

Appendices

Lexicon of Commonly Used Terms

Activities of daily living	Daily personal care activities, including ambulation, bathing, toileting, feeding, dressing and transfers. May also include cooking, cleaning, laundry, banking, shopping.
Advance directives	A patient's formal or informal instructions concerning expectations of care and choice of treatment options in response to potential illnesses or conditions (legal connotations vary by jurisdiction; includes a living will).
Accountability	The fiduciary and professional responsibility to those receiving care and the community.
Alternate, complementary, integrative therapies	Terms often used to describe independent healing systems outside the realm of conventional medical theory and practice.
Assess	To identify, describe, evaluate and validate information.
Autonomy	The state of being self-governed.
Beneficence	The provision of benefits and the balancing of harms and benefits for the purpose of doing the most good.
Bereavement	The state of having suffered the death of someone significant.
Care	All interventions, treatments and assistance to the patient and family.
Care plan	See "Plan of Care" on page 94

Caregiver Anyone who provides care.

Formal caregivers are members of an organization and accountable to defined norms of conduct and practice. They may be professionals, support workers, or volunteers. They are sometimes called “providers.”

Informal caregivers are not members of an organization. They have no formal training, and are not accountable to standards of conduct or practice. They may be family members or friends.

Confidentiality The protection and control of information privy to persons.

Discrimination / prejudice Any act by another that inhibits a person’s ability to fully participate in society, especially when related to age, gender, national and ethnic origin, geographical location, race, colour, language, creed, religion, sexual orientation, diagnosis, disability, availability of a primary caregiver, ability to pay, criminal conviction, family status.

Essential services The critical services required to implement the plan of care.

Essential step Any activity that is required to meet a stated objective.

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

Family Those closest to the patient in knowledge, care and affection.

May include:

- the biological family
- the family of acquisition (related by marriage/contract)
- the family of choice and friends (including pets).

The patient defines who will be involved in his/her care and/or present at the bedside.

Goal A desired future condition:

- statement of intent
- broader in focus than an objective
- specific enough to indicate direction and thrust
- quantitative or qualitative.

Grief Sorrow experienced in anticipation of, during and after a loss.

Hospice palliative care	Care that aims to relieve suffering and improve the quality of living and dying (see page 17 for more details).
Illness	<p>Absence of wellness due to disease , another condition, or aging.</p> <p>An acute illness is one that is recent in onset and likely to be time-limited. If severe, it could be life threatening.</p> <p>A chronic illness is likely to persist for months to years. With progression it may become life threatening.</p> <p>An advanced illness is likely to be progressive and life threatening.</p> <p>A life-threatening illness is likely to lead to death in the near future.</p>
Indicator	A statistical compilation of multiple similar or related performance measures/metrics. It is used to link related organizational issues, to evaluate interrelated leading or lagging indicators, or to effectively reduce the overall number of metrics or measures to a manageable level.
Interdisciplinary careteam (related to patient / family care)	<p>A team of caregivers who work together to develop and implement a plan of care.</p> <p>Membership varies depending on the services required to address the 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.</p>
Justice	The fair treatment of all individuals, without discrimination or prejudice.
Life closure	The process of putting personal, social (including financial and legal), and spiritual affairs in order, giving of gifts (eg, personal treasures, money, etc), creation of a legacy, reminiscence, and saying goodbye in preparation for death. This usually occurs close to the end of a person's life.
Measure	To find out the extent, size, quantity, capacity, etc.
Mission	A short statement of an organization's purpose; what it is and what it does.
Needs	Issues identified by caregivers that require attention in the plan of care.

Nonmaleficence The avoidance of doing harm.

Norm A statement of usual or average practice. Less rigid than a standard.

Objective A desired accomplishment or hoped for result:

- specific
- narrower in focus than a goal (may flow from a goal and be a means to achieve a goal)
- quantitative and measurable.

Outcome A measurable end result or consequence of a specific action or essential step.

Pain An individual, subjective, unpleasant sensory and emotional experience that is primarily associated with tissue damage or described in terms of tissue damage, or both (Adapted from the International Association for the Study of Pain – see <http://www.iasp-pain.org/dict.html#RTFToC25>).

Patient The person living with an acute, chronic, or advanced illness.

The term **patient**, as opposed to **client**, is used in recognition of the individual's potential vulnerability at any time during the illness. The word **patient** derives from the Latin **patiens**: to suffer, to undergo, to bear.

The patient is a contributing member of the interdisciplinary team.

Plan of care The overall approach to the assessment, management, and outcome measurement to address the expectations and needs prioritized as important by the patient and family.

Policy A course of action selected from alternatives and in light of given conditions to guide and determine present and future decisions.

Preferred practice guideline The recommended approach to guide the provision of care related to a particular issue. Must be flexible to take into account the exceptions/variations needed to meet the wide range of patient/family expectations and needs. May be consensus or evidence based.

Principle A fundamental truth.

- Provider** A formal caregiver who is a member of an organization and accountable to defined norms of conduct and practice. They may be professionals, support workers, or volunteers.
- Procedure** A mode of conducting an activity. Often guided by preferred practice guidelines.
- Program** An organization with a number of component parts. It may be part of a larger host organization, or independent. It may or may not have its own governance structure.
- Proxy** A person or agency of substitute recognized by law to act for, and in the best interest of the patient.
- Quality care** The continuous striving by an interdisciplinary team/program to meet the expectations and needs of the patients and families it serves.
- Quality of life** Well-being as defined by each individual.
It relates both to experiences that are meaningful and valuable to the individual, and his/her capacity to have such experiences.
- Regional team** Regional teams are functional units within hospice palliative care organizations designed to provide formal caregivers and oversight to multiple patient/family careteams within a given population/region/setting of care.
- Risk** A measure of the presence of variables that are likely to contribute to the development of an undesirable illness or condition.
- Setting of care** The location where care is provided.
Settings for hospice palliative care may include the patient's home, an acute, chronic, or long-term care facility, a nursing home/skilled nursing facility, a hospice or palliative care unit or freestanding facility, a jail or prison, the street, etc.
- Service** An organization providing assistance or service to others. Services tend to be part of a larger organization (e.g., a host organization or a program). They have one or more component activities. Most will not have their own governance structure.
- 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
This 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.

Standard	An established measurable condition or state used as a basis for comparison for quality and quantity.
Strategies	The specific methods, processes, or steps used to accomplish goals and objectives. Strategies impact resources (inputs) in some positive or negative way. They are executed in a tactical manner so as to link goals and objectives to day-to-day operations
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.
Tactics	The specific actions that link goals to day-to-day operations.
Therapeutic relationship	a relationship between skilled caregivers and the patient/family that aims to change the patient's and family's experience of illness and bereavement. It combines the art and science of the process of providing care with the knowledge and skills needed to deliver a wide range of therapeutic interventions
Total pain	Suffering related to, and the result of, the person's physical, psychological, social, spiritual and practical state.
Truth-telling	The communication of what is known or believed to be true without deceit or falseness. Patients may voluntarily decline to receive information and designate someone else to receive information on their behalf, as long as there is no evidence of coercion.
Unit of care	Those who are the focus of a plan of care. In hospice palliative care this is typically the patient and his/her family.
Value	A fundamental belief on which practice is based.
Vision	A short statement of an organization's aspirations; what it hopes to become and achieve.
Volunteer	A person who freely gives of his/her time, talent, and energy. Volunteers are members of an organization and accountable to that organization's standards of conduct and practice.

Additional Resources

URLs were last updated March 23, 2002.

Canadian Hospice Palliative Care Association, 131C - 43 Bruyère Street, Ottawa, Ontario, Canada K1N 5C8. Phone (613) 241-3663, Toll-free in Canada (800) 668-2785, Fax (613) 241-3986. See <http://www.cPCA.net>.

Center for Palliative Studies, San Diego Hospice. See <http://www.sdhospice.org/cps.htm>.

International Association for Hospice and Palliative Care. C/o UT MD Anderson Cancer Center, 1515 Holcombe Blvd. Box 08, Houston, Texas, USA 77030. See <http://www.hospicecare.com/>.

A Pathway for Patients and Families Facing Terminal Illness. Standards and Accreditation Committee. Alexandria, VA: National Hospice and Palliative Care Organization, 1997. See item #713800 at http://www.nhpco.org/store/category.cfm?category_id=77.

Approaching Death: Improving Care at the End-of-life. Field MJ, Cassel CK (eds), Institute of Medicine. Washington, DC: National Academy Press, 1997. See http://www.nap.edu/catalog/5801.html?se_side.

CAPCManual: How to Establish a Palliative Care Program. von Gunten CF, Ferris FD, Portenoy RK, Glajchen M. New York, NY: Center to Advance Palliative Care, 2001. See <http://www.capcmanual.info>.

Compendium of Pediatric Palliative Care. Children's International Project on Palliative/Hospice Services (ChIPPS). Alexandria, VA: National Hospice and Palliative Care Organization, 2000. See <http://www.nhpco.org/public/articles/index.cfm?cat=89>.

Improving Care for the End of Life: Sourcebook for Health Care Managers and Clinicians. Lynn J, Schuster JL, Kabcenell A. New York, NY: Oxford University Press, 2000. See <http://www.oup-usa.org/isbn/0195116615.html>.

Improving Palliative Care for Cancer. Foley KM, Gelband H. Washington, DC: National Academy Press, 2001. See http://www.nap.edu/catalog/10149.html?se_side.

Inter-Institutional Collaborating Network On End Of Life Care (IICN). See <http://www.growthhouse.org/iicn.html>.

Issues of Quality in Health Care. Health Canada. See <http://www.hc-sc.gc.ca/hppb/healthcare/qaehs/index.html>.

Just Access to Hospice Care. Jennings B, Ryndes T, D'Onofrio C, Bailey MA. Washington, DC: Georgetown University Press, in press (anticipated early 2003).

Le Citoyen: Une Personne du Début . . . À la fin de sa vie. Lambert P, Lecomte M. Québec, QC: Gouvernement du Québec, 2000. See <http://www.aqsp.org/rapportll.html>.

Oxford Textbook of Palliative Medicine. Doyle D, Hanks GWC, MacDonald N. New York, NY: Oxford University Press, 1998. See <http://www.oup-usa.org/isbn/0192630571.html>.

Textbook of Palliative Nursing. Ferrell BR, Coyle N. New York, NY: Oxford University Press, 2001. See <http://www.oup-usa.org/isbn/0195135741.html>.

Further Information

A **Model to Guide Hospice Palliative Care** is available from The Canadian Hospice Palliative Care Association in both English and French in this printed format, on a CD-ROM, and on the Internet at <http://www.cPCA.net>.

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Information/Additional Copies

For further information, or to obtain additional copies of **A Model to Guide Hospice Palliative Care**, contact the CHPCA national office at:

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**“The standards of practice we create
And the people we train
Will look after us
When it’s our turn to receive care . . .

Are you ready?”**

Frank D. Ferris, 1997

A MODEL TO GUIDE HOSPICE PALLIATIVE CARE

was developed by members of the

The Canadian Hospice Palliative Care Association

In partnership with the 11 provincial hospice palliative care associations:

Association Québécoise de Soins Palliatifs

BC Hospice Palliative Care Association

Hospice and Palliative Care Manitoba

Hospice Association of Ontario

Hospice Palliative Care Association of Prince Edward Island

Newfoundland & Labrador Palliative Care Association

New Brunswick Palliative Care Association

Nova Scotia Hospice/Palliative Care Association

Ontario Palliative Care Association

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