

Standards for Volunteer Hospice Palliative Care from BCHPCA

Benchmarks of performance and credibility

Core Values

Excellence

Collaboration

Accountability

Integrity

Diversity

Standards

#1 Competence

As a hospice palliative care volunteer, you feel safe, supported, and competent in carrying out your responsibilities

- A) Training (7)
- B) Self-Care (4)
- C) Ethics (3)
- D) Acknowledgement, recognition, Experience (3)
- E) Supervision (3)
- F) Confirmation/Evaluation (6)
- G) Governance (2)

#2 Accessibility

As a hospice palliative care volunteer, you are confident that your organization has a reasonable community profile based on a reputable history of quality care

- A) Availability (4)
- B) Public Awareness (2)
- C) Accommodation (3)

3 Client/Family Perspective

As a hospice palliative care volunteer, you are confident in your ability to respect and respond to the concerns and needs of the clients and families you support

- A) Assessment (3)
- B) Boundaries (5)
- C) Client/family participation (7)

4 Continuity of Care

As a hospice palliative care volunteer, you participate as a member of an interdisciplinary team which is focused on meeting the overall care needs of the people you serve

- A) Teamwork (3)
- B) Access to Information (2)
- C) Communication (3)
- D) Joint Evaluation (3)

5 Safeguards

As a hospice palliative care volunteer, you feel confident that the policies, procedures and practices in place provide you and the people you serve with a blanket of security and safety

- A) Screening (5)
- B) Confidentiality (2)
- C) Scope (4)
- D) Safety (4)
- E) Risk Management (2)

A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice (Revised and Condensed Edition: 2013 (CHPCA))

From Applying a Model to Guide Hospice Palliative Care: An Essential Companion Toolkit for Planners, Policy Makers, Caregivers, Educators, Managers, Administrators, and Researchers (CHPCA 2005)

Values

All hospice palliative care activities recognize and support the following values

- V1 The intrinsic value of each person as an autonomous and unique individual
- V2 The value of life, the natural process of death, and the fact that both provide opportunities for growth and self-actualization
- V3 The need to address patients' and families' suffering, expectations, needs, hopes and fears
- V4 Care is only provided when the patient and/or family is prepared to accept it
- V5 Care is guided by quality of life as defined by the individual
- V6 Caregivers enter into a therapeutic relationship with patients, and families based on dignity and integrity
- V7 A unified response to suffering strengthens communities

Guiding Principles

All hospice palliative care activities recognize and support the following principles

GP1 Patient/Family Focused

GP2 High Quality

GP3 Safe and Effective

GP4 Accessible

GP5 Adequately Resourced

GP6 Collaborative

GP7 Knowledge-Based

GP7 Advocacy-Based

GP9 Research-Based

p. 9 Every person in a hospice palliative care program/service is a leader, teacher and a change agent (to be effective, the organization needs to ensure that every person has these skills so they can apply them daily)

The Way Forward National Framework: A Roadmap for an Integrated Palliative Approach to Care (Final March, 2015 CHPCA)

Lexicon of Terms (p. 56)

Advanced Care Planning

A process people can use to think about their values and what is important to them with regard to their health care choices; explore medical information that is relevant to their health; communicate their wishes and values to their loved ones, substitute their decision making and health care team; and record their health care choices and decisions in the event they can no longer speak for themselves. The process may involve decisions with their health care providers and people who are significant in their lives. Advanced Care Planning may result in the creation of an advanced directive or “living will,” which is a person’s formal or informal instructions about their future care and choice of treatment options.

Aging

Aging is a natural process that happens to all living things. In people, the process of aging has an effect on the body and mind, and can affect health and quality of life. For example, as people age, their hearts become slower, their blood vessel and arteries become stiffer, their bones shrink in size and are more likely to break, their muscles lose strength, they may become less coordinated or have trouble balancing, and their memory becomes less efficient. The changes that occur with aging affect quality of life and increase the risk of dying. (See “frailty.”)

Autonomy

The capacity for self-determination, and one of the rights associated with liberty. Respect for autonomy means acknowledging the person’s right to make choices and take actions based on their own values and belief systems and not interfering with the person when he or she exercises that right.

Care

All interventions, treatments and assistance provided to the person and family to treat disease and enhance health and wellbeing.

Care Plan (see ‘Plan of Care’)

Caregiver

Anyone who provides care. Formal caregivers are members of an organization and accountable to defined norms and professional standards of practice. They may be professionals, support groups, or volunteers. They are sometimes called “Providers.” Family caregivers are not members of an organization. They are family members and often significant people (as identified by the care recipient) who provide unpaid care and assistance to individuals living with a debilitating physical, mental, or cognitive condition. Family caregivers usually have no formal training. While they are expected to follow certain ethical norms, they are not accountable to professional standards or practices.

Chronic Disease

A chronic disease is one that may develop slowly, last a long time, be incurable, and be progressive and /or life limiting. Examples of life-limiting chronic diseases include cardiovascular disease, chronic kidney disease, congestive heart failure, diabetes, dementia, emphysema, multiple sclerosis, amotrophic lateral sclerosis and some forms of cancer. The disease and its treatment may cause symptoms such as fatigue, pain and sleep problems; they can also limit people’s activities, cause them psychological distress, and have a negative effect on their quality of life. A chronic disease can’t be cured, but it’s symptoms can be managed.

Expectations

Issues, hopes and fears identified by the person and/or family that require attention in the plan of care.

Family

Those closest to the patient in knowledge, care and affection. The person defines his or her “family” and who will be involved with his/her care and present at the bedside may include: the biological family, the family of acquisition (related by marriage/contract) the family of choice and friends (including pets.)

Frailty

Frailty is a nonspecific state of vulnerability caused by changes to a number of physiological systems (see aging), 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 can have a negative effect on their quality of life.

Goals of Care

Describes people’s goals of their care and should include treatment of the disease and /or symptom management. In some cases, it includes limits on the interventions that people want such as (do not resuscitate orders).

Home Care

Home care includes an array of services for people of all ages, provided in the home and community setting, that encompasses health promotion and teaching, curative intervention, end of life care, rehabilitation, support and maintenance, social adaptation and integration and support for family caregivers.

Hospice Palliative Care

Care that aims to relieve suffering and improve the quality of life.

Illness

Absence of wellness due to disease, other conditions, or aging. An acute illness is one that is recent in onset and likely to be time-limited. If severe, it could be life threatening. A chronic disease is likely to persist for months to years. If it progresses, it may be life threatening. An advanced illness is likely to be progressive and life threatening. A life-limiting illness is one that

affects health and quality of life and can lead to death in the near future. A life-threatening illness is one that is likely to cause death in the immediate future.

Integrated Palliative Approach to Care/Community-Integrated Palliative Care

Care that focuses on meeting a person and families 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 person when treatment is no longer effective and more of an approach to care that can enhance their quality of life throughout the course 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, advanced care planning, psychosocial and spiritual support and pain/symptoms management. As the person’s illness progresses it includes regular opportunities to review a person’s goals and plan of care and referrals if required, to expert palliative care services.

Interdisciplinary, multidisciplinary or interprofessional team

Caregivers with different training and skills who work together to develop a team and implement a person’s plan of care. Memberships vary depending on the services required to address a person’s and families’ identified issues, expectations, needs and opportunities. An interdisciplinary team typically includes one or more physicians, nurses, social workers, psychologists, spiritual advisors, pharmacists, personal support workers, and volunteers. Other disciplines may be part of the team if resources permit.

Outcome

A measurable end result or consequence of a specific action, usually related to a person’s health or overall well-being.

Palliative Approach to Care

Is a see-integrated palliative approach to care.

Pain and symptom management

Pain and other symptoms that cause discomfort (e.g.: shortness of breath, fatigue, changes in mood or functional ability, psychosocial or spiritual distress) can be caused by underlying diseases. They can also be caused by the treatment of these diseases, the side effects of treatment, and the process of aging. An integrative palliative approach to care focuses on helping people manage pain and other symptoms as a way to reduce discomfort and improve quality of life. Many different techniques can be used to manage symptoms including medications, exercise (physiotherapy), breathing, meditation, the use of heat and cold, biofeedback process, diet, repositioning, counselling and psychosocial support.

Person

Someone living with a chronic, progressive illness. Based on the person's preferences and wishes the person directs and guides his or her own care plan as far as possible, and is a contributing member of an interdisciplinary team.

Plan of care

The written plan that describes the person's assessed health needs and goals and the care that will be provided to meet those needs and goals.

Performance indicators

A statistical compilation of standardized measures/metrics used to evaluate specific parameters of a health service, such as access and quality.

Providers

A formal caregiver who is a member of an organization and accountable to norms of conduct and standards of practice. They may be professionals, support workers or volunteers.

Quality Care

The continuous striving by an interdisciplinary team/organization to meet the expectations of the people and families it serves and the standards established by the organization, health authority, profession and accreditation bodies.

Quality of Life

Wellbeing as defined by each individual. Quality of life relates both to experiences that are meaningful and valuable to a person in his/her capacity to have such experiences.

Regional Health programs or authorities

Health planning organizations responsible for setting policies, allotting resources to support care and approving organizational plans to deliver services.

Regional Team

Regional Teams are functional units designed to provide oversight and expert support for formal care-givers and multiple care-teams within a given population/region/ setting of care.

Setting of Care

The location where care is provided. Settings of care may include the person's home, primary care settings (e.g. a doctor's office, a nursing station, community clinic), an acute, chronic or long-term care facility, a hospice or palliative care unit, a jail or prison or in the case of homeless individuals, the street.

Spirituality

An existential construct inclusive of all the ways a person makes meaning of his/her sense of self around a personal set of beliefs, values, and relationships. Spirituality is sometimes understood in terms of transcendence or inspiration. Involvement in a community of faith and practice may or may not be a part of an individual's spirituality.

Substitute decision-maker

A person or agency chosen by an person or appointed by the state to act on his or her behalf. Substitute decision-makers are normally held to substituted judgement or best interest standards.

Suffering

A state of distress associated with events that threaten the intactness of a person. It may be accompanied by a perceived lack of options for coping.

Value

Something that is morally desirable and/or a fundamental belief on which spirituality and/or a practice is based. A value can be intrinsic – perceived as worthy or treasured in and for itself (e.g. liberty) – or a value can be instrumental perceived as worthwhile for pragmatic purposes (e.g., money to obtain goods of services).