Norms of Practice

Hospice Palliative Care

Provincial Palliative Care Network Manitoba

December 2005

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ACKNOWLEDGMENTS

Manitoba Provincial Palliative Care Network (Manitoba PPCN)
Norms of Practice Working Committee
Jan Marie Graham
Shannon Pyziak
Cheryl Smith
Merle Teetaert

Manitoba Provincial Palliative Care Network (Manitoba PPCN)
Assiniboine RHA – Merle Teetaert, Cheryl Cormack
Brandon RHA – Bev More, Leslie Hayward
Burntwood RHA – Linda Sudnevic, Penny Thackeray
Central RHA – Jan Marie Graham
Churchill RHA – Vicky McEwan
Interlake RHA – Shannon Pyziak
Norman RHA – Darby Johanson
North Eastman RHA – Cheryl Smith
Parkland RHA – Pat Tichon
South Eastman RHA – Anne Plett
Winnipeg RHA – Dennis St. Laurent, Lorena McManus
CancerCare Manitoba – Pam Johnston
Hospice Palliative Care Manitoba – Margaret Clarke, Brenda Hearson
Manitoba Health – Margarete Schulz, Leanne Neufeld

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- Canadian Palliative Care Association Nursing Standards Committee
- Canadian Hospice Palliative Care Association
- Canadian Nurses Association Code of Ethics
- CancerCare Manitoba
- College of Registered Nurses of Manitoba
- Hospice & Palliative Care Manitoba
- Edmonton Palliative Care Program
- Pediatric Palliative Care Norms of Practice
- Peterborough Palliative Care Program
- Provincial Palliative Care Network, Manitoba
- Regina Palliative Care Program
- Saskatoon Palliative Care Program
- Victoria Hospice Society
- Winnipeg Palliative Care Sub-Program

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INTRODUCTION

All individuals residing in Manitoba have a right to receive hospice palliative care that is planned, coordinated and delivered by caregivers that have expertise in palliative care. The first palliative care programs were initiated in Canada in the 1970s and the main focus was the care of adults. It is important that one remembers that children also experience life threatening illnesses and that although their needs may be similar, they are also unique. Care must be flexible to accommodate the needs of the client and family as the unit of care, whether the care is provided in their home, hospital, personal care home, or hospice.

Palliative care is available to adults and children with consideration given to spiritual and cultural diversity. We live in a multi-cultural society. Culturally appropriate care is the cornerstone of palliative care practice which respects the clients' world view and experience.

Decision-making regarding hospice palliative care must be structured around primary values that are central to ethical practice. These include safe, competent and ethical care, health and well-being, choice, dignity, confidentiality, justice, accountability, and quality practice environments.

The purpose of this document is to provide a benchmark in the provision of hospice palliative care. The hope is that this information will guide health care professionals in establishing relevant policies, standards and programs that will advance the field of hospice palliative care. In turn, the quality of life for clients with life-threatening illnesses and their families will be enhanced.

"You matter because you are you and you matter to the last moment of your life. We will do all we can to help you, not only to die peacefully but to live until you die."
(Cicely Saunders, St. Christopher's Hospice London, 1976)

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WHAT IS PALLIATIVE CARE

Palliative Care is a broad term that encompasses caring for people with a life-threatening illness and improving the quality of their lives from the time of a diagnosis through treatment, at the end of life, and into the bereavement period.

DEFINITION OF PALLIATIVE CARE

(World Health Organization, May 12, 2002)

Palliative Care: an approach which improves the quality of life of clients and their families facing the problems 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.

Palliative Care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a natural process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of client care
- Offers a support system to help clients live as actively as possible until death
- Offers a support system to help the family cope during the client's illness and in their own bereavement
- Uses a team approach to address the needs of clients and their families, including bereavement counseling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Canadian Hospice Palliative Care Association, (2002) describes Hospice Palliative Care:
Hospice palliative care aims to relieve suffering and improve the quality of living and dying.

Hospice palliative care strives to help patients and families:

- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears.
- prepare for and manage self-determined life closure and the dying process
- cope with loss and grief during the illness and bereavement.

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Hospice palliative care aims to:

- **treat** all active issues
- **prevent** new issues from occurring
- **promote** opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization.

Hospice palliative care is appropriate for any patient and/or family living with, or at risk of developing, a life-threatening illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and/or needs, and are prepared to accept care.

Hospice palliative care may complement and enhance disease-modifying therapy or it may become the total focus of care.

Hospice palliative care is most effectively delivered by an interdisciplinary team of healthcare providers who are both knowledgeable and skilled in all aspects of the caring process related to their discipline of practice. These providers are typically trained by schools or organizations that are governed by educational standards. Once licensed, providers are accountable to standards of professional conduct that are set by licensing bodies and/or professional associations.

ELIGIBILITY CRITERIA

The following eligibility criteria were developed by the Provincial Palliative Care Network and have been approved by the Home Care Managers Network, Manitoba.

Service Level A

Focus is on maximizing quality of life throughout the trajectory of the illness.

Criteria

- Diagnosis of a terminal illness
- There is an issue of symptom control, psychosocial or spiritual distress, or functional impairment related to the terminal illness for which the program is being consulted

Service Level B

Focus is to alleviate suffering and maximize quality of life in the final six months of life.

Criteria

- Diagnosis of a terminal illness
- The focus of care is on quality of life rather than the underlying disease
- Estimated life expectancy of six months or less

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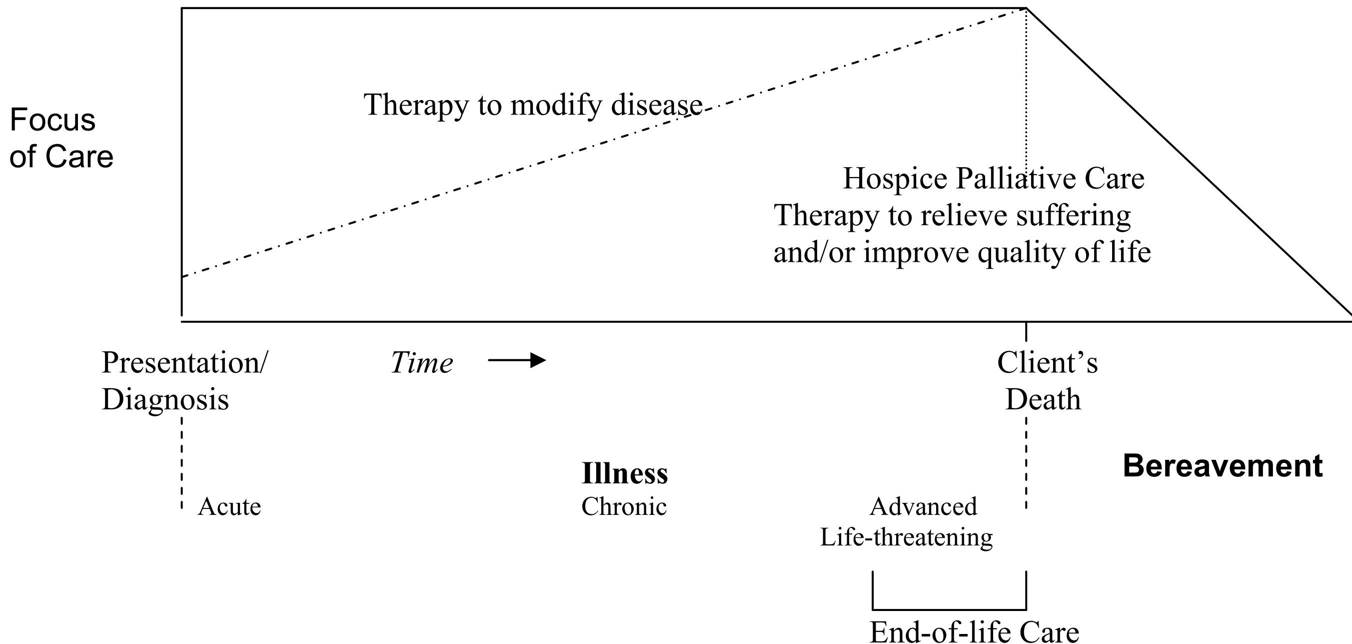
THE ROLE OF HOSPICE PALLIATIVE CARE DURING ILLNESS (CHPCA, 2002)

While hospice palliative care has grown out of and includes care of clients at the end of life, today it should be available to clients and families throughout the illness and bereavement experiences. The following figure illustrates the typical shift in focus of care over time.



The top line represents the total "quantity" of concurrent therapies. The dashed line distinguishes therapies intended to modify disease from therapies intended to relieve suffering and/or improve quality of life (labeled hospice palliative care). The lines are straight for simplicity. In reality, the total "quantity" of therapy and the use of concurrent therapies will fluctuate based on the client's and family's issues, their goals for care and treatment priorities. At times, there may not be any therapy in use at all.

VALUES (CHPCA, 2002)

All hospice palliative care activities recognize and support the following values:

1. The intrinsic value of each person as an autonomous and unique individual.
2. The value of life, the natural process of death, and the fact that both provide opportunities for personal growth and self-actualization.
3. The need to address clients' and families' suffering, expectations, needs, hopes and fears.
4. Care is only provided when the client and/or family is prepared to accept it.
5. Care is guided by quality of life as defined by the individual.
6. Caregivers enter into a therapeutic relationship with clients and families based on dignity and integrity.
7. A unified response to suffering strengthens communities.

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GUIDING PRINCIPLES (CHPCA, 2002)
The following principles guide all aspects of hospice palliative care:

1. **Client/Family Focused.** As clients are typically part of a family, when care is provided the client and family are treated as a unit. All aspects of care are provided in a manner that is sensitive to the client's and family's personal, cultural, and religious values, beliefs and practices, their developmental state and preparedness to deal with the dying process.

2. **High Quality.** All hospice palliative care activities are guided by:
   - The ethical principles of autonomy, beneficence, nonmaleficence, justice, truth-telling and confidentiality
   - Standards of practice that are based on nationally-accepted principles and norms of practice, and standards of professional conduct for each discipline
   - Policies and procedures that are based on the best available evidence or opinion-based preferred practice guidelines
   - Data collection/documentation guidelines that are based on validated measurement tools

3. **Safe and Effective.** All hospice palliative care activities are conducted in a manner that:
   - Is collaborative
   - Ensures confidentiality and privacy
   - Is without coercion, discrimination, harassment or prejudice
   - Ensures safety and security for all participants
   - Ensures continuity and accountability
   - Aims to minimize unnecessary duplication and repetition
   - Complies with laws, regulations and policies in effect within the jurisdiction, host and hospice palliative care organizations.

4. **Accessible.** All clients and families have equal access to hospice palliative care services:
   - wherever they live
   - at home, or within a reasonable distance from their home
   - in a timely manner (timelines will be defined by each organization based on its activities)

5. **Adequately Resourced.** The financial, human, information, physical and community resources are sufficient to sustain the organization's activities, and it's strategic and business plans. Sufficient resources are allocated to each of the organization's activities.

6. **Collaborative.** Each community's needs for hospice palliative care are assessed and addressed through the collaborative efforts of available organizations and services in partnership.

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7. **Knowledge-Based.** Ongoing education of all clients, families, caregivers, staff and stakeholders is integral to the provision and advancement of quality hospice palliative care.

8. **Advocacy-Based.** Regular interaction with legislators, regulators, policy makers, healthcare funders, other hospice palliative care providers, professional societies and associations, and the public is essential to increase awareness about, and develop hospice palliative care activities and the resources that support them. All advocacy is based on the Canadian Hospice Palliative Care Association's model to guide hospice palliative care.

9. **Research-Based.** The development, dissemination, and integration of new knowledge are critical to the advancement of quality hospice palliative care. Where possible, all activities are based on the best available evidence. All research protocols comply with legislation and regulations governing research and the involvement of human subjects in effect within the jurisdiction.

The Manitoba PPCN has adapted the following principals from the **Norms of Practice for Pediatric Hospice Palliative Care**, March 2003:

1. **Right to Information.** It is the client's right to be given information about his/her disease, potential treatments and outcomes, appropriate resources and options. Information will be shared when they are ready, in a timely and culturally sensitive manner. Respecting the client's right to confidentiality (The Personal Health Information Act, PHIA), the family, caregivers, and service providers may also be informed about the disease, potential treatments and outcomes, and appropriate resources and options.

2. **Right to Choice/Empowerment.** Respecting the level of participation desired by the client and family and the appropriate use of available resources, decisions are made in collaboration with caregivers and service providers. The client and family's choice of therapies and settings of care that may enhance quality of life are supported.

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PROCESS OF PROVIDING HOSPICE PALLIATIVE CARE

Domains Associated With Illness and Bereavement

The issues commonly faced by clients and families can be categorized into 8 domains, each of which is of equal importance. The issues in each domain are examples and not an exhaustive list.

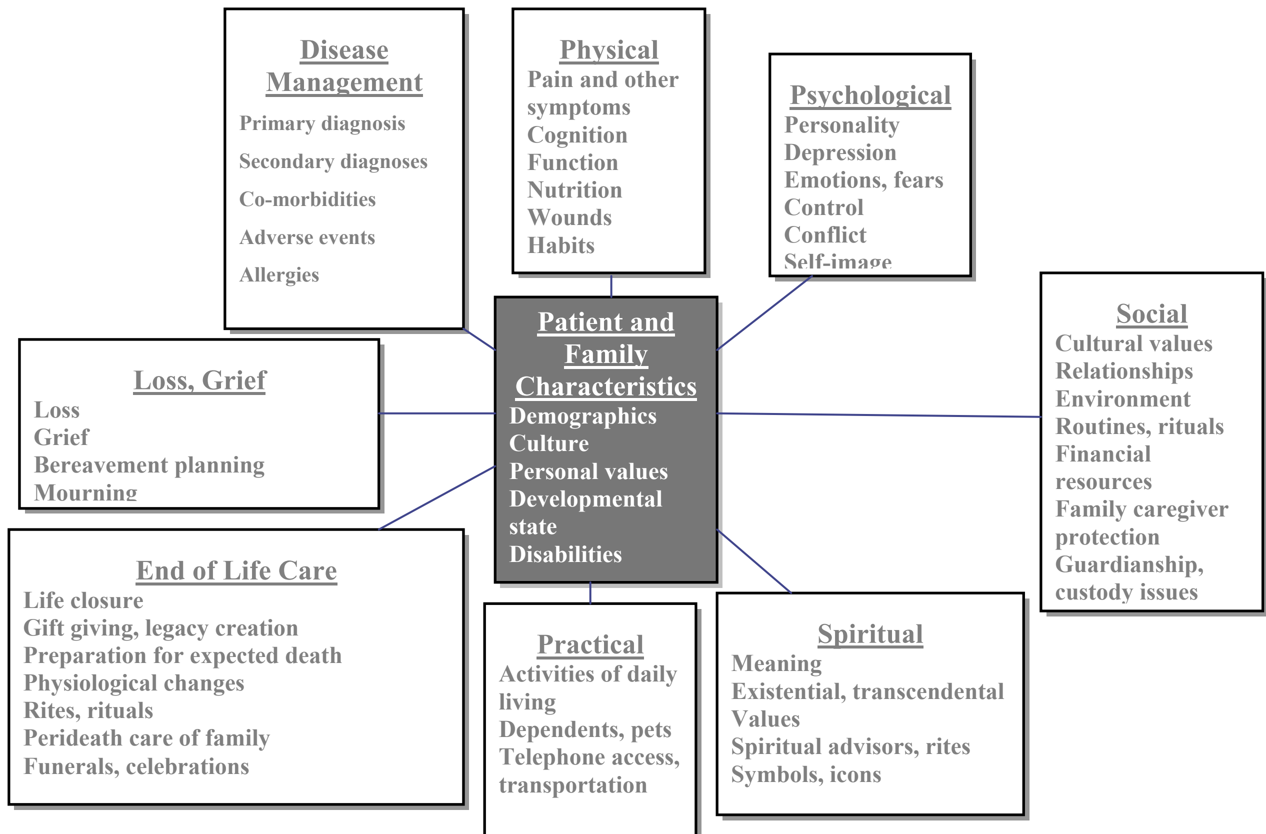

Figure 1

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Square of Care

The Square of Care is a conceptual framework that details the provision of care to each of the domains (Figure 1) commonly faced by clients and families. This tool can serve to guide issue identification and the provision of care during each therapeutic encounter.

Square of Care

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

Figure 2

The steps in the process of providing care include:

- Assessment
- Information Sharing
- Decision-making
- Care Planning
- Care Delivery
- Evaluation of Care/Confirmation

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PRINCIPLES, NORMS, AND INDICATORS

For each of the steps in the process of providing care, the following is a list of the principles, norms, and indicators of practice.

1. Access to Services

Principles

- It is the right of individuals to have access to quality end-of-life care in a timely, efficient, and appropriate manner including :
  - Information
  - Resources
  - Services

Norms

- Individuals must meet established eligibility criteria
- There is a standardized referral process
- All potential clients and families, providers, and referring organizations can access the team's services
- The team identifies and removes barriers that prevent clients, families, informal caregivers, providers, and organizations from accessing services
- The organization provides access 24-hours, seven days a week to a help line, palliative care expertise, or essential services
- The team responds promptly to those who ask for services and information
- The team sets and follows guidelines for response times
- The team has a process for responding to clients who refer themselves to the organization
- The team gives potential clients, families, providers, and organizations simple written information about the :
  - Range of its services and costs, if any
  - Effectiveness and outcomes of its services
  - Alternatives that are available to address the clients' and families' needs throughout the illness and bereavement experience, as applicable
- The team's process for deciding whether to offer services to potential clients and families includes:
  - Obtaining, with consent, the potential client's history
  - Using set criteria for accepting clients
  - Determining if its services fit the potential clients' and families' needs and wishes
  - Identifying and addressing the client's immediate and urgent needs
  - Using set guidelines to decide on priorities for service
  - Taking into account the views of all providers involved with the client and family eg. physician, social worker, nurse
  - Recording the decision

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Indicators	*Dimension*
% of requests for service responded to within 4 working days: • # of requests for service responded to within 4 working days/total # of requests for service	Responsiveness: Timeliness
% of requests for Palliative Care Drug Access Program responded to within 2 working days: • # of requests for PCDAP responded to within 2 working days/total # of requests for PCDAP	Responsiveness: Timelines System Competency: Appropriateness

2. Assessment

Principles

- Assessment guides the clinician to identify and understand the client's experience of his/her illness/condition including the issues, risks and opportunities related to the illness and bereavement experience
- Assessment is comprehensive, timely, and ongoing so that adequate information is available to guide decision-making and the plan of care
- Where possible, history-taking tools and examination techniques are evidence-based
- Assessment is carried out respecting confidentiality
- Documentation supports the information gathered

Norms

- Client and family concerns and issues, needs and expectations are identified and prioritized on initial assessment and an ongoing basis
- Assessment includes gathering information about:
  - family developmental level
  - psychosocial and support systems
  - financial resources
  - physical environment
  - medical history
  - spiritual/cultural values, beliefs, and practice
  - potential risk factors
- Examination techniques, laboratory tests, and diagnostic studies are carried out when they have the potential to benefit the client without undue risk or burden

Indicators	*Dimension*
% of Edmonton Symptom Assessment System (ESAS) completed: • # of ESAS completed on admission to palliative care program/# of clients on palliative care program • # of ESAS completed within 24 hours of admission	Responsiveness: Availability, Responsiveness: Continuity System Competency: Effectiveness

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to a Palliative Care bed/total # of admissions to Palliative Care beds • # of ESAS completed on palliative care clients admitted to acute care/total # of palliative care admissions to acute care	
% of Palliative Performance Scale (PPS) completed: • # number of clients with completed PPS/# of clients on program	Responsiveness: Availability, Continuity System Competency: Effectiveness

3. Information-sharing

Principles

- It is the right of the client and family to be informed about hospice palliative care and what it can offer throughout their illness and bereavement experiences
- It is the right of the client to choose to be informed about his/her disease, its meaning and implications, available therapeutic options, and their potential benefits, risks and burdens
- With the involvement of the client and/or family, caregivers are given adequate and appropriate information to provide care effectively
- All communication respects the limits of confidentiality set by the client

Norms

- Confidentiality is defined by the client, professional codes of ethics, and the Personal Health Information Act (PHIA)
- In accordance with the ethical principle of truth-telling, caregivers establish what the client and family already know, and what they would like to know before sharing information
- Information is shared in a timely fashion, in a language, manner and setting understandable and acceptable to the client and family
- Where possible, translation is provided by a member of the health care team or a recognized translator
- Confirmation of the client's and family's understanding and need for additional information is assessed regularly

Standard

- ***100% of RHA staff and palliative care volunteers have signed the Oath of Confidentiality as per PHIA***

4. Decision-making

Principles

- It is the right of the client to:
    - make informed decisions and determine goals for care

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    - establish priorities for present and future care from the available appropriate therapeutic options
    - change his/her mind at any time
- The client:
    - 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 province such as:
        - the individual's parent(s) or legal guardian(s), if under 16 years of age
        - substitute decision maker appointed under The Vulnerable Persons With a Mental Disability Act
        - Committee of the person for personal care appointed under The Mental Health Act
        - Public Trustee with committee of the person for personal care under The Mental Health Act
        - The Health Care Directives Act
        - the individual's nearest relative with authority under Manitoba legislation or law: spouse, children (18 years of older), parents, or siblings.
- All decision-making processes respects confidentiality as defined by the client
- Family members are included in the decision-making process whenever possible
- Where there is conflict between the client, the family, and/or the health care provider, all options are discussed openly and an attempt is made to reach consensus

Norms

- The client's decision-making capacity is assessed regularly
- The client's and family's goals for care are assessed regularly
- Requests to withhold or withdraw therapies, requests to initiate therapeutic interventions that appear to have no potential to benefit the client and family, and requests to hasten death (i.e. euthanasia or assisted suicide), and the factors underlying those requests, are discussed openly and documented
- The client and family prioritize the importance of identified issues
- The client is offered therapeutic options to modify the disease process, 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
- Consent to treatment is obtained
- Discussion and documentation with all clients regarding designation of a proxy decision-maker and specification under what circumstances that person should act
- Discussion and documentation with all clients regarding advance directives to guide the proxy decision-maker should the client become incapable of making decisions

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- When a client lacks capacity to make decisions, approaches to decision-making are guided by surrogate decision-making legislation and regulations in effect within the jurisdiction
- A process that is acceptable to the client, family, and caregivers is used to attempt resolution of conflict
- Therapies, therapeutic options and client and family choices are reviewed regularly

Indicators	*Dimensions*
% of clients who die in setting of choice: • # of clients who die in place of choice/total # of deaths *NOTE: If do not die in place of choice, please document why.*	Client/community focus System competency: effectiveness
% of clients with an Advanced Care Plan: • # of clients with an Advanced Care Plan/total # clients registered with Palliative Care Program	System Competency: Appropriateness, Effectiveness
% Death at home with Notices of Anticipated Death • # of deaths at home with Notices of Anticipated Death/# of deaths at home	System Competency: Appropriateness, Effectiveness

5. Care Planning

Principles

- Palliative care is provided in the client's and family's setting of choice, dependent upon appropriate and available resources
- Each plan of care is customized, flexible and aims to:
    - meet the changing needs of the client and family in an appropriate safe manner that optimizes potential benefit and minimizes risks and burden
    - support the desire of the client and family for control, independence, intimacy, and their sense of dignity
    - support the importance, meaning and roles of each person who is involved with the client and family
    - ensure consistency of information
    - ensure continuity of care and caregivers

Norms

- The plan of care includes strategies to:
    - address each of the concerns, issues and expectations of the client and family
    - provide backup coverage if caregivers are unable to fulfil their role in the plan of care
    - provide caregiver respite
    - cope with emergencies
    - ease transition between settings of care
    - provide bereavement care

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- The plan of care is developed and reviewed with the client, family, and health care team regularly
- The plan of care recognizes the need for discussion regarding care of the client's dependents (e.g. children, elders, pets)
- Care Plan can be completed by Palliative Care Coordinator, Home Care Case Coordinator, Facility Staff, etc.

Indicators	*Dimensions*
% of clients who have care plans: • # of completed plans of care/# of clients on program	Responsiveness: Continuity
% of families accessing bereavement support: • # families accessing bereavement services/# deaths on program	Client/community focus: Responsiveness: Continuity: System Competency

6. Care Delivery

Principles

- The client and family may be as active in the delivery of care as they desire
- Care is provided by an interdisciplinary team of competent and compassionate caregivers who work in collaboration with the client and family
- Caregivers have the resources they need to provide care
- All aspects of care, including expert consultation, are prioritized and provided in a safe and timely manner. For example:
  - acute aspects of care are attended to within hours
  - urgent/emergent aspects of care are responded to rapidly.
- All care is provided when the client and family needs it and are prepared to accept it, whether the care is provided in their home, hospital, personal care home, or hospice
- All care is provided to maintain the sense of dignity, privacy, and opportunity for intimacy of the client and family
- There is continuity in the plan of care and consistency of information across all settings of care, and amongst all involved caregivers, programs, and services

Norms

- Care is provided, in collaboration with the client and family, by an interdisciplinary team of caregivers with the skills necessary to implement the plan of care
- Consultants and/or specialists are engaged as needed to assist the care team with ethical issues, specialized investigations, therapeutic interventions or other activities
- Essential services are available 24 hours per day, 7 days per week
- The care delivered is based on the changing needs of the client and family
- 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
  - best practice and/or evidence-based practice
  - regulations, guidelines, and policies as outlined by professional regulating bodies

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- Family and friends are educated about their potential role and supported in their decision-making to become informal caregivers
- Caregivers:
    - receive orientation, ongoing education and training as needed to be competent and confident in providing care
    - are educated about the appropriate use of medications, therapies, equipment and supplies
    - are provided with adequate informational and physical resources
    - receive physical, psychological and spiritual support to provide effective care and ensure their wellbeing
- Potential risk factors in the setting of care are identified and attempts are made to minimize these risks
- Care is provided in a language and manner that is understandable and acceptable to the client and family
- Care is provided without discrimination or prejudice
- The program's activities are delivered through collaborative relationships where appropriate
- Care provides opportunity for the client and family to explore their life experience. For example:
    - finding a meaning in their life and/or experience of illness
    - creating a legacy for family members

Indicators	*Dimensions*
# of sessions of formal Palliative Care Education provided	Worklife: Learning Environment System Competency: Competence, System Alignment Client/Community Focus, Communication, Organizational Responsibility & Involvement in the Community
# of participants in Palliative Care Education sessions	

7. Evaluation of Care/Confirmation

Principles

- There is ongoing evaluation throughout each therapeutic encounter.
- There is an evaluation of how programs and services met the changing needs of the client and family.

Norms

- The evaluation in each encounter will include the client's, family's, and caregiver's understanding of:
    - the plan of care
    - the coordination of care
    - the appropriate use of medications, therapies, equipment and supplies

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    - satisfaction with the provision of care
    - perception of the level of stress
    - the ability to provide and participate in the plan of care.
- Programs and services will be evaluated by determining the effectiveness of the plan of care.

Indicators	*Dimensions*
% of families satisfied with the client's care • # of families satisfied with the client's care/total # of respondents	System Competency: Effectiveness
% of clients pain and symptom management achieved: • # of clients at 4/10 on ESAS within 72 hours admission to program/total # of clients on program	System Competency

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ORGANIZATIONAL DEVELOPMENT AND FUNCTION

Square of Organization

The Square of Organization can be used as a tool to guide the development, function and evaluation of the organization's palliative care program and services and each of its principal activities.

The Square of Organization

Principal Activities

Governance & Administration
Planning
Operations
Quality Management
Communications, Marketing
Principal Functions

Financial
Human
Informational
Physical
Community
Resources

Figure 3

The principal functions of the organization include:

- Governance and Administration
- Planning
- Operations
- Quality Management
- Communications, Marketing

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PRINCIPLES, NORMS, AND INDICATORS
For each function of a program, service, and/or organization, the following is a list of the principles, norms, and indicators of practice.

8. Governance and Administration
Principles
- Governance and administration are essential to the development, implementation, maintenance, operations, and accountability of hospice palliative care programs, services, and/or organizations
- Governance includes senior leadership and representatives of the host organization(s), community, formal and informal caregivers, clients and families

Norms
- The board and senior management guide the development and function of the program, service, and/or organization
- The organizational structure supports the activities and defines internal accountability of the program, service, and/or organization

Standard
- ***Each RHA will provide palliative care services.***

9. Planning
Principles
- The strategic planning process defines the mission, vision, values, purpose/activities and developmental directions of the program, service, and/or organization
- The business/operational planning process defines the resources and functions that will be needed to implement the strategic plan

Norms
- A strategic plan guides the development of the infrastructure and principal activities. The strategic plan includes:
    - a needs assessment
    - mission and vision statements
    - values, principles, principal activities and service delivery models
    - developmental goals, objectives, strategies and tactics for development
    - timelines and strategic decision-points during development.
- A business/operational plan guides the development of the resources and functions it will need to support its infrastructure and principal activities. The business/operational plan includes a:
    - governance and administrative structure
    - plan(s) to acquire/manage each of the needed resources

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  - plan to implement each of the principal activities and the infrastructure
  - quality management plan
  - communication/marketing plan.
- The business development plan is congruent with the overall strategic plan

Standard

- ***Strategic plan for palliative care in place regionally.***
- ***Strategic plan for palliative care in place provincially.***

10. Operations

Principles

- Norms of practice, standards of practice, policies and procedures, and data collection/documentation guidelines give direction to all activities
- Individual practitioners are also guided by the standards of professional conduct for their discipline
- Data and documentation record all activities of the program
- Adequate financial resources are essential to support activities and ensure long-term viability
- Formal caregivers, who are appropriately trained and receive continuing hospice palliative care education and evaluation, are essential to develop infrastructure and principal activities
- Ongoing support to ensure the staff's physical, psychological and spiritual well-being is integral to the provision of hospice palliative care
- Readily accessible records and information resources are integral to the provision of hospice palliative care
- Adequate physical resources are integral to the provision of hospice palliative care
- Safety, security and emergency systems are essential to ensure the integrity of the program, service, and/or organization

Norms

- CHPCA norms of practice guide the development of standards of practice
- Best practice guidelines, ideally based on evidence or expert opinion, guide the development of policies and procedures
- Validated measurement tools guide the development of its data collection/documentation guidelines
- Sufficient human, physical, informational, and financial resources support activities and meet strategic and business goals
- Policies and procedures guide:
  - the fundraising, budgeting, and disbursement of funds
  - staff and volunteer recruitment and retention, orientation and education, support, incentive/recognition

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- o the development and maintenance of its formal relationship with community resources
  - o purchasing, stock control, maintenance and disposal of physical resources
  - o purchasing, storage, maintenance and disposal of information resources and resource directories
  - o the collection, storage, reporting and destruction of health, financial, human resource and asset records
- Formal caregivers and volunteers:
  - o have the knowledge and support needed to respect the personal boundaries that are an integral part of effective therapeutic relationships
  - o reflect the cultural diversity of the community they serve
- All components of service delivery are supported by safety, security and emergency systems
- Health records are readily accessible to support care delivery and quality management
- The library and other information resources are readily accessible to support orientation, education, training and other activities
- New knowledge is disseminated in a timely manner to appropriate individuals, and where appropriate, integrated into day-to-day activities

Indicators	*Dimension*
100% of regions collect palliative care data and submit to MB Health	System Competency
# of sessions of formal Palliative Care Education provided	Worklife: Learning Environment System Competency: Competence, System Alignment Client/Community Focus, Communication, Organizational Responsibility & Involvement in the Community
# of participants in Palliative Care Education sessions	
Regional palliative care manual is reviewed/revised biannually	System competency, Worklife: Learning Environment
% of Regional Palliative Care Coordinators (Nursing) with CNA certification • #Regional Palliative Care Coordinators (Nursing) with CNA certification/total # Regional Palliative Care Coordinators (Nursing) in province	System competency, Worklife: Learning Environment
total # of nurses with CNA certification in hospice palliative care in region	System competency, Worklife: Learning Environment

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% of physicians in region with PALLIUM certification • # of physicians in region with PALLIUM certificate/total # of physicians in region	System competency, Worklife: Learning Environment
% of nurses in region with PALLIUM certification • # of nurses in region with PALLIUM certificate/total # of nurses in region	System competency, Worklife: Learning Environment
% of pharmacists in region with PALLIUM certification • # of pharmacists in region with PALLIUM certificate/total # of pharmacists in region	System competency, Worklife: Learning Environment
% of PPCN meetings with educational sessions • # of educational sessions at PPCN meetings/total # of PPCN meetings	System competency, Worklife: Learning Environment
% of HCAs with Support Worker Training Certification • # of HCAs with Support Worker Training Certification/total # of HCAs in region	System competency, Worklife: Learning Environment
% of trained companion volunteers • # of trained companion volunteers/total # companion volunteers in region	System competency, Worklife: Learning Environment

11. Quality Management

Principles

- Ongoing evaluation improves the quality of activities
- A quality management process:
  - regularly reviews all components of service delivery to assess effectiveness and efficiency
  - provides recommendations for a revised action plan
- Compliance with all legislation, regulations and policies governing hospice palliative care is essential

Norms

- An ongoing process to improve performance uses routine measures of outcomes, resource utilization, adverse events/occurrences (e.g., medication and other therapeutic errors, complaints), and stakeholder satisfaction
- The organization:
  - regularly reviews the outcome and resource utilization data for clients and families, care teams, regional teams, the organization, and the population served
  - has a risk management program
  - ensures compliance with legislative and regulatory mandates
  - has an ongoing evaluation to assess and improve caregiver and employee satisfaction with their work lives
  - regularly assesses whether the expectations and needs of clients, families, and communities are being met

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- facilitates annual financial audits
- participates in the ongoing accreditation process using the Canadian Hospice and Palliative Care Association (CHPCA) norms of practice and Canadian Council of Health Services Accreditation (CCHSA) standards as a benchmark to measure performance
- regularly reviews and updates its strategic and business plans

Indicators	*Dimension*
% of families satisfied with the client's care • # of families satisfied with the client's care/total # of respondents	System Competency: Effectiveness
# of complaints (written or verbal) regarding palliative care services received annually	System Competency: Effectiveness Client/Community Focus: Respect & Caring, Acceptability
# of adverse events/occurrences regarding palliative care services received annually	System Competency: Effectiveness Client/Community Focus: Respect & Caring, Acceptability

12. Communications/Marketing

Principles

- Communication and marketing increases awareness of, and facilitates access to, the activities of the program, service, and/or organization

Norms

- Internal and external communication and marketing initiatives disseminate information about clinical services and other activities, raise awareness, promote increased use of services, and support fundraising activities
- Materials are written and presented in a manner appropriate to their intended audiences
- Information about the program, service, and/or organization, its activities, and how to access services, is readily available to clients, families, caregivers, and the public
- The program, service, and/or organization has:
    - a communication strategy
    - a plan for media liaison
    - a plan for communication in the event of an adverse situation/occurrence

Standard

- ***Strategic plan includes a communication strategy***

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GLOSSARY

Accountability
The fiduciary and professional responsibility to those receiving care and the community.

Advance Care Planning
The process of dialogue, knowledge sharing, and informed decision-making that needs to occur at any time when future or potential end-of-life treatment options and preferences are being considered or revisited. The primary goal of Advance Care Planning is to seek consensus on care plans that reflect the best interests of clients/patients/residents.

Adverse Event/Occurrence
An event, accident, or circumstance that resulted in an unintended, undesired outcome.

Bereavement
The state of having suffered the death of someone significant.

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.

Client
The person living with an acute, chronic, or advanced illness. The term “client” includes patients, residents in facilities, and community members.

Committee
A Committee may be appointed by a Court when there is no private individual to act on his or her behalf. The Committee takes control of all property including any debts that are owed. The Committee has a wide variety of powers including the powers to make investment and to enter into leases. (Mental Health Act)

Confidentiality
The protection and control of information privy to persons.

Culture
The shared values, beliefs and practices of a particular group of people, which are transmitted from one generation to the next and are identified as patterns that guide the thinking and action of the group members.

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Edmonton Symptom Assessment System
The assessment tool is designed to assist in the assessment of nine symptoms common in cancer clients: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, wellbeing and shortness of breath. The severity at the time of assessment of each symptom is rated by the client. The ESAS provides a clinical profile of symptom severity over time.

Family
Those closest to the client 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 client 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.

Health Care Directive
A self-initiated document that allows individuals to make health care preferences known in the event that they are unable to express them. In Manitoba, a Health Care Directive may indicate the type and degree of health care interventions the person prefers and/or may indicate the name(s) of a person(s) who has been delegated to make decisions (i.e. "Proxy").

In the absence of evidence to the contrary, a person who is 16 years of age or older is presumed to have the capacity to make a Health Care Directive.

Generally speaking, a Health Care Directive is binding on health care professionals, unless the request for interventions is illegal or inconsistent with accepted standards of practice.

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.

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

Organization
A group of individuals with a common purpose.

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Palliative Performance Scale
A scale designed for measurement of a palliative care client's physical status.

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

Personal Health Information Act (PHIA)
PHIA is a provincial law that protects the privacy of an identifiable individual's personal health information including health or health care history, behaviors from illness or treatment, type of care or treatment provided, Personal Health Information Number, age, home conditions, and other private matters relating to the client and disclosed to staff.

Principle
A fundamental truth.

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 client.

Quality care
The continuous striving by an interdisciplinary team/program to meet the expectations and needs of the clients 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.

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.

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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.

Team
An interdisciplinary group of health care professionals (providers) from diverse fields who work in a coordinated fashion toward a common goal.

Value
A fundamental belief on which practice is based.

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APPENDIX A

Core Data Items as Identified from Health Canada = a multi-site study

Prepared by: Leslie Gaudette June 8, 2001

A. Patient Specific Information

1. Patient Gender
   Male
   Female

2. Birthday
   - CCYYMMDD (or at least CCYYMM)
   - Needed for calculation of age at diagnosis, admission to program, and death

3. Place of Usual Residence
   - would be nice to have postal code
   - not reported/used in multi-site study, but would be very useful for larger studies
   - needs some work to define residence prior to entry into palliative care

4. Diagnosis
   - preferably in ICD9 (note that many centres used their own system)
   - this will give primary site of cancer
   - may want to have flexibility to provide more than one diagnosis code

5. Date of Death
   - CCYYMMDD
   - Needed to calculate age at death and time from admission to death, and time in last care setting prior to death

6. Place of death
   - same as list in #8 below, with the addition of home
   - note; in many instances this can be derived from the setting form which the last discharge to death is made, however it is probably better to report this as a separate variable

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B. Data Items Needed for Each Care Episode

> *A care episode is defined as the time spent in a specific care setting (e.g., acute care, hospice, home, etc.). A palliative care patient will normally have more than one care episodes as part of the total care received in a program.*

The following variables were reported or derived in three different ways in our study:

1) once for each patient to indicate when they entered and were discharged from a palliative care program over a number of care settings;
   (This permits calculation of days stay in a palliative care program, i.e. the overall length of time a patient receives palliative care)

2) *once for each patient stay in a given care setting (e.g. for the Sarrazin Centre in Quebec, or for the tertiary palliative care setting in Grey Nuns in Edmonton).*
   (This permits calculation of days stay in a given setting, however, some patients could be included more than once).

3) each time a patient moves from one care setting to another, as was done for one program that tracked patients across most care settings.
   (This is an ideal approach as it enables both total patient stay and stays in each care setting to be calculated. It also enables a better understanding of care needs over the end-of-life trajectory).

7. Date of Admission to Program/Care Episode
   - CCYYMMDD
   - Needed for calculation of days stay

8. Type of Care Setting Admitted to:
   - this may vary from program to program, but could include settings such as
     - dedicated palliative care unit
     - acute care ward in hospital
     - chronic care ward in hospital
     - long-term care institution
     - hospice
     - home care

9. Setting Admitted from:
   - same list as in #5 above, but would also include > new patient =

10. Date of Discharge/Transfer from this Setting
    - CCYYMMDD

11. Place of Discharge/Transfer from this Setting

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- same list as in #5, but would also include > death =

C. Derived Variables

12. Age at Admission

13. Age at Death

14. Length of Stay Per Care Episode

15. Length of Stay Per Patient

16. Vital Status at Discharge/Transfer

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