



Program Statistics

Year	10/11	11/12	12/13	13/14	14/15	15/16	16/17	17/18
Total Clients	340	405	461	436	558	618	647	647
New Clients						428	493	418
Deaths					378	400	316	426
LOS All Patients						154 days	159 days	188 days
ER Visits for Patients on IPCP						307	448	595



Where We Have Come



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Where We Have Come

- 2004 Launch of Provincial Integrated Palliative Care Program
- 2004 Health Council Award "One of the Six Best Practices" in Canada
- Ongoing development of the specialized integrated palliative care team
- 2007 LEAP training for providers ongoing approx.100 to-date with goal 50% of all providers
- 2008 Palliative Home Care Drug Pilot (ongoing)
- 2010 Long-Term Care Quality Improvement Pilot (1 year)
- 2010 First Annual Provincial Palliative Care Conference
- **2010** Acute Care Quality Improvement Pilot (1 year and ongoing)
- 2014 "Paramedics Providing Palliative Care at Home" program
- 2015 LEAP training for all Paramedics
- 2015 Palliative Care Framework and Action Plan developed
- 2015 Adoption of Australian Model for Population-based Palliative Approach
- 2015 Opening of the new 10-bed Provincial Palliative Care Centre
- 2015 Implementation of Provincial Advance Care Planning Policy
- 2016 "Person-Centred Perspective Goals of Care/Advanced Care Planning" project (1 year)
- □ 2018 "Early Integration of Palliative Care" project (4 years)

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What happens once you made a referral?

- Referrals to the Program can be made by completing the Provincial Integrated Palliative Care Program Client Referral form found at local health care facilities
- Referrals are received by each Regional Home Care office and go through an intake process to determine which service is the most appropriate at this time. It may be *"palliative and end of life"*
- Intake Nurse determines if the need is LOW, MEDIUM or HIGH and refers to the appropriate Regional Home Care Coordinator who will set up an appointment with your patient
 - After assessments, you will be contacted by the care coordinator. At all times, although we will make suggestions and recommendations, you will remain the primary care provider for your patient



Patient Flow

- All patients admitted to palliative care beds are part of the P-IPCP even if not receiving community services
- Clinical practice guidelines, best practices and standards for the Program have been determined in collaboration with many partners including the medical consultant, Director of the division and the Provincial Palliative Care Quality Team
- A number of clinical indicators for patient care are determined and reported on regularly by the Provincial Palliative Care Quality Team assigned to the Program



What Does Improved Palliative Care Look Like



A common language and baseline skill set for all care providers Applying a palliative approach in all care settings



INTEGRATION

The act of bringing together smaller components into a single system that functions as one



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Recognition that everyone has a role to play. The approach is based on collaboration between all providers including communities partners

A change in attitudes and knowledge about end of life and death



References and Resources

- Health PEI Palliative Care Framework and Action Plan 2015-2020
- <u>https://src.healthpei.ca/palliative-care</u>
- <u>https://www.cihi.ca/sites/default/files/document/access-palliative-care-2018-en-web.pdf</u>
- https://pallium.ca/
- <u>http://spiritualcare.ca/download/nova-scotia-palliative-care-competency-framework-2017/?wpdmdl=9810</u>
- <u>http://hpcintegration.ca/</u>



Resources

Videos:

Mayo Clinic, 10 things palliative care clinicians wished everyone knew about palliative care <u>http://medprofvideos.mayoclinic.org/videos/ten-things-palliative-care-clinicians-wished-everyone-knew-about-palliative-care</u>

Get Palliative Care, September 2014, Palliative Care: YOU Are a Bridge https://youtu.be/IDHhg76tMHc

The BMJ, March, 2017, Palliative care from diagnosis to death https://youtu.be/vS7ueV0ui5U

Pallium Canada, 2015, Palliative Myths – Episode 1 https://youtu.be/HvguLSL-AJU

Pallium Canada, 2015, Palliative Myths – Episode 2 https://youtu.be/NUH3ukYPk5k

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