The Public Health Approach to Palliative Care

Principles, Models, and International Perspectives

A White Paper for The BC Centre for Palliative Care

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Prepared by: Eman Hassan MD. MPH. PhD
QualiHealth Consulting
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EXECUTIVE SUMMARY

The BC Centre for Palliative Care (BC CPC) provides leadership to promote excellence in palliative and end of life care for all British Columbians. The Centre was established in 2014 by the Institute for Health System Transformation and Sustainability with funding from the Ministry of Health in support of the BC Provincial End of Life Action Plan. Establishment of the BC CPC represents an important opportunity for greater public engagement to support the development of quality person and family centred care and outcomes for all British Columbians living with and dying from serious or advanced illness. The Centre works collaboratively with health system partners including regional health authorities, care providers, professional bodies and community organizations across BC to promote education around end of life care issues and support evidence-based practice and policy development.

The BC CPC recognizes the social dimensions of living with advanced illness, death, dying, grief and loss and that there is an urgent need in BC to move forward in innovative ways to address both societal concerns and the current issues with the access and quality of palliative care services. This report was commissioned by the BC CPC to provide evidence base for the effectiveness of the public health approach in addressing these concerns and issues and in meeting the expectations of the public and other stakeholders.

This report delivers an in-depth understanding of the public health approach principles and elements and describes exemplary public health palliative care (PHPC) models. The experience of Spain, United Kingdom, Australia, Japan, and India with PHPC models are presented in detail in this document. The experience of Germany, Italy, and France, Norway, and Hawaii with the public health palliative care models are described in other publications.\(^1\)\(^2\)\(^3\)\(^4\)\(^5\) The report is based on a review of peer reviewed journal articles, books, reports and websites of governmental and non-governmental organizations and other grey literature. In addition, the report findings are informed by consultations from palliative care leaders and researchers in BC.

The BC CPC intend to use this document to spark and shape discussions about how to advance the PHPC approach in BC through the development of a provincial end-of-life coalition with representatives from clinicians, educators, community agencies, and the public. Ensuring public participation in this process will contribute to the sustainable health care system that meet the need to create for all British Columbians living with and dying from advanced illness and families.

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**Key Findings**

The PHPC approach promotes holistic, evidence-based, innovative, community-based, whole systems oriented end-of-life care.

Compassionate Communities – a key feature of PHPC – offer access to the many social aspects of care that are not provided by the health care system (e.g. respite for caregivers, companionship for people with dementia who are often socially isolated, bereavement support for caregivers) but which are central to the well-being of patients’ with advanced illness and their family / friend caregivers.

There is strong evidence to suggest that the public health approach presents sustainable solutions to the problems of access, equity, and quality of palliative care.

With regards to its impact on patient and system outcomes, the public health approach showed that it:

- improves the person and provider experience
- enhances the quality of life prior to death
- makes it possible for more people to die in dignity in home-like settings
- creates compassionate caring communities
- results in cost savings

The public health approach in the reviewed countries can be described in the form of three models:

1. **Whole Systems Model**
   
   **Example: Catalonia, Spain**
   
   A ‘Top down/whole systems’ model aims to extend health services to community settings through system’s efforts. The model focuses on establishing necessary system infrastructure and resources such as: polices, strategy, data system, quality assurance, capacity development, evaluation, and research resources. The ‘whole system’ model significantly enhanced the quality and value of palliative care delivery in Catalonia. (See **Figure 10** Catalonia WHO Public Health Palliative Care Project: Results at 10, 15, and 20 Years)
2. Health Promoting Model
   Example: Kerala, India
A ‘Bottom up/health promoting’ model recognizes the social character of frailty, illness and dying; emphasizes education and information-sharing; and enhances collaboration and participatory relationships between the health system and the community. In Kerala, the health promoting model involved community-led engagement and development strategies. This resulted in the creation of compassionate communities in which the responsibility of care for experiences of death, dying and loss is shared among province-wide networks of community members and groups. In Kerala, the model successfully expanded the range of palliative care beyond health services and professional care, significantly increased palliative care coverage, and enhanced quality at the end-of-life. (See Figure 11 Kerala’s Experience: Typical activities of NNPC volunteer groups)

3. Whole Systems, Health Promoting Model
   Examples: United Kingdom, Australia and Japan
A ‘Mixed’ model recognizes health promotion and awareness as integral parts of a whole system approach to palliative care. This model, which is applied in the UK, Australia and Japan, includes national engagement programs and awareness campaigns, which are often funded and led by the government, to involve the community in planning their own palliative and end-of-life support programs and to prompt and direct society’s efforts towards common national objectives. (See Figure 16 Japan: Overview of the Long Term Care System Reform, Table 5 UK National Palliative Care Programs Mapped to the Essential Public Health Approach Elements, Table 7 Australia’s National Palliative Care Programs Mapped to the Essential Public Health Elements)

The three PHPC models emphasize the importance of partnerships:
- Partnership between communities, governments, and service providers
- Partnership between care providers: specialists in palliative care, primary care providers, specialists in elderly care and oncology, psychiatrists, and social workers

The implementation of the PHPC models in the examined countries followed a systematic process to integrate incremental transformative changes in existing services and programs, building on existing strengths and making efficient use of the available resources. This process allowed for earlier successes to be achieved and this helped in garnering greater confidence in the PHPC model and sustained support.

Having different models for the public health approach to palliative care indicates that the approach needs to be tailored to the society’s demographic, economic, social, cultural and political factors, taking account of the health system structure.
DEFINITIONS

Following are some definitions of the terms used to conceptualize the public health approach to palliative care.

Access
Access is defined as the “extent to which an individual who needs care and services is able to receive them; more than having insurance coverage or the ability to pay for services; determined by the availability and acceptability of services, cultural appropriateness, location, hours of operation, transportation needs, costs and other factors.”

Equity
Achieving health equity requires that all individuals have fair opportunities and access to conditions and services that will help them achieve optimal health. Equity in health demands that we care about the range of human experiences and work towards making health care and policies responsive to all people, by paying attention to their diverse identities as people, and by paying attention to the diversity in their daily lives.

Chronic diseases
Chronic diseases are “diseases of long duration and generally slow progression.” Examples of chronic diseases include cancer, chronic respiratory diseases, diabetes, heart disease and stroke.

Terminal illness
A terminal illness is “an incurable medical condition caused by injury or disease. These are conditions that, even with life support, would end in death within weeks or months.”

Life-Limiting Illness
Life-limiting illness are illnesses that can be reasonably expected to cause the death of the individual within a foreseeable future. This definition is inclusive of both malignant and non-malignant illnesses that are expected to shorten an individual’s life.

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6 The College of Family Physicians of Canada. Glossary -Primary Care Toolkit for Family Physicians. The College of Family Physicians of Canada 2007
End-of-Life Care

End-of-life care is associated with advanced, life-limiting illnesses, and focuses on comfort, quality of life, respect for personal health care treatment decisions, support for the family, psychological and spiritual concerns.\(^5\)

Palliative care

**WHO definition** - Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.\(^11\)

**Definition by BC End-of-life Care Action Plan, 2013**

Palliative care is specialized medical care for people with serious illness. It focuses on providing patients with relief from the symptoms, pain, and stress of a serious illness – whatever the diagnosis. The goal is to improve quality of life for both the patient and the family and is provided in a variety of locations, including people’s homes and community settings, hospices, residential care settings and hospitals. Palliative care is provided by a team of doctors, nurses and other specialists who work with a patient’s other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness and can be provided together with any beneficial treatment.\(^5\)

**Definition by CHPCA**

Palliative care is a special kind of health care for individuals and families who are living with a life-limiting illness that is usually at an advanced stage. The goal of palliative care is to provide comfort and dignity for the person living with the illness as well as the best quality of life for both this person and his or her family. Palliative care services are helpful not only when a person is approaching death but also during the earlier stages of an illness.\(^12\) In Canada, hospice care and palliative care are used to refer to the same thing - this specific approach to care. However, some people use hospice care to describe care that is offered in the community rather than in hospitals.\(^7\)

Informal/family caregiver

An informal/family caregiver is an individual who is providing unpaid and on-going care or social support to a family member, neighbour or friend who is in need due to physical, cognitive or mental health conditions.\(^13\)

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\(^{11}\) [http://www.who.int/cancer/palliative/definition/en/](http://www.who.int/cancer/palliative/definition/en/)

\(^{12}\) [http://www.chpca.net/family-caregivers/faqs.aspx](http://www.chpca.net/family-caregivers/faqs.aspx)

\(^{13}\) Canadian Hospice Palliative Care Association. Fact Sheet: Hospice Palliative Care in Canada. Canadian Hospice Palliative Care Association 2012
A Public Health Approach to Palliative Care

Primary health care
Primary health care is “the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process.”

Public health
Public health is defined as an organized activity of society to promote, protect, improve, and when necessary, restore the health of individuals, specified groups, or the entire population. It is a combination of sciences, skills, and values that function through collective societal activities and involve programs, services, and institutions aimed at protecting and improving the health of all people.

Health promotion
The process of enabling people to increase control over, and to improve their health. The Ottawa Charter for Health Promotion describes five key strategies for health promotion: build healthy public policy; create supportive environments; strengthen community action; develop personal skills; and re-orient health services. Health promotion is a public health system core function.

Partnerships
Partnerships is defined as “… collaboration between individuals, groups, organizations, governments or sectors for the purpose of joint action to achieve a common goal. The concept of partnership implies that there is an informal understanding or a more formal agreement (possibly legally binding) among the parties regarding roles and responsibilities, as well as the nature of the goal and how it will be pursued.”

Community-based end-of-life care service
Community-based end-of-life care service is defined as “the provision of end-of-life care service in community contexts that results in increased patient and family agency and participation in end-of-life care.”

Community engagement in end-of-life care
Community engagement in end-of-life care is a process which enables communities and governments and service providers to work together to understand, build capacity and address issues to improve their experience of end-of-life and bereavement and their related wellbeing. Community engagement activities by end-of-life care services go beyond working in the community to working with the community to improve its

16 http://www.ncpc.org.uk/sites/default/files/Public_Health_Approaches_To_End_of_Life_Care_Toolkit_WEB.pdf
experience of end-of-life care. Communities are encouraged to take initiative in caring for end-of-life experiences within community contexts.  

Community development in end-of-life care
A society wide approach to end-of-life care. Communities reorient towards death, dying, loss and care and make a commitment to care for relevant experiences within social settings. Schools, workplaces, church organizations and other social groups create policies and practices that respond to death, dying, loss and care. People within communities are aware of issues relating to end-of-life care and local authorities support and promote activities that strengthen social capital (trust, empathy, cooperation) in relation to end-of-life care.  

Compassionate Communities
Compassionate communities represent a major form of community development efforts that aims to accommodate death, dying, loss and care into our public health ideas, and to create supportive environments for those experiences. 

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1. PALLIATIVE CARE IS AN INCREASINGLY IMPORTANT PUBLIC HEALTH ISSUE

A. Palliative care overview
As outlined in the 2001 report by the Parliament of Canada, Canadians have the right to compassionate end-of-life care that addresses their needs in line with their preferences, and to dignified death free from suffering. Individuals with life-limiting illness suffer from a range of other issues that are linked to their health conditions or social circumstances such as loneliness, isolation, job loss, stigma, depression, anxiety and fear, or even suicide. These can lead to further debilitating health problems. What complicates the end-of-life issue is that the affected patients are not the only ones who suffer and need support. Caring for a dying family member places immense emotional, financial, and social stresses on the whole family. The profound needs of the terminally ill and dying persons and their caregivers necessitate quality palliative care.

Palliative care is an approach to care that aims to achieve the best quality of life for the terminally ill, persons who face a debilitating chronic condition, and their families according to the individual’s goals of care. Palliative care strives to:

- minimize suffering
- treat all active issues
- prevent new issues from occurring
- address person’s physical, psychological, social, and spiritual issues, and their associated needs, hopes and fears
- promote opportunities for meaningful and valuable experiences, and personal and spiritual growth
- prepare for and manage end-of-life choices
- help families and survivors cope with the challenges of providing care, as well as with loss and grief

Figure 1 illustrates how hospice palliative care plays a significant role in patient’s experience through the illness trajectory, not only at the end-of-life. Treatments of the disease decrease as illness progresses, while palliative care increases as the person reaches the end-of-life. Palliative care also provides support for the family during this entire period. After the patient dies, it is important to provide bereavement counselling for family and friends.

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18 PARLIAMENT of CANADA. QUALITY END-OF-LIFE CARE: THE RIGHT OF EVERY CANADIAN. 2001
B. Guiding principles to palliative care:
The Canadian Hospice and Palliative Care Association has set well-defined principles to guide programs towards good quality hospice palliative care. These principles are:

- **Person/Family Centred**
  When palliative care is provided, the ill person and his/her family are treated as a unit. The person is engaged in all aspects of care which are provided in a manner that is sensitive to the person’s and family’s personal, cultural, and religious values, beliefs and practices, their developmental state and preparedness to deal with the dying process. There is a valuable distinction to be made between patient-centred and person-centred, with the former being focused on the illness role and the latter focussing on the whole person for whom illness is but one part of life.

- **Ethical**
  All hospice palliative care activities are guided by the ethical principles of autonomy, beneficence, non-maleficence, justice, truth-telling and confidentiality. All research protocols comply with legislation and regulations governing research and the involvement of human subjects in effect within the jurisdiction.

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• **Accessible**
All individuals and families have equal access to hospice palliative care services when they need it and where they need it: at hospitals, long-term care facilities, hospices, and the home.

• **High Quality**
All hospice palliative care activities are guided by standards of practice based on nationally accepted principles and norms of practice, and standards of professional conduct for each discipline.

• **Safe and Effective**
All hospice palliative care activities are conducted in a manner that ensures confidentiality, privacy, safety and security. Care that is beneficial and does not create undue risk or burden. Care without any form of coercion, discrimination, harassment or prejudice.

• **Team-Based/Circle of Care**
Hospice palliative care is most effectively delivered by an inter-professional team of health care providers who are both knowledgeable and skilled in all aspects of care within their discipline of practice. The professional team works with family members, friends and other caregivers to form a circle of care around the person and family. Palliative care teams typically include physicians, nurses, allied health care professionals (e.g. physiotherapists), social workers, spiritual advisors, bereavement support workers, trained volunteers, and informal caregivers such as family members and friends.

• **Adequately Resourced**
The financial, human, information, physical and community resources are sufficient to support the organization’s activities and its plans.

• **Collaborative**
Each community’s needs for hospice palliative care are assessed and addressed through collaborative efforts/partnerships among organizations and services in the community.

• **Advocacy-Based**
Regular interaction with legislators, regulators, policy makers, health care funders, other hospice palliative care providers, professional societies and associations, and the public increases awareness of hospice palliative care activities and the resources required to support them.

• **Evidence-Informed and Knowledge-Based.**
The development, dissemination and integration of new knowledge improve the quality of hospice palliative care. All activities are based on the best available evidence. Ongoing
education of all persons, families, caregivers, staff and stakeholders is integral to providing and advancing quality hospice palliative care.

**Figure 2 Guiding Principles to Palliative Care Programs**

![Guiding Principles to Palliative Care](image)

*Source: Canadian Hospice Palliative Care Association. A model to guide hospice palliative care 2013*

**C. Why palliative care became an important public health issue?**

More than a decade ago the World Health Organization made a global call for all countries to consider palliative care as a public health problem and include it in their health agendas. 24 Since then an increasing number of health systems across the world started to look into the escalating unmet care needs of the frail elderly and terminally ill people, and many concur with the WHO that palliative care is indeed a public health issue. 25 26

Like elsewhere in the developed world, end-of-life care provision in Canada is facing extreme challenges due to the rapidly evolving palliative care practice, socio-demographic changes in

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the end-of-life context, and health care system constraints. These challenges have led to palliative care being on public and government agendas across Canada as an increasingly important public health issue. In 2014, the outcomes of a national dialogue on EOL care revealed strong public support for greater access to palliative care. Bill 52 in Quebec passed in June 2014, legalizing medical-aid-in-dying (euthanasia) and promising palliative funding. In May 2014, a private members’ bill was approved in Parliament calling for a national palliative care strategy.

The following section presents an analytic overview of the palliative care challenges and documented gaps in the provision of health care services across Canada.

Changes in palliative care practice
Historically, palliative care was mostly offered to people with cancer in hospice settings. Palliative care provision is evolving to keep pace with the changes in people’s experience with illness and dying.

Today, it is recommended that palliative care is

Provided on the basis of need, not diagnosis or prognosis – Palliative care is no longer limited to illnesses that are deemed terminal. According to modern definitions and models, palliative care should be available to persons with chronic conditions, people who are frail, as well as terminally ill patients.

Not restricted to end stage of life – Research has confirmed that palliative care is more beneficial to patients and family caregivers when provided early in the course of illness ideally at time of diagnosis. Multiple studies showed that early palliative care improves symptom management, quality of life and mood among patients with advanced cancer.

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27 Canadian Hospice Palliative Care Association. Fact Sheet: Hospice Palliative Care in Canada. Canadian Hospice Palliative Care Association 2014
28 Williams et al. Canada’s Compassionate Care Benefit: Is it an adequate public health response to addressing the issue of caregiver burden in end-of-life care? BMC Public Health 2011; 11:335
29 https://cmadialogue.ca/en/
31 http://www.parl.gc.ca/Parliamentarians/en/members/CharlieAngus%282825470%29/Motions?sessionId=151&documentId=6261234
32 http://www.eapcnet.eu/LinkClick.aspx?fileticket=zdTuqg5EJo%3D&tabid=38
In addition to these benefits, two studies based on randomized controlled trials among patients with non-small-cell lung cancer carried out by Temel and colleagues concluded that early integration of palliative care with standard oncologic care may result in prolonged survival, improved patient perception of prognosis, greater documentation of resuscitation preferences in medical records, as well as less aggressive care and resource use at the EOL. Similar benefits were reported for caregivers. A recent randomized controlled trial showed that early palliative care in the form of coaching and bereavement support, significantly lowered depression and stress burden among family caregivers of patients with advanced cancer.

These benefits demonstrated for both patients and caregivers have led to the development of new models of care such as the Bow tie model, which aims to facilitate earlier acceptance of palliative care in conjunction with disease modification therapies from the time of diagnosis. (See Figure 3) The Bow tie model serves as a communication tool that helps people see and accept palliative care as an essential part of medical care and thereby maximize the time that people would benefit from the wide variety of palliative care interventions available.

Figure 3 The Bow Tie Model: Early Integration of Palliative Care in Disease Management

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42 Dionne-Odom et al. Benefits of Early Versus Delayed Palliative Care to Informal Family Caregivers of Patients With Advanced Cancer: Outcomes From the ENABLE III Randomized Controlled Trial. JOURNAL OF CLINICAL ONCOLOGY 2015; 33 (13): 1446-1452
Not limited to any one care setting - Palliative care is provided wherever a person’s care takes place, whether this is the patient’s own home, a community care facility, hospice in-patient unit, hospital, or outpatient or day care service.

Multidisciplinary and provided at all levels of care - Care is not limited to specialist palliative care services but is provided at primary and secondary levels of care as well. Services are broad and multidisciplinary to address the patients’ multidimensional needs and this requires integration and alignment of services across different sectors including the health, social, and non-governmental sectors.

Growing demand for palliative care
Health care systems and particularly provision of palliative care are under stress to meet the complex needs of the increasing number of frail individuals, persons who are facing life-threatening illness, the dying and the bereaved. It is estimated that 90% of Canadians who die can benefit from palliative care. However only about 30% of Canadians have access.  

- Population is aging
Older people frequently have multiple debilitating conditions such as dementia that escalate their palliative care needs dramatically.

In Canada, seniors make up the fastest-growing age group. In 2011, an estimated 5.0 million Canadians were 65 years of age or older, a number that is expected to double by 2036 to reach 10.4 million. The number of Canadians aged 80 years and over is projected to increase as well to nearly 5 million in 2036 compared with 1.4 million in 2013. The estimated prevalence of dementia is higher among those aged 80 years and older, with a rate of 212 per 1,000. Older seniors represent 55% of Canadians with dementia.

British Columbia will have the oldest population west of Quebec by 2036. It is projected that the percentage of BC population aged 65 and over will increase from 15.7% in 2011 to reach between 24% and 27% in 2038. As for older seniors, the estimated number of British Columbians who are 80 years of age or older in 2013 (207,000 older seniors) will double by 2036.

44 Canadian Hospice Palliative Care Association. Fact Sheet: Hospice Palliative Care in Canada. Canadian Hospice Palliative Care Association 2012 http://www.chpca.net/media/7622/fact_sheet_hpc_in_canada_may_2012_final.pdf
46 http://www.statcan.gc.ca/daily-quotidien/140917/dq140917a-eng.htm
This trend will continue for the next several decades due mainly to an increase in life expectancy, the aging of the baby boomer generation, and immigration. With time, this will have dramatic impacts on the need for palliative services and the health system will be under increasing pressure to provide timely, high quality health care to the elderly population.

- **More people suffering and dying from debilitating chronic conditions**

People who have two or more chronic diseases live for months or years in a state of fragile health or “vulnerable frailty”. The frail state of these people often makes their needs too complex and broad to be handled by the current structure and functions of the health system.

In Canada, approximately 40% of the population have at least two chronic conditions and two thirds of all deaths are due to chronic conditions. Each death disrupts and burdens the life of about 5 or more other people physically, mentally, and financially. It seems likely, then, that two-thirds (over 20,000) of BC’s 30,000 annual deaths are the result of chronic illness and impact the lives of approximately 60,000 caregivers and other loved ones. As the population ages, this number will increase exponentially.

**Deficiencies in end-of-life care**

**Inadequate access**

Although the current demand for palliative care in Canada is high, the access to and uptake of the available palliative services are unexpectedly low. A report by the Royal Society of Canada Expert Panel in 2011 says that 95 per cent of Canadians would benefit from palliative care and yet, "as many as 70 per cent of Canadians lack access because hospice and palliative care programs are unevenly distributed across Canada.” Poor access has also been attributed to other factors as affirmed by researchers and advocates:

- **Palliative care is unknown/poorly understood in society**
  Only about half of Canadians are aware of the hospice palliative care concept and had the lowest awareness of access at home.

- **Lack of awareness of the available palliative care services**
  Many Canadians are unaware of what options exist and what palliative care

50 Canadian Hospice Palliative Care Association. Fact Sheet: Hospice Palliative Care in Canada. Canadian Hospice Palliative Care Association 2014 http://www.chpca.net/media/330558/Fact_Sheet_HPC_in_Canada%20Spring%202014%20Final.pdf
52 http://www.hpcintegration.ca/resources/what-canadians-say.aspx
programs available in the community. Recent survey showed that only 21% of patients had heard the term advance care planning.

- **Services are not available in all the care settings.**
  The availability of high quality care at end-of-life varies widely in different settings.

- **Shortage of palliative care specialists**
  By international standards, Canada has fewer doctors specializing in palliative care than some comparable countries. The number of palliative care physicians working either part- or full-time in Canada comprises just 0.28% of all Canadian doctors, compared to 0.52% in the US and 0.38% in Australia.

- **Primary care providers often lack basic palliative care skills and knowledge**
  Most primary health care providers are not adequately trained to provide palliative care and therefore lack the knowledge and skills needed to support the patient’s complex care needs. A recent survey by the CHPCA, through The Way Forward initiative, showed that most family physicians and nurses across Canada are seeking support, education, and resources to increase their capacity in providing palliative and end-of-life care to their patients:
  
  - Over 80% of GP/FPs and nurses want education to help them with the most challenging aspects of managing palliative care patients including pain management, addressing depression, and supporting their patient’s emotional needs
  - 68% of GP/FPs and 77% of nurses would like access to palliative care nurses to provide support in the community
  - Over 60% of GP/FPs and nurses would like around the clock access to a palliative care physician for telephone advice

- **Funding is inadequate and cost is often cumbersome to families**
  Residential hospice palliative care programs are few and far between and have often been at least 50% funded by charitable donations. Canadian families

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53 Canadian Hospice Palliative Care Association. Hospice Palliative Care in Canada: A Brief to the Special Senate Committee on Aging, 2007. Available at http://www.chpca.net/media/7487/Brief_to_Spec_Sen_Comm_on_Aging-HPC_in_Canada.pdf
58 Canadian Hospice Palliative Care Association. Fact Sheet: Hospice Palliative Care in Canada. Canadian Hospice Palliative Care Association 2013
59 Canadian Hospice Palliative Care Association, The Way Forward Survey: General/Family Practitioners and Nurses in Primary Care, for The Way Forward initiative, Ipsos Reid; 2014. - See more at: http://www.hpcintegration.ca/resources/health-care-professional-research/primary-care-research.aspx#sthash.IVTj2d0G.dpuf
frequently shoulder at least 25% of total cost of palliative care due to home based services.\textsuperscript{60}

**Inequitable access**
Significant inequity is observed between urban, rural, remote, and First Nation communities, as well as culturally and linguistically diverse and vulnerable populations.\textsuperscript{61} Access to palliative care is often described as a situation of privilege rather than a universal entitlement for Canadians.\textsuperscript{62}

**Poor quality of care**
People who receive palliative care suffer uneven provision of services and disruptive, ineffective care. The following documented deficiencies in the current care provision have contributed to this:

- **Care is not person/family-centred**
  Patients are often not informed of their care options and many are not engaged in planning for their own end-of-life.\textsuperscript{63} Most patients do not receive end-of-life care in their place of choice: research tells us that 70\% of Canadians receive most of the end-of-life care in hospitals while most Canadians prefer a home-like setting.\textsuperscript{64} In BC, 50-60\% of deaths occur in acute care, with a gap in capacity for home death.\textsuperscript{65} A recent study showed that, agreement between patients’ expressed preferences for end-of-life and documentation in the medical record was only 30.2\%.\textsuperscript{66} Moreover, the emotional and spiritual needs of the persons and the bereaved are frequently not adequately addressed or overlooked. Palliative care teams often lack professionals who can provide psychological, spiritual, and bereavement support. Besides, only a few programs offer culturally and linguistically appropriate care.

- **No standardised approach to care**
  National standards for quality end-of-life care in all care settings do not exist. In 2013, the CHPCA published guiding principles and norms of palliative care

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\textsuperscript{60} Canadian Hospice Palliative Care Association (CHPCA). Fact Sheet–Hospice Palliative Care in Canada. 2014
http://www.chpca.net/media/330558/Fact_Sheet_HPC_in_Canada%20Spring%202014%20Final.pdf
\textsuperscript{61} http://www.chpca.net/media/7622/fact_sheet_hpc_in_canada_may_2012_final.pdf
\textsuperscript{62} Williams et al. Canada’s Compassionate Care Benefit: Is it an adequate public health response to addressing the issue of caregiver burden in end-of-life care? BMC Public Health 2011; 11:335
\textsuperscript{63} CHPCA Hospice Palliative Care in Canada: A Brief to the Special Senate Committee on Aging, 2007. Available at http://www.chpca.net/media/7487/Brief_to_Spec_Sen_Comm_on_Aging-HPC_in_Canada.pdf
\textsuperscript{64} http://www.chpca.net/media/7622/fact_sheet_hpc_in_canada_march_2013_final.pdf
\textsuperscript{65} Canadian Institute for Health Information. Health Care in Canada, 2011: A focus on seniors and aging. (Ottawa: CIHI, 2007).
\textsuperscript{66} Institute for Health System Transformation and Sustainability. Shaping Priorities of the BC Centre for Palliative Care Report on an Invitational Consultation. (Vancouver: IHSTS, 2014)
practice. Complying with these norms is voluntary.  

- **Continuity of care is poor**
  Canadian patients and family members often experience difficult transitions between providers and settings due to poor information sharing. Barriers include limited staff time, patient privacy regulations and lack of a clear structure and common information system to guide and support sharing of patient information.  

- **Inadequate system integration**
  The complexity and wide range of needs of older people, dying persons, and caregivers requires joint working between many sectors and between all levels of the health system. Essentials elements for system integration are lacking, such as common clinical best practices, tools and processes across sectors; and shared functional and clinical infrastructures.

- **System level accountability is not clear**
  Accountability frameworks are essential in supporting and advancing the care of patients across sectors, while aligning with operational accountabilities within each sector/service. However, the provision of palliative care lacks a clearly defined system accountability framework that defines the roles, responsibilities and performance expectations of the involved sectors and ensure reporting on system-level outcomes.

- **Lack of performance measures and quality indicators.**
  Continuous credible assessment, monitoring, and reporting- the main drivers of high quality palliative care- are inadequate at the national level and vary in adequacy and consistency among provinces. National quality indicators do not exist and there are no palliative care registries at the provincial level in BC to assess the quality of the care that palliative patients receive.

**Cost of dying is high**
Effective palliative care programs have been shown to improve quality of end-of-life while decreasing cost. Palliative care reduces visits to emergency departments, hospital admissions,

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68 Canadian Hospice Palliative Care Association. A model to guide hospice palliative care. Ottawa, ON: Canadian Hospice Palliative Care Association, 2013

69<https://www.cnaaiic.ca/~/media/cna/files/en/cna_cma Heal_provider_summit_transformation_to_integrated_care_e.pdf?la=en>

70 Canadian hospice Palliative care Association (CHPCA), Palliative Care in the Community: An Environmental Scan of Frameworks and Indicators, the Way Forward initiative: An Integrated Palliative Approach to care, 2013.

71 Meier De, Beresford I. Palliative care cost research can help other palliative care programs make their case. J Palliat Med. 2009;12(1):15-20
length of hospital stay, ICU admissions and, as well, protects the patients from receiving unnecessary diagnostics and interventions.

However, in Canada the current deficiencies in the provision of palliative care resulted in unnecessary use of emergency departments and inpatient hospital care. Furthermore, terminally ill patients who find no appropriate alternative to a prolonged stay in hospital often receive costly aggressive treatment that neither prolong nor improve life.72 As a result, end-of-life care continues to contribute significantly to the escalating cost of the health system. About 20% of health care spending in Canada occurs in the last year of life and the cost of dying for a person with a terminal disease is four times the cost of a sudden death ($40,000 versus $10,000 respectively).73 In BC 38% of health care expenditures occur in last year of life. Families, primary EOL caregivers, also experience substantive financial stress in terms of caregiving costs, unpaid leaves, and job loss. It has been estimated that family caregivers provide 75% to 90% of all home care and contribute $6000 worth of unpaid hours in the last four weeks of life alone.74

The provision of palliative care in Canada and in BC in particular is in immense need of a cost-effective approach that can both improve quality of end-of-life care and relieve the financial burden on the health care system, on patients, and on families.

2. CALLS FOR A NEW APPROACH TO PALLIATIVE CARE

A. British Columbians call for a holistic value-based approach based on best practices

In BC, the need for palliative care has never been greater. Into the foreseeable future, BC is certain to continue to face system wide challenges in providing high-quality, cost-effective, person-centred care for the seriously ill and frail. Over the next 25 years, the number of people who need palliative care is projected to continue rising at a higher pace than the national average.75 As described earlier in this document, there is evidence that the current palliative care needs of British Columbians are far from being met due to a substantial gap between the need for and access to end-of-life care, and due to the uneven provision of services as well as disruptive, ineffective care.

72 Canadian Institute for Health Information. Health Care use at the end-of-life in western Canada (Ottawa: CIHI,2007)
73 Canadian Hospice Palliative care Association (CHPCA) Fact sheet- Hospice Palliative Care in Canada. March 2013
75 http://www.statcan.gc.ca/daily-quotidien/140917/dq140917a-eng.htm
There is an overwhelming consensus among the wide range of palliative care stakeholders in BC that: “the current state of the palliative care system necessitates urgent reform to reflect the rapidly evolving environment for service delivery and public expectations.”

**BC Government endorses a needs-based integrating approach to fix gaps in palliative care**

In June 2013, the provincial government made the commitment in its Throne speech to double the number of hospice beds by 2020.

In February 2014, the BC Ministry of Health published their Strategic Priorities paper with various palliative care-related priorities for the health system:

- Patient-centred care;
- Integration of end-of-life/palliative care into primary and community care;
- Increase access to an appropriate continuum of residential care services.

The Provincial End of Life Action Plan (2013) and the establishment of the BC Centre for Palliative Care under the Institute for Health System Transformation and Sustainability represent an important opportunity for greater public and patient engagement to support innovation in the development of quality patient and family centred outcomes for all British Columbians living with and dying from advanced illness.

**Palliative care stakeholders in BC affirm the need for a holistic value-based approach**

In May 2014, the BCHPCA presented an opening roundtable in which national and provincial public health experts advocated for a public health approach to death, dying, and end of life care.

In the same year, the BC CPC invited experts on palliative care and representatives of key stakeholder groups to provide advice on strategic priorities for the BC CPC’s palliative care improvement activities. The stakeholders echoed the public’s and the government’s call for an effective, holistic value-based integrating approach that:

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• Supports a societal shift in expectations around living with and dying from advanced illness
• Ensures patients have easy access to palliative care that reflects their goals and embraces their autonomy
• Drives higher quality care at a lower cost
• Ensures services reflect clients’ goals and are appropriate to their needs and preferences
• Integrates palliative care into all levels of the health system so that care can be provided by any health professional
• Makes efficient use of community resources
• Creates less need for emergency visits and unplanned hospitalizations.

In response, the BC CPC drafted a strategic plan and developed a vision and mission statement that focus its current activities on the following key areas:

1. CONVERSATIONS: Supporting Advance Care Planning (ACP) and Goals of Care conversations as essential strategies to engage the public and health care providers and implement and measure the provision of patient centred care at end of life;

2. CAPACITY: Support doubling of Hospice spaces to ensure community based capacity and collaborate in promoting uptake of the Integrated Palliative Approach to Care and enhanced Palliative Care consultation to ensure that the right care is provided at the right time by all providers in all settings. This will require leadership and coordination support for education and mentoring as well as enhanced participatory approaches;

3. CARING: Promote patient, public and community engagement in uptake of a public health approach which integrates social and health based approaches to the development of Compassionate Communities. To achieve this, the BC CPC currently works with different stakeholders and partners in BC to catalyse effective societal change towards the development of a public health palliative care model, in accordance with best practices worldwide, and by engaging the BC public in designing a model for this province. Indeed, this document is part of the BC CPC’s committed efforts in this regard. The document aims to provide the evidence base for the effectiveness of the public health approach to address current gaps in the provision of palliative care and in meeting the expectations of the public and other stakeholders in BC.
B. Worldwide advocacy for a public health approach to quality palliative care

Interest in using a public health approach to improve palliative care has been growing worldwide. The WHO was the first to call for a public health approach to palliative care more than a decade ago. In its 2002 paper, the WHO noted that:

“It is essential to promote a public health approach in which comprehensive palliative care programs are integrated into the existing health systems and are tailored to the specific cultural and social context of the target populations”. 81

Several European and Asian countries as well as Australia responded to the WHO call and are farther advanced than the rest of the world in applying a population-based, public health approach to palliative care: United Kingdom, Spain, Australia, Japan, and India. Their experience with the public health palliative care model is discussed in a later Chapter of this document. In 2014, two major developments in support of this approach have been the WHO’s inclusion of palliative care as an indicator for Universal Health Coverage; and the unanimous passing of a resolution at the World Health Assembly for recognition of palliative care as a component of comprehensive care throughout the life course. 82

Parallel to the WHO efforts, a fast growing international movement, The Public Health Palliative Care International (PHPCI), is advocating globally for a combined public health palliative care approach- with a focus on health promotion and community engagement/partnership. 83 It does so through the PHPCI biannual conference and forum, educating and training PHPCI members, fostering research and evaluation, and collaborating with palliative care/hospice organisations.

The PHPCI views “death, dying, loss and care as everyone’s responsibility” and a public health approach will place the community as an equal partner in the long and complex task of providing quality healthcare at the end-of-life.

“The public health approach has the most potential to enhance the quality of life and sense of well-being to the widest number of people in sickness, in dying and in loss, as well as in health toward one another.” (PHPCI website)84

The following Chapter provides an overview of the public health approach and the existing public health palliative care models.

83 http://www.phpci.info/
3. A PUBLIC HEALTH APPROACH TO PALLIATIVE CARE

In Europe, Australia, Asia, and the WHO- collaborating palliative care centres, the public health approach has demonstrated that it provides the best approach for establishing/integrating effective palliative care into a society. The approach offers evidence-based, holistic, cost-effective strategies to close existing gaps in end-of-life care and meet the complex needs of the population within their community. Practical examples of the public health palliative care model are discussed in the next chapter.

This chapter provides an overview of the public health approach: conceptual principles, operational levels of, and the essential public health strategies to effectively address a population health problem. In addition, the conceptual congruence between the public health approach and palliative care, and the potential impact of this approach on attributes and outcomes of the palliative care delivery will also be discussed. The overview will be followed by an introduction to the “WHO Public Health Palliative care Model” and the “Health Promoting Palliative Care/Compassionate Communities” by Dr. Allen Kellehear.

A. What is a public health approach?

The public health approach has an enviable record of contributions to population health worldwide and has a long history in addressing major health and social issues effectively. To analyze and solve a problem, the approach applies the public health sciences including: epidemiology, health research, and policy analysis.

Definition
By definition, public health combines the science, art, and skills to organize and direct the society’s efforts to protect, maintain, and improve the health and wellness of the whole population and to maximize quality of life when health cannot be restored.

Principles
Both the public health approach and the palliative care approach are based on a common set of conceptual principles. The conceptual congruence between the two approaches played a fundamental role in the introduction and consequently the worldwide plausibility of the public health palliative care model.

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88 WHO Definition -available at: http://www.who.int/trade/glossary/story076/en/
As illustrated in Figure 4, the public health approach has three core principles that are distinct from those of palliative care and that are key to addressing a health problem or service delivery.\(^8^9\)

1. Population/community-based view
2. Prevention/Promoting-focused
3. Whole-systems approach

**Figure 4 Conceptual congruence between the public health approach and palliative care**


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• **Population/community-based**

A central concept of a public health approach is that it focuses on the health of entire populations not on specific individuals. It is one of the most basic notions that distinguishes public health from the rest of health care. Public health enquire about, intervenes with, and measures health at the population level.

A population/community-based approach means that the approach considers a broad mix of interventions (e.g. changing social norms, formulating public policies) and applies them in different settings in the community to ensure that the health problem is addressed in a comprehensive manner.

• **Prevention/Promoting-focused**

The approach values preventive and health promoting interventions for their known cost-effectiveness impact on achieving greater gains in population health. Therefore, the approach seeks to prevent health problems.

Through the health promotion focus, the approach seeks to optimize health/wellbeing- not only enhance it-, and it does so by: building public policy, creating supportive environments, strengthening community action, developing personal skills, and building partnerships between the health sector and broader society. (Ottawa Charter for Health promotion, 1986)

Health promotion embraces both actions directed at strengthening the capabilities of individuals and actions directed towards changing social, environmental, political and economic conditions so as to alleviate their impact on public and individual health.

• **Whole Systems-oriented**

The approach aims to create structured systems in which it is difficult to make mistakes or behave in a way that can cause harm to anyone. The public health approach applies this at every level of the health system and other systems involved in the problem. It includes review and reorientation of service provision, development of laws and policies, standardization of care, and cross-sector collaboration under a shared accountability framework.

• **Holistic**

The concept of health and wellness in the public health model is “Holistic” – Health is “a state of complete physical, mental and social well-being” and Wellness is “as a state of dynamic

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physical, mental, social, and spiritual well-being that enables a person to achieve full potential and an enjoyable life”. The public health approach gives full consideration to the full spectrum of determinants of health and recognizes the complex interactions that occur between them.

- **Evidence-based and Data driven**
A public response is initiated upon the availability of accurate information about a threat to the population’s health/wellbeing. Public health decisions are driven by population health data and needs assessment information and are based on the best available evidence.

- **Advocacy/Participatory-based**
The approach emphasizes the importance of regular interaction with legislators, policy makers, health care providers, professional societies, and the public to increase awareness of the problem and promote engagement in developing and implementing interventions in an integrated, multifaceted way. The approach promotes shared responsibility of the problem and shared accountability for outcomes.

- **Partnership/Team work**
By definition, public health is about team work and partnering formally and informally with governmental, non-governmental and private sector organizations in the community to align and direct society’s resources and efforts towards a problem that threatens the health/wellbeing of a population.

- **Research and innovation-based**
Every step of the public health approach is informed by innovative solutions and cutting-edge research and based on the best evidence\(^{94}\) to ensure that resources and efforts are directed to interventions known to have the greatest impact on population health.

- **Disparity elimination**
Public health is essentially concerned with good access to appropriate care and equity in that access.\(^ {95}\) The public health approach ensures that people with equal needs have the same access to the same care. There is evidence that the public health approach eliminates disparities in health and ensures universal access to health care through:\(^ {96}\)
  1) Community and population wide preventive and health promoting strategies;
  2) Analysis of health surveillance data to identify populations experiencing barriers to care, to determine these barriers, and to target these populations with appropriate interventions.

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\(^{95}\) A Public Health Perspective on End-of-life Care edited by Joachim Cohen, Luc Deliens. Oxford

Operational Levels
The public health approach involves interventions that operate at all levels of society. 97

- **Individual**
  To change the beliefs, attitudes, or behaviors of individuals.

- **Interpersonal**
  To change beliefs, attitudes, and behaviors shared within social networks such as families, peer groups, and friends.

- **Organizations & Institutions level**
  To influence organizations and institutions such as schools, workplaces, places of worship, and community centres, to introduce policies and rules to change the culture or practices among their members and create supportive environments.

- **Community level**
  To change the policy of a local community or improve the space, facilities, or other community elements relevant to the target of the intervention.

- **Structure & systems level**
  It operates at the provincial, and federal structures and systems to affect the environment surrounding communities and individuals.

**Figure 5 The Public Health Approach Operates at All Levels**

![Diagram showing various levels: Individual, Interpersonal, Organizations, Community, Structures & Systems]  

*SOURCE: Centres for Disease Control. Social Ecological Model.*

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97 Centers for Disease Control. Social Ecological Model. The model can be found at  
Ten Essential Strategies/Elements

To apply the public health approach in practice, a group of well-defined, holistic, value-based strategies are essential—The Ten Public Health Strategies/Elements. These strategies create a comprehensive infrastructure that provides a supportive context for any public health priority in a community. (See Figure 6) The Ten Essential Strategies objectify the principles of the public health approach illustrated in Figure 1.

For the public health strategies to be effective, they must be incorporated by governments into all levels of their health care systems, be owned by the community, and involve the society through collective and social action. To effectively address health concerns, the ten strategies are implemented simultaneously and not necessarily in order.

Figure 6 The Ten Essential Strategies of the Public Health Approach

SOURCE: Centres for Disease Control and Prevention. Essential public health services. 2014

98 Centers for Disease Control and Prevention. Office for State, Tribal, Local and Territorial Support. 2014
To demonstrate how the Essential Public Health Strategies can be implemented, the following section presents examples of national or community practice for each strategy:

#1: **Monitor health status to identify threats to population health**
- Establishing surveillance systems to enable accurate periodic assessment of the community’s health status and needs [Population-based Community Health Profile]:
  - Identification of health risks
  - Attention to vital statistics and disparities
  - Identification of assets and resources
  - Health services needs
- Maintenance of population health registries

#2: **Diagnose and investigate health problems in the community.**
- Identification of health threats through epidemiological investigation of health trends and health determinants
- Identification and selection of evidence-based interventions
- Development of society-wide action plan

#3: **Inform, educate, and empower people about health issues**
- Initiatives using health education and communication sciences to:
  - Build knowledge and shape attitudes
  - Inform decision-making choices
  - Develop personal skills and behaviours for healthy living
- Health education and health promotion within the community to support healthy living;
- Media advocacy and social marketing efforts- e.g., targeted media public communication: Toll-free information lines

#4: **Mobilize community partnerships to identify and solve health problems**
- Identification of system partners and stakeholders
- Constituency development - convening community groups to undertake defined preventive and support programs
- Coalition development- building skilled coalition to draw upon the full range of potential human and material resources
- Formal and informal partnerships to promote health and well-being improvement
- Establishing a committee to oversee the implementation of community-wide health strategies

#5: **Develop policies and plans that support individual and community health efforts**
- Define and develop consistent policy regarding prevention and treatment services
- Community and state improvement planning
- Leadership development at all levels
- Identify accountable entities to achieve each objective of the state strategy
- Standardization of care
#6: **Enforce laws and regulations that protect health and ensure safety.**
- Review, evaluation, and revision of legal authority, laws, and regulations
- Education about laws and regulations
- Advocating for regulations needed to protect and promote health
- Support of compliance efforts and enforcement as needed

#7: **Link people to needed personal health services and assure the provision of health care when otherwise unavailable.**
- Identification of populations with barriers to care
- Effective entry into a coordinated system of care
- Ongoing care management at all care settings
- Culturally appropriate and targeted health information for at risk population groups
- Assurance availability of culturally and linguistically appropriate materials and staff
- Transportation and other enabling services

#8: **Assure a competent health care workforce.**
- Assess competency of the health care workforce
- Continuing education and life-long learning opportunities to health care professionals
- Training of informal care providers in the community
- Adoption of essential competencies within all health professional licensure and certification programs.
- Leadership development

#9: **Evaluate effectiveness, accessibility, and quality of health services.**
- Evaluation must be ongoing and should examine:
  - Personal health services
  - Population based services
  - The health system
- Evaluation of effectiveness and impact of system and community efforts based on analysis of timely health status and service utilization data
- Quality Improvement and Performance Monitoring

#10: **Research for new insights and innovative solutions to health problems.**
- Identification and testing of innovative solutions and cutting-edge research
- Linkages between public health practice and academic/research settings
- Building internal capacity to mount timely epidemiologic and economic analyses and conduct health services research (e.g., survey design; conducting interviews and facilitating focus groups)
B. Applying the public health approach to palliative care—Impact on care attributes and outcomes

**Figure 7 Applying the public health approach to palliative care—Impact on care attributes and outcomes**

<table>
<thead>
<tr>
<th>Public Health Approach Conceptual Principles</th>
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<tr>
<td>Holistic</td>
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<td>Evidence-based &amp; Data Driven</td>
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<td>Advocacy &amp; Participatory based</td>
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<td>Partnerships/Team Work</td>
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<td>Research &amp; Innovation based</td>
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<td>Disparities Elimination</td>
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<td>Whole Systems Approach</td>
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<tr>
<td>Population/Community-based</td>
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<td>Prevention/Promotion-focused</td>
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Applying Public Health Approach Principles to the Current State of Palliative Care Provision

- Population-needs based programs
- Care available to everyone who needs it at the place of his/her choice
- Patient/Family needs-based care
- Culturally considerate care and support
- Evidence-based standardized care provided by knowledgeable, skilful providers at all levels of the health care system and in the community
- Smooth transition of patients between levels of care
- All involved systems and sectors share information and work together towards one goal under a shared accountability framework
- **Compassionate Communities** *(see CC Charter by Kellehear and Able)*
- Well informed patients & well supported trained carers
- Care experience improving through ongoing performance and outcomes evaluation, research and innovation activities.

Less suffering & better quality of life for patients/ families
Satisfied patients and family
Dignified death for all palliative patients
Satisfied health care providers
Efficient use of available community resources
Reduced unnecessary use of health care services
System cost savings
Reallocate savings to more needy areas of care
C. Existing Public Health Palliative Care Models

WHO Public Health Palliative Care Model

In 1990, the WHO pioneered a public health strategy to integrate palliative care into existing health systems. To help governments develop and implement plans and policies for the WHO Public Health Palliative Care Model, three WHO collaborating centres for palliative care have been established in: Oxford, United Kingdom; in Barcelona, Spain; and in London, United Kingdom. Based on experience with the 1990 model, an enhanced Model has emerged - The WHO Public Health Palliative Care Model. (See Figure 8)

The WHO Public Health Palliative Care Model provides a framework for palliative care implementation within the context of culture, disease demographics, socioeconomics, and the health care system structure and resources of a country. It encompasses four components that must be addressed to ensure effectiveness:

1) Appropriate policies
2) Adequate drug availability
3) Education of health care workers and the public
4) Implementation of palliative care services at all levels throughout the society.

Figure 8 WHO Public Health Palliative Care Model- Overview

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100 2. Institut Català d’Oncologia. http://www.iconcologia.net/index_eng.htm Accessed April, 1 2015
101 Palliative care, policy and rehabilitation. King’s College London, 2010 [http://www.kcl.ac.uk/palliative Accessed April, 1 2015
For each component, the WHO defined short, intermediate, and long-term outcomes to promote evaluation and benchmarking activities.\textsuperscript{102}

**Figure 9 WHO Palliative Care Model- Provider distribution at different levels of care.**

The WHO Public Health Palliative Care Model has demonstrated that it provides an effective and efficient strategy for establishing and integrating palliative care into a health system.\textsuperscript{103,104} The 20 year experience of Catalonia, Spain with the WHO Public Health Palliative Care Model is presented in detail in Chapter 4.


\textsuperscript{104} Kumar S. Models of delivering palliative and end-of-life care in India. Curr Opin Support Palliat Care 2012;6(3):371–8

The Health Promoting Palliative Care Model

The health promoting palliative care concept was first introduced in 1999 by Dr. Allan Kellehear, a Professor of Palliative Care at Middlesex University in London, UK, in his book ‘Health Promoting Palliative Care’. Professor Kellehear criticized current palliative care models for focusing on a distress-oriented approach to life-threatening illness rather than interventions that promote overall well-being.

He postulates that an approach that combines the principles of health promotion and palliative care has the potential to move life threatening illness, death, dying, grief into the public arena. In Kellehear’s model, community participation, education, and public policy development are brought to bear on the experience of living with life-threatening illness, which is understood as a universal human experience. He argues that the social and psychological troubles associated with dying, death, caring, and bereavement are amenable to health promotion strategies in community settings. Furthermore, a health promoting approach to palliative care is expected to increase resistance to negative changes in health care, and to increase advocacy for society-wide policy change, for additional government and private revenues, and for social and political support.

Dr. Kellehear was successful in creating a critical mass of supporters for his view worldwide. In 2003, the Public Health Palliative Care International (PHPCI) Association was inaugurated under his leadership to advocate and promote the philosophy, concepts and methods of health promotion into palliative care services everywhere.

“Compassionate Communities”: A practical model of the health promoting palliative care approach.

A further development of the health promoting palliative care concept was presented in Dr. Kellehear’s book: “Compassionate Cities: Public health and end-of-life care”. “Compassionate Communities” was introduced as a practical model of the health promoting approach to palliative care. The model aims to deprofessionalise/demedicalize end-of-life care, return it to the community, and build up social capital that can then be mobilised when citizens come to the end of their life.

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“The way forward to high quality end-of-life care is based on a true public health/health promotion model of the community, for the community, by the community”. (Dr. Kellehear October 24, 2013 at McMaster University)

**Key operational policies are essential for a “Compassionate Community”:**

- It fosters and supports compassion in the workplace, worship place, school and aged care facility;
- It demonstrates a strong commitment to social and cultural difference;
- It promotes and supports grief and palliative care services for rural and remote areas, indigenous populations and the homeless.
- Any implementation, policy or planning committee should include members with direct personal experience of ageing, living with a life-threatening illness or loss;

**The Compassionate Cities Charter describes in detail** these policies in the form of 13 social changes to be committed by cities in order to embrace community empathy and help reduce the negative social, psychological and medical impact of serious illness, caregiving, and bereavement in society. \(^{110}\) (See Table 1)

So far, The Neighbourhood Networks model in Kerala, India is the most developed version of the health promoting palliative care/compassionate communities.\(^{111}\)

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\(^{110}\) [http://media.wix.com/ugd/14d74a_c6e21bb0a3f047dfa4191382b784beae.docx?dn=CCCharter.docx](http://media.wix.com/ugd/14d74a_c6e21bb0a3f047dfa4191382b784beae.docx?dn=CCCharter.docx)

\(^{111}\) Compassionate community networks: supporting home dying. BMJ Supportive & Palliative Care 2011; 1:129–133.
### Table 1 The Compassionate Cities Charter

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Schools</td>
<td>Annually review policies or guidance documents for dying, death, loss and care</td>
</tr>
<tr>
<td>2</td>
<td>Workplaces</td>
<td>Annually review policies or guidance documents for dying, death, loss and care</td>
</tr>
<tr>
<td>3</td>
<td>Trade unions</td>
<td>Annually review policies or guidance documents for dying, death, loss and care</td>
</tr>
<tr>
<td>4</td>
<td>Worship places</td>
<td>Have at least one dedicated group for end-of-life care support</td>
</tr>
<tr>
<td>5</td>
<td>Hospices &amp; Nursing homes</td>
<td>Have a community development program involving local area citizens in end-of-life care activities and programs</td>
</tr>
<tr>
<td>6</td>
<td>Museums &amp; Art galleries</td>
<td>Hold annual exhibitions on the experiences of ageing, dying, death, loss or care</td>
</tr>
<tr>
<td>7</td>
<td>City</td>
<td>Host an annual peacetime memorial parade representing the major sectors of human loss outside military campaigns</td>
</tr>
<tr>
<td>8</td>
<td>City</td>
<td>Create an incentives scheme to celebrate the most creative compassionate organization, event, and individual/s.</td>
</tr>
<tr>
<td>9</td>
<td>City</td>
<td>Publicly showcase, in print and in social media, the local government policies, services, funding opportunities, partnerships, and public events that address ‘the community’s compassionate concerns’ with living with ageing, life-threatening and life-limiting illness, loss and bereavement, and long term caring.</td>
</tr>
<tr>
<td>10</td>
<td>City</td>
<td>Work with local social or print media to encourage an annual city-wide short story or art competition that helps raise awareness of ageing, dying, death, loss, or caring.</td>
</tr>
<tr>
<td>11</td>
<td>All compassionate policies and services</td>
<td>Demonstrate an understanding of how diversity shapes the experience of ageing, dying, death, loss and care – through ethnic, religious, gendered, and sexual identity and through the social experiences of poverty, inequality, and disenfranchisement.</td>
</tr>
<tr>
<td>12</td>
<td>People</td>
<td>Seek to encourage and to invite evidence that institutions for the homeless and the imprisoned have support plans in place for end-of-life care and loss and bereavement.</td>
</tr>
<tr>
<td>13</td>
<td>City</td>
<td>Establish and review these targets and goals in the first two years and thereafter will add one more sector annually to our action plans for a compassionate city – e.g. hospitals, further &amp; higher education, charities, community &amp; voluntary organizations, police &amp; emergency services, and so on.</td>
</tr>
</tbody>
</table>
4. A PUBLIC HEALTH APPROACH TO PALLIATIVE CARE - INTERNATIONAL PERSPECTIVES

The development and evolution of public health oriented palliative care vary greatly among countries depending on the health system structure and resources and the demographic, socioeconomic and cultural context of society.

This Chapter presents the experiences of the following five countries/cities with the planning, implementation and achievements of Public Health Palliative Care Models:

1. Spain - The Catalonia World Health Organization Demonstration Project
2. India - The Neighbourhood Network in Palliative Care (NNPC) in Kerala
3. United Kingdom – A Public Health Approach to Palliative Care in the United Kingdom
4. Japan - Building Dementia-Friendly Society in Japan
5. Australia – A Public Health Oriented Palliative Care System in Australia
A. Catalonia World Health Organization Demonstration Project

In 1989, the Health Department of Catalonia (Spain) and the Cancer Unit at the WHO (Geneva) designed and planned a demonstration project for implementation of palliative care resources and services, based on the WHO Public Health Model.

The project’s aims were to:
1) implement palliative care services throughout Catalonia (cancer/non cancer) and
2) serve as a model for other countries/governments

The objectives of the Catalonia WHO Demonstration Project (WHO DP) were to achieve:
- public coverage for cancer and non-cancer patients,
- easy access to palliative care by every person who need it,
- equity in access across the region,
- high quality palliative care that is effective and efficient.

The project was initiated at the end of 1990, and evaluated at 10, 15, and 20 years after initiation. The following section sheds light on the implementation elements and results of the Catalonia WHO project over a period of 20 years.

Overview
Catalonia is one of Spain’s richest and most highly industrialised regions. About 17% of the 7.3 million population is older than 65 years (2009). The life expectancy is 79 years for men and 85 years for women (2010). There are 59,500 deaths per year (2009), chronic conditions account for more than two thirds of all deaths, (35,700 to 44,600 deaths): 28% of all deaths are due to cancer, and 32% to 47% are due to noncancer illnesses. Health care Catalonia is financed publicly and services are provided by a mixture of public and non-profit organizations. Health care resources include hospitals, an extended primary care system, and socio-health centres that care for geriatric, terminally ill, and chronically ill patients by offering rehabilitation, day-care and long-term care.

Project Implementation Highlights
To achieve the project’s objectives, the following elements of the WHO Public Health Model and related activities were implemented:

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1. Assessment of population needs
Population needs for palliative care were assessed before initiating the project and periodically to inform planning and evaluation of palliative care services. To estimate the size of the populations in need of palliative care services, mortality data and prevalence estimations for chronic conditions in Catalonia were used, assuming:

- A mean duration of terminal status of 3 months for cancer patients and 9 to 12 months for non-cancer patients, and
- That 60% to 70% of the patients dying from cancer and 30% to 60% of patients with non-cancer life-limiting illnesses need palliative care interventions (Optimal direct coverage).

In 2009 the population needs assessment revealed that a total of 20,000 to 31,000 patients with chronic conditions needed palliative care (10,000 cancer patients and 10,000 to 21,000 non-cancer patients).

Results: Knowing this information, the planning for palliative care services was modelled within the context of disease demographics, socioeconomics, and health care system structure and resources of each of the 14 districts in Catalonia.

2. Restructuring the health services system
For each district, a palliative care service model was developed. The model outlines the levels of palliative care services using various demographic scenarios and proposes ways to integrate palliative care into the conventional health system using resources that already exist in the district. Criteria to access each level/type of palliative care services were described. (See Table 2)

Table 2 Demographic scenarios and proposals of organization of specialist palliative care services

<table>
<thead>
<tr>
<th>Demographic Area</th>
<th>Demography (Citizens, n)</th>
<th>Examples</th>
<th>Conventional Resources</th>
<th>Proposed Model of PC Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Metropolitan</td>
<td>500,000</td>
<td>3 areas of metropolitan Barcelona (Central, North, South)</td>
<td>University hospital reference + general hospitals + SHCs</td>
<td>Reference PCS (PCU, OC, HST, and training and research) at the University hospitals 2–3 SHCs with units</td>
</tr>
<tr>
<td>Urban</td>
<td>200,000</td>
<td>5 urban areas: Girona, Tarragona, and Lleida</td>
<td>University general hospital + 1–3 SHCs</td>
<td>HST + OC in hospital + PCU in hospital and/or SHC</td>
</tr>
<tr>
<td>Rural-Urban</td>
<td>80–150,000</td>
<td>16 districts: Osona, Bages, Empordà, and others</td>
<td>District general hospital + SHC</td>
<td>1 HST, 1 HCST 1 PCU in hospital or SHC Preferably as comprehensive system</td>
</tr>
<tr>
<td>Rural</td>
<td>&lt;50,000</td>
<td>High Pyrenees</td>
<td>Community hospital + SHC</td>
<td>Comprehensive system with an HST/HCST mixed acting in all levels No PCU needed</td>
</tr>
<tr>
<td>Common in all districts: Primary care centers every 20,000 habitants + nursing homes</td>
<td>1 HST/district/100,000 habitants + 1 HST in every hospital</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

PCS = palliative care service (including one or more resources); PCU = palliative care unit; OC = outpatient clinic; HST = hospital support team; SHC = social health center (center with PC + intermediate + rehabilitation + long-term psychogeriatric care); HCST = home care support team.

*From Gómez-Rialatte et al., 2010.*
**Results:**

- In 2010, there were 237 specialized palliative care services compared to only 2 palliative care units in acute hospitals in 1989. A typical palliative care service includes: a 16-bed unit, an outpatient clinic, a day unit, and a home care team.
- Palliative care services integrated into all levels of the health care system.
- More than 50% of services are provided in a community setting, nevertheless 83% of hospitals provide palliative care services.
- The number of doctors providing fulltime palliative care increased from 118 in 2001 to 240 in 2010.

**Table 3 Catalonia WHO Project- Palliative Care Services (1989-2010)**

<table>
<thead>
<tr>
<th>Types of Palliative Care Services</th>
<th>1989</th>
<th>2001</th>
<th>2005</th>
<th>2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home care support teams*</td>
<td>0.5</td>
<td>52</td>
<td>70</td>
<td>72</td>
</tr>
<tr>
<td>Palliative care units</td>
<td>1</td>
<td>50</td>
<td>63</td>
<td>60</td>
</tr>
<tr>
<td>Hospital support teams</td>
<td>0.5</td>
<td>20</td>
<td>34</td>
<td>49</td>
</tr>
<tr>
<td>Outpatient clinics</td>
<td>—</td>
<td>—</td>
<td>14</td>
<td>50</td>
</tr>
<tr>
<td>Psychosocial support teams</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>6</td>
</tr>
<tr>
<td><strong>Total services</strong></td>
<td>2</td>
<td>122</td>
<td>181</td>
<td>237</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Location of Palliative Care Services</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>2</td>
<td>31</td>
<td>NA</td>
<td>49</td>
</tr>
<tr>
<td>Sociohealth centres</td>
<td>—</td>
<td>39</td>
<td>NA</td>
<td>60</td>
</tr>
<tr>
<td>Community</td>
<td>—</td>
<td>52</td>
<td>NA</td>
<td>128</td>
</tr>
<tr>
<td><strong>Total services</strong></td>
<td>2</td>
<td>122</td>
<td>181</td>
<td>237</td>
</tr>
</tbody>
</table>

**3. Development of a public financing system for palliative services.**

**Results:**

- Palliative care services including medications are offered completely free of charge at the point of care.

**4. Legislation and standards**

- Change/revise legislation and standards governing provision of services to ensure high quality, culturally sensitive, consistent and equitable services to all those in need.
- Revise legislation/policies governing availability and delivery of opioid analgesics to support effective pain management in palliative care.

**Results:**

- Right of access to palliative care became a basic human right in the Catalan Government’s Statute on Health.
- In 1990, palliative care services were legislated by a government decree.
In 1993, the Catalan standards for palliative care services were released. The standards emphasize multi-professional care, advance care planning, continuing care, and case management as essential elements in service provision.

In 1993, morphine/opoid availability and delivery were promoted by a decree of the Spanish Ministry of Health.

5. Training and education of primary health care professionals

**Results:**

- **Training:** About 70% of the primary care professionals received training in palliative care (3.4% up to Advanced/Master’s degree, 15.2% intermediate, and 51.9% basic level).
- **Education:** A total of 423 health care professionals (60% physicians and 40% nurses) earned a Master’s degree in palliative care at the University of Barcelona. All nursing schools, 50% of medical schools, and social work courses now include modules of palliative care. Most generalists have a 1-2 month palliative care course included in their training.

6. Develop a monitoring and evaluation strategy to drive quality improvement

**Results:**

- The activities, outputs, and outcomes of the project have been evaluated periodically over 20 years. The results of 3 comprehensive evaluations were published in the Journal of Pain and Symptom Management.
- The problems encountered during implementation were addressed through improvement actions.

7. Promoting research and innovation

**Results:**

- Several palliative research and training units were established.
- From 1998 to 2010, five epidemiological studies, three clinical trials, five observational studies and 3 qualitative studies were conducted. The gaps detected through these studies prompted program improvement activities.
- The WHO established (QUALY) observatory, a WHO Collaborating Centre for Public Health Palliative Care Programs, at the Catalan Institute of Oncology to support other countries in the development of palliative care programs as an element of public health element, and to generate evidence and knowledge in the field through research.

**Project Outcomes**

- **High coverage (indicating easy equitable access to care)**
  - As of 2010, 100% of the population in Catalonia have access to a wide range of palliative care services that are available in acute care hospitals, socio-health centres, and in the community throughout the 14 rural and urban districts. The 10 and 15
year evaluations also reported high geographic coverage (~ 95%). This indicates easy equitable access to care by anyone who needs it.

- The palliative care coverage for cancer is one of the highest described- (>70%)
- Between 30-50% of advanced geriatric and chronically ill patients received palliative care in their homes or a community setting.
- AIDS patients and children facing a terminal illness have access to palliative care beds designated to them.

  o Majority of deaths occurred at home or in the community
    - 60% of the patients who received home care support services died at home.
    - Home care support teams treat 50% of the population estimated to be in need for palliative each year.

  o Significant reduction in severity of symptoms
    - On a visual analogue scale, the level of pain reported by 396 patients who received palliative care was very low (the mean basal pain mean was 2.9 and the median was 2.0). 116
    - More than 90% of another group of patients reported improved level of pain after receiving palliative care and 83.2% of the patients in the same group said that their dyspnea was managed effectively.
    - The effective control of pain has been attributed to the increase in opioid prescription to patients with late stage cancer.

  o Patients highly satisfied with the care they received
    When asked, patients were highly satisfied with the care they received (the mean satisfaction score for 100 patients was 8.5/10 exceeding the mean satisfaction score of 7.2/10 for other health care services in Catalonia.). Emotional support, providers’ communication, and perception of safety were the aspects that received the highest scores.

  o Remarkable reduction in use of acute resources leading to huge savings
    - During the 20 years that followed the project initiation (1990 - 2010) a radical yet sustained reduction in the utilization pattern of acute services resources was observed. 117 118 (See Table 4)
    - This resulted in substantial cost savings for the health system: a net saving of 8 million Euros/year in 2005 (at 15 years) and 16.7 million Euros/year in 2010 (at 20 years).

Table 4 Catalonia WHO Project- Achieved outcomes 2001-2010

<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>Patients needed palliative care (n)</td>
<td>(~ 20,000 – 31,000)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients received care (n)</td>
<td>9,000</td>
<td>21,400</td>
<td>23,100</td>
<td></td>
</tr>
<tr>
<td>Service Coverage - Geographic area cover (%)</td>
<td>95%</td>
<td>&gt;95%</td>
<td>100%</td>
<td></td>
</tr>
<tr>
<td>Service Coverage – Cancer (%)</td>
<td>67%</td>
<td>79%</td>
<td>73%</td>
<td></td>
</tr>
<tr>
<td>Service Coverage – Non-cancer (%)</td>
<td>NA</td>
<td>25–57%</td>
<td>31–58%</td>
<td></td>
</tr>
</tbody>
</table>

Resource Utilization\textsuperscript{119}

| Hospital admissions | 63% | 16% |
| Emergency department use | 52% | 16% |
| Mean length of stay in hospital (days) | 12.0 | 8.0 |

Costs and Savings

| Total cost of palliative services (millions) | €40.3 | €52.6 |
| Total savings (millions) | €48.0 | €69.3 |
| Net savings (millions) | €3.0 | €8.0 | €16.7 |
| Net savings per patient received palliative care | €690.0 |

Conclusion

The Catalonia WHO Public Health Palliative Care Project demonstrated a systematic and comprehensive approach to establishing/integrating palliative care services into a health system. More importantly, the Project provided clear evidence for the effectiveness and efficiency of a whole system model of the public health approach to high quality seamless palliative care that is readily available at all care settings and provided by competent multi-professional teams. Catalonia’s experience indicated that shifting the use of acute resources to palliative care beds for treating advanced disease inpatients in a publicly funded and freely accessible health system improves the quality of care at end-of-life, lessens patients’ suffering, and generates substantial cost savings for the health system.

Figure 10 Catalonia WHO Public Health Palliative Care Project: Results at 10, 15, and 20 Years

The Catalonia WHO Demonstration Project for Public Health Palliative Care Implementation: Results at 10, 15 and 20 Years.

Strategic Plan
- Assessment of population needs
- Define criteria of access to specialist PC
- Develop a model of care that uses a systematic approach to assess and address the multidimensional needs of patients and their families
- Change legislations/policies governing provision of services to ensure: high quality, culturally sensitive, consistent and equitable services to all those in need
- Revise legislations/policies governing delivery of opioid analgesics
- Develop a palliative care funding model
- Train all health care professionals in basic PC competencies
- Integration of basic PC into conventional health care services
- Make specialist PC services available throughout the health care system
- Develop professional standards
- Develop monitoring & evaluation strategy.
- Promote and support research

Results
- Geographic Coverage: 95%
- PC services are completely free of charge at the point of care
- PC services extended to advanced geriatric and chronically ill patients.
- Increase in number of Home care support teams in all settings*
- Improvement in pain management (On a visual analogue Scale: Mean basal pain: 2.9
  Median: 2.0 for 396 patients)
- Health care professionals highly satisfied with training they received (Mean score is 8.4/10)
- A Palliative Research Group was set up
- Fewer hospital admissions, ER visits and shorter length of stay

Services - Accessibility, Uptake, Quality
- Geographic Coverage: > 95%
- 79% of cancer patients received PC.
- 25–57% of people dying from non-cancer conditions received PC.
- % of deaths at home increased
- 25% increase in opioid consumption for management of pain in cancer patients

Patients
- Highly satisfied with received care (Mean score is 8.5/10) – Satisfaction is higher with emotional support and communication with providers
- Significant reduction in severity of symptoms: pain, weakness, insomnia, and anxiety

Resource Utilization:
- Fewer hospital admissions and ER visits
- Shorter length of stay

Cost: €40.3 million/year
Net saving: €8.0 million/year

2001
- 21,400 patients received PC

2005
- 23,100 patients received PC
- Cost: €52.7 million/year
- Net saving: €16.7 million/year

2010
- 237 PC Services

Services - Accessibility, Uptake, Quality
- Geographic Coverage: 100%
- 73.3% of cancer patients received PC.
- 31%–58% of people dying from non-cancer conditions received PC.
- All effective drugs needed for PC are made available and accessible and are funded, for the most part, by the NHS.

Patients
- 91% had a multidimensional assessments
- 91.8% reported improved level of pain
- 83.2% their dyspnea was managed effectively.

Primary Care Professionals
- 70.5% of primary care professionals received training in PC

Research and Training Unit established
Surveillance Unit established to monitor needs and demands

Resource Utilization:
- Fewer hospital admissions and ER visits
- Shorter length of stay

*Palliative Care (PC) Support Team includes: Physicians, nurses and allied health professionals in all settings: hospitals, long-term care centres and the community.
B. Neighbourhood Network in Palliative Care (NNPC)-Kerala, India

The Neighbourhood Network in Palliative Care (NNPC) in Kerala, India has won the World Health Organisation (WHO) recognition as an exemplary model for community-led palliative care programs.

Kerala’s experience demonstrates the implementation of a public health approach to palliative care, within a community-led operational structure supported by health system. This was achieved by means of:

- **Community mobilization and participation** - Identifying partners in the community to set a common agenda and implement it through joint plans of action
- **Capacity development** - training and education of:
  - health care professionals,
  - community leaders,
  - community volunteers,
  - family caregivers.
- **Public awareness and promotion of palliative care.**

This section describes how palliative care in Kerala, India has evolved over the past 14 years to create a compassionate society accountable for the wellbeing its terminally ill citizens.

**NNPC Philosophy**

The Neighbourhood Network in Palliative Care (NNPC) was established in 2001 based on the notion that “there is enough social capital available in the community to build a ‘care net’ readily accessible and available to the terminally ill patients, who are in continuous need for social, psychological and spiritual support in addition to the medical and nursing care.”

**The objectives of the Neighbourhood Network in Palliative Care (NNPC) were to:**

- Engage and empower the local community to look after terminally ill patients;
- Develop a cost-effective method for the provision of palliative care in a community-based setting.

**NNPC Structure:**

- A network of trained volunteers in the community
- Community-based palliative care centres
- A support system of trained health care professionals and palliative care institutions

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120 Sallnow L, Chenganakkattil S. The role of religious, social and political groups in palliative care in Northern Kerala. Indian J Palliat Care 2005;11:10-4
NNPC Operating Model
- Recruit people who can spare at least 2 hours per week to care for the sick in their community neighbourhood and enrol them in structured training,
- On successful completion of training, the volunteers form groups of 10–15 volunteers per community (NNPC groups),
- The NNPC groups work closely with existing palliative care facilities in their areas (see Figure 10 for the group’s typical activities),
- After gaining enough experience, the groups may set up and run palliative care centres.

**Figure 11 Kerala’s Experience: Typical activities of NNPC volunteer groups**

*Training: 16 hours of interactive theory plus 4 days of clinical practice under supervision, with an evaluation at the end of the training.

**Care: is provided under professional guidance and support from trained primary care doctors and nurses; addresses patient’s financial problems, emotional, spiritual and social needs, may include basic medical care such as: bedsore prevention and mobilty.

NNPC Approach
The NPPC engaged already existing local volunteer groups providing palliative care in their communities. Examples provided below:
Not-for-profit organizations - Examples.

- A large state-sponsored not for profit women’s organization, working in health awareness and poverty reduction.
- Aspire, a support group for people affected by quadriplegia and paraplegia.
- National Literacy Movement, volunteers from the Literacy Movement help with fundraising, administration tasks, and community needs assessment studies.
- Other groups: local libraries, sports and arts clubs, political parties- examples:
  - The Bankmen’s club is heavily involved in fundraising and many of its retired members volunteer in NNPC.
  - The Forest Protective Staff Association took the initiative of planting trees around the Institute of Palliative Medicine (IPM) in Calicut and maintaining its gardens. After seeing the work carried out at the IPM, many of the members became NNPC volunteers.

Religious groups Various religious groups/organizations (Hindu/Muslim/Christian) in Kerala play a pivotal active role in raising public awareness, fundraising, and recruiting new volunteers and running clinics and inpatient centres. Religious-based groups helped palliative care to make inroads into the tribal population.

University students. The ‘Palliative Care in Campus’ initiative” is the outcome of a formal collaboration between NNPC and the National Social Scheme (a community-service-promoting organization). The student led initiative provides training to students, coordinates NNPC activities on campus and raises funds.

NNPC Achievements 122

1. Palliative care in Kerala has become a social movement.
   - A regional Palliative Care Day marked on 15 January every year
   - The media endorses the movement. The largest circulating newspaper in India with an estimated readership of over 9 million, ran an award winning campaign for 3 months entitled “We are with you” - over 100,000 people participated in it.
   - Palliative care has become a politically attractive topic for politicians.

2. Maximized access to good palliative care by:
   - Increasing availability of care. In 2010, NNPC has grown into a huge network of 230 palliative clinics caring for around 25,000 patients at any point in time. In some districts this translates to coverage of over 60% of those in need of care. Most of the care is delivered in the home.
   - Providing a holistic type of care by addressing the medical and non-medical needs of patients and families.
   - Providing care that is free to patients at all care setting.

A Public Health Approach to Palliative Care

- Linking chronic/terminally ill patients to the centres in their community,
- Reaching inaccessible populations through religious groups.

<table>
<thead>
<tr>
<th>Community-based palliative care (NNPC) in Kerala Workforce</th>
<th>2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full time doctors (n)</td>
<td>85</td>
</tr>
<tr>
<td>Nurses (n)</td>
<td>350</td>
</tr>
<tr>
<td>Trained volunteers (n)</td>
<td>&gt;10,000</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patients</th>
<th>2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients care for at any point of time (n)</td>
<td>25,000</td>
</tr>
<tr>
<td>Cancer patients (%)</td>
<td>30%</td>
</tr>
<tr>
<td>Terminal non-cancer patients (%)</td>
<td>50%</td>
</tr>
<tr>
<td>HIV/elderly (%)</td>
<td>20%</td>
</tr>
<tr>
<td>Coverage of patients in need for palliative care (%)</td>
<td>&gt;60%</td>
</tr>
</tbody>
</table>

3. **Reduced unnecessary hospital admissions and ER visits** by providing good care to the terminally ill patients in their own homes.

4. **Created a compassionate caring society with empowered individuals** (in terms of knowledge, skills and confidence).

5. **Enhanced social capital** by pooling and efficiently using the community’s resources

6. **Created social pressure that prompted structural changes such as policy and service reorientation**:
   - **Pain and Palliative Care Policy** – issued by the Government of Kerala in 2008. The policy emphasizes a community-based approach to palliative care and highlights the need to integrate palliative care with primary healthcare.
   - **Palliative Care Practice Guidelines** – issued by Local Self Government Department and Health Department in 2009
   - **Integration of social health services** into the community-based palliative care units.

Conclusion

So far, Kerala’s model represents the most developed version of the health promoting palliative care/compassionate communities concept. The Neighbourhood Networks in Kerala offers palliative care to more than 12 million people, liaising with medical services. Kerala’s model demonstrated that raising the social capital of a community and moving beyond the traditional institutional and biomedical models of palliative care can bring tremendous improvements in access to underserved populations and the provision of holistic care in a truly meaningful sense.

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C. Public Health Approach to Palliative Care in the United Kingdom

Overview
In the UK, there has been a growing interest over the past decade in embedding the public health approach and community compassion in end-of-life care. This interest was prompted by the socio-demographic changes, brought about by the ageing population in the UK, and diminishing resources of the health care system. The proportion of people aged 65+ is projected to rise from 17.7% currently (11 million) to 23.5% in 2034. Around 70% of people would prefer to die at home, yet around 60% of the 500,000 people who die each year in England die in hospitals.

UK National End-of-life Care Strategy
To address these challenges, the 2008 National End-of-life Care Strategy supported a public health partnership approach to improve the quality of care at the end of patients' lives and enable more patients to live and die in the place of their choice. It is important to note that a combination of the National Health Services resources and the voluntary sector in the UK funds and provides palliative care free of user fees at all care settings.

The strategy sets out key areas with related actions:
- **Raise profile of end-of-life care**: Partner with local communities to increase awareness of end-of-life care;
- **Strategic commissioning**: involving all relevant provider organizations;
- **Early identification of patients**: training health care professionals in identifying people reaching the end-of-life and in communication skills;
- **Enhance capacity of all staff groups**: end-of-life care to be embedded in all training curricula;
- **Patient-centred care**: involving all people reaching the end-of-life in care planning;
- **Coordination of Care**: establishing a central coordinating facility as a single point of access through which services can be coordinated as well as locality-wide registers;
- **Rapid access to care**: all health care and support services to be available in the community, 24 hours a day, 7 days a week;
- **Delivery of high-quality services in all settings**;
- **The last days of life and death**: the Liverpool Care Pathway, or equivalent tool, is recommended;
- **Involving caregivers/family in decision-making** and providing them with all the information they require;
- **Evaluation and research**.

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125 http://www.ageuk.org.uk/Documents/ENGB/Factsheets/Later_Life_UK_factsheet.pdf?dtrk=true
Numerous programs were established by a wide range of organizations in the statutory, voluntary and private sectors to support the strategy objectives. Table 5 presents examples of current end-of-life care initiatives and programs mapped to the ten essential elements of the public health approach.

The fourth annual report on the 2008 Strategy revealed a steady improvement in the proportion of people who died in their usual place of residence which combines people’s homes and care homes. 2011 data showed a drop in hospital deaths to 51%, while the percentage of deaths at home and in care homes increased to 21.8% and 19.4% respectively.127

Figure 12 UK data shows steady increase in the proportion of people who died at home or in home like settings.

### Table 5 UK National Palliative Care Programs Mapped to the Essential Public Health Approach Elements

<table>
<thead>
<tr>
<th>Public Health Approach Essential Elements</th>
<th>Corresponding UK Palliative Care Programs Examples</th>
</tr>
</thead>
</table>
| 1 Monitor health status                   | - National End-of-life Care Intelligence Network-Data Repository  
- National Council for Palliative Care Data (England)  
- Marie Curie Cancer Care End-of-life Care Data (Scotland)  
- Electronic Palliative Care Coordination Systems (locality end-of-life care registers) |
| 2 Diagnose and investigate health problems | England  
- Dying Matters- website/events/campaign  
- Together for Short Lives  
- e-hospice UK-website/mobile application  
Scotland  
- Palliative Care Zone- on NHS website  
- Good Life, Good Death, Good Grief- website/events/campaign.  
- To Absent Friend-People’s Festival of Storytelling & Remembrance  
- Death on the Fringe- shows/events |
| 3 Inform, educate, and empower people about health issues. | England  
- Dying Matters- a national coalition led by National Council for Palliative Care in England  
- Hospice UK – alliance of organisations advocating and raising awareness of EOL/Hospice care across the UK.  
- Good Life, Good Death, Good Grief- Alliance Stakeholder Group led by the Scottish Partnership for Palliative Care  
- Cheshire Living Well, Dying Well Public Health Partnership |
| 4 Mobilize community partnerships and action | England  
- NHS end-of-life care program [including: the Gold Standards Framework for Care Homes; the Liverpool Care Pathway for the Dying Patient; and Preferred Priorities for Care (advance care planning)].  
- A new palliative care funding system is under development.  
- Quality Standard for end-of-life care by NICE (2011)  
Scotland  
- National Statement on caring for people in the last days and hours of life (2014)  
- Living and Dying Well- Government’s action plan on palliative and end-of-life care. (2014)  
- Palliative Care Guidelines (2014)  
- A Framework for the Delivery of Palliative Care for Children and Young People (2012) |
| 5 Develop policies/standards/regulations and community-wide plans | England  
- Dying Matters- website providing information to the public.  
- Good Life, Good Death, Good Grief- website.  
- e-hospice UK-website/mobile application  
- Together for Short Lives-website |
| 6 Enforce laws and regulations that protect health and ensure safety. | England  
- National Audit Office (NAO) |
| 7 Link people to needed personal health services and assure the provision of health care when otherwise unavailable. | England  
- Dying Matters- website providing information to the public.  
- Good Life, Good Death, Good Grief- website.  
- e-hospice UK-website/mobile application  
- Together for Short Lives-website |
### Public Health Approach

#### Essential Elements

- Assure competent public and personal health care workforce.
- Evaluate effectiveness, accessibility, and quality of personal and population-based health services.
- Research for new insights and innovative solutions to health problems.

#### Corresponding UK Palliative Care Programs

<table>
<thead>
<tr>
<th>Essential Elements</th>
<th>Examples</th>
</tr>
</thead>
</table>
| Assure competent public and personal health care workforce. | - The National Council for Palliative Care - Training programs and toolkits, Conferences/forums.  
- Gold Standards Framework Centre for training primary care providers  
- End-of-life care for all (e-ELCA)- e-learning to enhance training and education of health and social care staff in England  
- Palliative & End-of-life Care Work-Based Learning Resource-by NHS Scotland  
- Quality End-of-life Care for All (QELCA) training program  
- Securing end-of-life care modules in social work qualifying programmes. |
| Evaluate effectiveness, accessibility, and quality of personal and population-based health services. | - National Quality Indicators for Palliative Care by-Healthcare improvement Scotland  
- Annual Reports on Palliative Care Strategy Implementation (NHS Board Update Reports)  
- Gold Standard Framework Accreditation Program |
| Research for new insights and innovative solutions to health problems. | - National End-of-life Care Intelligence Network- research  
- Marie Curie Palliative Care Research Centre  
- Palliative Care Research Society  
- The Cancer, Palliative and End-of-life Care Research Group at the University of Southampton  
- Bath University, The Centre for Death and Society |

### UK Providers prioritize public health approaches to death, dying, and loss

In 2013, the National Council for Palliative Care (NCPC), the umbrella charity for all palliative and hospice care providers reported an increasing uptake of compassionate communities by palliative care services in England. In the same year, an online survey of 220 palliative care providers across the four UK countries reported that most of the providers were prioritizing public health approaches to death, dying and loss, most commonly adopting a 'compassionate community' model. Respondents to the survey identified working with schools and working directly with local community groups to be their most successful work. The findings confirmed the relevance of a public health approach for palliative care services.128

To further promote this trend, the NCPC partnered with Public Health England to provide technical advice and support to community organizations interested in pioneering a public health partnership approach to end-of-life care in line with the “Dying Well Community Charter” and the public health approach to end-of-life Toolkit.129 130

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130 [http://www.ncpc.org.uk/sites/default/files/Public_Health_Approaches_To_End_of_Life_Care_Toolkit_WEB.pdf](http://www.ncpc.org.uk/sites/default/files/Public_Health_Approaches_To_End_of_Life_Care_Toolkit_WEB.pdf)
The following are examples of UK palliative care providers using the public health/health promoting approach to palliative care, and compassionate communities model.

**Dying Matters**

Dying Matters is a broad based and inclusive national coalition of almost 30,000 members. It aims to change public knowledge, attitudes and behaviours towards dying, death and bereavement.

**Approach**

- **Raising awareness and promote conversation about death and end-of-life issues:**
  - Annual National Dying Matters Awareness Week (in May),
  - Community outreach events in partnership with other community organizations,
  - A community forum and blog on website to share stories and thoughts about death and dying.
  - Building compassionate schools and workplaces through onsite educational sessions and promoting activities.

- **Providing information to patients and carers and link them to services that exist in their local community.**

- **Training and education of health care professionals, carers, and volunteers**
  - A volunteer training program about Advance Care Planning
  - Information on website for all types of carers
  - Sponsoring demonstration projects such as **Find Your 1% Project**, which aims to engage GPs in identifying the individuals on their lists who might be in their last year of life, so that they can undertake end-of-life care planning with them. The Project showed that the confidence of GPs in talking about dying with patients improves end-of-life care.

**The Cheshire Living Well, Dying Well (CLWDW) Public Health Program**

The Cheshire Living Well, Dying Well (CLWDW) Public Health Program aims to improve health and wellbeing of the people of Cheshire by breaking down taboos and supporting a change in public knowledge, attitude and behaviour so that people consider, discuss and plan for end-of-life throughout their lives. The Program model has been presented at the House of Lords and consequently referred to as a model of good practice in Parliament.

**Approach**

During 2010, Cheshire Hospice consulted with the local community about end-of-life issues and concerns. The community groups and organisations supported a broad public health approach to death, dying and loss. To bring this strategic direction to reality, a partnership was

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131 [http://www.dyingmatters.org/overview/about-us](http://www.dyingmatters.org/overview/about-us)
established to enable and support the implementation of the CLWDW Public Health Program.\textsuperscript{132}

**Highlights of the Program**

1. The Program was referred to as a model of good practice in Parliament
2. Appointed a Public Health Lead for the Program
3. Identified a Champion for the Program at Health and Wellbeing Board Level.
5. A range of awareness and training sessions for the community and public health workforce.
6. Compassionate Communities established to date:
   - ‘Good Neighbour Scheme’ in Middlewich, using a timebanking model.\textsuperscript{133}
   - ‘Vintage Blacon’ a faith based bereavement group.
   - St. Luke’s Community Support – A satellite group in Alsager have set up palliative day care support with hospice support. This includes home visits and support for people with life limiting illness, families, carers, and early dementia.
7. External evaluation has been commissioned to evaluate the impact of the program

**Severn Hospice**

Severn Hospice in Shropshire, England, aims to raise awareness that the end-of-life care is everyone’s responsibility.\textsuperscript{134}

**Approach**

Through public forums and discussions Severn Hospice called for volunteers who are able to dedicate a portion of their week to the care of the frail and vulnerable in their own local community. A growing number of volunteers responded to this message. Before they are allocated to care for people, the volunteers are subjected to a short training session on how to reduce anxiety and panic and alleviate feelings of isolation and loneliness. Severn Hospice has now a wide and diverse network of volunteers drawn from all walks of life—retired as well as employed.

**Evaluation**

The evaluations of Severn Hospice model revealed a consistent decrease in the need for out-of-hours and emergency support from the health system. The volunteer support also reduced isolation and anxiety, and supported people in the self-manage of their condition.

**St Christopher’s Hospice**

St Christopher’s Hospice in South London uses a health promoting approach to palliative care by engaging local schools to achieve a greater understanding about dying, death, practical care,
and grief and loss among school students, teachers, and parents. The aim of such knowledge was not only to reduce the community’s fear and anxiety about these topics but also to prevent harms related to isolation, loneliness, and stigma among the patients at the hospice.

**Approach**

St Christopher’s Hospice discussed the idea of engaging school students with the head teachers, and with the patients, families, and staff in the hospice to ensure that the idea and approach were acceptable to both sides. According to the plan, the students attended four sessions (1 – 3 hours each) at the hospice, meeting with patients and asking them questions that address their fears and curiosities. When the students returned to school, they discussed their experiences with the teachers and often produced artwork or performances which in turn, helped to raise awareness in the larger community. The age group of the students who have participated in this process so far ranges from 9 to 16 years old.

**Evaluation**

The evaluations of the student–teacher–parent engagement showed a change in attitudes from uncertainty and fears to understanding and confidence, normalizing the idea of death and dying. The engagement helped as well in alleviating social isolation and feeling of loneliness among patients at the hospice.

**The National Gold Standards Framework (GSF) Centre**

The GSF Centre in End-of-life Care is the national training and coordinating centre for the GSF programs in the UK, enabling generalists to provide a gold standard of care for people nearing the end-of-life. Figure 13 presents a description of the GSF. The GSF is extensively used by primary care teams across the UK and has demonstrated its effectiveness in terms of improving consistency of care and improving the experience of care for patients, carers, and staff. To ensure and celebrate sustained best practice in the different settings, the GSF Centre developed Quality Hallmark Accreditation Programs: Primary Care Accreditation, Acute Hospital Accreditation, and Community Hospital Accreditation. The home care organizations that received the GSF Quality Hallmark Award reported significant reduction in hospital admissions and hospital deaths, better integrated cross boundary coordination. (See below)

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135 http://www.stchristophers.org.uk/
136 http://www.goldstandardsframework.org.uk/about-us
138 http://www.goldstandardsframework.org.uk/accreditation
Figure 13 The UK Gold Standards Framework—Overview

**The Gold Standards Framework**
One gold standard for all patients nearing the end-of-life to enable patients to die well

**Three processes**
1. Identify the key group of patients—using a register and agreed criteria
2. Assess patients’ main needs, both physical and psychosocial, and those of the carers
3. Plan ahead for problems—move from reactive to proactive care by anticipation and prevention

**Five goals**
1. Symptoms controlled as much as possible
2. Living and dying where they choose
3. Better advanced care planning information, feeling safe and supported with fewer crises
4. Carers feeling supported, involved, empowered, and satisfied with care
5. Staff feeling confident, satisfied with good communication, and team working with specialists

**Seven key tasks**
- Communication
- Coordination
- Control of symptoms
- Continuity and out of hours
- Continued learning
- Cover support
- Care in the dying phase

*Source: Goldstandardsframework.org.uk*

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Figure 14 UK Data: The GSF Home Care Program reduce crisis admissions and hospital deaths

**GSF Care Homes Programme—Decreasing crisis admissions & hospital deaths Dec 2008**
Conclusion

A whole-system and care-pathway approach is a key feature of the End-of-life Care Strategy in the United Kingdom (UK).\textsuperscript{140} In 2008, the National Strategy recognized ‘raising national awareness’ as part of the whole-system approach. Since then a broad range of developments has been taking place under the banner of public health/health promoting end-of-life care across UK.\textsuperscript{141} These developments serve a common vision: vulnerable and terminally ill people enjoy a high quality end-of-life in a supportive compassionate community. There is evidence that the UK’s public health palliative care model is effective and that individuals, families and communities can have the skills, knowledge and expertise to play key roles in their own end-of-life care.

\textsuperscript{140} End-of-life Care Strategy: promoting high quality care for all adults at the end-of-life. London, Department of Health, 2008

\textsuperscript{141} Murray Hall Community Trust And National Council for Palliative Care. Dying Matters Coalition: An Overview of Compassionate Communities in England. July 2013
D. Building Dementia-Friendly Society in Japan

Overview
In Japan there are 31.7 million people over 65 years old and by 2050, it is expected that one in every three persons will be 65 years old or over. In addition, there are 4.6 million people diagnosed with dementia. “A huge number of people with dementia throughout Japan are unable to receive appropriate treatment and support due to a lack of accurate knowledge and information and to insufficient understanding on the part of the people around them. Anxiety and isolation worsen their condition and their daily lives are a far from life with dignity.”- by these words, the Japanese society voiced its concerns and views about the dementia problem in their country. (People with Dementia Conference October, 2006 Japan)

The Japanese society realized that greater awareness and action on the part of nongovernmental organizations and individual citizens are needed as well as efforts by national and local governments and professionals in health care and social services- in other words a collective societal action is required. As such, the Ministry of Health, Labour and Welfare in Japan adopted a public health strategy to address dementia.

Japan’s Campaign to Build Compassionate Communities
In 2005 the Ministry of Health, Labour and Welfare in collaboration with hugely diverse groups of community organizations, launched a 10-year nationwide dementia care initiative. The Initiative, which is called “The Campaign to Understand Dementia and Build Community Networks”, aims to create safe and comfortable communities for people with dementia. The campaign is led by the “100-Member Committee”, an alliance of more than 100 community organizations and individuals. The Campaign is comprised of four major programs, each of which is led by a working group responsible for its planning and implementation.

The Campaign’s Four Programs

1. Nationwide caravan to train one million dementia supporters
The goal of this program is to train 7 million volunteers by 2017 to be "dementia supporters" who have good knowledge and understanding of dementia. As of September 2014 there were 5.5 million dementia supporters across the country who proactively identify, watch over, and assist people with dementia and their families in local communities and workplaces. The operating model of this program is based on a multi-tier knowledge transfer and training structure that involves all members of society. (See Figure 15)

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143 http://www.ilcjapan.org/agingE/index.html
144 http://longevity.ilcjapan.org/f_issues/0703.html
145 http://longevity.ilcjapan.org/f_issues/0603.html
146 http://www.ncgg.go.jp/topics/dementia/documents/Topic4-4HirokoSugawara.pdf
2. Building dementia-friendly communities

The objective of this program is to promote, support, and recognize initiatives that aim to build dementia friendly communities in which people with dementia are empowered to have high aspirations and enjoy a sociable and safe life, knowing they can contribute and participate in meaningful activities. Such empowerment can have a profound impact on a person’s quality of life, not only for individuals with dementia but also for their carers and loved ones. The increasing number of compassionate communities programs that is seen in Japan now is a result of a national Japanese prize that is annually offered to communities that have become ‘dementia-friendly’.

Some features of dementia-friendly communities in Japan include:

- **Regional Comprehensive Support networks** - These are groups of health-care providers, long-term care providers, users of their services, local residents, and government officials in a region/local community who work together to identify the needs of their community and plan and implement appropriate prevention and community-based services in order to build a community where people at risk of dementia can enjoy living independently in their homes.

- **Happy cafés** - have been set up in various locations across the country as a means of promoting socialization and preventing elderly from withdrawing from society.

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147 http://www.ncgg.go.jp/topics/dementia/documents/Topic4-4HirokoSugawara.pdf
148 http://longevity.ilcjapan.org/f_issues/0603.html
- **Wandering-watch program** - educating elementary and junior high school students to help persons with dementia who have lost their way.
- **“Community support centres”**
  These centres provide a full range of services to the elderly and patients with dementia in their own communities. A variety of educational and physical exercise classes are offered to reduce the risk among old people of requiring long-term care in the future: muscle strengthening sessions, prevention of malnutrition, and prevention of social withdrawal. Home visits are made to the people who find it difficult to attend classes.
- **Patients’ networks** - building networks of patients who have dementia so that they can meet and develop a sense of companionship and solidarity and share experiences and feelings.

3. **People with Dementia Annual Conference**¹⁴⁹

The first “People with Dementia Conference” was held in October 2006 to ensure that dementia care programs are shaped according to the needs of the people they serve. The unique feature of this conference is that groups of patients with dementia were given the opportunity to discuss and speak up in public about their personal experience with the illness, suffering, capabilities, needs, and wishes. In the second day of the conference, the participants summarized their needs, wishes, and messages to their families and communities into a 17-point Appeal.

*Parallel to the campaign, Japan made major revisions to the health care system and the long-term care insurance system in 2005-2006.*

**Reform of the health care and long-term care insurance systems**¹⁵⁰

The reform aims to create a system through which old people including people who have dementia can receive the services and care that meet their changing needs and allow them to live with dignity in a friendly community. Figure 16 illustrates the priorities/goals of the system reform.

The basic perspectives of the system revision are:

- **Prevent the need for long term care** ---- by shifting to a “prevention-oriented system”
- **Promote “Aging in Place”**----- by establishing a new service system focusing on community-based services, residential care, and a regional support network
- **Ensure fairness related to benefits and financial burden** for in-home service users and long-term care facility residents ----by reviewing the facility benefits and insurance premium and system management
- **Assure quality of services** based on users’ appropriate choices and providers’ competence---- by mandating data reporting for monitoring and audit purposes,

¹⁴⁹ [http://longevity.ilcjapan.org/f_issues/0703.html](http://longevity.ilcjapan.org/f_issues/0703.html)
¹⁵⁰ [http://longevity.ilcjapan.org/pdf/Overview%20of%20the%20Revision%20of%20LTCI.pdf](http://longevity.ilcjapan.org/pdf/Overview%20of%20the%20Revision%20of%20LTCI.pdf)
improving expertise in services and living environments (training of care providers and defining care standards), and reviewing service providers’ regulations.

Conclusion
Japan’s aging demographic is a powerful social and political force. The variety and scale of the community and governmental initiatives that have been implemented in the elderly and dementia care context since 2005 indicate that the Japanese society places great emphasis on prevention, awareness/promotion, population needs, community development and partnerships, supportive systems and environments, and capacity of health care providers. The Japanese experience demonstrates that addressing dementia/elderly care requires a concerted and collaborative effort from all sectors of society to build dementia-friendly communities supported by a high quality and integrated health and social care system.

Figure 16 Japan: Overview of the Long Term Care System Reform

<table>
<thead>
<tr>
<th>Basic Perspectives of the Reform</th>
</tr>
</thead>
<tbody>
<tr>
<td>Formation of Productive Aging Society</td>
</tr>
<tr>
<td>Overview of the Reform</td>
</tr>
</tbody>
</table>

- The number of persons slightly requiring long-term care or support increased remarkably
- Orientation toward prevention of the need for care, based on the situations of persons slightly requiring long-term care or support
- Fairness on benefits and payment for in-home services users and residents in Long-term Care Insurance facilities
- Adjustment of Long-term Care Insurance benefits and pension benefits
- Increase in the number of the elderly with dementia or living alone
- Review of Service Systems and Regional Comprehensive Care
- Strengthening support for persons with moderate to severe care level, partnership between medical and long-term care

1) Establishment of New Prevention Benefit
- Based on the situations of persons slightly requiring long-term care or support, persons eligible for prevention benefits, contents of services and care management service are reviewed.
- Regional Comprehensive Support Centers will manage the care management to prevent the need for care in new prevention services.
2) Establishment of Regional Support Projects
- The effective project to prevent the need for care, which is designed for the elderly at risk of requiring care or support, shall be incorporated into the Long-term Care Insurance System.
1) Review of Accommodation Expenses and Meal Expenses
- Insurance benefits for accommodation expenses and meal expenses shall be provided for residents in three types of Long-term Care Insurance facilities (including short-stays) and users of commuting services.
2) Consideration for People with Low Income
- New supplementary benefits shall be provided in order to reduce payment for people with low income who utilize Long-term Care Insurance facilities.
3) Establishment of Community-based Services
- Community-based Services were established to provide diversified, flexible services reflecting the characteristics of each region.
2) Enhancement of Residential Services
- Expansion of residential care facilities
- Review of for-profit private nursing homes
3) Establishment of Regional Comprehensive Care System
- Establishment of Regional Comprehensive Support Center as a core body in the community
4) Strengthening Support for Elderly with Moderate to Severe Care Level, Partnership and Coordination between Medical and Long-term Care
E. A Public Health Oriented Palliative Care System in Australia

Overview
Similar to other developed countries, Australia’s population is ageing and there is increasing demand for equitable access to high quality end-of-life care. Life expectancy has improved over the past 20 years by 6.1 years for males and 4.2 years for females. Increased longevity has brought advanced levels of frailty and higher rates of chronic diseases. Although most Australians prefer to die at home, data indicates that only 26% of people die at home or in a nursing home. Of the 144,000 people who die annually in Australia, it is estimated that between 36,000 and 72,000 people will need palliative care. Another challenge is that there are specific groups that experience difficult access to the type of care they need and prefer, such as Aboriginal people, people from culturally and linguistically diverse backgrounds, and people living in rural and remote areas.

Australian National Palliative Care Strategy
The 2010 National Palliative Care Strategy in Australia recognized the need for a population needs-based whole systems approach to improve quality of palliative care and increase coverage of services geographically and in its reach to all groups in the community. After consulting with the palliative care community in Australia, four strategic directions were identified: (See Table 6)

Table 6 Australia’s National Palliative Care Strategy 2010

<table>
<thead>
<tr>
<th>Priority Area</th>
<th>Number</th>
<th>Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Awareness and Understanding</td>
<td>Goal 1</td>
<td>To significantly improve the appreciation of dying and death as a normal part of the life continuum.</td>
</tr>
<tr>
<td></td>
<td>Goal 2</td>
<td>To enhance community and professional awareness of the scope of, and benefits of timely and appropriate access to, palliative care services.</td>
</tr>
<tr>
<td>Appropriateness and Effectiveness</td>
<td>Goal 3</td>
<td>Appropriate and effective palliative care is available to all Australians based on need.</td>
</tr>
<tr>
<td>Leadership and Governance</td>
<td>Goal 4</td>
<td>To support the collaborative, proactive, effective governance of national palliative care strategies, resources and approaches.</td>
</tr>
<tr>
<td>Capacity and Capability</td>
<td>Goal 5</td>
<td>To build and enhance the capacity of all relevant sectors in health and human services to provide quality palliative care.</td>
</tr>
</tbody>
</table>

National Policies and Programs funded by the Australian Government have been developed to support the State and Territorial Authorities and service providers to achieve the National Strategic Goals. (See Table 7)

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## Table 7 Australia’s National Palliative Care Programs Mapped to the Essential Public Health Elements

<table>
<thead>
<tr>
<th>Public Health Approach</th>
<th>Corresponding National Palliative Programs in Australia</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1 Monitor health status</strong></td>
<td>- Palliative Care Services in Australia- Data &amp; Reports since 1999 (by Australian Institute of Health and Welfare)154</td>
</tr>
<tr>
<td><strong>2 Diagnose and investigate health problems</strong></td>
<td></td>
</tr>
</tbody>
</table>
| **3 Inform, educate, and empower people about health issues.** | - CareSearch- Australian Palliative Care Knowledge Network.155  
- Palliative Care Australia156 - activities  
- Advance Care Planning Australia.157 |
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**National Programs Supporting Palliative Care Quality and Outcomes**

**National Care Standards and Service Planning and Development Guides**
The Australian Government and Palliative Care Australia released documents that define the national standards for palliative care, guide the planning and development of services, and recommend guidelines for palliative care provision in the community setting. The documents provide a framework for needs-based and equitable access to quality end-of-life care:

1. Standards for Palliative Care Provision  
2. Palliative Care Service Provision in Australia: A Planning Guide  
3. A Guide to Palliative Care Service Development: A population based approach  
4. Palliative Care Guidelines in the Community Setting

**National Standards Assessment Program (NSAP)**
Australia’s NSAP enables palliative care service providers to engage in improvement and accreditation cycles through self-assessment against the National Palliative Care Standards, action plan development and implementation, as well as peer mentorship, audit and survey tools. The majority of service providers across Australia have completed at least one cycle to date.

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Palliative Care Outcomes Collaboration (PCOC)
PCOC is another national quality improvement program that measures and benchmarks patient outcomes between providers using data collected routinely via a standardized clinical assessment process and tools. Four outcome measures are assessed: time from referral to first contact, time in unstable phase, change in pain, and change in symptoms relative to the baseline national average. Benchmarking takes place in national and juridical meetings to allow the providers to share their experiences and reflect on the success factors and challenges they face. Recent data from PCOC demonstrates systematic improvement of outcomes in the patients cared for by the providers participating in PCOC. (See Figure 17)

Figure 17 Australia data: steady improvement in the severity of pain and other symptoms in patients cared for by providers participating in the national quality improvement program

![Figure 17: Steady improvement in the severity of pain and other symptoms in patients cared for by providers participating in the national quality improvement program.](image)

National Palliative Care Performance Indicators
The Australian Institute of Health and Welfare collects information and publishes periodical reports on the extent to which palliative care agencies are meeting the goals of the National Palliative Care Strategy.

National Programs Building Capacity of Palliative Care Providers
Palliative Care Curriculum for Undergraduates (PCC4U)
For students: The program offers medical, nursing, and allied health undergraduates learning modules including case studies and video vignettes in palliative care.
For academics: Offers a hub of teaching and learning resources to support the inclusion of palliative care in health curricula.

**Palliative Care Accredited Online Training Program**

The online training helps health professionals implement the Guidelines in their community-based practice. The program consists of four free, accredited, online training modules for which Continuing Professional Development points can be accrued.

**Program of Experience in the Palliative Approach (PEPA)**

The program offers practicing health professionals free placements in palliative care services (2-5 days duration) and free palliative approach workshops with CPD points that can be accrued. The programs also offers opportunity for palliative care specialists to travel to Aboriginal health service setting to facilitate palliative care learning.

**Advance Care Planning (ACP) Australia**

This is a capacity-building program based on Respecting Choices Model, a whole-systems integrated model that proved to increase acceptance and uptake of ACP at a community level. Through the program’s website, information and educational resources are available to help Australians understand the important elements of Advance Care Planning. The website includes culturally appropriate information and resources for Aboriginal audience. The program offers health professionals a one-day practice-based workshop and online training courses.

**Decision Assist**

Decision Assist provides Specialist Palliative Care and Advance Care Planning Advisory Services via a national 1300 number; tele-health advice; a one-stop palliative care resource website; and training workshops. Decision Assist is funded by the Australian Government and a number of leading health, academic, and aged care organisations are contracted to deliver Decision Assist services under a consortium-style arrangement.

**Rural Palliative Care Project (RPC)**

The RPC Project aims to increase the capacity of primary care providers, in partnership with palliative care specialist services, to provide quality palliative care to rural and remote Australia. The Project implemented the following eight elements in 40 rural and remote sites:

1. **Governance**
   Each RPC Project site had a local multi-disciplinary governance committee that guides the direction and focus of the project.

2. **Specialist palliative care services**
Generalist and specialist palliative care providers worked together in a formal partnership.

3. Sustainability
Projects were supported by sustainable quality improvement processes based on best practices. Organisation support was essential to continually drive quality improvement.

4. Data collection
Data collected to measure the impact of the project, give a clearer picture of what is happening in the region, and to ascertain how further initiatives may be more relevant.

5. Link nurses
Link nurses served as a communication and coordination conduit between all the health providers and the palliative care patients and carers.

6. Education
Generalists enrolled in the Program of Experience in a Palliative Approach (PEPA) placement to build their palliative care capacity.

7. Multi-disciplinary team meetings
The multi-disciplinary team meetings greatly benefitted the patients and their carers as it promoted coordinated holistic care.

8. Patient held records
Patient held records improved the continuity of care and communication, as well as providing families with a record of what happened towards end-of-life for their loved one.

National Programs Promoting Awareness and Understanding of Death and Dying
Palliative Care Australia (PCA) is the top national advocacy body for palliative care. PCA works to raise awareness of palliative and end-of-life care, improve the understanding and availability of services, and improve knowledge networks. In addition to its leading role in awareness, PCA produced the Palliative Care Standards and the Service Planning and Development Guides and is facilitating the National Self-assessment Program.

Examples of the PCA awareness work are:

Communication Campaigns
In 2013 PCA ran a highly successful campaign in the lead up to the Federal Election. Political candidates were provided with information about palliative care and afterwards were asked to discuss their views on palliative care priorities.

National Palliative Care Week (NPCW)
The NPCW is an annual week of awareness raising events organised by PCA during the month of May. PCA develops awareness materials and provides them at no cost to
interested organizations. The theme for NPCW during 2014 was “Palliative Care is Everyone’s Business Let’s Work Together” and focussed on the palliative care workforce and included political engagement and sustained media pressure components. The campaign’s theme for 2015 is “Dying to talk; talking about dying won’t kill you” aiming to normalize conversations about death, dying, and to promote Advance Care Planning.

The Australian Palliative Care Knowledge Network (CareSearch).
CareSearch is a one-stop shop of evidence-based information and practical resources for palliative care patients, carers, families, health care professionals, and researchers.

eHospice
eHospice (website/iPhone and iPad application) is a leading resource for latest news and information for families and health care professionals about hospice and palliative care sectors worldwide.

Australian Palliative Care Conference
The annual conference draws delegates from around the world and keynote speeches from renowned academics covering burning issues in palliative care and sharing their knowledge and expertise.

National Programs Supporting Research and Innovation in Palliative Care:
The Palliative Care Clinical Studies Collaborative
The world’s largest phase III clinical trial group, improving the evidence for prescribing at the end-of-life.

Encouraging Best Practice in Residential Aged Care (EBPRAC) program
This program is comprised of a number of projects aiming to improve clinical care in residential aged care by identifying and implementing evidence-based practices. Consortia of researchers, educators, and residential care staff work together to develop standardized monitoring and impact evaluation systems for these projects.

Community Engagement and Partnerships in Palliative Care in Australia
Compassionate Communities Network
A number of like-minded Australians developed The Compassionate Communities Network after the 1st International Public Health and Palliative Care Conference in 2009. Membership is open to everyone who is interested in social approaches to end-of-life. However, no information is available on the Network’s current or past activities.
Alzheimer’s Australia

As the lead charitable organization for all types of dementia, Alzheimer’s Australia manages a wide range of national programs to deliver services such as provision of information, a dementia help line, Dementia Awareness month, counselling, training and education to people with dementia, their families and carers as well as to professionals working in the dementia field. Alzheimer’s Australia assumes a leading role in building dementia friendly communities across Australia by providing technical advice and support to organizations interested in following the Alzheimer’s Australia’s Guidelines and Toolkit to become dementia friendly. ¹⁷² A number of cities and towns in Australia are currently working with Alzheimer’s Australia to become Dementia Friendly.

Kiama Town in New South Wales is Dementia Friendly

Kiama is a township in New South Wales. Alzheimer’s Australia, Kiama Municipal Council and the University of Wollongong are working together to make Kiama dementia friendly by:

1. Listening to what is important for people living with dementia
2. Establishing a Local Dementia Alliance
3. Supporting local businesses follow the Guidelines for Dementia friendly organisations
4. Raising awareness about dementia across the community
5. Promoting volunteering, employment and social engagement opportunities for people with dementia

Conclusion

Palliative care in Australia is highly regulated and well supported by government-funded national policies and programs. Australia’s approach to improve and drive quality of end-of-life care focuses mainly on strengthening the governance of palliative service provision; building palliative care knowledge and capacity of the workforce; integrating of specialist services into all levels of care; reorientating and systematizing clinical practice based on evidence; and establishing monitoring, evaluation, and quality improvement systems. The wealth of palliative care data that is being collected and goes back to 1999 provided evidence for the effectiveness of

this approach in terms of place of death and improved patient outcomes. Four out of five unstable patients now have their problem managed within 3 days. The proportion of patients with moderate pain whose pain improves to become mild or absent increased from 44% in 2009 to 53% in 2014. The proportion of deaths that occurred in the hospital decreased from 54% to 51% over a 10-year period (from 2002-2012). In addition to quality of care, Australia provided exemplary model of care to effectively address the access and holistic issues of care in remote and rural areas (Rural Palliative Care Project).

The palliative care awareness and promotion activities in Australia employ innovative multifaceted ways to reach out to all sectors, population groups, and influential groups in the society. The awareness campaigns and activities are planned and led by national programs and for the most part are funded by the Federal Government. It is noted that the community engagement and partnerships component of the public health approach to palliative care in Australia is still in the early development stage. However, the methodology to engage the society in building compassionate communities is clearly defined and available in the form of guidelines and toolkits to enable a national, systematic implementation process.
