



**GUIDELINES  
FOR  
PALLIATIVE CARE SERVICES  
IN THE  
INDIAN HEALTH SYSTEM**

**DECEMBER 2006**

*These guidelines are designed to support the development of palliative care services in IHS, Tribal, and Urban Indian Health programs. They do not represent official Indian Health Service policy.*

In our country today, 2.6 million Americans have identified themselves primarily as American Indians and Alaska Natives (AI/AN) and 4.1 million have identified themselves as AI/AN in combination with another racial or ethnic group. The Indian health system, composed of Indian Health Service, Tribal and urban Indian health programs provides care to approximately 1.6 million beneficiaries belonging to more than 560 federally recognized tribes.<sup>1</sup> In this diverse and dispersed system, care must be delivered throughout all stages of life, and is provided in remote frontier settings and major metropolitan areas in 35 states.

All cause mortality in American Indian and Alaska Native peoples is 1.5 times that of all other U.S. races, with heart disease and cancer implicated as the leading causes of death.<sup>2</sup> Diabetes now affects one out of every four adult American Indians and Alaska Natives age 45 and older, and the risk of diabetes-related mortality is four times that of the general population.<sup>3</sup> Advances in health care in the Indian health system have led to a decrease in infant mortality and fewer deaths from infectious disease, leading to a population that is living longer and experiencing more age-related disease. Although only 12% of AI/AN are age 55 and older, this cohort has grown by 25% over the previous 10 years.<sup>4</sup> Overall life expectancy for AI/AN has increased from 51 years in 1940 to 71 years in 1998.<sup>5</sup>

American Indians and Alaska Natives are now living longer, and for the most part, dying of chronic diseases. They need and deserve quality palliative care to ensure comfort and quality of life as they near the end of life. Yet, formal palliative and end-of-life care services have been largely unavailable to the majority of users in the Indian health system, while services that have been available have been largely ad hoc and improvised. There is no common understanding of what constitutes the basic essentials of palliative care in a comprehensive health system.

The Indian Health Service has embarked on a sustained effort to improve access to quality palliative care in the Indian health system, an effort that is significantly supported by the National Institutes of Health, National Cancer Institute Division of Cancer Control and Population Sciences through the Quality of Cancer Care Committee. The guidelines that follow are intended to provide a framework for the core palliative and end-of-life services that are an essential part of the comprehensive set of health care services delivered through the Indian health system. The guidelines rely heavily on the Clinical Practice Guidelines for Quality Palliative Care developed by the National Consensus Project for Quality Palliative Care (released in May of 2004)<sup>6</sup> but were adapted specifically for programs delivering care within the unique circumstances of the Indian health system. The intent of these guidelines is to ensure that those seeking care in the Indian health system can receive compassionate and competent care consistent with the mission of the Indian Health Service, “to raise the physical, mental, social and spiritual health of American Indians and Alaska Natives to the highest level.”<sup>7</sup>

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<sup>1-3, 5, 7</sup> Indian Health Service-A Culture of Caring. Indian Health Service. Department of Health and Human Services. 2003.

<sup>4</sup> Garrett, M. Census Information on American Indians and Alaska Natives: Implications for Long Term Care. In: American Indian and Alaska Native Roundtable on Long Term Care: Final Report 2002. Indian Health Service. Department of Health and Human Services. 2002.

<sup>6</sup> <http://www.nationalconsensusproject.org>

## **BACKGROUND**

This is a minimum standard, aimed at providing an outline for palliative care as a basic health care service of the Indian health system. Health centers, clinics, hospitals, and Service Units, in consultation with their tribes/communities, retain the flexibility to target these palliative care services to those at highest need in their individual communities.

- 1) These standards are based on the National Consensus Project Guidelines for Quality Palliative Care published in May of 2004, with modification for the Indian health system (IHS/Tribal/Urban Health Programs).
- 2) Definition: The World Health Organization has defined palliative care as “the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families.” The National Consensus Project states that “Palliative care ideally begins at the time of diagnosis of a life-threatening or debilitating condition and continues through cure, or until death, and into the family’s bereavement period. It can be delivered concurrently with life-prolonging care or as the main focus of care.”

Target Population: Persons living with a life-threatening or debilitating illness, or a persistent or recurring condition, that adversely affects their daily functioning or will predictably reduce life expectancy.

The format of these guidelines is such that the formal guidelines are on the left side of the page, while specific actions suggested for implementation of each guideline are on the right side of the page. The intent of this format is to provide program directors with a tool to use in program development, and identify the minimum specific tasks necessary to use these guidelines for program formation.

## STRUCTURE AND PROCESSES OF CARE

<p>1) A palliative plan of care should be in place for all persons facing a life-limiting illness. This plan should:</p> <ul style="list-style-type: none"> <li>a) Be based on a comprehensive assessment and formulated along with professional guidance from an interdisciplinary team.</li> <li>b) Include patient and family/caregiver understanding of disease and expectation of care.</li> <li>c) Address patient and family/caregiver goals, values and needs with regard to palliative care.</li> <li>d) Be specific to the individual patient's diagnoses and health status.</li> </ul> <p>2) Patient and family/caregiver goals should be re-evaluated regularly as goals may change at different stages of illness, and adjustments should be made to the care plan as needed.</p> <p>3) An interdisciplinary care team composed of the core services of medicine, nursing, pharmacy, social service, mental health and counseling (which can include spiritual support and traditional healers) should direct the patient's care. It is the responsibility of this team to ensure that the patient and family/caregivers have the services required by the care plan, either by providing those services or by arranging and supervising those services.</p> <ul style="list-style-type: none"> <li>a) This team should meet on a regular basis to review, evaluate and revise the care plan.</li> <li>b) Members of the palliative care team should have had experience or training in palliative care or should be willing to seek specific palliative care training upon joining the team. Discipline specific education should be provided to members of the team and participation in training should be documented.</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Care plan documentation tool for end of life care is available.</li> <li><input type="checkbox"/> The tool documents: <ul style="list-style-type: none"> <li><input type="checkbox"/> Diagnoses</li> <li><input type="checkbox"/> Health status</li> <li><input type="checkbox"/> Patient and family/caregiver understanding, expectations, goals, values and needs</li> </ul> </li> <li><input type="checkbox"/> Documentation of regular review and updates to care plan.</li> <li><input type="checkbox"/> Interdisciplinary team: <ul style="list-style-type: none"> <li><input type="checkbox"/> Physician</li> <li><input type="checkbox"/> Nurse</li> <li><input type="checkbox"/> Pharmacist</li> <li><input type="checkbox"/> Social Services</li> <li><input type="checkbox"/> Behavioral Health</li> <li><input type="checkbox"/> Spiritual Support</li> </ul> </li> <li><input type="checkbox"/> Documentation of each team member's participation in care plan.</li> <li><input type="checkbox"/> Training plan for each member of interdisciplinary team.</li> </ul>
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<p>c) The team is responsible for coordination of care across settings and providers and should ensure accurate information transfer during transitions of care.</p> <p>4) Patients and families should have access to palliative care expertise 24 hours per day 7 days per week, whether provided by individuals within the Indian health system or available through consultation. The palliative care team should develop a relationship, formal or informal, with regional hospice programs in order to increase access to those services.</p> <p>5) Efforts should be made to develop a system to provide respite services for families and caregivers.</p> <p>6) The palliative care program should be included in the regular quality improvement process and data should be collected to monitor processes and outcomes.</p> <p>7) Emotional support for members of the palliative care team must be available for development of palliative care services.</p> <p>8) Established consultation and referral resources for specific palliative care expertise (including palliative care for children) and especially for pain management services should be in place.</p> <p>9) Palliative care should be included in the Purpose of Visit (POV) of all outpatient visits when palliative care services are provided.</p>	<p><input type="checkbox"/> Mechanism for transfer of relevant medical records.</p> <p><input type="checkbox"/> Mechanism for access to palliative care expertise at all times.</p> <p><input type="checkbox"/> Relationship with regional hospice programs in place.</p> <p><input type="checkbox"/> System for respite care.</p> <p><input type="checkbox"/> Method for data collection and review.</p> <p><input type="checkbox"/> Quality Improvement processes in place.</p> <p><input type="checkbox"/> System for staff support in place.</p> <p><input type="checkbox"/> Consultative resources identified and available to all clinicians.</p> <p><input type="checkbox"/> Code identified for Palliative Care (recommended code is V66.7) and clinical and data entry staff trained.</p> <p><input type="checkbox"/> Appropriate coding for palliative care services included as part of the QI process.</p>
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## PHYSICAL ASPECTS OF CARE

<p>1) The goal for symptom management should be a timely reduction in symptoms to the level that is acceptable to the patient and consistent with the patient’s goals of care.</p>	<p><input type="checkbox"/> Prompt response to patient symptoms included as part of the Quality Improvement process.</p>
<p>2) Pain and non-pain symptoms should be regularly assessed, documented with validated tools appropriate for all ages and levels of cognitive function, and managed in accordance with available national standards and best available evidence. Standardized scales should be utilized when available to assess pain and non-pain symptoms.</p>	<p><input type="checkbox"/> Tool for assessment of pain and non-pain symptoms.  <input type="checkbox"/> Availability of standardized scales.</p>
<p>3) Barriers to effective pain and symptom management should be assessed and documented, and efforts to overcome these barriers should be integrated into the plan of care.</p>	<p><input type="checkbox"/> Care plan includes assessment and documentation of barriers to pain and symptom management and plan for remediation.</p>
<p>4) Access to appropriate pharmacologic therapy for symptom management should be assured.</p> <p>a) Immediate access to basic pain and noxious symptom relief with opioid therapy should be available.</p> <p>b) Mechanisms should be in place for access to additional therapeutic agents within a short period of time (ideally within 72 hours).</p> <p>c) Urgent situations should be anticipated as able based on the patient’s condition, and on-site treatments such as an emergency kit should be available.</p> <p>d) Family and caregivers should receive adequate training to provide urgent and emergent treatment for pain and symptom relief using an emergency kit.</p> <p>e) The oral route is the preferred route of delivery for medications, but mechanisms should be in place for delivery of medications through other than oral routes.</p>	<p><input type="checkbox"/> Immediate availability of opioid medications, antiemetics, and anxiolytic therapy.</p> <p><input type="checkbox"/> Availability of additional medications within 72 hours.</p> <p><input type="checkbox"/> Emergency kit available for use in the home.</p> <p><input type="checkbox"/> Training for family/caregivers on use of emergency kit.</p> <p><input type="checkbox"/> Mechanisms for non-oral medication delivery routes in place.</p>

<p>5) Risk assessment and reduction strategies should be in place for any situations where controlled substances are provided for long-term symptom management. This includes an assessment of the risk of diversion and specific management strategies when a risk is identified. If a patient has both an addiction disorder and a life-limiting disease that causes pain, care should be provided that incorporates both palliative care and principles of addiction medicine. Opioid agreements may be considered in selected patients if felt necessary by the care team.</p> <p>6) The abilities of the families/caregivers to provide the needed physical care for patients should be assessed.</p> <p>a) Patient and family/caregiver understanding of the disease should be assessed and a mechanism for education and training of family/caregivers should be available.</p> <p>b) Mechanisms for respite care should be identified, if available, and mechanisms for emergent respite care should be in place.</p> <p>7) Admission to the hospital or referral center for symptom control or palliation should have the same priority as any other acute care admission.</p> <p>8) A comprehensive interdisciplinary treatment approach should be utilized, including pharmacologic, non-pharmacologic and alternative/supportive therapies as well as traditional therapies.</p> <p>9) A mechanism for timely referral to specialists in symptom management should be available.</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Formal risk assessment tool.</li> <li><input type="checkbox"/> Method for documentation of risk reduction measures in care plan.</li> <li><input type="checkbox"/> Access to expertise in principles of addiction medicine identified.</li> <li><input type="checkbox"/> Availability of opioid agreement.</li> </ul> <ul style="list-style-type: none"> <li><input type="checkbox"/> Assessment of caregiving abilities part of care plan.</li> <li><input type="checkbox"/> Training for families/caregivers available.</li> <li><input type="checkbox"/> Mechanisms for respite care identified. <ul style="list-style-type: none"> <li><input type="checkbox"/> Emergent</li> <li><input type="checkbox"/> Non Emergent</li> </ul> </li> <li><input type="checkbox"/> Policies and procedures reflect acute care priority for palliative care admissions for symptom management.</li> <li><input type="checkbox"/> Care plan reflects interdisciplinary, multimodality treatment approach.</li> </ul> <ul style="list-style-type: none"> <li><input type="checkbox"/> Mechanisms for referral to specialists to assist with symptom management are in place.</li> <li><input type="checkbox"/> Referral resources identified.</li> </ul>
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## PSYCHOLOGICAL AND PSYCHIATRIC ASPECTS OF CARE

<ol style="list-style-type: none"> <li>1) Psychological symptoms including depression, anxiety, delirium and cognitive impairment should be regularly assessed.</li> <li>2) The patient, family and key caregivers should be involved in the assessment process.</li> <li>3) Age and culturally appropriate validated tools and diagnostic criteria should be used in the psychological assessment.</li> <li>4) A mental health professional with the adequate training to address any identified psychological or psychiatric care needs should be a member of the care team. Mechanisms for management and/or referral for patient, family and key caregivers should be in place.</li> <li>5) Age and culturally appropriate information and management skills for dealing with psychological and psychiatric needs should be available to patients and family/caregivers.</li> <li>6) A bereavement risk assessment should be completed for families and caregivers and a culturally appropriate plan for grief and bereavement services should be developed as a core component of the palliative care program. These services should reflect normative, healthy responses to grief within the patient's and caregivers' cultures.</li> </ol>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Assessment tools available:             <ul style="list-style-type: none"> <li><input type="checkbox"/> Depression</li> <li><input type="checkbox"/> Anxiety</li> <li><input type="checkbox"/> Delirium</li> <li><input type="checkbox"/> Cognitive Impairment</li> </ul> </li> <li><input type="checkbox"/> Team members trained in use.</li> <li><input type="checkbox"/> Assessment is part of care plan.</li>   <li><input type="checkbox"/> Mental health professional part of care team.</li> <li><input type="checkbox"/> Referral mechanism identified.</li>   <li><input type="checkbox"/> Capacity to provide information and management skills.</li>   <li><input type="checkbox"/> Bereavement risk assessment</li> <li><input type="checkbox"/> Culturally appropriate. bereavement plan is part of care plan.</li> </ul>
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## SOCIAL ASPECTS OF CARE

<p>1) The palliative care team will regularly assess and review the social needs of the patient, family and caregivers. The members of the care team must possess population-specific and age-appropriate skills, and a social care plan should be formulated with the goal of promoting caregiver/family goals and minimizing the adverse effects of caregiving.</p> <p>2) The social aspects that require review include:</p> <ol style="list-style-type: none"> <li>a) Patient wishes about medical decision-making and the understanding of family/caregivers regarding this issue</li> <li>b) Patient wishes about lines of communication</li> <li>c) Documentation of existing family structure and living arrangements</li> <li>d) Evaluation of any housing and safety issues</li> <li>e) Patient and family/caregivers preferences for the location where care is to be provided</li> <li>f) Available social support</li> <li>g) Financial concerns and needs</li> <li>h) Transportation issues</li> <li>i) Access to medications, therapy and medical equipment</li> <li>j) Screening for domestic violence and substance abuse</li> <li>k) Preferences for post-death handling of the body</li> </ol> <p>3) Regular family/caregiver meetings should be held to review the course of illness, discuss treatment options and therapeutic decisions, and provide emotional support for the patient's caregivers.</p> <p>4) Team members should be able to address any identified needs and help patients and families with problem-solving. Mechanisms for referral to appropriate agencies for additional resources should be in place to meet the needs identified during the family assessment.</p>	<p><input type="checkbox"/> Social services involved in development and regular review of care plan.</p> <p><input type="checkbox"/> Social aspects:</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Decision making</li> <li><input type="checkbox"/> Communication</li> <li><input type="checkbox"/> Family structure</li> <li><input type="checkbox"/> Housing/safety issues</li> <li><input type="checkbox"/> Location of care preferences</li> <li><input type="checkbox"/> Social support</li> <li><input type="checkbox"/> Financial concerns</li> <li><input type="checkbox"/> Transportation</li> <li><input type="checkbox"/> Access to medical needs</li> <li><input type="checkbox"/> Domestic violence screening</li> <li><input type="checkbox"/> Substance abuse screening</li> <li><input type="checkbox"/> Post-death preferences</li> </ul> <p><input type="checkbox"/> Regular family/caregiver meetings are part of care plan.</p> <p><input type="checkbox"/> Identification of local aid agencies and referral mechanism in place.</p>
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## CARE OF THE IMMINENTLY DYING PATIENT

<p>1) The symptoms and signs of impending death will be recognized and communicated in a socially and culturally appropriate manner. Education surrounding the dying process will be provided to patients and family/caregivers at the level of detail desired. Education regarding possible complications and appropriate in-home management of these potential manifestations will be provided.</p> <p>2) Education regarding expectations at the end of life will be available and provided to family/caregivers as needed to facilitate caregiving at home if desired.</p> <p>3) Medications and equipment necessary to allow death in the manner desired by the patient and family/caregivers will be available for care regardless of setting (home or other facility).</p> <p>4) The care plan is revised to meet the need for higher intensity care as the patient enters the active dying phase.</p> <p>5) Concerns and expectations surrounding the end of life will be addressed respectfully. Providers will be open to discussing any related matters and will respond in a socially and culturally appropriate manner.</p> <p>6) If a hospice program is available, referral will be re-addressed with the family/caregivers if they have not already enrolled with hospice before the patient is imminently dying. If hospice care is not available, patients and family/caregivers will have access to admission or assistance with in-home care if warranted by the need for symptom management.</p> <p>7) All efforts will be made to facilitate patient and family/caregiver wishes regarding the location of death whenever possible.</p>	<p><input type="checkbox"/> Training mechanism for family/caregivers surrounding dying process and in-home management.</p> <p><input type="checkbox"/> Appropriate medications (including opioids and anxiolytics) and equipment available during active dying process.</p> <p><input type="checkbox"/> Care plan revised when patient actively dying.</p> <p><input type="checkbox"/> Local hospice availability identified.</p> <p><input type="checkbox"/> Mechanism for admission or assistance with in-home symptom management in place.</p>
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## ETHICAL AND LEGAL ASPECTS OF CARE

<p>1) The care plan is based on the patient’s informed decisions and his/her goals, preferences and choices. This may also include the wishes of the patient’s proxy. The adult patient with decisional capacity determines the level of involvement of family or other caregivers in communication about the care plan.</p> <p>2) A mechanism is in place to address concerns and for review and consultation regarding ethical and legal matters surrounding end-of-life care. Ethical concerns are resolved using ethical principles such as beneficence, respect for persons and self-determination, attention to justice, non-maleficence, and avoidance of conflicts of interest. Cultural variations in the application of professional obligations such as truth-telling, disclosure and decisional authority are recognized.</p> <p>3) If the patient is a minor, the minor’s views and preferences are acknowledged and given the appropriate amount of weight in the decision-making process. Appropriate professionals are available for assistance when the child’s wishes differ from the parent’s wishes.</p> <p>4) When patients are unable to communicate, assistance in the decision-making process is provided to proxy decision-makers, with an emphasis on any available advanced care directives or previously expressed wishes of the patient.</p> <p>5) Advanced care planning will be promoted in a culturally sensitive manner in an effort to adhere to the patient’s or proxy’s preferences for treatment across the health care spectrum.</p>	<p><input type="checkbox"/> Care plan includes documentation of patient’s wishes for communication with caregivers.</p> <p><input type="checkbox"/> Ethics committee or other review mechanism in place.  <input type="checkbox"/> Training available for staff engaged in palliative care in basic ethical principles and in values specific to the culture of the population served.</p> <p><input type="checkbox"/> Local expertise in pediatric palliative care including age-specific ethical issues identified.</p> <p><input type="checkbox"/> Documentation of advanced care planning and wishes for proxy decision-making in place.</p> <p><input type="checkbox"/> Training provided to team members surrounding culturally sensitive advanced care planning</p>
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The preceding guidelines were modified through use of an internet workgroup, with the guidance of several multidisciplinary members within and familiar with the Indian health system. An initial draft was circulated to all members of the workgroup, and each individual's comments were taken into account as the final revision was completed.

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Additional Palliative Care professionals were consulted in the development of these guidelines and heartfelt thanks are extended to the following for sharing their expertise with the Indian health system:

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Mayo Clinic

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University of Pittsburgh School of  
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National Cancer Institute

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