APPENDIX 14

MHS Benefits and Services for Children with Life-Threatening Conditions vs The National Quality Forum Domains of Care and Preferred Practices for Quality Palliative and Hospice Care[1]

🟩 Service or Process is widely available.

🟨 Service or process is partially implemented.

🟥 Service or process is not available/not implemented.

Domain and Definition	Preferred Practice	MHS
<u>1. 1 Structures of Care.</u> *To provide patients and their families care that addresses their multi-faceted needs, palliative and hospice programs should establish the organizational components that ensure that the provision of this complex care can be achieved. These structural elements provide the foundation that enables the program to achieve their aims.*		
	1. Provide palliative care by an interdisciplinary team of skilled palliative care professionals, including, for example, physicians, nurses, social workers, chaplains and others who collaborate with primary healthcare professional(s).	🟨 This team could be developed at any location that elected to do so. Components of these teams are available at a tertiary care centers, usually centered in the pediatric hematology/oncology service.
	2. Provide access to palliative and hospice care that is responsive to the patient and family 24 hours a day, seven days a week.	🟨 Available for selected pediatric oncology patients.
	3. Provide continuing education to both primary care practitioners as well as specialized palliative care professionals, on the domains of palliative care and hospice care.	🟨 Sites with pediatric residency programs and hematology/oncology fellowships are providing this training, although to a limited degree.
	4. Provide adequate training and clinical support to assure that professional staff is confident in its ability to provide palliative care for patients.	🟨 Varies widely with interest, training, and available time of staff.
	5. Hospice and specialized palliative care professionals should be appropriately trained, credentialed, and/or certified in their area of expertise.	🟥 Most healthcare providers for children with LTC do not have specialized training in palliative care.

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[1] www.nationalconsensusproject.org/guideline.pdf. Last accessed January 5, 2006.

1.2 General Processes of Care. *Providing high-quality palliative and hospice family-centered care requires the institution of formal processes that often transcend the requirements of routine medical practice. Implementing such processes permits proactive management of the symptom and end-of-life needs of patients cared for by these programs.*		
	6. Formulate, utilize and regularly review a care plan based on a comprehensive interdisciplinary assessment of the values, preferences, goals and needs of the patient and family.	Varies widely with interest, training, and available time of staff.
	7. Healthcare professionals should present hospice as an option to all patients and families when death within a year would not be surprising, and reintroduce option as patient declines.	Varies widely with interest, training, and available time of staff.
	8. Enable patients to make informed decisions about their care by educating them on the process of their disease, prognosis, and the benefits and burdens of potential interventions.	Routinely provided by pediatric hematology/oncology service.
	9. Provide education and support to families and unlicensed caregivers based on the patient's individualized care plan to assure safe and appropriate care for the patient.	Varies widely with interest, training, and available time of staff.
2. Physical Aspects of Care. The amelioration of physical symptoms such as pain, fatigue, nausea and vomiting is an essential component of the improvement of quality of life for palliative care and hospice patients.		
	10. Measure and document pain, dyspnea, and other symptoms using available standardized scales.	Pain routinely assessed.
	11. Assess and manage symptoms and side effects in a timely, safe, and effective manner to a level acceptable to the patient and family.	Goal of pediatric hematology/oncology services. Varies with interest, training and available time of staff.
3. Psychological and Psychiatric Aspects of Care. *The presence of physical symptoms or entry into the end-of-life phase of an illness engenders a variety of emotional responses that must be dealt with if quality of life is to be preserved. This care ranges from emotional support appropriate to all patients to specific management of psychological disorder.*		
	12. Measure and document anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms using available standardized scales.	Varies widely with interest, training, and available time of staff.
	13. Manage anxiety, depression, delirium, behavioral disturbances, and other common psychological	Varies widely with interest, training, and available time of staff.

	symptoms in a timely, safe, and effective manner to a level acceptable to the patient and family.	
	14. Assess and manage psychological reactions of patients and families to address emotional and functional impairment and loss (including stress, anticipatory grief and coping), in a regular ongoing fashion.	Varies widely with interest, training, and available time of staff.
	15. Develop and offer a grief and bereavement care plan to provide services to patients and families prior to and for at least 13 months after death of the patient.	Bereavement counseling purchased through TRICARE is specifically excluded as a benefit.
4. Social Aspects of Care. *The impact of disabling symptoms and entry into the terminal phase of an illness has important ramifications on all aspects of family life, ranging from childcare to word conditions to financial coping. The palliative care team and hospice must be able to assess these problems and either provide resources or make the appropriate referrals to alleviate these burdens.*		
	16. Conduct regular patient and family care conferences with physicians and other appropriate members of the interdisciplinary team to provide information, discuss goals of care and advanced care planning, and offer support.	Varies widely with interest, training, and available time of staff.
	17. Develop and implement a comprehensive social care plan which addresses the social, practical and legal needs of the patient and caregivers, including but not limited to: relationships, communication, existing social and cultural networks, decision-making, work and school settings, finances, sexuality/intimacy, caregiver availability/stress, access to medicines and equipment.	Varies widely with interest, training, and available time of staff.
5. Spiritual, Religious, and Existential Aspects of Care. *Under the stressful conditions of the palliative care setting, the patient's and family's concerns about religious and spiritual matters could become of paramount importance. Programs must be able to assess these needs and provide appropriate resources to meet them.*		
	18. Develop and document a plan based on assessment of religious, spiritual and existential concerns using a structured instrument and integrate into the palliative care plan.	Varies widely with interest, training, and available time of staff.
	19. Provide information about the	A hospital chaplain is available at all military

	availability of pastoral/spiritual care services and make pastoral/spiritual care available either through organizational pastoral counseling or through the patient’s own clergy relationships.	hospitals.
	20. Specialized palliative and hospice care teams should include pastoral care professionals appropriately trained and credentialed in palliative care.	A hospital chaplain is available at all military hospitals.
	21. Specialized palliative and hospice pastoral care professionals should build partnerships with community clergy, and provide education and counseling related to end-of-life care.	Varies widely with interest, training, and available time of staff.
6. Cultural Aspects of Care. *Patient and family reactions to symptoms and entry into the last stages of life are conditioned in part by their cultural beliefs and values. Palliative care and hospice programs must be able to recognize these diverse approaches and tailor their interventions to accommodate them.*		
	22. Incorporate cultural assessment as a component of comprehensive palliative and hospice care assessment, including, but not limited to: locus of decision-making, truth telling and decision-making, dietary preferences, language, family communication, perspectives on death, suffering and grieving and funeral/burial rituals.	Varies widely with interest, training, and available time of staff.
	23. Provide professional interpreter services and materials in the patient’s and family’s preferred language.	Available for most non-English speaking families served by the MHS.
7. Care of the Imminently Dying Patient. *When a patient’s death becomes imminent, a host of unique needs – both patient-centered and family-centered – must be addressed. These unique needs require unique programmatic components to help the patient achieve a “good death.”*		
	24. Recognize and document the transition to the active dying phase and communicate to the patient, family, and staff the expectation of imminent death.	Varies widely with interest, training, and available time of staff.
	25. The family is educated regarding signs and symptoms of imminent death in a developmentally, age and culturally-appropriate manner.	Varies widely with interest, training, and available time of staff.
	26. Ascertain and document patient and family wishes about the care setting for site of death, and fulfill	Varies widely with interest, training, and available time of staff.

	patient and family preferences when possible.	
	27. Provide adequate dosage of analgesics and sedatives as appropriate to achieve patient comfort during the active dying phase and address concerns such as fear of analgesics hastening death.	Varies widely with interest, training, and available time of staff.
	28. Treat the body post-death with respect according to the cultural and religious practices of the family.	Routinely provided by nursing services.
	29. Facilitate effective grieving by implementing in a timely manner a bereavement care plan after the patient's death when the family becomes the focus of care.	Bereavement counseling purchased through TRICARE is specifically excluded as a benefit.
8. Ethical and Legal Aspects of Care. To ensure that all patient and family rights are protected and preserved, systematic processes and procedures must be implemented and disseminated.		
	30. Document the designated surrogate/decision-maker in a state-specific legal document for every patient in primary, acute, and long-term care and in palliative and hospice care.	Routinely provided at MTFs for adults, not discussed with child.
	31. Document the patient/surrogate preferences for goals of care, treatment options, and setting of care at first assessment and at frequent intervals as conditions change.	Varies widely with interest, training, and available time of staff.
	32. Convert the patient treatment goals into medical orders and ensure that the information is transferable and applicable across care settings, including long-term care, emergency medical services, and hospital, such as the Physicians Orders for Life-Sustaining Treatments – POLST Paradigm Program.	Varies widely with interest, training, and available time of staff.
	33. Make advance directives and surrogacy designations available across care settings, e.g., by internet-based registries or electronic personal health records.	Potentially available in electronic personal health record.
	34. Develop healthcare and community collaborations to promote advance care planning and completion of advance directives for all individuals, e.g., Respecting Choices, Community Conversations on Compassionate	Varies widely with interest, training, and available time of staff.

	Care.	
	35. Establish or have access to ethics committees or ethics consultation across care settings to address ethical conflicts at the end-of-life.	Available at tertiary care centers.
	36. For minors with decision-making capability, document the child's views and preferences for medical care, including assent for treatment, and give appropriate weight in decision-making. Make appropriate professional staff members available when the child's wishes differ from those of the adult decision-maker.	Varies widely with interest, training, and available time of staff.