

# The Way Forward



**A Roadmap for the Further Development  
of the Integrated Palliative Approach to Care  
for Prince Edward Island**

March 2015

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### Background and Summary

In 2012, **The Way Forward** project was launched. This project is a three year collaborative initiative, supported by one-time funding (\$3 million) from the Government of Canada, encompassing 37 organizations that make up the Quality End-of-Life Care Coalition of Canada (QELCCC) and the Canadian Hospice Palliative Care Association (CHPCA). The main focus of the project is to identify and share best practices, and develop tools and resources to better integrate a palliative approach across all settings of care, including home care, long-term care, acute care, and primary care. The cornerstone of the project is **The Way Forward National Framework: A Roadmap for the Integrated Palliative Approach to Care**. The National Framework is a practical and implementable roadmap developed with and for system planners, policy makers and service providers across all settings of care to help identify and remove barriers to integrating hospice palliative care.

After consultation in 2012 and 2013, a first draft of the National Framework was circulated across the country for feedback with the final version anticipated to be completed by 2015.

The PEI Provincial Integrated Palliative Care Team (P-IPCT) has been fortunate to have at its disposal the National Framework to use as a roadmap for the further development of a fully integrated palliative care service for all Islanders. This paper provides a brief overview of the current structure of Palliative Care on PEI and highlights its success stories and achievements that demonstrate consistency with **The Way Forward**. The paper also outlines next steps towards a fully integrated Palliative Care system for PEI using **The Way Forward** as a guide.



## Overview of Hospice Palliative Care on PEI

In Prince Edward Island (PEI), the practice of hospice palliative care is relatively young with its roots in care planted in the late 1970's.

By way of definition, palliative care is the combination of active and compassionate therapies intended to comfort and support individuals who are living with or dying from a progressive life threatening illness, their families and the bereaved. The focus of care is on preserving the quality of the individual's life so that their suffering is minimized but their experience of life is not. Palliative care is not about dying: it is about living well until the very end (Health PEI).

The P-IPCP (Provincial Integrated Palliative Care Program) is managed and coordinated by the Provincial Integrated Palliative Care Team (P-IPCT), an inter-professional team that includes a Medical Consultant, Resource Nurse, Drug Pilot Program Manager/Social Worker, and Spiritual Care Advisor. The main focus of the team is providing tertiary palliative care services for the province and being available for consultation and support in the care of patients/their families who are experiencing complex issues including pain or other symptoms in all care settings. Home care staff (care coordinators and district nurses) work with the team to assist with the patient assessment and care coordination, advanced care planning, pain and symptom management and end of life care. As well, pharmacists, physiotherapists, occupational therapists, hospice volunteers, bereavement coordinators and others provide expertise to the team as required.

The P-IPCP encompassed the delivery of service in a number of care settings including home care, long-term care, the Provincial Palliative Care Unit, Prince County Hospital Palliative Care Unit, O'Leary Palliative Care Unit, Queen Elizabeth Hospital, designated palliative care beds located in the community hospitals, and PEI Cancer Treatment Center. Patients can be referred to the program through many sources including family members, physicians and other health care providers.

The program recognizes the critical importance of the patient/doctor relationship and therefore aims to encourage primary care physicians to remain actively involved in the care of the patient and family.

Since the official launch of the P-IPCP in 2004, a number of achievements have been accomplished consistent with **The Way Forward** document to create a seamless network of palliative care services for PEI. In 2004, the program was presented a Health Council Award for "One of the Six Best Practices" in Canada. This award was the launch to many ongoing successes for the program as follows:

- **Making palliative care a core service and unique administrative program.** Since 2004, the province has made palliative care a more distinct program of the health system with the formation of the P-IPCP. The role of the program continues to evolve as additional resources are added to the team. Even though the province has recognized palliative care as a distinct program, this program requires official designation as a "core" service. Palliative care must become part of the larger discussion about strategic direction in the PEI health care system.
- **Developing a specialized inter-professional palliative care team.** The province has developed a specialized integrated palliative care team to coordinate hospice palliative care services. The Team integrates with other services such as home care to fill gaps and facilitate care and support staff across all sectors of care through consultation, education and development of provincial standards. In addition, six Palliative Care Home Care Coordinators, who work under the direction of the Director of Home Care, provide holistic assessment and care coordination for every patient referred to the program.



- **Making strategic use of palliative medicine specialists.** Medical leadership to the P-IPCT is provided by a palliative care medical consultant who has extensive training in palliative care. This expert along with a team of GPs who are skilled in palliative care, support the integration of the Palliative Approach to care and are a bridge between palliative care services and all care settings. They work closely with the client's family physician to plan and coordinate ongoing care.
- **Providing psychosocial, spiritual and respite support for patients/families.** The P-IPCT provides social work, spiritual advisors, counseling, support by volunteers, referral services to other agencies for patients and families, and bereavement support for families. Hospice volunteers are involved in friendly visiting, transport, and bereavement support. Respite care is also provided.
- **Consulting to care settings.** The P-IPCT includes a palliative care nurse consultant who provides specialist nursing advice, assessment, procedures, specific staff education and telephone follow-up to meet the care needs of a specific client.
- **Building relationships and capacity of acute care and long-term care providers.** During the past five years, the team has made great strides towards building relationships in acute care and long-term care settings. Specific examples include the implementation of the Long-term Care Quality Improvement Pilot (Appendix A) providing consultation, support and education for long-term care providers in the health system. This Pilot was initiated after a provincial needs assessment (summer 2010) and a family meeting (fall 2011) identified gaps in the system and needs of staff, patients and families around palliative and end of life care and communication during the dying process. The initiative aimed to embed the palliative care model into the long-term care setting (both Prince Edward Home and Beach Grove Home). This pilot has resulted in decreased stress on caregivers, increased knowledge and comfort of staff in providing palliative care. It also has eliminated the transfers from LTC to acute care when a registered patient in the pilot is identified as dying. Another example included the implementation of the Acute Care Quality Improvement Pilot in 2012 (Appendix A) at the Queen Elizabeth Hospital. This pilot project also provided consultation, support and education for acute care providers in the health system. It involved patients on the P-IPCP through the Home Care Program who were admitted to the Queen Elizabeth Hospital, the province's main referral hospital. The initiative was aimed to better meet families/patient's needs (short term) as well as introduce the palliative care approach/model into the acute care setting (long term). In addition, one of the objectives was to satisfy families, patients and staff. It has resulted in a decrease in the length of stay in acute care by 2.1 days and a vast decrease in the rate of readmission to acute care over the remainder of their illness and until death (HPEI data).
- **Creating a network of hospice, hospital and community services.** Health PEI has three palliative care units that provide a total of 20 beds. Within those 20 beds, 10 would be considered tertiary palliative care beds. In addition, the province has 4 designated palliative care beds in the smaller community hospitals. Hospice PEI and Southern Kings Hospice are two community-based services that provide volunteers and bereavement support for the P-IPCP. As well, the P-IPCT works with the inter-professional team of the Provincial Cancer Treatment Center to provide education and improve their capacity to provide end of life care. The Cancer Patient Navigator position for cancer patients acts as an advocate, educator and support person linking patients with the care and support they need.
- **Investing in education.** Education is a priority for P-IPCT and key to facilitating the integration process. Education is provided in all care settings and the focus is based on the provision of quality evidence informed palliative care. We currently have six facilitators certified to provide the LEAP (Learning



Essential Approaches to Palliative and End of Life Care) program offered by Pallium Canada. These team members are presently conducting LEAP sessions for approximately 90 health care professionals across care settings. It is the goal of the team to ensure that all health care professionals across all care settings receive training in palliative and end of life care. The inception of an annual Provincial Palliative Care Conference in 2010 is playing a vital role in the development of palliative care across the province and helps to educate professionals in all sectors of the PEI health system. In addition, a number of educational resources for patients/families/care givers have been published including: *“Living Well with a Life-limiting Illness”*; *“Care for the Dying”*; *“Ten Things to Know about Grief”*; *“Help for the Bereaved – The Healing Journey”*; *“Child and Teen Grief”*; *“Advance Care Planning Booklet”* and *“Making Informed Decisions About CPR.”*

- **Providing palliative care at home – A collaborative effort.** In addition to our community services, Health PEI partnered with Nova Scotia in 2014 to implement a Canadian Partnership Against Cancer (CPAC) project “Paramedics Providing Palliative Care at Home.” This project is designed to enhance the care provided by paramedics and be an additional support to existing resources for palliative patients and their caregivers. As part of this project, a new palliative Clinical Practice Guideline has been developed which will allow paramedics to assist with palliative emergency/crisis care across both PEI and Nova Scotia. As well, all PEI and NS paramedics (1,500) will be trained in pain and symptom management (one-day LEAP Mini) for palliative care patients in order to provide qualified emergency response teams to manage palliative crises in the home, without the requirement for transport to an Emergency Department. An example of collaboration and integration between health care professionals.
- **Dying at Home.** Presently on PEI, of the 70% of the population who wish to die at home, only 19% do so. In addition, according to *Raising the Bar: A Roadmap for the Future of Palliative Care in Canada. June 2010*, approximately 90% of dying persons could benefit from palliative care. Similar to other provinces, around 30% of the dying population presently receive palliative care services. Recognizing patients desire to remain in their homes as long as possible, the P-IPCP has seen a significant growth in the number of patients participating in the program over the last years (2010/11 - 340 patients, 2011/12 - 405 patients, 2012/13 - 461 patients, 2013/14 - 436 patients, 2014/15 - 477 – Patients served is a count of distinct individuals who received palliative care services from P-IPCP at any time during the fiscal year). From September 2014 - February 2015, 34% of those patients registered in the P-IPCP died at home.
- **Developing standards, guidelines and algorithms for integrated palliative care for each setting.** The implementation of the Palliative Home Care Drug Pilot Project has been a huge initiative to promote the practice of provincial policies and standards related to palliative and end of life care. This Drug Pilot Project continues to provide drug coverage to clients for pain and symptom management and make it possible for eligible patients to receive more of their care and treatment at home, avoiding hospital stays. The project provides medication support for clients whose life expectancy is in months rather than years. Patients are assessed using a variety of tools including PPSv2 and ESAS. The patient must be eligible for PEI Medicare and have no private drug plan and be living at home where home is defined as their home, living with family and friends, or living in a supportive residence. Following determination of eligibility, prescriptions can be written by the family physician and be obtained at the pharmacy of choice with a small co-pay of \$2 per prescription. Covered prescriptions are outlined in a Palliative Care Formulary. Since its’ inception in October 2008, the Drug Pilot Project has provided coverage to 547 patients at an average daily cost of \$9.66 per patient. The goal of the program is to make it possible for eligible palliative care patients to receive more of their health care treatment at home, avoiding hospital stays.



The project has been able to increase the time a patient spends at home during the last months of their lives by 25%. To date, \$9.5 M has been saved through decreased admissions to acute care hospitals. This additional 25% time spent at home has resulted in an estimated 9358 hospital days saved through this project. Also since the inception of this program, the number of home deaths has increased from 12 to 19% (HPEI data).

- **Promoting advanced care planning.** A provincial committee, including representation from the P-IPCT, has been established to develop and implement a provincial policy for advanced care planning and anticipate it to be rolled out across all settings in the next year. The work of this committee will become part of a provincial strategy for advanced care planning.
- **Evaluating outcomes.** The P-IPCP tracks diagnoses, overview of client profiles, % of advanced care planning initiated, total deaths, location of deaths, deaths within 48 hours of admission to hospital, average age and hospital admissions. The program also administers patient and family satisfaction surveys. Recent results indicated that patients were more satisfied with care delivered outside the acute care setting. In home care settings, the electronic system collects the following data: age, gender, visits, phone consultations, PPSv2, and ESAS. The PPSv2 and ESAS tools are used at the service delivery level. ESAS is completed for a patient at each visit. In nursing homes, ESAS, Wong Baker and PAINAD are being used as well as clinical practice guidelines to identify type of treatment required. In addition, we have provided nurses with the necessary training to assist with communicating with families on issues related to end of life care. This training allows nurses to discuss with families what care should be provided, what to treat and how to respond to someone who is dying.
- **Monitoring the program and ensuring quality.** The P-IPCP client assessment process has been standardized across the province and done mostly by Palliative Home Care Care Coordinators. A number of P-IPCP tools have also been standardized and include ESAS, initial holistic assessment, PPSv2, medication profiles and electronic documentation. A standardized home-based Care Plan for patients of the IPCP is developed and this Care Plan remains home for those patients registered in the Program. Work also continues on the implementation of a patient-centered care philosophy for palliative care services across all settings.

To date, for palliative care is the planning for a new stand-alone 10-bed Provincial Palliative Care Center (\$5.6 million) located in Charlottetown in close proximity to the main hospital. This new center will incorporate services such as a day program, respite services, an outpatient clinic and a 10-bed in-patient palliative care unit. It will also provide office space for members of the P-IPCT, Hospice PEI and support education and research at large.

In addition to above listed initiatives (consistent with **The Way Forward** document), the P-IPCT has adopted the Vision statement below. The Team's goal is for all seriously sick and dying residents of PEI regardless of diagnosis, age and location to have the opportunity to benefit from the integrated palliative care approach.



## Vision: FULL INTEGRATION

All Islanders faced with a life threatening illness can access integrated, flexible, culturally competent, patient centered quality palliative care in the setting of their choice, regardless of diagnosis, age and from diagnosis to bereavement.

## Next Steps on PEI

The P-IPCP is going through a phase of further enhancement and development. **The Way Forward** document has adopted the Australian Population-based Palliative Approach Model (see below) as the approach to continue to build the Integrated Palliative Care Programs into the future. This approach emphasizes that “the integrated palliative approach is a way of providing care and not a specialized set of services, it can be provided in all settings in the community where the person lives or is receiving care, including in the primary care provider’s office, at home, in long-term care facilities, in hospitals, and in shelters, on reserves and prisons.”

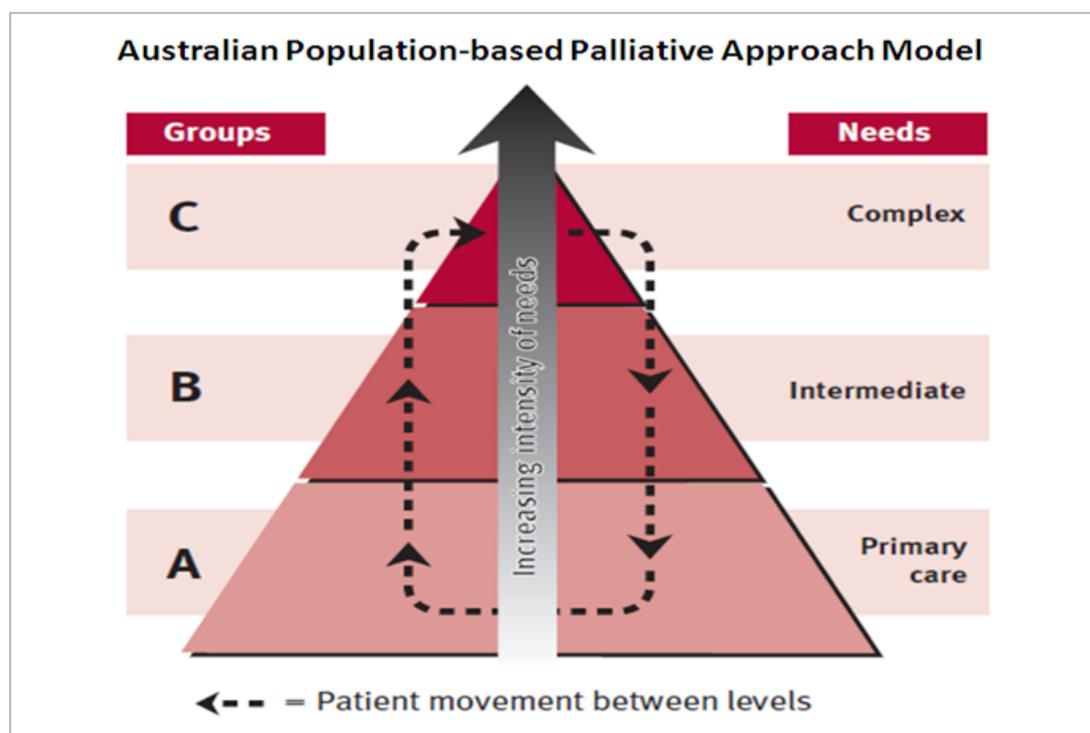


Exhibit 4. Original Australian model for population-based palliative approach [see Palliative Care Australia 2005, p 13]

**Group A (Primary Care)** – are those patients who do not require access to specialist care as their needs are met either through their own resources or with the support of primary care providers (for example, generalist medical and nursing as well as other specialist staff – pulmonary cardiac services, renal and so on).

**Group B (Intermediate)** – are those patients who may have sporadic exacerbations of pain or other physical symptoms or may experience social or emotional stress. This temporary increase in their level of need may require access to specialist palliative care services for consultation and advice. They will continue to receive care from their primary care provider.

**Group C (Complex)** – are those patients who have been identified as having complex physical, social, psychological and/or spiritual needs that do not respond to simple or established protocols of care. They usually require



highly individualized care plans developed, implemented and evaluated by knowledgeable and skilled specialist practitioners, in partnership with primary care providers. This group is likely to be the smallest of the three sub-groups of the population.

If the Australian model is adopted, a key role of the P-IPCT (Specialist Team) is to support generalist care teams in each care setting to become better skilled and more confident as they provide a significant amount of the integrated palliative approach to care. Another key role of the P-IPCT is to focus its work on the provision of tertiary care services, for complex palliative cases (Group C). The P-IPCT did adopt this model of care and the next step is to revisit the job descriptions for the Team and each member of the Team for the delivery of the integrated palliative care approach for PEI following this model.



### **Role of Specialist Team (Provincial Integrated Palliative Care Team)**

- Adopt the vision, goals and principles of an integrated palliative approach to care
- Strategic planning for P-IPCP
- Establish policy expectations for all care settings and providers
- Develop the tools that care settings need to provide the integrated palliative approach to care
- Advocate for legislation/regulations, where required
- Establish guidelines/standards of care consistent with national norms for palliative care
- Provide care to people who have complex physical, intensive or tertiary palliative needs that do not respond to simple or established protocols of care
- Support education of health care providers in all care settings



- Consult and provide advice to primary care providers as required
- Support communication across settings and seamless care transitions
- Develop a communications strategy to ensure patients and public understand the integrated palliative approach to care
- Provide on-call, after-hours, or weekend services to reduce the burden on primary care providers when required
- Establish the indicators and monitoring system to assess progress and evaluate impact of P-IPCP
- Support generalist teams to become better skilled and more confident in their integrated palliative approach to care
- Determine the role of the generalist teams in each care setting

In Support of **The Way Forward** document, the following next steps will be considered towards creating a fully integrated palliative service of care for PEI:

1. That the P-IPCT lobby immediately to have palliative care recognized as an official core service of Health PEI and that all palliative care related services and resources across the province be identified and become officially part of P-IPCP.
2. That the P-IPCP become a strategic initiative in the health care system and support the integrated palliative approach in all four main care settings – primary care, long-term care, home care and acute care.
3. That the P-IPCP become part of a larger discussion on the development of an integrated model of care for collaborative practices on PEI.
4. That the P-IPCP adopt the Australian Population-based Palliative Approach Model as the approach to continue to build the P-IPCP into the future and that upon the adoption of this model, the role of the P-IPCT be communicated across all care settings of HPEI including the role of the generalist care teams for each care setting – long-term care, primary care, home care, acute care.
5. That the further development of the P-IPCT be a priority for the Division of Community Health including the addition of Team members to support the Team’s mandate in providing tertiary care services and supporting and developing generalist care teams across all care settings.
6. That the P-IPCT embark on a Provincial Strategy for Palliative Care to support the further development of a fully integrated palliative care program for the province and that the immediate consideration be given to the hiring of a project lead to assist with the development of this Strategy encompassing the recommendations outlined in **The Way Forward National Framework** and this report.
7. That the main goal of the Provincial Strategy be to develop “An integrated collaborative approach which promotes flexible, seamless, patient-centered, high quality evidence based palliative care for Islanders in the setting of their choice.”



8. That the Provincial Strategy address the following key components for the integrated palliative care approach to care for PEI:
  - a) Vision, Goals and Principles
  - b) Policy Expectations for all Care Settings and Providers
  - c) Guidelines and Standards of Care - Accreditation Standards and Standards for Person- Centered Care
  - d) Promotion of a Culture Shift
  - e) Integration of Services and Disciplines
  - f) Education: Palliative and end of life care education to all health care providers, public and family caregivers focusing on standardized teaching modules and best practice models
  - g) Capacity Building
  - h) Provincial Strategy for Advanced Care Planning
  - i) Remuneration Systems and Incentives to Support the Delivery of the Integrated Palliative Approach
  - j) Communications Strategy
  - k) Indicators and Monitoring System to Assess Progress and Evaluate Outcomes
9. That a single central number to call to access the P-IPCP and/or P-IPCT be established and staffed 24/7 to provide virtual support for health care practitioners. This service will provide consultation and advice for providers in all settings providing the integrated palliative approach.
10. That the P-IPCT continue to build relationships with all sectors and settings – primary care, acute care, long-term care and home care to help ensure seamless transitions between settings.
11. That the P-IPCT identify core competencies and education programs for all staff working in palliative care regardless of setting.
12. That P-IPCT develop or adapt policies, guidelines and algorithms to guide the integrated palliative approach in all care settings.
13. That P-IPCT establish indicators that could be used across settings to assess both progress in implementing the integrated palliative approach and its impact on quality care and quality of life.
14. That P-IPCT identify and track indicators for palliative care in acute care, long-term care, home care and primary care.
15. That P-IPCT rollout the provincial strategy for advance care planning and develop and implement an educational module for all health care providers for the province.
16. That P-IPCT help build system capacity to provide culturally appropriate care across the province including adapting guidelines and algorithms to provide culturally appropriate services in Aboriginal communities and in diverse ethnic communities in PEI.



17. That P-IPCT extend the work of the recent Long-Term Care Quality Improvement Pilot project to all other long-term care facilities across the province by:

1. Building strong links with hospice palliative care volunteers and other community agencies to continue to care for the person in the LTC facility with support from experts.
2. Modifying staffing strategies where possible in LTC settings when a resident is nearing end of life.
3. Integrating hospice palliative care and end-of-life care education into mandatory education programs for LTC staff and supporting physicians.
4. Ensuring tools and guidelines are practical, accessible and easy to use in providing palliative care services to LTC.
5. Collecting data and measuring outcomes.
6. Sharing best practice in palliative care in LTC within the LTC sector.
7. Talking to families about the capacity of LTC to provide good quality palliative and end of life care.

18. That P-IPCT extend the work of the recent Acute Care Quality Improvement Pilot project to all other acute care facilities across the province by:

1. Building strong links with hospice palliative care volunteers and other community agencies to continue to care for the person in acute care facilities with support from experts.
2. Integrating hospice palliative care and end of life care education into mandatory education programs for acute care staff and physicians.
3. Ensuring tools and guidelines are practical, accessible and easy to use in providing integrated palliative care services to acute care.
4. Collecting data, measuring outcomes and enhancing capacity to appropriately recognize and “code” palliative patients and monitoring impact of the integrated palliative approach.
5. Sharing best practice in palliative care in acute care within the acute sector.

19. That P-IPCT develop a province-wide plan (as part of the Provincial Strategic Plan) to market palliative and end of life care that would augment the national efforts already underway through **The Way Forward** project.

The P-IPCT has been fortunate to have at its disposal **The Way Forward** National Framework to use as a roadmap for the further development of the integrated palliative approach to care for all Islanders. The Team will continue to focus their efforts on the priorities as outlined in the Framework to ensure that all Islanders have access to high quality hospice palliative and end of life care.



## APPENDIX A

### Long Term Care Pilot

The Long Term Care (LTC) Pilot was introduced to provide support and education to staff in LTC and decrease the number of transfers to acute care for dying residents. Five goals for the program were established:

- Provide support and continuity of care for the patient and family units as they go through the dying process.
- Decrease stress on families.
- Decrease transfers to acute care hospitals for end of life care and enable residents to die in their place of residence.
- Increase capacity in service delivery by educating medical and nursing staff about end of life care.
- Provide support to all staff.

An evaluation framework was established and the integration of the P-IPCP team into LTC resulted in very positive outcomes for residents, families and staff and no further transfers to acute care for dying residents.

### Acute Care Pilot

In the fall of 2011, a meeting was held with the families of patients who were registered in the P-IPCP the previous year. The focus of the meeting was to identify both the strengths and weaknesses of the service. The major concern resulting from the evening were directed at the acute care settings. Families expressed concerns with the lack of pain and symptom management and felt a general lack of support within the acute care environment. An Acute Care Pilot initiative was introduced to respond to these concerns. Four goals were identified:

- Provide support and continuity of care for the patient and family unit as they move between care settings.
- Increase capacity in service delivery by educations and supporting medical, nursing and other staff.
- Decrease length of stay in acute care.
- Provide support to Home Care Palliative Case Managers as patients return to community settings.

A comprehensive evaluation was conducted and the program surpassed its goals in terms of overall success.

