

**TEMPLATE**

**Palliative Care Outcomes**

**Goals of Care**

- 1- For the child/adolescent/family to receive and feel support during the illness and end of life process.
- 2 - For the child/adolescent/family to be comfortable during the illness and end of life process.
- 3- For the child/adolescent/family to be knowledgeable regarding the illness and end of life
- 4- To provide a smooth continuum of care for the child/adolescent/family through communication, referrals and advocacy
- 5 - For the child/adolescent to receive timely and appropriate medical care
- 6- To promote active participation of the child/ adolescent and family in decision making throughout the continuum of care
- 7- To promote the spiritual well being of the child/ adolescent and family

Needs	Organizational Monitors	Child/ Family/ Provider Monitors	Location of Data
<b>Systems, Access to Care and Coordinated Care</b>			
<b>Access to Care and Services</b>	Palliative care services are <b>available from the time of diagnosis</b>	Child/ adolescent will be <b>referred to Palliative care services within 48 hrs of diagnosis</b>	Health care record - referral date to palliative care service and date of diagnosis
	Palliative care services are <b>available across the continuum</b> of inpatient, outpatient and community settings.	Palliative care services <b>can be accessed from inpatient, outpatient or the community setting.</b>	Health care records, policies and procedures, satisfaction surveys
	<b>Admission criteria</b> are met to enter the Palliative Program.	The child/adolescent/family <b>is admitted within 24 hours to the Palliative program</b> following initial referral.	Admission criteria, Admission Paperwork, Referral to Team, Health care Record
<b>Systems</b>	<b>Adequate # of providers and facilities</b> in geographical area per population base	Providers/facilities <b>located within 60 miles of child.</b>	Healthcare Provider and Facility List, Complaints, Satisfaction Survey
	<b>Adequate # of multicultural providers</b> per population base	<b>Satisfaction with availability of multicultural providers &gt; 90%.</b>	Background Info on Providers (multicultural), Satisfaction, Complaints

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<b>Systems</b> (cont')	<b>Medication available</b> at pharmacy site where prescriptions are filled	Child/adolescent is able to <b>get medication within 24 hours of physician order.</b>	Pharmacy dispersion logs, Complaints
	<b>Waiting time</b> for appointment less than 2 weeks.	<b>Satisfaction with access to providers and services &gt; 90%.</b>	Appointment logs, Appointments that could not be filled, Satisfaction Survey, Complaints
	The organization has an <b>adequate # of providers 24 hours a day</b> to communicate with the family. Rate of reaching team members > 90%	Child/adolescent/family are able to reach the Palliative Team 24 hours a day for immediate and/or crisis needs. Rates of on-call responses being returned in 15 minutes.	Staffing Census, On Call List, phone calls per shift, complaints, satisfaction survey
<b>Coordinated Care</b>	Child/adolescent has <b>access to coordinated care</b>	Care coordinator is assigned to child/adolescent/family from the time of admission to palliative care.	Program description, program service list, Intake list with coordinator assignment review
	Coordinated care <b>facilitates access to resources and services, education of family and providers and promotes communication</b> between professionals and family.	Child/ adolescent/ family access services and resources as defined by their individual plan.	Satisfaction survey, plan of care, goals, claims data
	Care Coordinator <b>identifies educational opportunities for providers and child/ adolescent/ family</b> to support the goals of care	Child/ adolescent/ family attends educational opportunities as defined by their individual plan.	Satisfaction survey, plan of care, goals, claims data

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<b>Coordinated Care</b> (cont')	Care Coordinator <b>facilitates communication between child/ adolescent/ family and member of the health care team or other community players.</b>	Family and healthcare team collaborate in plan of care and child/adolescent treatment goals.	Satisfaction survey, plan of care, goals, claims data
	Care Coordinator <b>will promote continuity of care for military related issues</b> such as deployment, relocation, orders, leave, housing , etc. as it relates to the child/adolescent's healthcare.	Family will be able access appropriate entities and individuals to support their specific military needs (example, EFMP, Military One Source, parent to parent discussion forums, etc.)	Satisfaction survey, complaints
<b>Relationships</b>			
<b>Advocacy</b>	The Palliative Care Program defines <b>a process for advocating a child/ adolescent or parent issue.</b>	The family is able to effectively self advocate or have access to someone who can advocate on their behalf for their child/adolescent/ family needs'.	Communication Forms, Policies/Procedures, Client file, Satisfaction, Complaints
<b>Communicating with Healthcare Providers</b>	95% of professional staff who provide direct care to children who have life limiting conditions, will <b>complete a recognized Palliative Care curriculum</b> within 24 months of initial assignment	Healthcare providers are trained to communicate with children/ adolescents/ families regarding palliative care.	Training records, licensure, certification records

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<b>Communicating with Healthcare Providers</b> (cont')	<b>An individualized plan is developed</b> to direct the interventions and care of the child/ adolescent.	100% of children/ adolescents participating in a palliative care program will have a an individualized plan developed collaboratively with the child/family and addresses medical and quality of life goals.	Health Care Record, List of patient/family goals
	The <b>Care Team collaborates</b> formally on the care, treatment and goals of the child/adolescent/ family.	The child/ adolescent receives a smooth coordination of referrals, care and treatment for their illness and/or symptoms.	Team Meeting Minutes, Communication Forms, Policies/Procedures, Client file, Satisfaction, Complaints
	<b>Communication is provided in a understandable manner.</b>	There are bi-lingual providers, educational materials and interpreters available to non-English speaking patients/families.	Provider List, Educational Material, Interpreter Service availability
<b>Decision Making</b>	<b>Promote active involvement by child/adolescent/ family in decision making</b> affecting their care, treatment and services provided.	The child/adolescent/family rights and preferences are protected and preserved.	Health Care Record, Meeting minutes, consents for care
	<b>Informed consent is obtained and documented in</b> accordance with organizational policy	The child/ adolescent/family are involved in a complete informed consent process including proposed care, treatment, services, meds, interventions or procedures, benefits, risks, or side effects including potential problems, likelihood of achieving goals, and reasonable alternatives	Health Care record, team records, consent records

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<b>Family Needs</b>			
<b>Social and Emotional Needs</b>	A <b>psychosocial assessment</b> is part of a comprehensive assessment for palliative care needs.	The child/ adolescent/ family has access to counseling and supportive services throughout the continuum of diagnosis to end of life and beyond to address issues of bereavement.	Health Care Record (Physician Orders, Anecdotal Notes), Complaints from Family, Satisfaction Survey
	<b>Social work support is available</b> to child/ adolescent/ family.	Child/ adolescent/ families have access to social work support to address issues related to individual support networks, transportation, childcare and other logistics.	Health care records, policies and procedures, satisfaction surveys
<b>Financial Toll</b>	The family is <b>assessed for financial burdens</b> related to their child's health care needs.	Families desiring assistance with active or potential financial burdens incurred as a result of their child's health care needs will be referred to resources for assistance.	Health Care Record (Assessments, Plan of Care, Client/Family Goals) Policy/Procedures, Usage of Respite/Volunteer services, Satisfaction, Complaints
<b>Search for Meaning/Spiritual Care</b>	A <b>spiritual assessment</b> is performed within 48 hours of child/ adolescent/family admission to palliative care	The child/adolescent//family has access to the chaplain or other spiritually supportive individual identified by the family within 24 hours of referral for service.	Health Care Record (Assessments, Plan of Care, Client/Family Goals) Policy/Procedures, Satisfaction, Complaints
	There is a spiritual resource referral system in place.	The patient/family is referred to community resources that may assist in spiritual needs not met by the chaplain.	Patient Record (Anecdotal Notes, Referrals)

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<b><i>Palliative and End-of-Life Care</i></b>			
<b>Palliative Care</b>	The <b>plan of care</b> is developed within 72 hours of the assessment.	The plan of care will reflect child/ youth/family's goals for care and define a family centered approach to palliative care.	Assessment, Plan of Care, Philosophy statements, organizational values, mission
	The <b>plan of care is re-evaluated</b> every 30 days or sooner when indicated by a change in the child/ adolescent or family.	Newly identified issues and concerns are addressed and updated in the Plan for Care.	Health Care Assessment, Revised Plan of Cares for all disciplines
	<b>Goals are identified</b> for each area of need or concern.	The child/family has input to the goals developed for the Plan of Care.	Health Care Record, List of child/family goals
	Each <b>plan of care is implemented</b> within 24 hours.	The patient and family receive treatment and services as indicated in the plan of care.	Health Care Record
	The Palliative/Hospice Team <b>addresses and manages symptoms</b> within 24 hours of notification.	Pain Scale is below 4.	Health Care Record (Physician Orders, Anecdotal Notes), Complaints from Family, Satisfaction Survey
		Labored breathing is decreased within 15 minutes of intervention.	Health Care Record (Physician Orders, Anecdotal Notes), Complaints from Family, Satisfaction Survey
		Nausea is decreased within 15 minutes of intervention.	Health Care Record (Physician Orders, Anecdotal Notes), Complaints from Family, Satisfaction Survey

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<b>Palliative Care</b> (cont')	A <b>rehabilitation assessment</b> is performed by a physical therapist, occupational therapist or speech pathologist within 1 week after needs are identified through the initial physical assessment.	The patient's plan of care addresses the identified needs noted in the assessment.	Health Care Record (Assessment, Plan of Care)
	A <b>dietary assessment</b> is performed within 1 week by a dietitian 1 week after needs are identified through the initial physical assessment.	Intake is adequate for the physical and development needs of the child/ adolescent. (calories/per day)	Health Care Record (Assessment, Plan of Care)
<b>End of Life Care</b>	The wishes of the child/ adolescent/ family are addressed relating to end of life decisions	Care providers assist the child/adolescent/ family to formulate their "wishes" or advanced medical directives and offers options to review or revise as situations change.	Health care record, Plan of care
		The child/ adolescent/ family understand the mechanism for health care professionals and others to honor advance directives within the limits of the law dependent upon the environment of their care.	Health care record, Advanced directives
	There is a process to communicate with the child/adolescent /family regarding expectations at end of life phase.	Families are educated regarding signs and symptoms of imminent death.	Health Care Record (Anecdotal Notes)

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<b>End of Life Care</b> (cont')	There is a process to address pain and symptoms related to imminent end of life.	Adequate dosages of analgesics or other medications are provided to the child/adolescent throughout the active phases of dying. The pain scale is 2 or less	Health Care Record (Physician Orders, Anecdotal Notes)
	There is an Ethical Committee or Team available to address ethical issues.	The child/ adolescent/ /family is satisfied with assistance provided on ethical issues.	Committee Minutes, Satisfaction, Complaints
<b>Education</b>			
<b>Patient/Family Education</b>	Program information is provided during the patient's 1st assessment visit with the provider.	Child/ adolescent / family receives Admission Packets, Handouts, Educational Materials, Policy/Procedures	Admission checklist completed
	There are program materials and in-services regarding palliative care and the end stage of life for families.	Families are educated regarding palliative care and the signs and symptoms of end of life	Health Care Record (Anecdotal Notes), Educational Material
<b>Healthcare providers' education needs</b>	Palliative care professionals are trained, credentialed and or certified in their area of expertise.	Satisfaction with trained providers knowledge regarding palliative care and treatment > 90%.	Credentials, Resumes, Satisfaction, Complaints
	Healthcare professionals attend in-services related to palliative care biannually.	Satisfaction with trained providers knowledge regarding palliative care and treatment > 90%.	Provider In-service records, Satisfaction, Complaints
<b>Residents and fellow's education needs</b>	There are providers trained in the specific diagnosis of the patient.	Care and treatment delivered is appropriate to patient diagnosis and symptoms.	Patient /practitioner assignments, Patient Record/Care Plans



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<p><b>Resources for education</b></p>	<p>There are educational materials, in-services or a resource information available to families or the healthcare team.</p>	<p>Families obtain the requested information they need to support the care of their child/ adolescent.</p>	<p>Resource library, in-service, handouts, internet websites, resource materials satisfaction</p>