

Policy Title: Pediatric palliative care policy.	Policy code: C-PAL-002
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Approved by: Council of Pediatrics and Neonatology.	
Approved by: MOH Committee on Hospital Clinical Services and Policies.	
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1. Purpose:

- 1.1 The purpose of this policy is to guide all clinical pediatric/Neonatal departments in the Ministry of Health for:
- 1.1.1 Providing high-quality clinical care for children during the end-of-life stage of their illness.
 - 1.1.2 Understanding of the definitions of phases of palliative care.
 - 1.1.3 The designation of pediatric (and neonatal) patients to palliative, and/or end of life care, depending on their diagnosis and clinical condition.
 - 1.1.4 Clarifying the requirements for considering patients for end-of-life care.
 - 1.1.5 Clarifying criteria and procedures for end-of-life consultation (the pathway for consultation and care for end-of-life care).
 - 1.1.6 Management of end-of-life care for the pediatric/Neonatal patient with terminal illness, with establishment of the process of designation and implementation of palliative and/or end-of-life care including (but not limited to) the following:
 - 1.1.6.1 The assignment of palliative care, or end-of-life care, providers/team members involved in end-of-life decision and plan.
 - 1.1.6.2 Outlining the decision-making process and procedures.
 - 1.1.6.3 Implementation of the end-of-life care plan.
 - 1.1.6.4 Special considerations in decision making during end-of-life care.

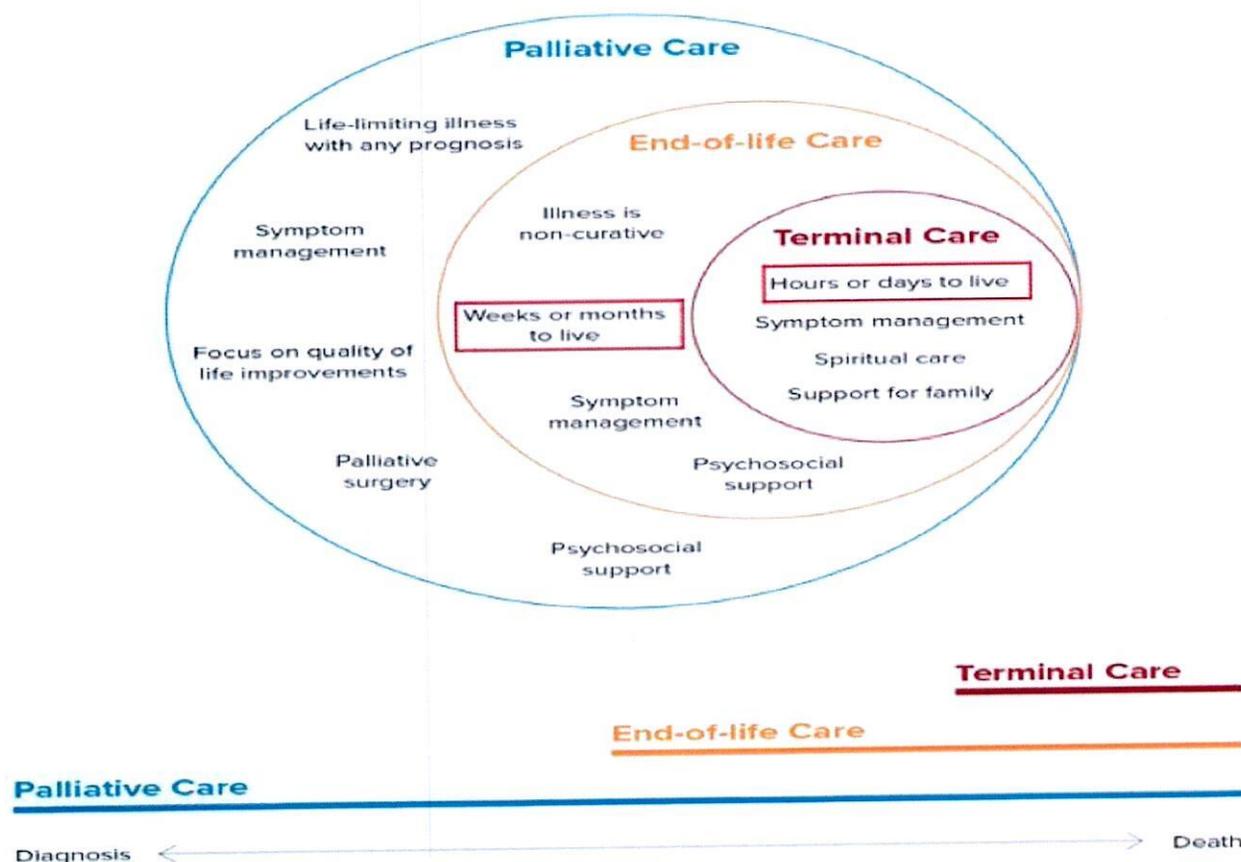
2. Definitions:

- 2.1 **End of Life:** The end of life is when an illness, injury, or condition progresses to the point where the health status of the patient is diminished below a level that would make it possible to live in a way that is meaningful or acceptable to that individual and ends with the patient's death. This period may be a noticeably brief time (as is the case for patients who die instantly from trauma) or extend for several weeks or longer (as is the case for patients with progressive cancer who experience a mounting symptom burden).

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Because the start of this end-of-life period is a combination of both a biological process and value judgments, a change in either the patient's biology (such as physiologic organ failure) or a value judgment about the patient's health status (such as living with severe impairments that require technology support) can mark the beginning of the end of life.

- 2.2 **Terminal Illness:** Is the advanced disease state from which there is no expectation of Recovery.
- 2.3 **Pediatric Palliative Care:** is an active and total approach to care of adolescents, children, and neonates, from the point of diagnosis, throughout their life and death. It embraces physical, emotional, social, and spiritual elements and focuses on the enhancement of quality of life for the patient and support for the whole family. It includes the management of distressing symptoms, care at the end of life and bereavement support.
- 2.4 **Best Supportive Care:** It is the care meant to support the patient's quality of life and alleviate suffering with treatments that are symptom-focused rather than disease-focused.
- 2.5 **End-of-Life Care (ELC):** Is the specialized and total care provided to infants, children, or adolescents during the end-of-life phase of an illness, which may last from hours to several weeks before death. It involves proactive planning, symptom management, assistance in shared decision making and holistic support for the child and their family, addressing physical, emotional, social, and spiritual needs. It primarily aims at maximizing comfort and quality of life during the end-of-life phase..

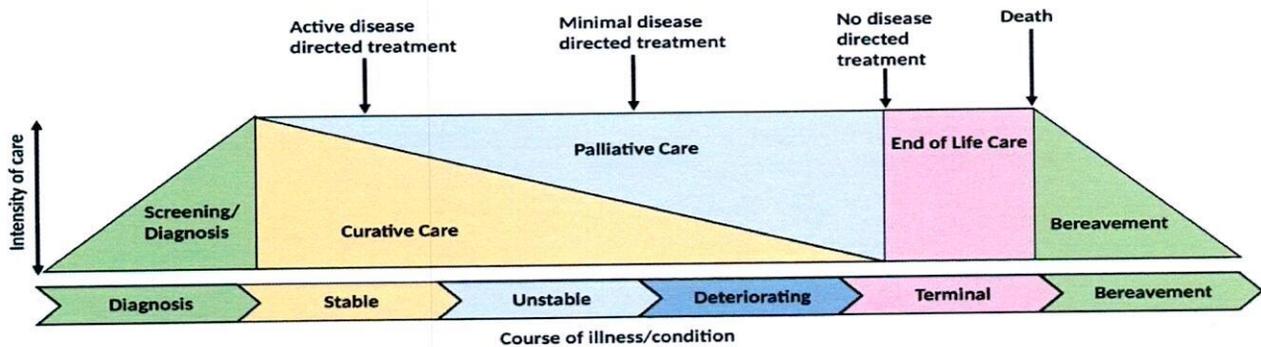


- 2.6 **Index Hospital:** General or specialized Ministry of Health hospital that the patient was admitted to and is residing in at the time he/she is deemed for end-of-life care.
- 2.7 **Attending Physician** - Any physician of the rank of Specialist, Senior Specialist or Consultant.
- 2.8 **Treating Physician** - Any physician who oversees the direct care of the patient in the index hospital.
- 2.9 **End of Life Care (ELC) Providers:**
- 2.9.1 ELC provider is an attending physician(s) who will be involved in deeming, guiding and/or initiating end-of-life care for a patient with a terminal illness.
- 2.9.2 The ELC providers should include the attending treating physician(s), in addition to an attending physician(s) from specialties/subspecialties related to the disease process (e.g., Pediatric Medicine Department, Pediatric Cardiology, Pediatric Gastroenterology , and/or Pediatric ICU, etc.).
- 2.9.3 If a patient is deemed for end-of-life care, it is the responsibility of the attending treating physician to continue management of the patient as per ELC management guide.
- 2.10 **Life-limiting conditions:** Conditions for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration, rendering the child increasingly dependent on parents and carers.
- 2.11 **Life-threatening conditions:** are described as those for which curative treatment may be feasible but can fail, such as cancer.
- 2.12 **Terminal Phase (Imminent Death):** It is the period when there is day-to-day deterioration, particularly of strength, appetite, and awareness. This may unfold gradually over days or weeks or occur precipitously following an unexpected event. These challenges may present as sudden changes in the clinical status needing urgent attention/intervention. More often they are predictable and reflect a final common pathway of many progressive illnesses.
- 2.13 **Terminal care:** This is care for the child in the last hours to days of life. Symptoms may be more apparent and require an interdisciplinary approach to their management. Emotional distress of the child and family should be acknowledged and supported by the care team as much as possible.
- 2.14 **Goals of care:** Goals of care describe what a patient wants to achieve during an episode of care, within the context of their clinical situation. Goals of care are the clinical and personal goals for a patient's episode of care that are determined through a shared decision-making process.
- 2.15 **Shared decision making:** Shared decision-making ensures that individuals, or caregivers, are supported to make decisions that are right for them (or those under their care). It is a collaborative process through which a clinician supports a patient/family to reach a decision about their treatment. The conversation brings together: the clinician's expertise, such as treatment options, evidence, risks, and benefits of what the patient knows best: their preferences, personal circumstances, goals, values, and beliefs.
- 2.16 **Interdisciplinary team:** A team of providers who work together to develop and implement a plan of care. Membership varies depending on the services required to identify and address the expectations and needs of the patient, caregiver, and family. An interdisciplinary palliative care team typically includes one or more doctors, nurses, social workers, spiritual advisers (when available) and pharmacists. Other disciplines

- may be part of the team if resources permit.
- 2.17 **MOH:** Ministry Of Health.
2.18 **ICU:** Intensive Care Unit.
2.19 **PICU:** Pediatric Intensive Care Unit.
2.20 **PPC:** Pediatric Palliative Care.

3. Designation For Palliative Care:

Any child that is unlikely to reach the age of adulthood, due to their disease process/prognosis, should be provided with pediatric palliative care services. End of life care is a phase in palliative care, and it is provided at the terminal phase of the disease when functional decline is evident and progressing over time. The trajectory of this decline will depend on the clinical characteristics of the disease and clinical status and disease progression of the child (as depicted in the following diagram).



3.1 Guiding categories of candidacy for pediatric palliative care maybe as follows in the attached table:

Category 1	<p>Life-threatening conditions for which curative treatment may be feasible but can fail, where access to palliative care services may be necessary when treatment fails, irrespective of the duration of that threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services.</p> <p><i>Examples: cancer, organ failures of heart, liver, kidney, transplant and children on long-term ventilation.</i></p>
Category 2	<p>Conditions where premature death is inevitable, these may involve long periods of intensive disease-directed treatment aimed at prolonging life and allowing participation in normal activities. Children and young people in this category may be significantly disabled but have long periods of relatively good health.</p> <p><i>Examples: cystic fibrosis, Duchenne muscular dystrophy and SMA Type 1.</i></p>
Category 3	<p>Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years.</p> <p><i>Examples: Batten disease, mucopolysaccharidoses and other severe metabolic conditions.</i></p>
Category 4	<p>Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. Palliative care may be required at any stage and there may be unpredictable and periodic episodes of care.</p> <p><i>Examples: severe cerebral palsy, complex disabilities such as following brain or spinal cord injury.</i></p>

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- 3.2 Conditions upon which the initiation of meetings (between the treating team and family/guardians of the child) for designation for end-of-life care, and/or non-escalation of treatment, include (but are not limited to) the following:
- 3.2.1 Presence of a diagnosed life-limiting condition with expected progression despite best available therapy.
 - 3.2.2 Diagnosis of a progressive neurodegenerative disorder.
 - 3.2.3 Undiagnosed illness with evidence of neurodegenerative regression.
 - 3.2.4 A disease process affecting essential life functions (e.g., breathing, with no known or available treatment).
 - 3.2.5 Advanced chronic illness leading to recurrent or prolonged PICU admissions with long-term deterioration.
 - 3.2.6 Persistent, refractory symptoms (e.g., pain, dyspnea) unrelieved by appropriate treatment.
 - 3.2.7 Dependence on life-sustaining technologies with deteriorating clinical conditions.
 - 3.2.8 Clear shift where the burden of treatment outweighs the benefit.
 - 3.2.9 Multi-organ dysfunction with poor or no response to therapy.
 - 3.2.10 Clinical consensus among health team members that further escalation is physiologically futile.
- 3.3 **Process Of Delivery Of Pediatric Palliative Care:**
- 3.3.1 Referral to pediatric palliative care services from general pediatrics or other pediatric subspecialties should be considered for children with shortened lives as early as possible in the disease trajectory (i.e. when it is recognized the child has a disease process rendering him/her for palliative care).
 - 3.3.2 The pediatric palliative care service is a consultative service providing guidance and support to pediatric medical/subspecialty teams looking caring for children with disease processes rendering them for palliative care).
 - 3.3.3 It is the responsibility of all health care providers involved in the care of a child, deemed for palliative/end of life care, to reduce suffering and increase the quality of life through holistic care. This care includes proactive symptom management, interdisciplinary working, and support of the child and family through the disease trajectory. In hospitals where specialist PPC teams are unavailable, care will be provided by the general ,or subspecialty pediatricians/treating physician, based on palliative care principles set in this policy and the attached/reference guides.
- 3.4 **Components of Pediatric Palliative Care:**
- 3.4.1 **Pediatric Palliative Care includes the following components:**
 - 3.4.1.1 Communication regarding goals of care.
 - 3.4.1.2 Advance care planning and support for primary treating Physician/team.
 - 3.4.1.3 Discussions around goals of care and advance planning can occur at any appropriate time after recognition the child has a palliative disorder according to the communication preferences of the family.
 - 3.4.2 Discussion about the goals of care with the family may be conducted in multiple locations of clinical care, including the outpatient clinic, day case and inpatient wards, and may be initiated before the end of life phase of the disease has been reached.
 - 3.4.3 Pediatric palliative care and end of life care may be provided in wards, monitored settings, hospice settings, or home, as seen fit by the treating caring/team and family/legal guardians.

4. Requirements for Deeming Patients for End-Of-Life Care.

- 4.1 The patient is deemed (by a minimum of two attending physicians - one being the treating attending physician and another ELC service provider(s) of the relevant disease processes) to have advanced, progressive, highly symptomatic and life-threatening terminal illness.
- 4.2 The patient and/or family understand the prognosis and accept the nature of palliative and end of life care, having received education and counselling- by the treating attending and/or palliative medicine physician and had time for reflection).
- 4.3 **Documentation** - by a minimum of two attending physicians, one being the treating admitting physician and an ELC service provider(s) of the relevant disease processes of the reason for end-of-life care with notes of (electronic or paper) :
 - 4.3.1 Patient current illness relevant to end of life care.
 - 4.3.2 Patient's comorbidities.
 - 4.3.3 Patient's functional status.
 - 4.3.4 Current clinical status, quality of life and comfort level.
 - 4.3.5 Prognosis, and possible illness trajectory.
 - 4.3.6 The lack of further disease modifying, outcome altering (survival and functional) management options.
 - 4.3.7 Documented agreement and consensus among the ELC providers.
 - 4.3.8 Documentation of agreement of the parent/legal guardian that the patient will be provided with end-of-life care.
 - 4.3.9 Whether patient has entered End-of-life phase or not.
 - 4.3.10 Decisions around preferred place of care and preferred place of death (e.g., Hospital or home).
 - 4.3.11 Symptom management plans and interdisciplinary plans of care made with a focus on preventing and alleviating symptoms and promoting comfort and quality of life.

5. Special considerations for end-of-life care management:

- 5.1 End of life care should not be provided in the emergency room. It is a process that aims to maintain the comfort and dignity of the dying patient and help support the family through the process. The setting best fitting such a process would be in an inpatient setting (general, or monitored - most appropriately in a private room, if possible).
- 5.2 Patients designated for palliative, or end of life care, and presenting to the healthcare facility hemodynamically unstable, or on mechanical ventilation, may not be considered for admission under intensive monitored settings, if deemed so, by the treating admitting team and/or facility pediatric intensivist and may be allocated a set up that is suitable for such process (e.g. a private room, if possible).
- 5.3 **Ventilatory Support in End-of-Life Care.**
 - 5.3.1 **Patient on mechanical ventilation** - It should be noted that, by law, once medical care is initiated, it cannot be withdrawn to result directly in death. However, ineffective medical management may not be escalated. Therefore, **if** the patient was deemed for end-of-life care **after** being intubated and mechanically ventilated, life support **cannot** be withdrawn, and he/she should be examined and generally evaluated for the different facets of management to ensure comfort, and dignity, avoiding continued suffering while on mechanical ventilation.

5.3.2 **Patients not on mechanical ventilation:**

- 5.3.2.1 Please refer to the agreed upon **management guides and standards for ELC** - acknowledged/approved by the pediatric and neonatology council.
- 5.3.2.2 If the physician providing ELC is unable to provide comfort without ventilatory support, then ventilatory support with continuation of the comfort measures stated above can be performed.
- 5.3.2.3 If the child is deemed at end of life and is NOT ventilated, the goals of care of the patient and family should be explored and documented. This includes discussions around no escalation to ineffective respiratory support, including intubation and ventilation that will increase suffering without beneficial effects.
- 5.3.2.4 The mechanical ventilators' settings and adjustments will be followed by the PICU team where PICU services are available, anesthesia/ICU team where PICU services are not available or any physician competent in airway and mechanical ventilation.

5.4 **Hemodynamic Instability**

- 5.4.1 Patients **who are hemodynamically unstable and on vasopressors:** It should be noted that, by law, once medical care is initiated it **cannot** be withdrawn to result directly in death. However, ineffective medical management may not be escalated. Therefore, **If** the patient was deemed for end-of-life care **after** being initiated on vasopressor support, medical support **cannot** be withdrawn, and he/she should be examined and generally evaluated for the different facets of management to ensure comfort and dignity avoiding continued suffering without escalation of management. (Please refer to the local and international standards and guides on ELC for pain, sedation, delirium etc. accordingly).
- 5.4.2 **Patients who are hemodynamically unstable but not on vasopressor support**
- 5.4.2.1 If the patient developed cardiac arrest and achieved ROSC and was deemed for end-of-life care after clinical assessment, history review and family discussion, it should be noted that, by law, once medical care is initiated it **cannot** be withdrawn to result directly in end of a life. However, ineffective medical management may not be escalated, and he/she should be examined and generally evaluated for the different facets of management to ensure comfort and dignity avoiding continued suffering without escalation of management.
- 5.4.2.2 If the patient was hemodynamically **unstable**, but **not** on vasopressor support, and deemed by ELC-provider(s) for ELC, with the patient or legal guardian in agreement for the ELC, the treating physician and/or ELC provider(s) should examine and evaluate for the different facets of management to ensure comfort and dignity avoiding continued suffering without escalation of management.
- 5.4.2.3 If the patient was hemodynamically **unstable**, but **not** on vasopressor support, and deemed by the ELC-provider(s) for ELC, with the patient/legal guardian not accepting the option of ELC, the medical care provided should be within the current medical practice standards of the index hospital/MOH.

5.5 **Patients who are hemodynamically stable but symptomatic** - If deemed for ELC, and **not** for ventilatory or vasopressor support, follow the palliative care and end of life care local and international standards and guides for the inpatient.

6. References:

- 6.1 Together for short lives. A guide to children palliative care.
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- 6.3 Watson, Max, and others (eds), 'The terminal phase', in Max Watson, and others (eds), Oxford Handbook of Palliative Care, 3 edn, Oxford Medical Handbooks (Oxford, 2019; online edn, Oxford Academic, 1 July).
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<https://www.england.nhs.uk/personalisedcare/shared-decision-making/>.
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- 6.7 Kuwait Ministry of Health Operational and Management Policy and Guide for Adults with Terminal Illness C-PAL-001, 6th November 2025.
- 6.8 World Health Organization. Definition of palliative care. 2002. Available from <http://www.who.int/cancer/palliative/definition/en/>. Accessed March 1, 2021.
- 6.9 A Comparison of Symptom Prevalence in Far Advanced Cancer, AIDS, Heart Failure, COPD and Renal Disease, J P Solano, *J Pain Symptom Manage* 2006; 31: 58–69.
- 6.10 Oxford textbook of Palliative Medicine, 4th edition (2010).