



# Lexicon of Terms Related to the Integrated Palliative Approach to Care

Like all health care practices, hospice palliative care has its own language and terminology. This lexicon of terms is designed to help those interested in implementing the integrated palliative approach to care develop a common language and understanding.

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**Advance 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 decision-maker 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 discussions with their health care providers and people who are significant in their lives. Advance care planning may result in the creation of an advance 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 vessels 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 system 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 well-being.

**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 workers, or volunteers. They are sometimes called "providers." Family caregivers are not members of an organization. They are family members and other 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 practice.

**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, amyotrophic 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 its 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 in his/her care and/or 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 have a negative effect on their quality of life.

**Goals of care** - Describes people's goals for 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 illness is likely to persist for months to years. If it progresses, it may become life threatening. (continued)
- An advanced illness is likely to be progressive and life threatening.

## Lexicon of Terms Related to the Integrated Palliative Approach to Care (cont'd)

- 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'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 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.

**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. Membership varies depending on the services required to address the person's and family's 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 the person's health or overall well-being.

**Palliative approach to care** - 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 treatments for those diseases, the side effects of treatments and the process of aging. The integrated 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 medication, exercise (physiotherapy), breathing, meditation, the use of heat and cold, biofeedback processes, diet, repositioning, counselling and psychosocial and spiritual 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 the 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.

**Provider** - 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 and needs of the people and families it serves and the standards established by the organization, health authority, profession and accreditation bodies.

**Quality of life** - Well-being as defined by each individual. Quality of life relates both to experiences that are meaningful and valuable to the person, and his/her capacity to have such experiences.

**Regional health programs or authorities** - Health planning organizations responsibilities for setting policies, allocating 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 caregivers 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, 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 in which a person makes meaning and organizes 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.

**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.

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

**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 or services).