

DEFINITIONS

Following are some definitions of the terms used in this document 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.”⁶

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”.⁷

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.¹¹

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 experience of end-of-life care. Communities are encouraged to take initiative in caring for end-of-life experiences within community contexts.⁸

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

⁷ http://www.ncpc.org.uk/sites/default/files/Public_Health_Approaches_To_End_of_Life_Care_Toolkit_WEB.pdf

⁸ Sallnow, L. and Paul, S. Understanding community engagement in end-of-life care: developing conceptual clarity. *Critical Public Health*, April 2014

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.¹¹

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.⁹

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

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.¹⁰

Frailty

Frailty is a nonspecific state of vulnerability caused by changes to a number of physiological systems, which may be related to a variety of physical, psychological, cognitive and social factors. Together, these changes lead to reduced function and strength, and affect the person’s resilience and ability to cope with any stress, such as an infection or disease or personal loss. Frailty is most commonly seen in the elderly but can also occur in adults and children who are seriously or chronically ill. Someone who is frail is at high risk of physical and cognitive decline, disability and death. Frailty can cause pain and discomfort. It can also limit people’s activities, cause them psychological distress and have a negative effect on their quality of life.¹¹

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

⁹ World Health Organization. Chronic Diseases. World Health Organization 2013; Available from: http://www.who.int/topics/chronic_diseases/en

¹⁰ Pan American Health Organization (PAHO). The search for equity: annual report of the director, 1995. Washington, DC: PAHO, 1996:ix

¹¹ <http://www.hpcintegration.ca/media/60044/TWF-framework-doc-Eng-2015-final-April1.pdf>

action; develop personal skills; and re-orient health services. Health promotion is a public health system core function.¹⁰

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.¹²

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.¹³

Palliative approach to 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.¹⁴

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 The Way-forward Initiative

Care that focuses on meeting a person's and family's full range of needs – physical, psychosocial and spiritual – at all stages of a chronic progressive illness. It reinforces the person's autonomy and right to be actively involved in his or her own care – and strives to give individuals and families a greater sense of control. It sees palliative care as less of a discrete service offered to dying persons when treatment is no longer effective and more of an approach to care that can enhance their quality of life throughout the course

¹² Canadian Hospice Palliative Care Association. Fact Sheet: Hospice Palliative Care in Canada. Canadian Hospice Palliative Care Association 2012

¹³ Available from: <http://www.health.gov.bc.ca/library/publications/year/2013/end-of-life-care-action-plan.pdf>

¹⁴ <http://www.who.int/cancer/palliative/definition/en/>

of their illness or the process of aging. It provides key aspects of palliative care at appropriate times during the person's illness, focusing particularly on open and sensitive communication about the person's prognosis and illness, advance care planning, psychosocial and spiritual support and pain/symptom management. As the person's illness progresses, it includes regular opportunities to review the person's goals and plan of care and referrals, if required, to expert palliative care services.¹⁵

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."¹⁰

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."¹⁶

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.¹⁷

¹⁵ <http://www.hpcintegration.ca/media/60044/TWF-framework-doc-Eng-2015-final-April1.pdf>

¹⁶ Russell G, Geneau R, Johnston S, Liddy C, Hogg W, Hogan K. Mapping the future of primary healthcare in Canada: A report to the Canadian Health Services Research Foundation.

http://www.cfhi-fcass.ca/migrated/pdf/researchReports/commissionedResearch/mapping_future_report_2007_e.pdf

¹⁷ Available from: <http://www.phac-aspc.gc.ca/php-ppsp/ccph-cesp/glos-eng.php#a>