



AN INTEGRATED PALLIATIVE APPROACH TO CARE • DES SOINS QUI INTÈGRENT L'APPROCHE PALLIATIVE



INNOVATIVE MODELS OF INTEGRATED HOSPICE PALLIATIVE CARE

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



Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs



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Prepared for: Canadian Hospice Palliative Care Association
Prepared by: Janet Dunbrack

Production of this document has been made possible through a financial contribution from the Government of Canada.

The views expressed herein do not necessarily represent the views of the Government of Canada.

For citation: Canadian Hospice Palliative Care Association, *Innovative Models of Integrated Hospice Palliative Care, The Way Forward Initiative: an Integrated Palliative Approach to Care*, 2013.



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ACKNOWLEDGEMENTS

We are grateful to all the reviewers for their valuable contributions to review, evaluate and comment on this discussion document, including:

Dr. Doris Barwich, Carolyn Tayler and Sue Young, Fraser Health, Canada

Dr. Robin Fainsinger and Dr. Doreen Oneschuk, Edmonton Zone Regional Palliative Care, Canada

Ann McKim and Dr. David Henderson, Colchester East Hants Health Authority, Canada

Dr. Jo Hockley, St. Christopher's Hospice, England

Chris Elgar and Hilary Lawson, Dorset Primary Care Trust, England

Alice Fuller, National Council for Palliative Care, England

Dr. Simon Allan, Arohanui Hospice, New Zealand

Ginny Green and Dr. Sue Marsden, Otago Community Hospice, New Zealand

Suzanne Brocx, North Haven Hospice, New Zealand

Mary Schumacher, Hospice New Zealand

Saskia Booiman, New Zealand Ministry of Health

Dr. Roderick MacLeod, HammondCare, Australia

Dr. Robyn Brogan and Denise Parry, Department of Health and Human Services, Tasmania, and Judith Harris, University of Tasmania, Australia

Fred Miegel, Palliative Care Northern Territory – Central Australia

Mark Cockayne, Silver Chain, Western Australia

Dr. Yvonne Luxford, Palliative Care Australia

Nadine Henningsen, Canadian Home Care Association

Irene Nicoll, Canadian Partnership Against Cancer

Julie Lachance, Health Canada





PREFACE

This paper is one of a series commissioned by The Way Forward initiative, guided by the Quality End of Life Care Coalition of Canada and the Canadian Hospice Palliative Care Association. This document will inform the development of a national framework for the integrated palliative approach to care that can be used across all settings of care – in the communities and locations where people and their families receive care and where they would prefer to die. The goal is to make high quality hospice palliative care services available to more Canadians in all care settings and earlier in the course of life-limiting conditions.

HOSPICE PALLIATIVE SERVICES FACING GROWING PRESSURES

Populations in jurisdictions across Canada and around the world are aging. Canada recently reported – for the first time – more people retiring than people entering the workforce. Hospice palliative and end-of-life care services in all jurisdictions are facing similar pressures from the aging population and from changing needs and expectations:

- In the past, hospice palliative care was provided only in the last six months of life. With advances in treatment, time of death is less predictable and people with a wide range of chronic life-limiting illnesses now need hospice palliative care services over a longer period of time.
- Patients and families want hospice palliative care provided at home – wherever home may be – by their family physician or care team.
- Health care systems want to reduce inappropriate and costly hospital and emergency admissions by providing more cost effective care in the community.
- The specialized palliative care workforce is not large enough to meet the growing demand and changing needs. There is growing pressure for other providers to care for people who do not have complex medical needs, so that specialized providers can concentrate on those who need their skills.

INNOVATIVE MODELS EXPLORE THE INTEGRATED PALLIATIVE APPROACH TO CARE

All these pressures are pushing health care systems to provide a more integrated approach to palliative care in the community: one that shifts hospice palliative care from being a specialized

service available to the few to a more general integrated service available to people with life-limiting conditions in all settings where they live and receive care. Developing the integrated palliative approach to care is a health care priority in Canada, yet no standard model exists. However, innovative programs developed in Canada and other jurisdictions are pointing the way.

How to use this document

This paper briefly describes 11 innovative models of the integrated palliative approach to care from Canada, England, New Zealand and Australia, including:



1. Fraser Health End-of-Life Care Program in British Columbia, Canada
2. Edmonton Zone Palliative Care in Alberta, Canada
3. Colchester East Hants Health Authority palliative home care model in Nova Scotia, Canada
4. St Christopher’s Hospice comprehensive model in England
5. Dorset Primary Care Trust model in southwest England
6. Arohanui Hospice regional program in New Zealand
7. Otago Community Hospice model in New Zealand
8. North Haven Hospice hub and spoke model in New Zealand
9. Palliative Care Northern Territory in Central Australia.
10. The Silver Chain Group that provides a range of health and social support services including comprehensive palliative care in Perth, Western Australia.
11. Living Well and Dying Well aged care homes model in Tasmania, Australia.

The models were chosen based on reports in the literature and recommendations from key informants. They were also chosen because they serve a mix of urban, suburban, rural and remote populations, and several deliver hospice palliative care services to a significant indigenous population.

Governments, regions, health care organizations and providers can use the experience of these innovators to develop their own integrated palliative approach to care.

This report is divided into two parts:

- An overview of the models and their success factors, impacts and lessons learned.
- A brief description of each model, highlighting its most innovative features.

For a more detailed description of the 11 programs, see Part II of this report beginning on page 17.

PART I: OVERVIEW

Each of the 11 models has taken different approaches to providing an integrated palliative approach to care in their communities, yet all share common elements that make them successful and transferrable to other locations, including across Canada.

All are focused on increasing the capacity of different parts of the health care system – primarily primary care, home care and long-term care – to provide hospice palliative care. All have interdisciplinary teams and services (e.g., 24 hour phone consultation) that support the delivery of the integrated palliative care in different settings, and all work to create a seamless network of primary-community-hospital-hospice services that support individuals and families as their needs change.

Here is a summary of the success factors, impacts and lessons learned from these models.

SUCCESS FACTORS

The success factors are organized into four key components that contribute to an effective, sustainable program: Vision, People, Delivery of Care and Supportive Tools.

VISION

1. Commitment to person-centred care

All models place the person and family at the centre of care. Most aim to provide care and support to patients wherever “home” is. All engage the person and family in planning for their care. Many focus on supporting the patient to stay as long as possible in their preferred place of care (usually home or a long-term care facility), rather than focusing on place of death.

2. Focus on building capacity in the community

All the models were driven by three main goals:

1. Provide high-quality, integrated hospice palliative care services to an aging population
2. Build the capacity to provide hospice palliative care in the community
3. Avoid inappropriate hospital admissions.

All are committed to building capacity among primary and community care providers to deliver hospice palliative care services in the setting of the patient’s choice and reduce inappropriate hospital admissions.

3. Focus on changing organizational culture

Shifting to the integrated palliative approach requires a change in most organizations’ culture. The people who work in those organizations much change their attitudes and the way they think about providing care. This change process takes times and requires patience. Many key informants emphasized that a change management process is the first step: it is essential to bring partners together to develop a shared vision and goals before proceeding to the next step.

4. Senior management support

For several models, support from a senior manager helped ensure funding and commitment for the project. In some cases, funds were shifted from acute hospital budgets to the integrated palliative care program. In one model, the program manager is a member of the senior management team for the region's health system, which helps ensure system-wide support and participation. Getting senior managers on side is important for scale up and sustainability.

PEOPLE

5. Dedicated coordinators

In most models, one or more designated people are responsible for bringing all partners together and keeping them engaged at both the program level and the individual client level. Some key informants stressed that a high degree of facilitation is required – sometimes for a year or more – before people really start to function as partners. Programs must recognize coordination is a job and budget for it. One model has two full-time palliative care coordinators for the district while another has seven. Others have a single coordinator whose role may involve education, convening meetings of partners, working across boundaries, and facilitating information sharing.

Most coordinators are nurses who may not provide direct care, but who understand hospice palliative care and have the skills to work across boundaries and bring people together. The most effective coordinators appear to be natural leaders/champions in hospice palliative care who are widely respected for their knowledge and expertise.

6. Interprofessional teams

All models are based on an interprofessional team, composed of physicians, nurses, allied health professionals, care aides and sometimes volunteers. The interprofessional team is standard practice in hospice palliative care, and it is essential to successfully integrating the palliative approach to care in other settings.

In some models, the interprofessional team provides a significant amount of direct hospice palliative care. In others, the team is a source of expert advice and consultation for family physicians who take the lead responsibility in caring for their patients and for other community-based primary care providers; the interprofessional team only takes responsibility for providing direct care for people with complex needs. In these cases, the team communicates regularly with the patient's family physician and involves the family physician in the person's care to the extent that he/she is willing and able to be involved. In some models, an interprofessional team may make site visits to remote areas to support local care providers. In places with large populations, a network of interprofessional teams may operate at several locations with central coordination.

Two of the models that focused on building hospice palliative care capacity within long-term care facilities created a core interprofessional team within the facility. The resident's family physician is part of that team, which can also draw in external experts as needed.

7. Strong role and more support for family physicians

All models involve family physicians in their patients' hospice palliative care. Their involvement ranges from having primary responsibility for care with the support of a palliative care interprofessional team, to being kept informed of the patient's progress if he or she is admitted to a secondary or tertiary level of care (e.g., a hospice, hospital). When a patient has to be admitted to a facility, the models support family physicians to play the role they wish to play in the patient's care. If a patient is discharged back home or to another community setting, the family physician is informed and supported to resume the person's care.

To encourage family physicians to play a more active role in hospice palliative care, all models provide education as well as support. Some models provide specific payments for family physicians who provide hospice palliative and end-of-life care. Physician compensation is particularly important in those jurisdictions where patients are responsible for paying family physicians directly.

8. Support for providers in long-term care facilities

The models that focus on integrating the palliative approach into long-term care facilities (usually called care homes, aged care homes or nursing homes) emphasize culture change and the importance of engaging all staff from the top down and the bottom up (e.g., managers, nurses, cleaners, gardeners). They pay particular attention to personal support workers: the staff who spend the most time interacting with residents and families and who will likely be the first to notice any changes in the person's situation. According to these programs, the most successful facilities are those with the flattest hierarchies. The interprofessional teams created in these facilities include clinical staff and personal support workers.

9. Key roles for nurses

In all models, nurses play key roles as program facilitators, care coordinators, members of interprofessional teams, home care providers, educators and advocates. Several key informants reported that, when it comes to the integrated palliative approach to care, nurses "get it". They are best placed to link together primary and secondary care services and to create partnerships. One program allows family physicians to enrol in its primary-secondary integration program only when they bring a nurse to the training because, based on experience, the program only succeeds when both primary care nurses and physicians are involved.

10. Relationships, partnerships and networks

All programs depend on relationships built over time – sometimes years. In some cases, the relationships involve gradually building community-based family physicians' trust in the shared care model. In others, people develop growing confidence in the partnership model as they learn to work together in interprofessional teams, collaborating to provide care for patients as they move between care settings. As members realize the benefits of partnership and as shared care systems are put in place, tested and reinvigorated over time, networks become more effective.

DELIVERY OF CARE

11. Integration of primary-secondary-tertiary care

All models work to integrate primary-secondary (and tertiary if available) hospice palliative care services within a region or geographic area. Before many of these programs started, family physicians tended to turn over all end-of-life care to palliative care specialists. In some cases, the palliative specialists encouraged this approach. With the integrated approach, all programs support family physicians and other primary care providers to be part of joint decision-making about cases and share responsibility for patient care.

The models are regional or local because it is easier to integrate primary and secondary services at this level. In six models, the lead organization is a regional health authority, in four models it is a hospice and in one, it is a not-for-profit health services corporation.

12. Cultural sensitivity

Effective implementation depends on developing culturally responsive programs and providing cultural safety training for providers. Several models address diversity, and the three New Zealand and Central Australian models have developed innovative approaches to serve indigenous communities. Between 20% and 60% of their clients are indigenous peoples, so these programs work closely with Maori or Aboriginal health and social services and indigenous health workers. The services demonstrate respect for culture through their philosophy of care expressed in Maori or Aboriginal terms, which includes strong support for families, communities and kinship relations.

Key informants report that the holistic person-centered philosophy of hospice palliative care is in harmony with the world views of the indigenous communities they serve, and the philosophy supports clinical staff and volunteers in providing culturally safe and appropriate services. The programs have also developed initiatives to recruit and train indigenous health workers – many of whom are personal support workers – in hospice palliative care skills.

13. Single access point and case management

Most programs have a single number to call to access palliative care services in the region as well as central triage of cases, so that each patient receives the most appropriate care in the most appropriate setting and has a single case manager who communicates with all partners. The advantages of this approach include: efficient use of resources, less duplication, ability to keep all partners informed and involved, and more timely care for patients/families.

14. 24/7 community support and care

To keep people in the community, avoid unnecessary hospitalizations, support family caregivers and reduce the burden on family physicians, most models provide a 24/7 service with after-hours nurse consultation and the possibility of nurse home visits in critical situations. One program helps family physicians in rural areas cover after-hours calls. In some cases, programs provide extra payment to physicians who make house calls. In all cases, the on-call support of the palliative care interprofessional team is available to community providers who are not necessarily trained in palliative care.

15. Advance care planning

All models seek out the patient's wishes and reflect them in the person's care plan. However, advance care planning practice varies. Some programs that function as part of larger health care systems integrate advance care planning into primary care, well ahead of the time when people will need end-of-life care. The palliative care team then focuses on goals of care and clinical care plans as needed. Other programs only begin advance care planning discussions within what is expected to be the patient's last year of life. In the models that involve long-term care facilities, staff engage patients identified as entering their last year of life¹ in advance care planning discussions leading to specific goals of care and a clinical care plan that, as far as possible, respects the patient's wishes.

SUPPORTIVE TOOLS

16. Common frameworks, standards and assessment tools

Most programs have common frameworks, standards and assessment tools that provide the foundation for the integrated palliative approach to care and ensure consistency across teams and settings. In some cases, the framework is a national or regional palliative care strategy; in others, it is a widely-accepted standard of care such as the model based on National Principles and Norms of Practice developed by the Canadian Hospice Palliative Care Association, the Gold Standards Framework and the Liverpool Care Pathway developed in the UK, or the Palliative Care Australia standards. While having a national or regional strategy helps a region or community establish the integrated palliative approach, it is not a prerequisite. Several jurisdictions developed their models in the absence of a high-level policy framework.

A number of programs have developed assessment tools and a minimum data set so they can monitor, assess and continuously improve their services. Common standards and tools establish expectations for the program and provide a common language that providers can use to communicate and compare information.

17. Flexible approaches to education

Education for providers is key in all models, but the way education is delivered to family physicians, community-based nurses, staff in long-term care facilities and other care providers varies. In some cases, primary care providers attend one-to-three day workshops in palliative care essentials with follow-up sessions and continuing education through annual seminars, monthly breakfast sessions, telehealth education, palliative care conferences and learning days. Some education sessions are targeted at physicians and/or nurses while others are for all primary care providers. A few programs offer training to private nursing agencies providing home care services for registered nurses, licensed practical nurses and personal support workers. Some programs offer a range of training sessions.

Education is mandatory for all primary care providers participating in a program. In all cases,

¹ Most palliative medicine specialists who were key informants for this paper stated that it is difficult to predict exactly how long a patient will live. The Gold Standards Framework recognizes this difficulty by suggesting that physicians ask themselves: *Would you be surprised if this patient died within the next year?*

time taken by staff for education is considered working time and is paid as such. A few sites offer training for family caregivers who care for someone at home.

18. Shared records

Several models use shared electronic records that can be accessed at the bedside using portable computers and tablets. Records can be updated on the spot and are immediately accessible to all providers involved in the person's care wherever they are located. Shared records are a factor in keeping family physicians involved and fostering good communication among members of interprofessional teams and other service providers. In most models, some part of the program continues to use paper records, but most are moving toward full electronic records.

19. Research, evaluation and quality improvement

All programs gather data that they use to monitor and improve their services. They use demographic and clinical information in admission and discharge forms, evaluation and performance indicators (e.g., Edmonton Symptom Assessment System, Karnofsky² scores, etc.) and charts to evaluate their services. They also measure system performance by analyzing care patterns and expenditures on types of care. Several programs use patient/family satisfaction surveys. Information from evaluations is reviewed at the manager level, discussed with staff and care providers in the organization and network of partnerships, and used to inform continuous quality improvement. One program publishes annual balanced score card reports that provide accurate information about trends in care.

A key indicator for all programs is the reduction in hospital admissions and lengths of stay as a result of increased capacity to provide the integrated palliative approach to care in the community. Most had either hard data or anecdotal evidence to indicate that the service reduces admissions. One program had hard data that the integrated services were cost saving; others found that the program was cost neutral. In some cases, the cost savings to the health care system from reduced hospital use have been used to contain overall health system costs or transferred to community-based settings. Diverting end-of-life care from acute and emergency hospital-based care has resulted in cost savings that have been invested, in many cases, in strengthening community-based care.

Some larger programs conduct clinical and psychosocial research as part of their commitment to evidence-based practice and the desire to share learning with others.

² The Karnofsky Performance Status Scale assesses health status on a scale from 0 to 100, with 100 representing "perfect" health

IMPACTS

Although the models may target different providers or settings, they all report having similar positive impacts on people who are dying and their families, health care providers and the health care system.

ON PEOPLE WHO ARE DYING AND THEIR FAMILIES

- Easier, faster and more equitable access to hospice palliative care through a single entry point, 24/7 service and support from interprofessional teams
- Better coordinated services and more seamless transitions between care settings
- Higher quality hospice palliative care services, improved after-hours service and better access to medications
- More culturally sensitive care
- More respect for their wishes and preferences in all care settings, more recognition of their dignity and voice, and more influence and control over their care – even when people are cognitively impaired
- Ongoing involvement of their family physician throughout the disease trajectory
- More confidence in community-based hospice palliative care and fewer requests for hospital admissions
- Fewer – and more appropriate – hospital admissions
- Fewer crises and fewer unneeded or unwanted interventions
- More people able to die at “home”(wherever they define “home”) or in their communities
- More people receiving the palliative approach to care regardless of their disease
- Less stress and burden on families, more meaningful time with the person who is dying and more support for family members.

ON HEALTH CARE PROVIDERS

- More skills for primary care providers, allied health care professionals (e.g., social workers, pharmacists) and care workers (e.g., licensed practical nurses, home care support workers)
- More confidence in their ability to provide hospice palliative care because of the strong system of education, support, consultation and good communication
- Greater sense of being valued for their work
- Better working relationships between primary and specialist providers
- Better, more respectful working relationships between physicians and nurses
- Better communication between primary care providers and other services in the system, and the ability to work within a coordinated system providing high-quality hospice palliative care

- Access to ongoing training and professional education
- Ability to remain involved in patients' care across different care settings
- Less distress, burnout and turnover

ON THE HEALTH CARE SYSTEM

- Practice innovations that improve quality, timeliness, care transitions and integration of hospice palliative care
- Fewer unplanned hospitalizations and lower acute care costs
- A more skilled workforce
- Advances in policies for advance care planning and after-hour services
- More effective use of resources with generalists providing primary palliative care and specialists providing consultation, advice, coordination and inpatient end-of-life care
- Progress in making high quality hospice palliative care available to more people with a wider range of diagnoses.

LESSONS LEARNED

In the course of developing and implementing their integrated palliative care models, these 11 innovative programs learned lessons – both about what to do and how to do it – that can help others. These lessons have been organized as follows:

START WITH THE RIGHT RESOURCES

- Have someone in charge to develop a program. The responsibility cannot be added onto an existing job and done off the corner of the desk. However, depending on the scope of the project, it may be able to be done by part-timer staff.
- “We had someone who was the go-to person. That made all the difference.”
- Obtain executive support at the senior level: it is critical for success.
 - Invest enough people and money to develop and sustain the partnerships.
 - Good clinical leadership is vital. Surround yourself with good people and staff who will help remove barriers rather than set them up.
 - Identify champions for the integrated approach to palliative care in a variety of organizations.
 - Employ passionate staff and support them with education and learning opportunities.
 - Look for opportunities for cost sharing. For example, if you are integrating the palliative approach into long-term care facilities, those facilities may be able to pay part of the cost of the program. There are advantages in terms of commitment to the program and uptake when organizations “put their money where their mouth is”.

DO YOUR HOMEWORK

- Gather information. There are many more models today than there were 10 years ago.
- Learn from other programs but use your knowledge of the local environment to tailor the program for your circumstances.
- Talk to the hands-on people about what is useful and realistic for them.
- Talk to service users in local communities to find out what their needs and solutions are.

BE STRATEGIC

- Focus on location of care as a more important outcome than location of death.
- Think outside the box.
- Integrating end-of-life care within other programs improves its visibility and sustainability. Keeping services integrated, not just in the community but also with hospital-based care, will make seamless care easier.
- Know your goals and those of others, and work to align them.
- The more options for care, the more comprehensive and integrated the program becomes.
- Ensure your model enhances the role of the primary care team.
- Understand the role of the service in delivering all levels of hospice palliative care. Maintaining and developing the ability of family physicians and home care to be the source of primary palliative care is key to allowing the specialized program to focus on providing secondary and tertiary care.
- Assign the most experienced team to the area of greatest risk.

ENGAGE PEOPLE AND GET BUY-IN

- The preparatory phase is key: spend time working with people to help them align their perspectives and goals. The prep phase will vary, depending on how aligned the staff are to begin with.
- Invite all the stakeholders to the table, develop the model, then implement it.
- Meet people where they are and help them to do better. Help them define what “doing better” would look like for them and work from there.
- Provide a high level of facilitation and support to bring people on board and keep them involved, especially when they are starting with little knowledge or low morale.
- Networking is crucial. Be willing to share. Never underestimate the power of having a cup of coffee with someone.

People want to do a better job and can suffer moral distress when they know they are not providing good care. Instead of implying that they are doing a bad job, look instead at how they can do it better.

- Engage with family physicians as members of the team.
- Involve and empower the entire care team, including community-based primary care providers. Empower others to lead – don't do it all yourself.
- Recognize and value each care provider's and care service's role
- Don't take over care from the primary providers; instead, help them to provide care. Always refer back to the family physician when possible and then play a consultative role.
- Use role modelling as a learning tool. Role model everything, including how to have a debriefing meeting.
- Focus on guidelines for operationalizing the program that allow clinicians to use point-of-care judgement. Rules do not work well for the endless variation of the human condition.
- Support the project team and have regular one-to-one meetings (monthly) as well as group meetings.

Credibility in rural/remote settings is a strong part of being able to do the job.

HELP EVERYONE SPEAK THE SAME LANGUAGE

- Create an overall vision and workplan at the beginning of program development that health care professionals and the community support.
- Have clear, measurable goals and objectives.
- Set a standard from the beginning about cultural safety and reflective practice by staff and management, and respect the staff on the ground as they are the ones who know the lay of the land.
- Design strong processes that enable best practice client outcomes and systematically implement them.
- Include a plan for resource deployment that all partners will support when difficult decisions must be made.
- Help people realize that hospice is a philosophy, not a building. Some rural groups want to found free-standing residential hospices which could dissipate resources in the region, especially given chronic staff shortages.

A vision results in passionate and committed staff.

DON'T LET THE PERFECT BE THE ENEMY OF THE GOOD

- Don't expect things to be perfect before you start – that is a recipe for paralysis. Start with the best service that you can, and develop and improve from there.
- Not everyone will get on board. Work with those who will.

- Relationships are vital and it takes time to develop them. If people start poles apart, it takes time to align viewpoints and goals. Once you are aligned, you can make progress. Strong relationships are based on common purpose and workable solutions.

MAINTAIN YOUR MOMENTUM

- Success depends on gradual culture change within organizations. Start small and build. Expect things to take a year or two to start gelling.

Remember, some people still see palliative care as failing.

- Don't give up. Family physicians can be resistant, but they will come around if you persist.
- Achieve small successes and build on them. Create positive energy around change.
- Develop and implement a sustainability plan.
- Many projects fail in rural/remote areas because they are personality-dependent. Once the leader leaves, that is the end of the project. You have to constantly create sustainability mechanisms.
- Continue to evolve to meet unmet and emerging needs.

MAINTAIN YOUR SANITY

- Have faith that things can change – it won't happen overnight, but it will happen if it's worth it. It may take years or decades.
- Be flexible.
- Have a sense of humour.
- Hire people with a sense of humour.
- Stay true to the community and people you serve.
- Hang on, hope and work.
- Engage in continual learning.
- Practise self-care and encourage others to do the same. Whole-person care applies to the care team as well as the patient.

COLLECT DATA FROM THE BEGINNING

- Have measurable goals and know your starting baseline.
- Use bedside clinical assessments and data collection from Day 1 to enhance clinical care and education on a daily basis. Use this information to improve the program within current resources, to demonstrate to administrative leaders the success of the program and to advocate for more resources to meet unmet needs.
- Ongoing data collection is key to monitoring and improving services and advocating and planning for future development.

PART II: THE INNOVATIVE MODELS

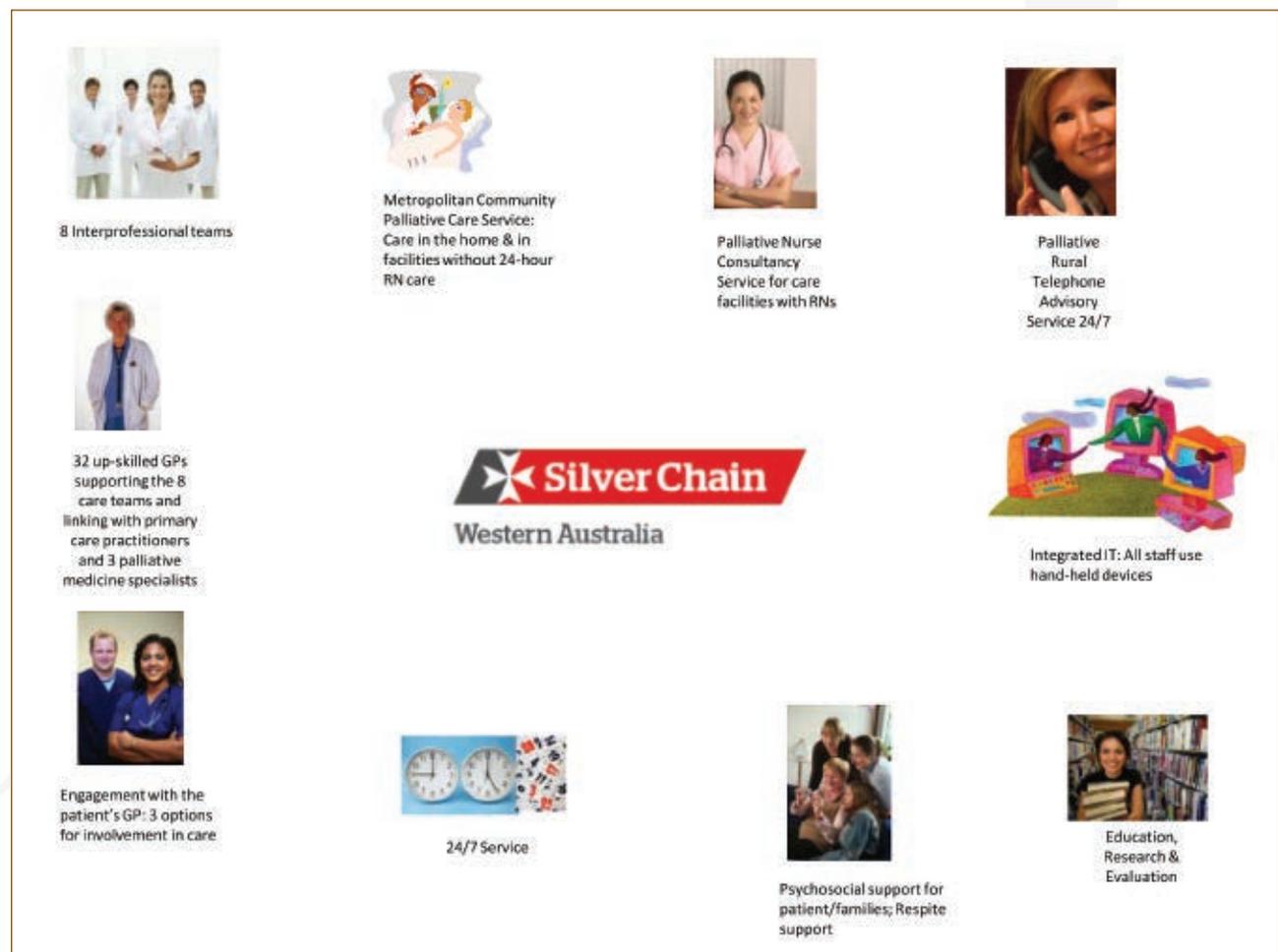
The following pages provide a brief description of each model, highlighting those innovative aspects that might inspire others. The 11 descriptions have been organized by setting (e.g., integration of a palliative approach into primary care or long-term care homes), and geographical focus (e.g., across a large health region or within specific rural areas).

Developing Integrated Palliative Services, Starting in the Community

The Silver Chain Group, Western Australia Providing Most Palliative Care in the Community

Key Innovations

- upskilling a group of family physicians in palliative care to support their peers
- giving family physicians choices about how involved they will be with their patients' care
- providing extensive support and consultation
- using electronic information systems to link all care providers
- continually evaluating impact.



The Silver Chain Group, a large not-for-profit organization, provides a range of health and social support services to help people in three areas of Australia remain at home during care.

As part of its community care responsibilities, Silver Chain in Western Australia provides

comprehensive hospice palliative care in the Perth urban area (5,000 square kilometres, 1.8 million people). In all other Australian states – and in most other parts of the developed world – the palliative care response began by creating palliative care beds in hospitals and then developing community-based services from the hospital service. In Western Australia, they established Silver Chain’s community palliative care service first and then developed hospital-based palliative care beds. As a result, government invested in community services, and significantly more people receive hospice palliative at home or in their community.

Other Australian states have a hospital-based palliative care beds-to-population ratio of 50-55 beds to 1 million people; in Western Australia it is 30-35 beds to 1 million people.

About 60% of the 3,000 people admitted to the Silver Chain hospice palliative care service each year are supported to die at home, compared to the national average of 25% to 30%. Recent analysis of Silver Chain data shows that the majority of those who died at home had no hospital admissions during their episode of care. Client surveys show a satisfaction rate of 98%. Silver Chain takes a population-based approach, providing hospice palliative care services for patients with malignant and non-malignant diseases and conditions.

According to the director of Silver Chain’s hospice palliative care service, no one single component of the model is responsible for the outcomes: success is based on how these components come together to create an integrated service focused on meeting the client’s and community’s needs. Because of its size, the organization has the critical mass to provide a high level of support for patients and families, primary care providers and other community-based providers.

The Silver Chain’s organizational vision is:

- Building capacity within families to care for their own members (with practical and psychosocial support, including respite)
- Integration and service coordination
- Interdisciplinary care planning
- Evidence-based, client-centered care.

Coordinating and integrating services. Silver Chain is centrally administered. All patients and families requiring hospice palliative care are referred to a single point of access, where staff are responsible for case management and care coordination across a variety of providers and settings. Silver Chain is also able to integrate its hospice palliative care with its primary care services, and builds on its long-standing partnerships and links with all care providers and types of care settings in the region.

Creating interprofessional teams. Silver Chain has eight palliative care teams located in districts throughout the greater Perth metropolitan area. The teams include medical consultants (palliative

medicine physicians), palliative specialist nurses, general practitioners (physicians), allied health professionals (social workers, counsellors, psychologists, pharmacists, and physiotherapists), care aides (support workers), registrars (specialist medical trainees) and volunteers. Services include: physical care and practical supports; symptom management; psychosocial support and counselling; links and referrals to other community and government services; respite; spiritual support; and bereavement support for children and adults. The teams provide direct care in the patient's home and in all care facilities that do not have a registered nurse managing care 24 hours a day. The teams also provide shared care with the patient's family physician and consultation support for family physicians who wish to remain the main care provider for their patient.

Making strategic use of up-skilled general practitioners and palliative medicine specialists.

Silver Chain employs 32 "up-skilled" general practitioners who have received training in palliative care beyond the GP level. These GPs support the eight teams and are a bridge between the palliative care service and primary care. They work closely with the client's family physician to plan ongoing care. Silver Chain also employs three palliative medicine specialists who have joint appointments with acute care facilities (mainly hospitals providing inpatient care).

Offering options for family physicians to be involved in their patients' care. Working with the up-skilled GPs, family physicians have three options for being involved in their patients' palliative care:

- Full care: The family physician is available to the patient, family and Silver Chain team 24 hours per day.
- Shared care: The family physician is available during business hours and Silver Chain physicians provide services outside business hours.
- The Silver Chain GP is the only medical decision-maker.

In the case of full or shared care, the patient's family physician can call on the Silver Chain GPs and interprofessional team for advice and support.

Taking a population-based approach to hospice palliative care. Silver Chain works to meet the needs of people with non-malignant diseases – and who, therefore, have a less predictable disease trajectory – as well as those with cancer. They do this by linking with Silver Chain's primary health care service and staff working with differing care pathways required for a variety of diseases. Other means of reaching the total population base include links with family physicians in the community, clinical networks and local area health teams.

Providing psychosocial and respite support for patients/families. Silver Chain provides social work, counselling, support by volunteers, referral services to other community agencies for patients and families, and bereavement support for families. Volunteers are involved in respite care, transport, bereavement support (including children's bereavement program), and a recollections program documenting clients' life stories. Care aides employed by Silver Chain also provide respite service in four-hour blocks of time. When respite care is provided in the last weeks of life, 80% of those clients are supported to die at home.

Consulting to hospitals and long-term care facilities. Silver Chain provides a palliative nurse consultancy service to public/private hospitals and residential facilities where client care is managed by a registered nurse 24 hours a day. The service provides specialist nursing advice, assessment, procedures, specific staff education and telephone follow-up to meet the care needs of a specific client. Referrals are accepted from medical practitioners, registered nurses and allied health staff providing care within the facility. Involvement is limited to a period of five days; however, a client can be re-referred at no charge to the facility or the client.

Providing service 24/7. The large scale of the Silver Chain service makes it possible to have staff available in shifts that provide 24/7 coverage. This allows for:

- rapid response to crisis events
- planned after-hours support for patients and family caregivers where required
- symptom assessment and management at home 24/7
- back-up support (on-call) by senior nursing and medical staff
- telephone availability 24/7
- home care equipment and supplies that can be provided 7 days a week through Silver Chain's equipment/supplies section (CarePlus)
- consultancy support to urban and rural care providers.

Offering 24/7 phone advice for physicians. Clinical nurse consultants who have specialist skills and knowledge provide 24/7 telephone advice for family physicians in urban and rural areas. This service enables family physicians to treat patients in their homes (including care homes and other residences) and reduces the need for hospital admissions.

Ensuring quick access to client information. Silver Chain uses an integrated information technology system across all areas of operation (ComCare software) that allows staff quick access to information while reducing the human resources and administrative costs associated with paper records. All staff use hand-held technology so they can access client information in all environments to support care decision-making and to collect clinical information that supports targeted care delivery, benchmarking and evaluation.

Investing in education. Silver Chain has three training positions for palliative medicine registrars (specialist medicine trainees) through an agreement with university-based medical schools in Western Australia. Every position in the organization has an associated Training Plan which identifies compulsory and mandatory training and competence requirements with an associated timeframe for completion. This information is entered in the electronic records system and monitored monthly. Monthly education sessions are provided for Silver Chain GPs and palliative specialist consultant physicians. Education is provided through direct contact with the Clinical Education team, self-directed learning packages, and online education.

Conducting research. The research conducted by Silver Chain focuses on developing improved clinical care tools such as a Symptom Assessment Scale, a Bereavement Risk Index, and an Australian-modified Karnofsky Scale. Silver Chain also works with university-based researchers on

research projects, often focusing on how to enable patients to maximize the time spent in the care setting of their choice. Silver Chain is an inaugural participant in a national benchmarked clinical outcome collaborative called the Palliative Care Outcome Collaborative (www.pcoc.org.au), whose purpose is to improve key indicators and clinical outcomes with more focus on monitoring symptoms.

Evaluating outcomes. Silver Chain evaluates all aspects of the care it provides. Data analysis includes an examination of patient profiles, length and type of care, hospital admissions, use of staff resources, cost effectiveness and patient satisfaction surveys. The program is working with a health economist to document what happens to people who do not receive Silver Chain services, in order to understand the differences and outcomes of those who do and do not receive services from Silver Chain.

Silver Chain reported 60% of deaths at home compared to the national average of 25% to 30%. Most people who die at home have no hospital admissions during their care.

For Silver Chain, the challenges to the sustainability of the model include: workforce recruitment and sustainability as the workforce ages, the long-term sustainability of its contract funding model with the government (the amount the government paid for the service last year did not cover actual costs, so the organizations had to use donations to close the gap), and the ongoing costs related to technological innovations, education and training.

Integrating Palliative Care Across a Health Region

Two programs – the Fraser Health End-of-Life Care Program in B.C. and the Edmonton Integrated Palliative Care Service Model in Alberta – are innovative models of moving more palliative care into the community, and promoting an integrated palliative approach across a health region. Fraser Health has focused on developing integrated community-based interprofessional teams, creating a network of services and promoting advance care planning before people become ill.

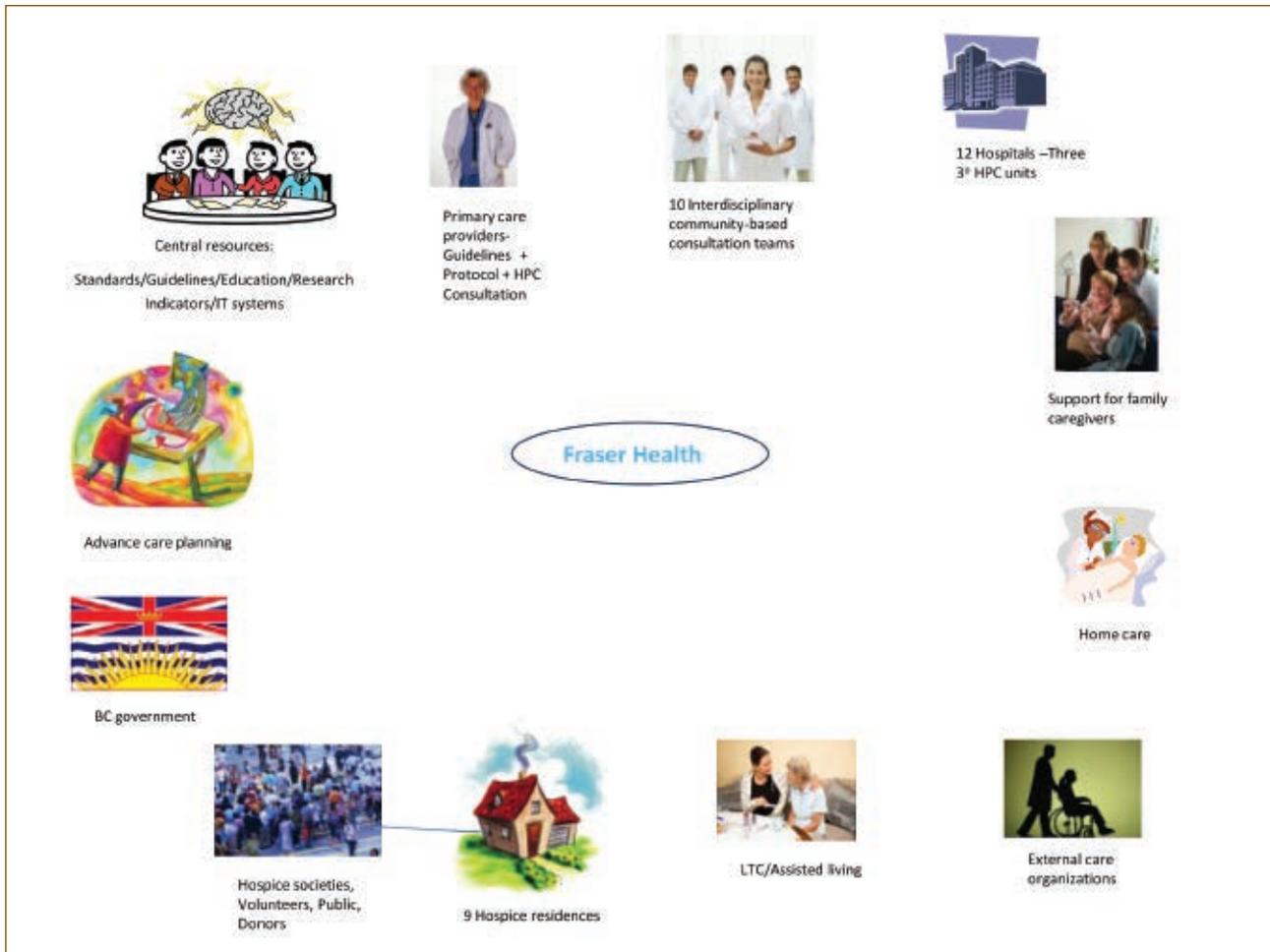
Fraser Health Authority End-of-Life Care Program Improving Care for All, Regardless of Where They Die

Key Innovations

- Senior management support at highest levels
- Program at the table in all regional health system planning
- Advance care planning program and tools used early – before people become ill
- 10 integrated community-based interprofessional teams
- A wide range of education programs

The End-of-Life Care program made a commitment to improve care to all patients, including those not referred to the program and receiving hospice palliative care services. Patients registered in the program = ~43% of total annual natural deaths in Fraser Health.

- Effective partnership with programs caring for people with chronic life limiting diseases, such as renal care
- Active research program



Fraser Health, a regional health authority in the Lower Mainland of British Columbia, Canada, serves 1.6 million people in a mix of urban and rural communities. The region encompasses 12 communities, has 12 acute care hospitals and experiences approximately 10,000 natural deaths per year. Because of the large number of people who retire to British Columbia, a significant proportion of the population is elderly. The Fraser Health End-of-Life Care Program provides hospice palliative care consultation services in all settings of care through inter-professional Consult Teams. It also provides direct care for patients and families admitted to the program’s specialty units: three tertiary hospice palliative care units and nine hospice residences. Through a partnership with Fraser Health’s Home Health Program, patients and families receive supportive or hospice palliative care in their homes. Fraser Health also works with residential care facilities (e.g., nursing homes) and acute care hospitals to provide education and consultation support for their staff. Each year, the program provides direct care for 4400+ people who die, and it partners with other providers and settings to influence care for the other roughly 5600 people who die in its catchment area. The Fraser Health End-of-Life Care Program is based on the values and guiding

principles of the Canadian Hospice Palliative Care Association's *Model*.³ It is supported by the British Columbia chronic disease management model and the provincial framework for end-of-life care. The program has benefited from senior management support at the highest levels of the Health Authority.

Building the capacity of primary care providers. Fraser Health's approach is to integrate palliative care across all care settings and disease management, building the capacity of primary care providers to provide palliative care through mentoring, support, education and the engagement of primary care providers as partners. The program helps GPs recognize patients in their practices who may require palliative care and encourages GPs to register their patients (with the patient's consent) in the End-of-Life Care program. When a patient is registered in the Fraser Health End-of-Life Care program,⁴ the community-based team notifies the patient's GP and asks what role he or she wants to play in the person's and family's care, and provides mentoring and support. To keep roles and expectations clear, the Program uses contracts with physicians working within the End-of-Life Care Program and discussions with family physicians outside the Program, who can be involved in their patients' care to the extent that they are willing and able to do so.

Establishing community-based interprofessional teams. Ten community-based consult teams cover all 12 communities in the Fraser Health region. Teams typically consist of advanced practice nurses, a physician, a social worker/counsellor and a volunteer coordinator. They are physically based in the community but see patients who are referred to the program regardless of where they are located. The teams integrate with other services such as hospitals and home care to fill gaps and facilitate care. They support primary staff across all sectors of care through consultation, education and standard development. The nurse coordinator on each team is primarily responsible for assessing new referrals, and for communication and coordination with other teams and across care settings.

Developing physician expertise and providing physician incentives. The program supports about 60 physicians at the tertiary, secondary and primary care levels: 25 are Consultants with palliative care certification contracted to the program; 26 are local GP associates with a minimum of 30 hours of palliative care education and ongoing training who provide hospice care and on-call service with Consultant backup; and 6 to 10 are "foster physicians" who take on orphan palliative patients. The program also provides some additional payment to GPs who take on palliative care patients. Family physicians with support from the Fraser Health End-of-Life Care program provide about 30% of palliative care, and Fraser Health palliative care physicians themselves provide shared care/consultation support in about 70% of cases.

Creating a network of hospice, hospital and community services. Fraser Health has nine hospice residences with a total of 108 beds, and three tertiary hospice palliative care units with a total of 30 beds that provide care for patients with complex or difficult needs. Hospice societies are

³ Ferris FD, Balfour HM, Bowen K, Farley J, Hardwick M, Lamontagne C, Lundy M, Syme A, West P. *A Model to Guide Hospice Palliative Care*. Ottawa, ON: Canadian Hospice Palliative Care Association, 2002.

www.chpca.net/media/7422/a-model-to-guide-hospice-palliative-care-2002-urlupdate-august2005.pdf

⁴ Registration in the EOLC Program is open. It can be initiated by the patient or a family member, or by a health care provider working in the EOLC Program or external to the Program.

community-based and have contracts with Fraser Health to provide volunteers and bereavement support. Fraser Health is responsible for operational funding and setting standards for all hospices in the region, working in partnership with hospice societies that may manage or co-manage the residence. In

addition to residential care, hospices provide volunteers and bereavement services to support the End-of-Life Care program in their communities. The community-centered nature of hospices tends to foster community involvement and enable family physicians to follow their patients in the hospice. Unlike most community-based hospices, the Fraser Health hospices charge inpatients a per diem fee of around \$30, which is waived for patients who are unable to pay (about 20% of cases).

Fraser Health works with management and staff of residential care facilities and nursing agencies to provide education and improve their capacity to provide end-of-life care rather than “take over” patients’ care. Both for-profit and not-for-profit organizations consider capacity building in end-of-life care a good business model because it enhances the organization’s reputation and enables it to maintain patients in their preferred care setting, rather than transferring them to hospitals.

Promoting advance care planning. The Fraser Health *Let’s Talk* and *My Voice* programs are models for advance care planning in Canada. The MOST (Medical Orders for Scope of Treatment) initiative for physicians includes: advance care planning, routine identification of a person’s wishes and goals of care, and medical orders that direct health care interventions in all sectors of care. Physicians are encouraged to have advance care planning discussions with patients before illness occurs, as a routine part of care. Advance care planning is integrated into all sectors of care for all patients with advanced illness. Care providers in all settings can access patients’ advance care planning records, which facilitates integration among and transfer between care settings.

Providing after-hours support for families. Fraser Health provides telephone support for patients/families from on-call palliative care clinicians between 9 pm and 8 am in partnership with B.C. Health Link. The Health Link nurse does an initial screening by phone and refers calls to an on-call Fraser Health Palliative Response Nurse for follow-up. The availability of timely after-hours support means that situations can be handled, and, in most cases, inappropriate emergency visits and hospital admissions are avoided and patients are able to remain in their preferred place of care.

Investing in education. Education is one strategy to help all health care providers implement a palliative approach in the setting in which they work. Nurses in home care are required to complete palliative care training during their first year of work, and their services pay for this training, which is provided by Fraser Health staff and home care agencies. Home support workers also receive training, which is defined by provincial standards. Consult teams provide education as part of clinical consultation on the care of individual patients and their families. They also provide education sessions for health care professionals and the public in Fraser Health communities, and

Forty-one percent of patients registered in the End-of-Life Care program die in hospice residences, 9% die in tertiary units, 2% die in residential facilities (long term care homes) and 12% die at home.

for the Fraser Health region as a whole. For example, the Program and teams provide:

- A two-day introductory hospice palliative care education for nurses from across the health region regardless of clinical practice setting, with other disciplines welcome to attend. 80% of attendees are from non-hospice palliative care specialty areas.
- Education about care of patients who have high acuity and/or complex needs for nurses working in specialty settings and Fraser Home Health.
- The province-wide Practice Support Program (PSP) for End of Life Care, providing palliative care education for physicians in general practice.
- In-person as well as on-line learning sessions for providers on Advance Care Planning.
- Education for physicians on the newly implemented MOST (Medical Orders for Scope of Treatment) program, focusing on the importance of providing diagnostic and prognostic information for patients and families, and supporting and encouraging Advance Care Planning conversations throughout the patient's care journey.
- Education for the program's interprofessional team members which includes: a biweekly journal club, videoconferences focusing on new clinical practice initiatives, educational sessions, and half-day forums providing educational updates and opportunities for consult team members to network and discuss clinical topics.
- Clinical practice site-specific education for nurses and other interprofessional team members.

Using common tools to improve communication and care. Common assessment tools, standards and guidelines, education, sharing of records⁵ and the network of relationships established over time facilitate communication across all care settings.

Investing in research. To support the integrated palliative approach to care and expand access to hospice palliative care beyond those living with cancer, the End-of-Life Care Program is an active partner in the nursing clinical-education-research partnership, iPANEL–Initiative for a Palliative Approach in Nursing: Evidence and Leadership

(www.ipanel.ca). The program's director is co-lead investigator on the iPANEL Research Team and three of the program's clinical nurse specialists are co-investigators. The Program would like to devote more resources to research and evaluation but staff resources are limited and are primarily devoted to providing care.

Overall, the program has been cost neutral – resources once spent in hospitals are now being used to support services in the community– but quality of care has improved and the number of people accessing end-of-life care has increased.

Integrating palliative care into other services for people with life limiting illnesses. Fraser Health works to improve care for all patients facing end-of-life issues, not just those registered in the program. It does this by developing partnerships between the End-of-Life Care program and other Fraser Health programs, such as the Fraser Health Renal Program. Many patients,

⁵ Record systems are currently a combination of electronic (mainly in acute care) and paper-based (in community settings). EOLC Program registration and other EOLC record systems are available within all care settings.

clients/residents who may not typically access or benefit from the formal palliative care program would benefit from a palliative approach. The palliative approach is being integrated into hospital, residential and home care. The Fraser Health intensive care units now include palliative status as an indicator.

Integrated Palliative Care Service

Building Relationships and Systems to Provide Integrated Palliative Care

The Edmonton integrated palliative care service model, launched in 1995, was a pioneer in the integrated palliative approach to care in Canada and a model for other countries. The model integrates care across care settings including the home, 5 hospices, a hospital-based tertiary palliative care unit, acute care hospitals and the regional cancer institute. The program's vision is *Improving the Quality of Living and Dying through Caring, Education, Research, Leadership and Outreach*. The program recognizes and incorporates the values and ethical principles identified by the Canadian Hospice Palliative Care Association's *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice (2002)*. Its overarching goal is to increase access to palliative care services in the most appropriate setting provided by the most appropriate caregiver.

Key Innovations

- Single number access to hospice palliative care
- Incentives for primary care physicians to provide palliative care
- Strong focus on education and research
- Development and consistent use of common assessment and monitoring tools
- Extensive data and reports – including Annual Score Card –to ensure quality and demonstrate impact of the program

Integrating the palliative approach to care in all settings is the result of almost 20 years of building relationships and systems.

Providing timely assessment and consultation services: The program has a number of physician and nurse consultation teams. People access the program using a single phone number. A triage physician in the program's central office screens all requests for consults and then directs the appropriate team members to the new consults based on need (e.g., patients with complex medical issues are directed to a physician). Physician and nurse community consultation teams visit the patient at the site of care, including home, long-term care and community hospitals. Permanent teams exist in the large hospitals. Coverage is provided 24/7. The regional cancer centre, Cross Cancer Institute, also has a consult service to cover inpatient and outpatient care and to provide community liaison between family physicians and oncologists.

Providing incentives for family physicians to participate: The family physicians who participate in the model provide primary care with 24-hour on-call coverage and serve as the attending physicians when a patient is admitted to a hospice. The provincial health plan implemented fee codes so that physicians can bill for direct contact with individual palliative care patients. Palliative



home care nursing services provide a 24-hour response service and maintain communication with family physicians.

Emphasizing education and research.

Edmonton is a leading palliative care education and research centre. Since the program was established in 1995, physicians from Canada and other countries have come to Edmonton to be trained in palliative care and the integrated model. Edmonton team members and academic associates are involved in clinical, psychosocial and health economics research. The new Palliative Care Institute, housed at Grey Nuns Hospital in Edmonton, brings together academic researchers from many disciplines.

Education programs are provided for staff, including support workers. A nurse educator supports the community consult teams. Primary care providers may have observer status or become trainees for one to three months. Edmonton is one of the sites where medical residents can train for the one-year palliative certification program accredited by the Royal College of Physicians and Surgeons of

The number of physicians referring patients to the program increased from 409 in 2000 to close to 500 in 2010. According to a 2005-2006 study, 77% of the physicians referring patients for consultation to the service were family physicians, representing 35% of the family physicians registered in the Edmonton area. In another study, 89% of patients discharged from the regional cancer institute chose to remain under the care of their family physicians.

Canada and the College of Family Physicians of Canada. Edmonton was the development centre for the Pallium LEAP (Learning Essential Approaches to Palliative Care) program, which is now used across Canada.⁶ Continuing education for physicians, including rural physicians, is provided through the University of Alberta. Distance and electronic learning are available.

Monitoring the program and ensuring quality.

A dyad leadership – a program manager and a section chief (clinical director) – is responsible for establishing and maintaining regional standards, collecting data and maintaining the database, evaluating outcomes, producing annual reports, reporting to Zone leadership, and planning and advocating for clinical and hospice palliative care resources to maintain the program and allow for growth required to meet clinical needs (as demonstrated by data). They issue balanced score cards on system performance and coordinate education and research.

According to most recent available Balanced Score Card (2009-2010), the program:

- Saved close to 20,000 acute care bed days per fiscal year
- Reached its target of 100% 24/7 palliative home care coverage (compared to 94% in 2007-2009)
- Reported steady use of common assessment tools to ensure continuity of care: 94% in home care and 97.5% in acute care
- Had a median service response time of one day for the palliative care team.

The program has been a leader in developing and using common assessment tools across all settings, including: the Edmonton Symptom Assessment System, the Mini Mental State Examination, the Palliative Performance Scale, the Edmonton Classification System for Cancer Pain, CAGE (patient alcohol use), and Opioid dose measures. Advance care planning is part the model, but is not a distinct program element. Advance care planning is considered the role of primary care and is seen as a discussion that should begin long before people are in palliative and end-of-life care.

Alberta has a provincial electronic health care record available to all health care staff by secure access in all locations of care. The exception at present is consults done in the home. In some cases when patients transfer location of care, older technology (fax) or paper is required to provide day-to-day updates not included in previously completed consults. A standard referral form is used for admission to hospice palliative care units and the Tertiary palliative care unit.

⁶Pallium is a Canadian program providing education and ongoing professional development in hospice palliative care through provision of educational materials and training workshops. The LEAP (Learning Essential Approaches to Palliative and End-of-Life Care) program is courseware developed by a pan-Canadian network of academic health leaders and community practitioners with enhanced skills in palliative care services. www.pallium.ca The program has recently moved its headquarters to Ottawa and continues to be offered across Canada

Implementing Palliative Care Standards Across Community Settings

Dorset Primary Care Trust End-of-Life Care Program Using a Common Standard to Enhance Services in the Community

The Dorset Primary Care Trust (PCT)⁷ serves a population of 400,000 people in a mix of urban and rural communities in the county of Dorset in southwest England (not including the largest cities, Bournemouth and Poole). It funds most health services, including hospitals and home care, but it does not fund residential hospices, which are supported by private donations. The region has a high proportion of older people, especially in farming areas, with many taking care of each other because the young people have moved to cities outside the region.

The PCT has a mandate to implement the national End-of-Life Care Strategy, which encourages use of the common Gold Standards Framework (GSF). The GSF gives all care providers a common standard of practice to work toward. In an area with a large rural population, family physicians and community hospital staff have gained skills and confidence to provide end-of-life care rather than leaving it to the acute hospital-based specialists.

Much of the PCT's success is due to having dedicated staff responsible for getting services to work together and its ability to move beyond a focus on cancer to offer hospice palliative services for people with all diseases and conditions. The tools used to achieve these outcomes include education, ongoing training, access to specialist palliative care advice when needed, and increased knowledge and connection to resources in the district program.

Dorset also has an NHS-funded Compassionate Community initiative to develop greater understanding and awareness of the role community plays in end-of-life care and the support services available. A variety of individuals from different organizations, including the health sector, came together to talk about ways to develop a compassionate community and improve quality of life for dying people and their families. The initiative encourages death, dying and bereavement to be seen and heard within the community rather than being hidden.

Key Innovations

- Full-time coordinators for the program
- Use of Gold Standards Framework
- Physicians sign agreements with end-of-life care program

⁷ A Primary Care Trust (PCT) is part of the National Health Service (NHS) operating at a local or regional level. PCTs are involved in local health planning, primary care development, making secondary and tertiary care available to patients, and getting health and social care systems working together for the benefit of patients. There are 151 primary care trusts in England, and they account for 80% of the NHS budget.



Engaging and supporting all settings and providers. The PCT model shares many of the same components of other models. Teams of specialist physicians, nurses and allied health professions (e.g., pharmacy, physiotherapy), located in acute care hospitals, community hospitals and hospices, provide inpatient care, outpatient clinics and advice and support to other care services. Most family physicians in the region are linked to the end-of-life care program through agreements. Community nurses and matrons, supplemented by Marie Curie nurses (a national nursing service provided at no cost to the patient), provide home care, which is closely linked to community hospitals. The three acute care hospitals have inpatient palliative care units and consultative teams. The 10 community hospitals provide respite and end-of-life care when the patient cannot be cared for at home. The community hospital is seen by many patients and families as *“almost as good as being at home”*. Many long-term care facilities and seniors’ residences have been engaged in the Gold Standards Framework, and clusters of care homes meet quarterly – along with professionals from both the hospital and community-based interdisciplinary teams – to exchange information and solve problems. Three community-based hospices provide end-of-life care in inpatient units. Their community nurse specialists link with other providers in the region to ensure integrated care and their volunteers provide support.

Providing leadership and breaking down boundaries. Since 2009, the Dorset PCT has employed two full-time coordinators – with backgrounds in specialist palliative care and clinical governance – who work with all health and services to foster collaboration, encourage adoption of the GSF principles and care approaches, and promote a patient/family centred (rather than system-centred) model. The two coordinators have a cross-boundary perspective and help to link all care providers in the region together. They organize regular meetings where care providers from all services can exchange information and advice, and they bring providers together from across various settings for training. Localities within the region have regular palliative care forums, attended by health and social care providers (e.g., care homes, district nurses, general practitioners, special palliative care providers, hospital staff). As a result, the coordinators have been able to foster close working relationships among care services and providers, and break down boundaries. The care homes engaged in the Gold Standards Framework training have become better known to acute and primary care providers.

Ensuring effective communication. Communication among services is good, and work is underway to develop electronic records that will make it easier for different settings and providers to share information about patients and their needs and care. All care providers are working toward a common information-sharing system, and a conference is planned for 2013 on best practice in records sharing and management.

NOTE: With the planned restructuring of the NHS, the Dorset PCT will be dissolved in favour of a larger, clinician-driven model, which may affect the ability to sustain the current end-of-life care program. The future model will put end-of-life care under the control of primary and community services rather than hospital services. A specialist palliative care service will provide assessment, specialist treatment and support for primary care teams. The family physicians in Dorset have earmarked funds for continuing to use the Gold Standards Framework and to work in care homes.

Reskilling Primary Care Providers in Palliative Care

In the past, most care at end of life was provided by primary care physicians. As hospice palliative care became more of a specialty, primary care providers lost some of their skills. Two hospice-based programs in New Zealand – Arohanui Hospice and Otago Community Hospice – have been particularly effective in engaging and “reskilling” family physicians in palliative care. They have also developed culturally sensitive services that meet the needs of the Aboriginal individuals and their families.

Arohanui Hospice Primary-Secondary Integration Program Building a Palliative Care Partnership

Arohanui Hospice, located in Palmerston North (population 76,000), on the southwest coast of the north island of New Zealand, is the national

Arohanui is a Maori word meaning *many loves*.

centre for the Liverpool Care Pathway and regional centre for hospice palliative care expertise. Its Primary-Secondary Integration Program, and the Palliative Care Partnership between general care teams and the Hospice specialist palliative care service, form the cornerstones of its approach to integrating palliative care in community services. These initiatives seek to avoid the de-skilling of general practitioners that can occur when palliative care services are built around a specialist service. The goal is to maximize existing services in the face of growing need and demand, and to prevent service fragmentation.

Key Innovations

- Requiring physician/nurse teams
- Centralized access and triage
- Central use of care plans that travel with the individual
- Compensation for primary care physicians who provide hospice palliative care
- Culturally sensitive care

Developing a Palliative Care Partnership.

Seven years ago, the director of palliative care at Arohanui Hospice and a local general practitioner (GP) started talking about involving GPs in palliative care. Patients were turning to the hospice for the free care (they had to pay for GP services) and the expertise. To reverse this trend, a team of six received funding from the district health board to develop the

The Partnership is characterized by good communication, joint decision-making, respect of all providers’ skills, specialist resources and support, shared responsibility for the patient’s care plan, ongoing care management review, and appropriate use of ancillary services such as district nurses and the Hospice day services.

integration program, which is governed by a partnership group made up of the Arohanui Hospice Palliative Care Service, general practice teams and a regional independent practice association.



Focusing on education and the role of nurses. The integration program involves three two-hour interprofessional evening sessions, based on the Gold Standards Framework and the Liverpool Care Pathway. Each GP is required to bring a nurse because nurses are key in care coordination and sustainability. Completion of both the education program and yearly updates is mandatory for registration in the Partnership, and GPs and nurses are paid by the district health board to attend the education sessions. The program reports that primary care teams have a strong desire to participate in their patients’ palliative care, and acknowledge the need for ongoing learning. Today 90% of the GPs in the district have completed palliative care education and signed partnership agreements with the Hospice.

Providing centralized access/triage and team care. Patients are referred to the Hospice, which does the initial assessment. All providers then contribute to developing a care plan, which is held by the patient who takes it to all care review discussions. The inter-professional Palliative Care team at the Hospice (specialist palliative care physicians and nurses, social workers, chaplains and counsellors) coordinates the case and provides advice/support, with the general practice team as the patient’s main point of contact. After-hours availability is agreed on and documented in the patient’s care plan. Care providers meet for daily rounds and for weekly discussion of all new patient referrals. If the patient is admitted to the inpatient unit at the Hospice, the general practice team is informed and encouraged to visit and provide input, while the Hospice team

provides primary inpatient management. If the patient is discharged from the hospice, the general practice team assumes lead responsibility for patient care with support from the specialist team.

Compensating general practitioners. General practice teams receive public funding for palliative care consultations with patients, home visits, nurse consultation (including telephone consultations) and the provision of prescription repeats. The total public funding per palliative care patient is NZ\$400; if the care required exceeds this amount, top-ups can be negotiated. According to general practice teams, the fact that patients don't have to pay for GP visits is a strong factor in the success of the program. GPs also feel more comfortable visiting palliative care patients knowing they do not have to charge the patient.

A 2006 evaluation of the program showed that the majority of district GPs and many practice nurses completed training and had cared for at least one patient using the funding stream of up to NZ\$400 per patient. Both clinicians and patients/families reported confidence and satisfaction in the model.

Providing culturally sensitive care. The program serves Maori, Pacific People and Asian communities, as well as people with disabilities and mental illness, the elderly and those in rural communities. Maori make up 17% of the population in the district and 13% of Hospice clients. The Hospice has a Maori health worker on staff and would like to enlarge its Maori workforce. Hospice staff report that the Maori view of life is in tune with the whole-person philosophy of palliative care, which supports staff in working with Maori communities to develop culturally safe and appropriate care.

Supporting for families/whānau. Whānau is a Maori word encompassing family, community members and kinship ties. A Maori patient may have 5 to 6 people accompanying him or her to appointments, and up to 30 visitors in the Hospice. Programs for families include a range of family support, social work services, pastoral and bereavement care.

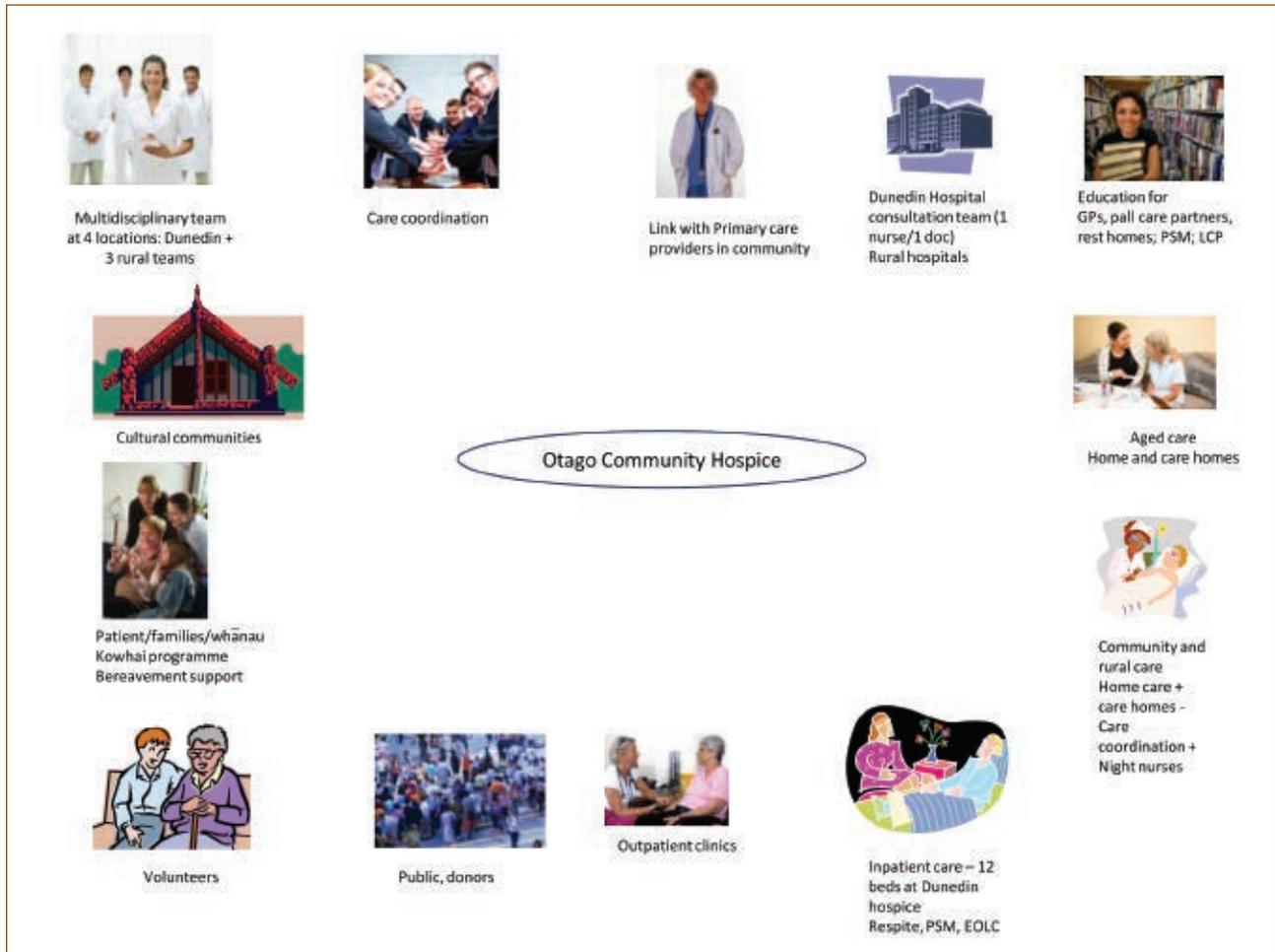
Otago Community Hospice

Otago Community Hospice is located in Dunedin (population 120,000) in the Otago region on the southeast coast of the south island of New Zealand. The Hospice, which serves urban and rural areas and a significant Maori population, provides a full range of services, working closely with general practitioners and community nurses. Its vision is *to show leadership in the provision of equitable palliative care in Otago*. Given that the need for palliative and end-of-life care in the region will probably double over the next 15 years, the Hospice believes the best model for ensuring service is to enable primary care providers in the community – including rural areas – to provide generalist palliative care, while the specialists focus on caring for complex cases. The only way to do that is to provide supports. A significant challenge is that people have to pay for services provided by primary care providers and there is no mechanism in this model to pay physicians (as there is in the Arohanui model).

Key Innovations

- Palliative care expertise located at Hospice (community-based) rather than hospital

- Care coordinators and teams located throughout the region
- Education based on Liverpool Care Pathway – including training for medical residents
- Culturally sensitive services, including education for family caregivers.



Keeping hospice palliative care grounded in the community. The Hospice – not the hospital – is the centre of palliative care expertise and education in the district, which keeps care grounded in a community-based model. As in the Arohanui Hospice model, the Otago Community Hospice works closely with community-based family physicians and other primary care providers.

Coordinating services across settings. The program has seven care coordinators: five in Dunedin and two in rural areas. Their responsibilities include: triage of referrals; initial assessments (usually a home visit); advance care planning discussions; follow-up assessments; linking with family doctor and hospital specialist; linking with district nursing (regional health authority) and home care services; linking with aged care providers and regional hospitals; and pulling in specialist members of the multidisciplinary team for symptom control advice as required.

Providing integrated, interdisciplinary care. The Hospice’s team of palliative specialist physicians, nurses, physiotherapists, care coordinators, social workers, counsellors, volunteers and support staff works from four locations – one in Dunedin and three in rural areas. The team provides specialist palliative care advice and support to primary care providers, including night

nursing wherever the patient's "home" is located (i.e., home or care home in urban and rural areas). It also coordinates with a physician-nurse consultation team at the Dunedin Hospital who support care providers with patients in hospital. The team supports care providers in long-term care and nursing homes with services that include: visiting patients as required and requested; providing 24/7 telephone advice; visiting and advising the aged care team; admitting patients to the Hospice inpatient unit when symptoms are too hard to manage at the care home; and delivering palliative care and Liverpool Care Pathway education for care home staff, including syringe driver education. If the Hospice discharges a patient to a care home, the Hospice care coordinator will visit the patient within 48 hours of discharge and remain available to provide advice throughout the end-of-life phase. At the hospice site, the team offers outpatient clinics as well as in-patient respite, pain and symptom management and end-of-life care. The inpatient care is patterned on the McGill model (Canada) of palliative care unit plus community services.

Promoting education. The Hospice offers a comprehensive education program for health care providers – primary care teams, care assistants and allied health professionals – by teleconference and in-person. The Liverpool Care Pathway (LCP) is a core end-of-life care skill. It also offers residency training for medical students from the University of Otago (located in Dunedin).

Providing culturally sensitive care. Hospice clinical practice and education are based on Maori principles of Te Whare Tapa Wha – the 4-sided house: family-related, spiritual, physical and psychological. In addition to providing psychosocial support, the Hospice offers care education for family caregivers and help in accessing the national Carer Support program that pays for alternative care, usually in a rest home, for the patient for a set time period in order to help family members have respite. The Maori philosophy of holistic care of the person is integrated into the Hospice's palliative approach, which is welcoming of Maori patients and families (whānau).

Note: The cost of visits to a family physician (about NZ\$40 per visit) can be an impediment for some patients/families who do not have private insurance. There is no special fund in Otago to cover these costs, as there is in the district served by Arohanui Hospice. There is also no national patient management system that supports good data collection across services.

Integrating the Palliative Approach to Care in Rural Areas

Three programs – Palliative Care Northern Territory in Central Australia, North Haven Hospice in New Zealand and Colchester East Hants Health Authority Rural Palliative Care Project in Nova Scotia – focus specifically on promoting and supporting the palliative approach to care in rural communities.

Palliative Care Northern Territory – Central Australia

Building Relationships to Provide More Palliative Care in Remote Communities

Palliative Care Northern Territory serves a population of about 50,000 spread over one million square kilometres. Most of the region is rural and remote desert with small communities and settlements. About 34% of the population is Indigenous; yet they make up half the palliative care

patients because the non-indigenous population tends to be young and transient. About 40% of deaths involve cancer and 50% are deaths resulting from chronic disease, including renal disease and early onset dementia. Primary care providers working in remote centres report experiencing psychological distress when dealing with difficult palliative cases, isolation and clinical and ethical problems – including whether to transport patients out of their communities for care in Alice Springs. Palliative Care Northern Territory is designed to provide support for providers in rural and remote communities, reduce their stress and improve the quality of hospice palliative care services.

Key Innovations

- Community support team that provides 24/7 consultation and coordination services
- Nurse-on-call service 24 hours a day
- Focus on patient-centred planning and preferred place of care
- Focus on changing health providers attitudes towards patient's choices
- An Aboriginal Palliative Care Model
- Training Aboriginal and non-Aboriginal providers to ensure more culturally sensitive care
- Heavy use of telephone and telehealth to support providers in remote areas.



Linking and supporting isolated providers by creating a trusted network.

The program's philosophy is to provide the best possible care in the setting desired by patients and families. Its model, which is based on years of building relationships and trust, involves an interprofessional palliative consulting team– the Community Support Team (palliative care physicians, specialist nurses, a social worker, an Aboriginal Health Worker). The team provides assessment, consultation and care coordination 24/7 for primary care providers in a variety of settings throughout the region (home, nursing homes, hospital, remote health centres) as well as consultation to the Alice Springs Hospital. It also connects with Aboriginal organizations and non-governmental social service organizations across the region, including a faith-based group that provides care for the aged.

Finding the right staff is the main challenge because palliative care is not a 9 to 5 job and the team must work closely and well together.

During working hours, all Community Support Team members are available to family physicians and other primary care providers in remote health centres. The Community Support Team also provides a nurse-on-call service 24 hours a day for urban and remote primary care providers. The nurses provide triage as well as advice for remote practitioners, which takes pressure off physicians after hours. The Community Support Team refers cases requiring specialist palliative care consultation to the palliative medicine specialists based at the Alice Springs hospital.

"Our role cannot realistically be to do hands-on care, but to support those who do. We recognize that at 2 a.m. a practitioner in an isolated area with a complicated case may need to consult someone for their own peace of mind. Often these practitioners have to put in a full day of work the next morning. Our support can sometimes make the difference between someone dying in their community or undergoing an expensive transfer to a hospital." Clinical Nurse Manager

Promoting patient-centred care. The program asks itself: *What does the patient want?* and *What can we realistically deliver?* One of the roles of the Community Support Team in Alice Springs is to help acute care hospital-based workers see the value of the holistic palliative approach and provide patient-centred rather than system-centered care. For example, it took time for hospital staff to see that it was an acceptable choice for a patient to want to live out the end of his life in a creek bed "on country", if he could have his pain and symptoms managed by community nurses in the country.

The model focuses on helping the patient spend as much time as possible in the preferred place of care, even if the place of death may be a hospital or nursing home. Service integration and partnership and the desire of most members of the network to go the extra mile makes this goal achievable in many cases. Integration is achieved both through formal agreements such as Memoranda of Understanding and service agreements with partners and also through the goodwill and respect that has developed as partners work together.

Engaging primary care providers and sharing the care. The involvement of primary care physicians is key to the model; however, the program reports that it can be a "hard sell"

persuading family physicians to provide palliative care. Many still prefer to leave palliative care to the consultation team. The team supports a core group of family physicians who are committed to providing palliative care, assisting as required in the care of their patients. It also encourages other physicians to get involved by providing education. In remote areas the nurse and some physicians must handle care, and the only realistic role for the team is support, advice and education.

Developing an Aboriginal Palliative Care Model. The program has developed an Aboriginal Palliative Care Model based on the three principles of culture, kinship and country. It focuses on communication, cross-cultural awareness, culturally-appropriate resources and service provider flexibility. The program involves a Palliative Care Aboriginal Health Worker, a government-funded position that is intended to provide a holistic approach to care and ensure:

- Cultural safety including: demonstrating respect for beliefs and understandings; recognizing the importance of kinship, gender and age; and facilitating traditional practices and practitioners
- Support and advocacy for Aboriginal clients in hospital and remote settings including: organizing family meetings; acting as liaison between patient/family and medical/social services; coordinating interpreters and seeking advice from Indigenous workers and elders; and arranging social and financial support
- Communication and relationship building including: mediating disputes; building relationships and trust; and supporting non-Indigenous staff who are caring for Indigenous clients.

Addressing cultural issues related to advance care planning. Advance care planning is a challenge for Aboriginal patients and families because of cultural taboos surrounding death and dying. The program works with Aboriginal women's organizations – the "grandmothers" who often hold families together – to address this issue.

The Community Support Team works with Aboriginal Health Workers and nurses in remote health centres, a nursing home in Alice Springs for Aboriginal patients, and various Aboriginal organizations to implement the Aboriginal Palliative Care Model.

Building capacity among Aboriginal and non-Aboriginal workers. The program recognizes that services will be stronger with more Aboriginal health workers and more non-Aboriginal workers who have the skills to work with Aboriginal communities, so it is working to build capacity among Aboriginal health workers and raise the skill level of non-Aboriginal primary care providers to provide end-of-life care for Aboriginal clients. The service prefers to hire local people because people coming from urban areas often have trouble adjusting to living in a remote area. In the words of the team manager, "A good vacancy is better than a bad hire. The team is too small to fracture with a bad hire."

The team has adapted the national Program of Experience in the Palliative Approach (PEPA) – an initiative to build workforce capacity – for Aboriginal communities. Innovations include a strong focus on community outreach to Aboriginal care workers and a one-day workshop facilitated by an Aboriginal Educator that focuses on teaching non-Aboriginal workers to work respectfully with

Aboriginal clients and encouraging them to take more PEPA training. The program includes clinical placements for Aboriginal Health Workers that accommodate cultural differences. Training and work placements are provided in Aboriginal communities and settlements rather than requiring learners to come to Alice Springs. Outcome evaluation indicates that Aboriginal Health Workers who receive this training have more confidence and skills in providing, coordinating and facilitating holistic end-of-life care and work more smoothly with the Community Support Team and other health care providers. The approach has also helped some Aboriginal clients to fulfil their wish to “return to country” to “finish up” (die).

Using technology to bridge distances. The program uses technologies such as telephone and telehealth to provide consultation and support for end-of-life care in remote areas through remote health centres and Aboriginal organizations. The team relies heavily on mobile phones, which team members find more useful than pagers because the phones take messages and allow a quick response. Members of the Community Support Team based in Alice Springs will make day visits and provide in-person support and education to communities within a 200 kilometre radius where roads exist. The team also “hitchhikes” rides on planes to communities when opportunities arise and can have “half-way” meetings with remote health centre staff to deliver equipment and offer moral support.

High staff turnover in remote settings requires the Community Support Team to engage in continual education and awareness-raising.

North Haven Hospice

A Hub and Spoke Model to Integrate Palliative Care in Rural Areas

North Haven Hospice in Whangarei (population 50,000), near the north tip of the north island of New Zealand, provides services in the Northland area, including outlying rural areas. The Hospice, the principal provider of hospice palliative care services in the district, is closely linked with all primary care providers and all locations of care, including hospitals. It operates on a hub and spoke model: the Hospice serving as the centre of palliative care expertise, providing inpatient and home care (in homes and long-term care facilities) and providing consultation, support and education for primary care providers in the community and in hospital. The hub and spoke model encourages regional collaboration, standardization of care and quality, equitable access across the district and economical use of resources. It aims to have most end-of-life care provided by primary care providers, with specialist palliative care services taking on complex cases.

North Haven Hospice:

- Affirms life
- Recognizes dying as a normal process and neither hastens nor postpones death
- Exists to help patients and families/ whānau attain a degree of preparation for death that is satisfactory for them
- Recognizes grief as a normal response to loss and continues to support family into the bereavement period
- Strives to provide a hospice/ palliative care service that is culturally appropriate and based on need, not the ability to pay.



Developing the interprofessional team at the hub. The Hospice team consists of a palliative medicine specialist and nurses, with occupational therapy and physiotherapy skills provided by the Whangarei Hospital. The team provides direct care at the Hospice inpatient unit, specialist palliative care to patients in the Whangarei Hospital (in collaboration with the attending family physician), and specialist nursing care in home and long-term care facilities throughout the region available seven days a week, with 24-hour telephone access and after-hours nurse visits if required. Hospice nurses work with family physicians, district health nurses and Maori Health providers to provide care. The team also supports primary care providers through consultation and education.

90% of the care provided by North Haven Hospice is delivered in the community (home care, rest homes, care coordination).

Forging links with primary care providers in community. The Hospice team consults with and supports primary care providers who have patients requiring palliative care. A strong emphasis is placed on increasing primary care capacity through education. Most family physicians have only two to three patients a year requiring end-of-life care, but that number

The national Department of Health is encouraging advance care planning, but so far the program has found it hard to engage primary care providers because of the time required for such discussions and the psychological difficulties experienced by both patients and care providers.

will increase with the aging population. Any patient who receives inpatient care at the Hospice is cared for by the Hospice team in consultation with the patient's family physician. If the patient is discharged, the family physician is given discharge information, liaises with the interprofessional team nurses and has access to the palliative medicine specialist if needed.

The Hospice's approach is to build capacity among community-based primary care providers through consultation and education. The Hospice has a specialist nurse educator and advisor whose role is to increase the capacity of primary care providers and break down silos between services. The program provides a range of courses for generalist care providers (family physicians and nurses) and care assistants. The Hospice has adapted Standards developed by Hospice New Zealand, and it provides Generalist Palliative Care Guidelines to support primary care providers. Many of the Hospice's education resources are online to provide flexible access for health workers.

Developing common tools. The Hospice promotes service coordination by working in partnership with primary care providers, meeting regularly with all care services, and promoting use of shared electronic health

records. The use of laptops and tablets at the bedside in all care settings means that case notes can be accessed, updated and shared quickly and easily. About 90% of primary care providers in the community now have electronic access to palliative care patient records.

The Hospice is currently working on systematic collection of data with other health care providers to develop quantitative measures.

Supporting families/whānau. The Hospice social worker, counsellor and bereavement support coordinator provide a full range of psychosocial supports for families, including counselling, social services, education days, bereavement support, telephone support and referrals to other health and social service organizations. They visit families at home or meet them at the Hospice. The Living Well day program for patients who are active enough to attend provides respite for families as well as some activities that involve both families and patients (e.g., social events, creating a patient-family photography album).

Adapting services for Maori communities.

About 20% of the clients served by the North Haven Hospice are Maori. Maori patients tend to present late in disease progression and require end-of-life services soon after referral. The whānau (extended family, community and kinship relationships) is central to Maori life, but many young people are moving away to cities, leaving an older population with fewer family resources. The Hospice works closely with Maori Health, a service funded by the district health board. At present, the Maori Health workforce consists mainly of care assistants. Maori nurses are being trained but there is concern that they will leave the northern region after training.

"The palliative care program has gained respect from some oncologists in Nova Scotia who now feel confident that they can release patients from their care knowing that someone with enhanced palliative care skills can continue to care for them in their home setting."

Director of Oncology Program

Connecting to regional hospices. Three community-based hospice organizations located in outlying areas are linked to the North Haven hub. These hospice organizations provide volunteer support to patients and facilitate any moves in or out of the North Haven inpatient unit as required.

East Hants Health Authority Palliative Home Care Model Enhancing Palliative Home Care

Colchester East Hants Health Authority serves a mix of urban and rural communities in central Nova Scotia. As is the case in many rural areas of Canada, the elderly in this region have fewer extended family supports as younger people move away to work. A demonstration project developed in the late 1990s grew into a palliative home care model for rural communities in Nova Scotia and Prince Edward Island that uses an interprofessional consultation team, education and the integration of service and a focus on care coordination to give more people access to the palliative approach to care at home. The program relies on longstanding professional relationships and frequent communication to ensure collaboration.



Providing expertise to support providers. The interprofessional palliative care consult team is key to providing integrated palliative care in small and rural communities. The core team includes physicians, nurses, a pharmacist and a social worker while the larger team includes the palliative

care consult team plus staff and volunteers from the Colchester East Hants Hospice, pastoral care, continuing care coordinators (Province of Nova Scotia Department of Health and Wellness), Victorian Order of Nurses (VON) nurses and home support workers. VON nurses provide home care through service contracts with the health authority. Home support workers provide personal care in the home, respite for families, emotional support, meal preparation and feeding, and light housekeeping. They communicate with other members of the interprofessional team through telephone contact, face-to-face conversations, weekly community rounds and recorded information in the patient's chart. Consultation nurses from this team spend their time in hospital and in the community, providing support to home care nurses, home support workers and family caregivers. They can also support the staff of long-term care facilities but there is less penetration of the palliative approach in these facilities.

The program required initial investments to create the palliative care team and integrative structures and provide education. As the program matures, it is expected to be cost-neutral. Challenges to long-term sustainability include: staff turnover, changes in local management and provincial government support.

The Colchester East Hants Hospice Society works closely with the program, providing much of the bereavement support services in the district. A physician from the palliative care program sits on the Board of the Hospice Society, which facilitates coordination of planning and service delivery. The Hospice provides its staff social workers to the community interprofessional team, which supports integration. It also provides volunteer visiting, practical support (e.g., food vouchers, equipment), advocacy and system navigation, wish fulfillment for patients, and community education (volunteer training and annual conference for medical professionals and volunteers). The Hospice volunteer coordinator attends weekly hospital rounds and assesses all patients/families referred for volunteer support. A new palliative care unit in a local hospital provides secondary and tertiary care closer to home for those who need it. The Hospice volunteers are a daily presence on the hospital palliative care unit.

Engaging family physicians. The consult team provides advice to physicians caring for patients in the community. If a patient is admitted to hospital, the family physician with hospital admitting privileges continues to be the primary care provider for the patient in hospital, with consultation from the palliative care team. If a family physician does not have hospital admitting privileges, the hospital assigns a doctor who connects with the palliative care team. There are limited provincial fee codes to pay primary care physicians appropriately for palliative care work, which may discourage those physicians from being involved. If they are not involved, the patient in hospital may have a new primary care physician because of rotations, which creates a challenge for seamless continuity of care.

Focusing on access, case management and care coordination. Families who need support call one number to access the palliative care service in the region. Individuals are then

Colchester East Hants Health Authority has the best record in Atlantic Canada for days spent at home in the last year of life. (CIHI, 2011)

assessed to determine their care needs. Home care patients are assigned two case managers: one for resources (continuing care coordinator) and one for clinical care planning (palliative care consult nurse). This approach enables care providers to talk across boundaries.

Providing navigation services for cancer patients. Oncology nurses with Cancer Care Nova Scotia help patients with cancer and their families navigate the health care system. The navigators act as advocates, educators and support persons linking patients with the care and support they need. In this part of the program, which is available only to cancer patients, the navigator exchanges information with the consult team by attending palliative care community rounds. Once a patient enters palliative care, the cancer care navigator becomes less involved.

Charting and communication. In the home, the consult nurse and VON home care nurses share patient charts, which also helps communication. Weekly community rounds are held to coordinate care (i.e. “Who is doing what for whom this week?”). Charts accompany the patient if he or she has to be hospitalized. Weekly hospital rounds are held to discuss complex cases. Charts help communication but, as they are not yet electronic, they can become out of date if changes are made after phone consultation.

Providing education. To enhance the capacity to provide the integrated palliative approach to care, both the hospital-based service and the community-based hospice provide education for nurses (e.g., hospital, home care, long-term care nurses), physicians and allied professionals (e.g., nurse practitioners, physiotherapists, occupational therapists) based on the Pallium LEAP program.⁸

Although all primary care providers can benefit from palliative care education sessions, nurses are the main enrollees.

⁸ Pallium is a Canadian program providing education and ongoing professional development in hospice palliative care through provision of educational materials and training workshops. The LEAP (Learning Essential Approaches to Palliative and End-of-Life Care) program is courseware developed by a pan-Canadian network of academic health leaders and community practitioners with enhanced skills in palliative care services. www.pallium.ca

Integrating the Palliative Approach in Community-based Long-Term Care Settings

Two of the programs – St. Christopher’s Hospice in England and the Living Well and Dying Well Program in Tasmania –focus on improving access to hospice palliative care services in long-term care facilities. Most residents consider the long-term care home to be their “home”, and the focus of these programs is on bringing care to the person’s home wherever that home may be.

St. Christopher’s Hospice Care Homes Project Helping care homes meet the gold standard

The birthplace of the modern hospice movement, St. Christopher’s Hospice has a long history of innovation. It has grown from a residential hospice to include an expanded inpatient unit, home care, long-term care homes, support for affiliated hospitals in the region south of London, and an active research and education program. It was the first regional training centre for the Gold Standards Framework, a systematic evidence-based approach to optimize care for patients nearing the end of life.



Changing the system. The Gold Standards Framework focused on systems change: influencing the way that care providers think about death and dying, and about what patients need during

that time. The program was implemented using a three-phase, simultaneous top-down (managers) and bottom-up (front line staff) approach. Training for managers of care homes focused on critical thinking about providing palliative care and change management. St. Christopher's provided support for the project over a period of years: its facilitators continued to work with the homes on change management, education, coordination and sustainability.

The 120 care homes serve 2500 residents. About 25% of residents who require palliative care have a cancer diagnosis.

Educating and supporting staff. In the care homes project, St. Christopher's Hospice worked with 120 care homes to apply the Gold Standards Framework (GSF) approach. The project involved training all staff in addition to clinical staff (e.g., domestics, gardeners). St. Christopher's provides the facilitators to deliver the GSF Care Homes Training Programme, which consists of basic palliative care education (including advance care planning), role modelling, videos and discussions. All staff received two-day induction training while nurses and care assistants with more than one year of service in the care home also received in-depth training. The amount of support provided was tailored to each home's needs. For example, St. Christopher home care nurses went into five of the homes to help with training and care – and all homes are now linked to St. Christopher's broader care network, including primary care providers, home care services, hospital and hospice services (if required). In some homes, the program also provided creative therapy groups.

Establishing learning clusters. St. Christopher's organized the 120 homes into clusters to promote information exchange and learning. Care home managers in some clusters meet regularly to discuss challenges and issues. Residents in care homes in these clusters tend to have high rates of dying at "home", which benefits the resident and family and reduces costs to the care home (e.g., transfers to the hospital, staff time and loss of per diem payments while the resident is in another facility).

Supporting care homes to seek GSF accreditation. Encouraging care homes to seek accreditation under the Gold Standards Framework helped to reinforce the importance of being able to work to these standards. Being accredited helps ensure that the homes will maintain high quality care, and they will also receive recognition for their efforts. Families are more likely to choose homes that are accredited, and accredited homes are entitled to extra per diem fees from district health authorities for providing palliative care.

Leveraging care home funding. The Care Homes Project was different from many other models in that the costs were shared with the care homes themselves. The homes paid a significant portion of the cost of curriculum materials and facilitators. St. Christopher's initially provided one staff person to coordinate the project (as well as nurses who went into the homes to help), while the five health districts involved in the project hired first four and then eight staff to provide support. To maintain the program, St. Christopher's has asked the district health authorities and the care homes to share the cost of a salary for a nurse.

Evaluating the program. St. Christopher's is evaluating the project with 45 of the care homes to identify sustainable models of GSF implementation. Phase one of the evaluation, involving 19 care homes, showed a decrease in the number of care home residents dying in hospital. As a result, the project was able to transition from charitable funding to district health funding (by primary care trusts which are funded by the National Health Services).

In 2007-2008, the proportion of people dying in 71 of the care homes ranged from 55% to 61%. By 2010-2011, that proportion had increased to a range of 75% to 86%.

Tasmania's Living Well and Dying Well Program: Culture change in aged care homes and better care for residents with dementia

The North West Area Health Services serves the northwest area of Tasmania (population 107,000). It provides a full range of palliative and end-of-life care services to the general population and is the regional centre for the Gold Standards Framework. Since 2011, the health authority has been piloting the Living Well and Dying Well Program with aged care homes (long-term care facilities), focusing on improving hospice palliative care for residents with dementia. The goal of the program, which is based on the National Palliative Care Strategy (2010) and the National Guidelines for a Palliative Approach in Residential Aged Care (2006), is to help staff provide patient-centred care and ensure residents and their families have access to integrated primary and secondary hospice palliative care services.

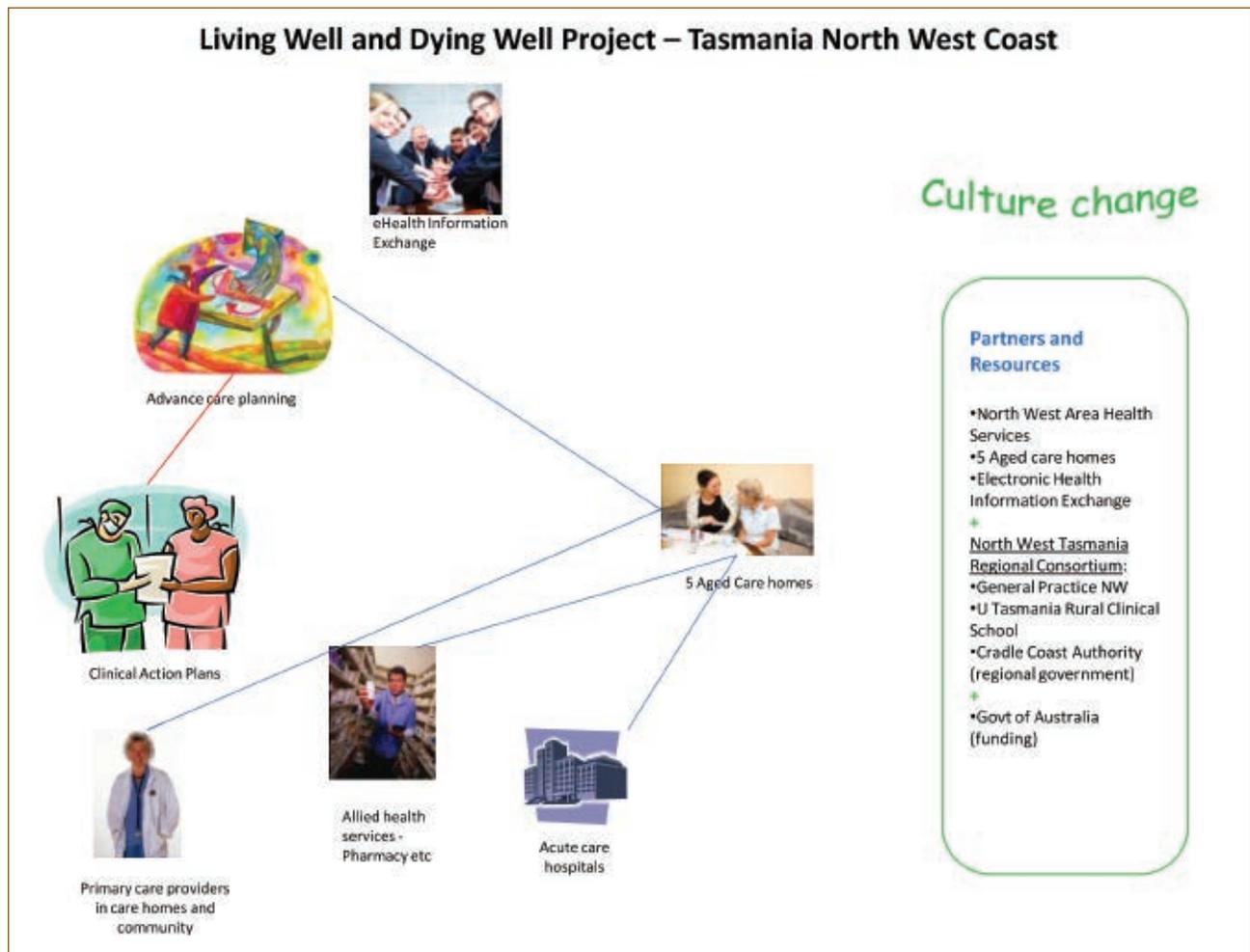
60% of residents in aged care homes in northwest Tasmania die within the first year of admission to the home – therefore, aged care homes are key to improving access to high quality hospice palliative care.

Changing Culture. Led by two project facilitators – a palliative medicine specialist and a specialist nurse educator – who were highly respected in their fields, the program started by creating a culture of respect for residents' wishes in the homes: developing common goals, creating interprofessional teams that involve the personal support workers who spend the most time with patients and families, and flattening hierarchies to improve communication, information sharing and continuity of care. All staff in the aged care homes – including domestic and maintenance staff – received palliative care training.

Promoting Advance Care Planning. As part of the education, staff were trained in Dignity, Preferred place of care, Advance care planning, and Goals of care (DPAG). They worked with residents to develop an advance care plan. Advance care planning with people with dementia can be challenging, particularly if they have trouble communicating. Care home staff learned how to hear and respect the patient's evolving preferences for day-to-day care and to hear and respect patients when they refused aggressive treatment, even though their substitute decision-maker might want such treatment. Listening to residents with dementia involves staff looking at the advance directive that the person may have made while less cognitively impaired, and having repeated conversations with the patient to determine their wishes to the greatest extent possible. Staff also learn how to manage delirium to help the patient retain as much cognitive clarity as

possible. As part of the training, the program developed a Dignity in Risk assessment process for staff that help them be aware of their own tendencies to impose their own values, which may affect their ability to respect and maintain the resident's dignity. As part of advance care planning, nurses start conversations with patients about:

- how much information they want to know about their condition
- how involved they wish to be in decision making
- their preferred place of care, which may be the care home, a hospital or at home with family.



Developing Clinical Action Plans. These conversations and the person's care wishes, which may include preferences such as "allow natural death", are summarized in the person's advance care plan. Nearer the end of life, the plan will identify the person's goals of care, which can include comfort and preventing crises. Through this planning, realistic and achievable goals can be negotiated with the person and the care team so the appropriate care path is chosen. That information is used to create the person's Clinical Action Plan.

Engaging and Supporting Primary Care Physicians. Once care home staff were trained and working in teams with common goals, the program began to engage primary care physicians with patients in the homes, training them to play more active roles in providing hospice palliative care.

To ensure the care required at end of life is not too much of a burden, particularly for overstretched rural physicians, the State of Tasmania funds GP Assist, an after-hours workforce support service. Palliative medicine specialists located in the hospitals help educate primary care physicians. They are also there to share the care if a resident's care can no longer be managed in the home and the person has to be admitted to an acute care hospital.

Although the Living Well and Dying Well pilot project is centered on aged care homes, it involves many care providers in the health district. Senior leadership at the district level has been crucial in approving staff time, shifting resources from acute care to the pilot project and helping to engage a broad network of care services.

Using Electronic Health Records to Share Information. One of the key features of the Living Well and Dying Well program is an electronic health record, funded by the Government of Australia, that ensures residents' Clinical Action Plan and any other wishes can then be shared electronically among all care providers – primary care providers, after-hours GP services, acute care hospitals and pharmacists –and updated and communicated quickly in locations such as the care home, physician's office or pharmacy.

Providing earlier access to an integrated approach to palliative care. The program, which has been piloted in five aged care homes, focuses on the last year of life and is working to introduce the palliative approach earlier in residents' care. If additional funding can be secured, it will be expanded to other aged care homes.

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Pallium education program: www.pallium.ca

Fraser Health Hospice Palliative Care: http://www.fraserhealth.ca/your_care/hospice_palliative_care/

Fraser Health Advance Care Planning: http://www.fraserhealth.ca/your_care/advance-care-planning/

Edmonton Zone Regional Palliative Care: <http://www.palliative.org/>

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Colchester East Hants Health Authority: <http://www.cehha.nshealth.ca/services/#P> (follow alphabetical services list to palliative care)

Colchester East Hants Hospice Society: <http://cehhospice.org/>

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ENGLAND

Department of Health links to palliative care information: <http://www.dh.gov.uk/health/search?q=end%20of%20life%20care>

End of Life Care Strategy: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_086345.pdf

Gold Standards Framework: <http://www.goldstandardsframework.org.uk/>

Liverpool Care Pathway: <http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/>

St Christopher's Hospice: <http://www.stchristophers.org.uk/>

Dorset Primary Care Trust Palliative Care: <http://www.dorset.nhs.uk/localservices/palliative-care.htm>

Dorset Compassionate Community initiative: www.dorset.nhs.uk/localservices/compassionate-community.htm

NEW ZEALAND

New Zealand Ministry of Health links to palliative care strategy and other information: <http://www.health.govt.nz/our-work/life-stages/palliative-care>

Cancer Control New Zealand palliative care needs assessment consultation: www.cancercontrolnz.govt.nz/needs-assessment-consultation-0

New Zealand palliative care workforce forecast project: www.healthworkforce.govt.nz/our-work/workforce-service-reviews/palliative-care

Hospice New Zealand: <http://www.hospice.org.nz/>

Arohanui Hospice: <http://www.arohanuihospice.org.nz/>

Liverpool Care Pathway for New Zealand: <http://www.lcpnz.org.nz/pages/home/>

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Otago Community Hospice: <http://www.otagohospice.co.nz/>

North Haven Hospice: <http://www.northhavenhospice.org.nz/Home.aspx>

AUSTRALIA

Australia Government Department of Health and Ageing Palliative Care Program (links to National Palliative Care Strategy): <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-program.htm>

PEPA - Program of Experience in the Palliative Approach: <http://www.pepaeducation.com/>

Guidelines for a Palliative Approach in Residential Aged Care:
http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/pc29.pdf

Guidelines for a Palliative Approach for Aged Care in the Community Setting:
<http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-pubs-compac-guidelines.htm>

Palliative Care Australia: <http://www.palliativecare.org.au/Home.aspx>

Palliative Care Australia Standards:
www.palliativecare.org.au/Portals/46/Standards%20for%20providing%20quality%20palliative%20care%20for%20all%20Australians.pdf

Northern Territory Government Department of Health Palliative Care (links to NT PEPA program; Aboriginal palliative care model is described on NT PEPA poster): http://www.health.nt.gov.au/Palliative_Care/index.aspx

Northern Territory Government: Remote Health Atlas – Territory Palliative Care:
http://remotehealthatlas.nt.gov.au/territory_palliative_care.pdf#search=%22palliative%22

National Rural Health Alliance. Care providers write about their experiences.
<http://nrha.ruralhealth.org.au/ftp/twitter/partyline-41-back-page.pdf>

Silver Chain, Western Australia: www.silverchain.org.au

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www.healthnetworks.health.wa.gov.au/modelsofcare/docs/Rural_Palliative_Model_of_Care.pdf

Tasmania Department of Health and Human Services Palliative Care: <http://www.dhhs.tas.gov.au/palliativecare>

University of Tasmania Rural Clinical School – Gold Standards Framework in Registered Aged Care Facilities:
<http://www.utas.edu.au/rural-clinical-school/research/research-projects-partnerships/ehealth/gold-standards-framework-project>



THE WAY FORWARD INTEGRATION INITIATIVE

Annex D - Saint Vincent Hospital
60 Cambridge St. North, Ottawa, Ontario
K1R 7A5

email: info@hpcintegration.ca
tel: 1-800-668-2785 ext. 228
fax: 613-241-3986

www.hpcintegration.ca

