III. The Model to Guide Patient and Family Care

To change their experience of an illness, patients and families seek assistance from healthcare providers who they believe will be knowledgeable and skilled at addressing their issues, expectations, needs, hopes and fears. They are seeking help to:

- identify and assess each of their existing and potential issues, and opportunities for growth

- share information about their illness and bereavement experiences

- establish goals of care

- choose and prioritize therapeutic [i] options that are of potential benefit to them, yet have acceptable risk and burden (to treat existing issues, prevent new ones and promote growth)

- plan their care

- obtain the chosen therapies

- assess the outcomes of the therapeutic interventions.

The Process of Providing Hospice Palliative Care

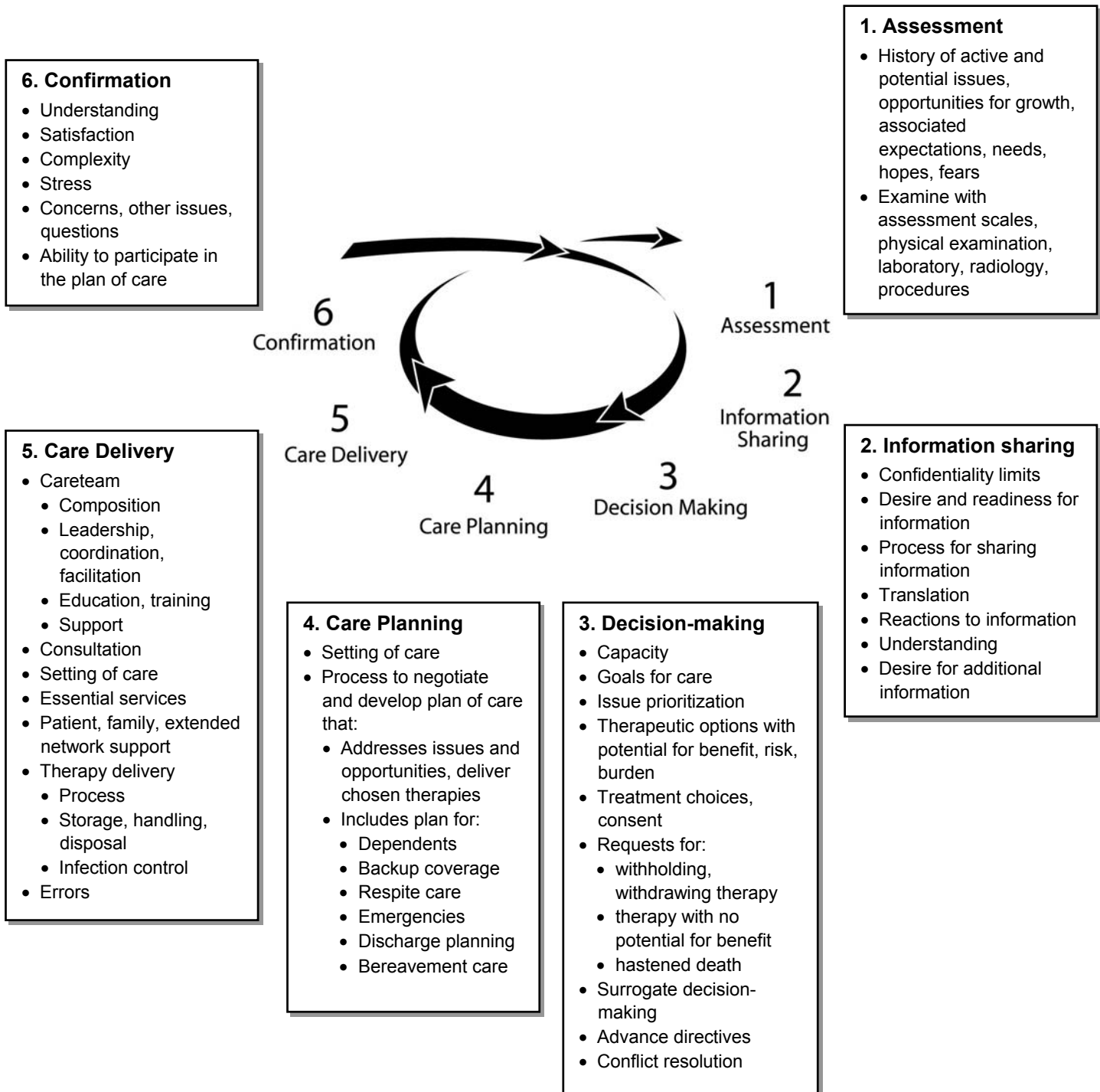Providing care is a process for creating "wanted" change that is based on:

- the development of a therapeutic relationship between those who provide the care (caregivers) and those who receive it (the patient and family as a unit [37]). The relationship evolves with time as familiarity, trust and confidence are established

- a therapeutic process that evolves through a series of therapeutic encounters between the caregivers and the patient and family

- the understanding that only therapies with a potential for benefit and acceptable risk or burden will be offered

- change strategies

- the continued affirmation of the patient's and family's values and choices.

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[i] Therapies include medications, counseling, psychotherapy, integrative therapies (acupuncture, aroma, art, chiropractic, imagery, massage, music, recreation, relaxation, touch), other non-pharmacological therapeutics, dressings, equipment, supplies, etc.

During each therapeutic encounter, the process for providing care involves six essential and several basic steps that guide the interaction between caregivers, and the patient and family. While these steps do not need to occur in any specific order, each one must be completed during each encounter.

Figure #10: Essential and Basic Steps During a Therapeutic Encounter

6. Confirmation
- Understanding
- Satisfaction
- Complexity
- Stress
- Concerns, other issues, questions
- Ability to participate in the plan of care

1. Assessment
- History of active and potential issues, opportunities for growth, associated expectations, needs, hopes, fears
- Examine with assessment scales, physical examination, laboratory, radiology, procedures

6 Confirmation
5 Care Delivery
4 Care Planning
3 Decision Making
2 Information Sharing
1 Assessment

2. Information sharing
- Confidentiality limits
- Desire and readiness for information
- Process for sharing information
- Translation
- Reactions to information
- Understanding
- Desire for additional information

5. Care Delivery
- Careteam
  - Composition
  - Leadership, coordination, facilitation
  - Education, training
  - Support
- Consultation
- Setting of care
- Essential services
- Patient, family, extended network support
- Therapy delivery
  - Process
  - Storage, handling, disposal
  - Infection control
- Errors

4. Care Planning
- Setting of care
- Process to negotiate and develop plan of care that:
  - Addresses issues and opportunities, deliver chosen therapies
  - Includes plan for:
    - Dependents
    - Backup coverage
    - Respite care
    - Emergencies
    - Discharge planning
    - Bereavement care

3. Decision-making
- Capacity
- Goals for care
- Issue prioritization
- Therapeutic options with potential for benefit, risk, burden
- Treatment choices, consent
- Requests for:
  - withholding, withdrawing therapy
  - therapy with no potential for benefit
  - hastened death
- Surrogate decision-making
- Advance directives
- Conflict resolution

A Model to Guide Hospice Palliative Care

The Square of Care: A Conceptual Framework

The application of the process of providing care (see figure #10 on the previous page) to each of the domains/issues commonly faced by patients and families (see figure #7 on page 15) can be illustrated in the conceptual framework, the **"Square of Care"** that follows. This tool can serve to guide issue identification and the provision of care during each therapeutic encounter.

Figure #11: The Square of Care

Common Issues	Process of Providing Care					
	Assessment	**Information Sharing**	**Decision-making**	**Care Planning**	**Care Delivery**	**Confirmation**
Disease Management						
Physical						
Psychological						
Social			**Patient and**			
Spiritual			**Family Care**			
Practical						
End of life/ Death Management						
Loss, Grief						

See figure #36 on page C1 at the center of this guide for the detailed "**Square of Care.**"

Elaboration of the Square of Care

Each essential step can be expanded to include all of the details needed to guide the process of providing care, including:

- principles of practice for each essential step (see pages 28-37)

- norms of practice for each basic step (see pages 28-37)

- preferred practice guidelines for each issue (see page 38)

- data collection and documentation guidelines for each issue (see page 38).

All of these details can be placed in the appropriate square in the grid created by the "Square of Care."

Principles and Norms of Practice

For each of the essential and basic steps in the process of providing care, the CHPCA has developed principles and norms of practice.

1. Assessment

Principles

P1.1   Assessment guides clinicians to identify and understand each of the issues, risks and opportunities related to the patient's and family's illness and bereavement experiences, and their associated manifestations and predicaments.

P1.2   Reliable information that is relevant to the patient's and family's situation is gathered from anyone who is able and willing to provide it (e.g., patient, family, friends, formal and informal caregivers – past and present).

P1.3   The absence of commonly occurring issues is as important as their presence.

P1.4   Where possible, history-taking and examination techniques and tools are evidence-based.

P1.5   Assessment is repeated at intervals sufficient to ensure that adequate information is available to guide changes to decision-making and care planning.

Norms of Practice

N1.1   Screening questions are used to assess all domains of care and identify all active (unresolved or new) or potential issues and opportunities of importance to the patient, family and caregivers.

N1.2   History taking gathers detailed information about:

- Each identified issue or opportunity (including the disease). This includes:

    - status

    - potential cause

    - associated expectations, needs, hopes and fears

    - perceived benefits and burdens of any previous therapeutic interventions

    - difficulties adhering to therapeutic regimens

- Adverse events

- Allergies.

N1.3   Further information about the status of each identified issue is gathered using a variety of examination techniques, including assessment scales, physical examination, laboratory testing, radiological studies and investigational procedures.

N1.4   Only examination techniques with the potential to provide beneficial information without undue risk or burden are used.

2. Information-sharing

Principles

P2.1   It is a patient's and family's right to be informed about hospice palliative care and what it can offer throughout their illness and bereavement experiences.

P2.2   It is the patient's right to choose to be informed about his/her disease, its meaning and implications, available therapeutic options, and their potential benefits, risks and burdens.

P2.3   Respecting the patient's right to confidentiality:

- families are entitled to information about the patient's disease or condition, available therapeutic options, and their potential benefits, risks and burdens

- caregivers are entitled to the information they need to provide care effectively.

P2.4   All communication respects the limits of confidentiality set by the patient.

Norms of Practice

N2.1   Limits of confidentiality are defined by the patient before information is shared.

N2.2   What the patient and family already know, what they would like to know, and whether they are ready to listen is established before sharing information.

N2.3   Information that is as accurate as possible is shared:

- in a timely manner, as it becomes available

- only in settings where privacy can be ensured

- in a language and manner understandable and acceptable to the patient and family.

N2.4   When language is a barrier, translators who understand the medical concepts and terminology facilitate information sharing.

N2.5   Emotional and physical reactions to information are assessed regularly and responded to effectively.

N2.6   The patient's and family's understanding of the shared information, and its implications, is assessed regularly.

N2.7   The patient's and family's desire for additional information is assessed regularly.

3. Decision-making

Principles

P3.1   It is the patient's right to:

- make informed decisions and determine goals for care

- establish priorities for present and future care from the available appropriate therapeutic options

- change her/his mind at any time.

P3.2   The patient:

- must provide voluntary consent to any therapy before it is initiated

- may request to have any therapy withdrawn at any time

- may designate an alternate (proxy) decision-maker, and specify when that person will act on his/her behalf (according to the laws in effect in the jurisdiction).

P3.3   All decision-making processes respect the limits of confidentiality defined by the patient.

P3.4   Family members are included in decision-making processes whenever possible.

Norms of Practice

N3.1   The patient's decision-making capacity is assessed regularly.

N3.2   The patient's and family's goals for care are assessed regularly.

N3.3   Requests to withhold or withdraw therapies, requests to initiate therapeutic interventions that appear to have no potential to benefit the patient and family, and requests to hasten death (i.e., euthanasia or assisted suicide), and the factors underlying those requests, are discussed openly.

N3.4   The patient and family prioritize the importance of each of the identified issues.

N3.5   The patient is offered therapeutic options to modify the disease, relieve suffering and improve the quality of life that:

- are appropriate for the disease status and prognosis, goals for care, prioritized issues and the presumed etiologies of those issues

- have the potential for benefit

- are not associated with unacceptable risk or burden.

N3.6   The patient and family are assisted to select treatment priorities from the options offered, and consent to treatment is obtained.

N3.7   All patients are asked to designate a proxy decision-maker and specify under what circumstances that person should act.

N3.8   All patients are asked to provide advance directives to guide the proxy decision-maker should the patient become incapable of making decisions.

N3.9   When a patient lacks capacity to make decisions, approaches to decision-making are guided by surrogate decision-making legislation and regulations in effect within the jurisdiction.

N3.10   A process is used to resolve conflict that is acceptable to the patient, family and caregivers.

N3.11   Therapies, therapeutic options and patient and family choices are reviewed regularly.

4. Care Planning

Principles

P4.1   Caregivers respect the patient's choices to have, withhold or withdraw therapeutic interventions.

P4.2   Care planning takes into account the patient's and family's culture, personalities, emotional status, coping strategies, developmental state and pre-existing psychiatric diagnoses.

P4.3   Each plan of care is customized, flexible and aims to:

- support the importance, meaning and roles of each person who is involved with the patient and family

- support the patient's and family's desire for control, independence, intimacy, and their sense of dignity for as long as possible

- ensure continuity of the plan of care, information and caregivers.

Norms of Practice

N4.1   Patients and families are assisted to select an appropriate setting of care.

N4.2   The plan of care is negotiated and developed with the patient, family and careteam coordinators.

N4.3   The plan of care includes strategies to:

- address each of the patient's and family's issues or opportunities, expectations, needs, hopes and fears, and deliver their chosen therapies

- care for dependents (e.g., children, elders, pets)

- provide backup coverage if caregivers are unable to fill their role in the plan of care

- provide caregiver respite

- cope with emergencies

- plan for discharge

- provide bereavement care.

N4.4   The plan and setting of care are reviewed regularly by the careteam and/or the organization's regional team and adjusted to compensate for changes in the patient's and family's status and choices.

5. Care Delivery

Principles

P5.1   Care is provided by a specific interdisciplinary careteam that forms to care for each patient/family unit.

P5.2   Each careteam has the leadership it needs to facilitate careteam formation and function, and coordinate care planning and delivery.

P5.3   Caregivers have the resources they need to provide care.

P5.4   Expert consultation is provided in a timely manner whenever it is needed.

P5.5   All aspects of care are prioritized and delivered in a safe and timely manner, including:

- requests for initial evaluation and ongoing follow up
- the implementation of decisions
- the delivery of chosen therapies, equipment and supplies.

P5.6   Acute issues are attended to within hours.

P5.7   Urgent/emergent situations are responded to rapidly.

P5.8   All care is provided in a manner that

- is respectful of the patient and family and their choices
- is understandable and acceptable to the them
- maintains their sense of dignity
- maintains their privacy
- provides ample opportunity for intimacy.

P5.9   The patient can be as active in the delivery of care as s/he desires.

P5.10   There is continuity:

- of the plan of care and information across all settings of care, and among all caregivers and organizations who are involved in the careteam
- of the caregivers providing care.

P5.11   For aspects of care not provided by the hospice palliative care organization, partnerships are created with other healthcare providers in order to assist patients and families with all the issues they face.

Norms of Practice

N5.1   Each careteam includes (if the patient wishes them to be involved):

- the patient and family

- the patient's primary care and specialist providers

- formal caregivers **ii** with the skills needed to implement the plan of care and deliver the chosen therapies

- informal caregivers who may be family or friends

- community resources acceptable to the patient and family (e.g., spiritual advisors).

N5.2   A designated formal caregiver leads, coordinates and facilitates the careteam's activities and function.

N5.3   An informal caregiver is designated to assist the careteam leader.

N5.4   Family and friends are educated about their potential role and supported in their decision-making to become informal caregivers.

N5.5   Informal caregivers receive the orientation, ongoing education and training they need to be competent and confident to provide care.

N5.6   Informal caregivers are educated about the appropriate use of medications, therapies, equipment and supplies.

N5.7   Informational resources designed for the informal caregivers support the education they receive.

N5.8   Informal caregivers have the physical, psychological and spiritual support and assistance they need to provide effective care and ensure their well-being.

N5.9   Consultants and/or facilitators are engaged as needed to assist the careteam with ethical issues, specialized investigations, therapeutic interventions or activities (e.g., rites and rituals).

N5.10   The setting of care is maintained so that it is safe, comforting, and provides ample opportunity for privacy and intimacy. **iii**

N5.11   Essential services are available 24 hours per day, 7 days per week.

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ii Formal caregivers on the team may include, but are not limited to: chaplains, dieticians, nurses, pharmacists, physicians, psychologists, social workers, speech pathologists, integrative therapists, occupational therapists, physiotherapists, recreational therapists, volunteers

iii Where possible, settings of care are homelike, with access to the outdoors

N5.12   The patient, the family, and their network of extended family, friends and community are:

- educated about the appropriate use of medications, therapies, equipment and supplies so they will understand what is happening and why

- supported so they will be able to maintain their own well-being, adapt to the ongoing changes that are taking place, and support each other.

N5.13   All therapeutic interventions are delivered in a safe and timely manner that:

- is consistent with the organization's standards of practice and policies and procedures

- optimizes their potential for benefit

- minimizes the potential for medication interactions, adverse effects or burden

- is consistent with manufacturer's/supplier's instructions

- is acceptable to the patient and family.

N5.14   No medications are mixed if their compatibility is not known.

N5.15   All medications, equipment and supplies are stored and maintained so that they are stable and safe for use.

N5.16   All potentially hazardous materials, including toxic or controlled medications, biological substances and equipment or supplies (e.g., sharps) are stored, handled and disposed of safely.

N5.17   No medications or supplies are used that are damaged or outdated.

N5.18   No equipment is used that is in need of repair, or is outdated.

N5.19   An infection control program guides all clinical activities.

N5.20   Any errors in therapy delivery are reported to supervisors immediately.

N5.21   Appropriate antidotes are started as quickly as possible.

N5.22   Any error is discussed openly with the patient or surrogate decision-maker and/or relevant family.

N5.23   Errors are documented appropriately.

N5.24   All approaches to delivering care are reviewed regularly and adjusted to compensate for changes in the patient's and family's status and choices.

6. Confirmation

Principles

P6.1   Overall understanding, satisfaction, sense of complexity, level of stress, concerns, questions and desire for additional information are assessed during each therapeutic encounter.

Norms of Practice

N6.1   By the end of each therapeutic encounter, the formal caregiver assesses and reinforces the patient's, family's and informal caregiver's understanding of:

- the situation

- the plan of care

- the appropriate use of medications, therapies, equipment and supplies.

N6.2   By the end of each therapeutic encounter, the formal caregiver assesses the patient's, family's and informal and formal caregivers':

- satisfaction with the process of providing care and their overall situation

- perception of the complexity of the situation

- perception of the level of stress

- concerns, questions and desire for additional information

- ability to provide and participate in the plan of care.

Preferred Practice Guidelines

Preferred practice guidelines that are based on the best available evidence or opinion are used to develop issue-specific policies and procedures. While the CHPCA consensus-building process has not engaged in the development of preferred practice guidelines, a number of resources are available on the Internet.[38]

Data Collection/Documentation Guidelines

Data collection/documentation guidelines that are based on validated measurement tools are used to develop issue-specific standards for data collection and documentation, paper and electronic health records, and population data surveillance strategies. While the CHPCA consensus-building process has not engaged in the development of data collection/ documentation guidelines, some principles guiding data collection are outlined below.

Principles Guiding Data Collection

During each therapeutic encounter, data collection and documentation aim to record:

- the presence or absence of each commonly-occurring issue

- the status at a "point in time" of each active issue

- what was done during the encounter.

The data collected must be clinically useful. The task of collecting data must be practical not burdensome. The data must be collected in a format that is easy to review as part of the quality management activities, and readily identifies errors and risks. Documentation that an issue is absent is as important as documenting that it is present. Absence of any documentation related to an issue suggests that it was not assessed. If the process used during the encounter followed accepted policies and procedures, only the status and outcomes of the process need to be documented. If the process varied from accepted policies and procedures, it should be documented as well.

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[37] Kristjanson LJ. The family as the unit of treatment. In Portenoy R, Bruera E (eds). Topics in Palliative Care. New York, NY: Oxford University Press, 1997; 1: 245-261.

[38] **Preferred Practice Guideline Resources on the Internet:**

A Comprehensive Guide to the Care of Persons with HIV/AIDS. See http://www.hc-sc.gc.ca/hppb/hiv_aids/can_strat/care_treat/guide.html.

A Guide to End-of-Life Care for Seniors. Fisher R, Ross MM, MacLean MJ. See http://www.rgp.toronto.on.ca/iddg/eol.htm.

Canadian Medical Association Clinical Practice Guidelines. See http://www.cma.ca/cma/common/linkNavigate.do?skin=129.

Compendium of Guidelines and Position Statements. Phillips DF, Sabatino C, Long KN. Washington, DC: Last Acts, 2001. See http://164.109.40.20/scripts/la_tsk01.exe?FNC=DisplayAPublication__Ala_newtsk_publication_home_html___563

Edmonton Regional Palliative Care Program. See http://www.palliative.org.

Guidelines for Social Work in Hospice. Alexandria, VA: The National Hospice and Palliative Care Organization, 1994. See item #712653 at http://www.nhpco.org/store/category.cfm?category_id=77.

Internet Resources on Quality in Health Care. Health Canada. See http://www.hc-sc.gc.ca/hppb/healthcare/pubs/quest/AppB.html.

Multicultural Palliative Care Guidelines. Taylor A, Box M. Palliative Care Council of South Australia, Inc., 1999. See http://www.pallcare.asn.au/mc/mccontents.html.

National Guideline Clearinghouse, Agency for Healthcare Research and Quality (US). See http://www.ngc.gov/STATIC/whatsnew.guidel.asp?view=whatsnew.guidel.

National Hospice and Palliative Care Organization, Alexandria, VA, USA. See http://www.nhpco.org.

Pain and Policy Studies Group, University of Wisconsin Comprehensive Cancer Center, see http://www.medsch.wisc.edu/painpolicy/index.htm.

Palliativedrugs.com. See http://www.palliativedrugs.com.

The Cochrane Library. See http://www.update-software.com/cochrane/.

Search Google for Guidelines related to Hospice or Palliative Care: http://www.google.com/search?as_q=Guidelines&num=30&hl=en&btnG=Google+Search&as_epq=&as_oq=Palliative+Hospice&as_eq=&lr=&as_ft=i&as_filetype=&as_qdr=all&as_occt=any&as_dt=i&as_sitesearch=&safe=off.

Notes