

<b>Policy Title:</b> Operational and Management Policy and Guide for Adults with Terminal Illness.	
<b>Policy Owner:</b> MOH committee on hospital clinical services and policies.	<b>Policy Code:</b> C-PAL-001
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<b>Approvals</b>	<b>Signature</b>
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<b>Approved by:</b> MOH Assistant undersecretary of technical affairs.	

## 1. Introduction:

- 1.1 Palliative care is an approach to patient centered health care that focuses on the optimal management of distressing symptoms in the terminally ill adults when disease-directed, life-prolonging therapies are no longer effective, appropriate, or desired.
- 1.2 The goal of palliative care is to anticipate, prevent, and reduce suffering; promote adaptive coping; and support the best possible quality of life for patients / families / caregivers, regardless of the stage of the disease or the need for other therapies.
- 1.3 The psychosocial and spiritual support according to patient / family / caregiver needs, values, beliefs, and cultures are incorporated into the care provided.
- 1.4 The principles of palliative and end of life care are relevant to terminally ill patients with both malignant and non-malignant disease. Therefore, the principles of palliative care should not be applied solely to cancer patients at the end of life.
- 1.5 The palliative medicine service was established in the Ministry of Health in Kuwait in 2011 and provides care primarily for oncology patients by means of consultation and/or transfer of care to the palliative medicine service when deemed possible. Due to the current shortage of specialized manpower and facilities for palliative and end of life care, the palliative medicine team is at present only able to provide their care and expertise to cancer patients. It is, therefore, paramount that not only do the different clinical departments be aware of the consultation process and care of such cohort of patients, but also be equipped with the appropriate knowledge on how to provide care for terminally ill patients-deemed for end-of-life care-should the need arise.

## 2. Purpose:

The purpose of this policy is to guide all clinical departments in MOH to provide:

- 2.1 Understanding of the definitions of phases of palliative care.
- 2.2 Requirements for deeming patients for end-of-life care.
- 2.3 Criteria and procedure for end-of-life consultation (Pathway for consultation and care for end-of-life care).
- 2.4 A guide for management of end-of-life care in adults with terminal illness.

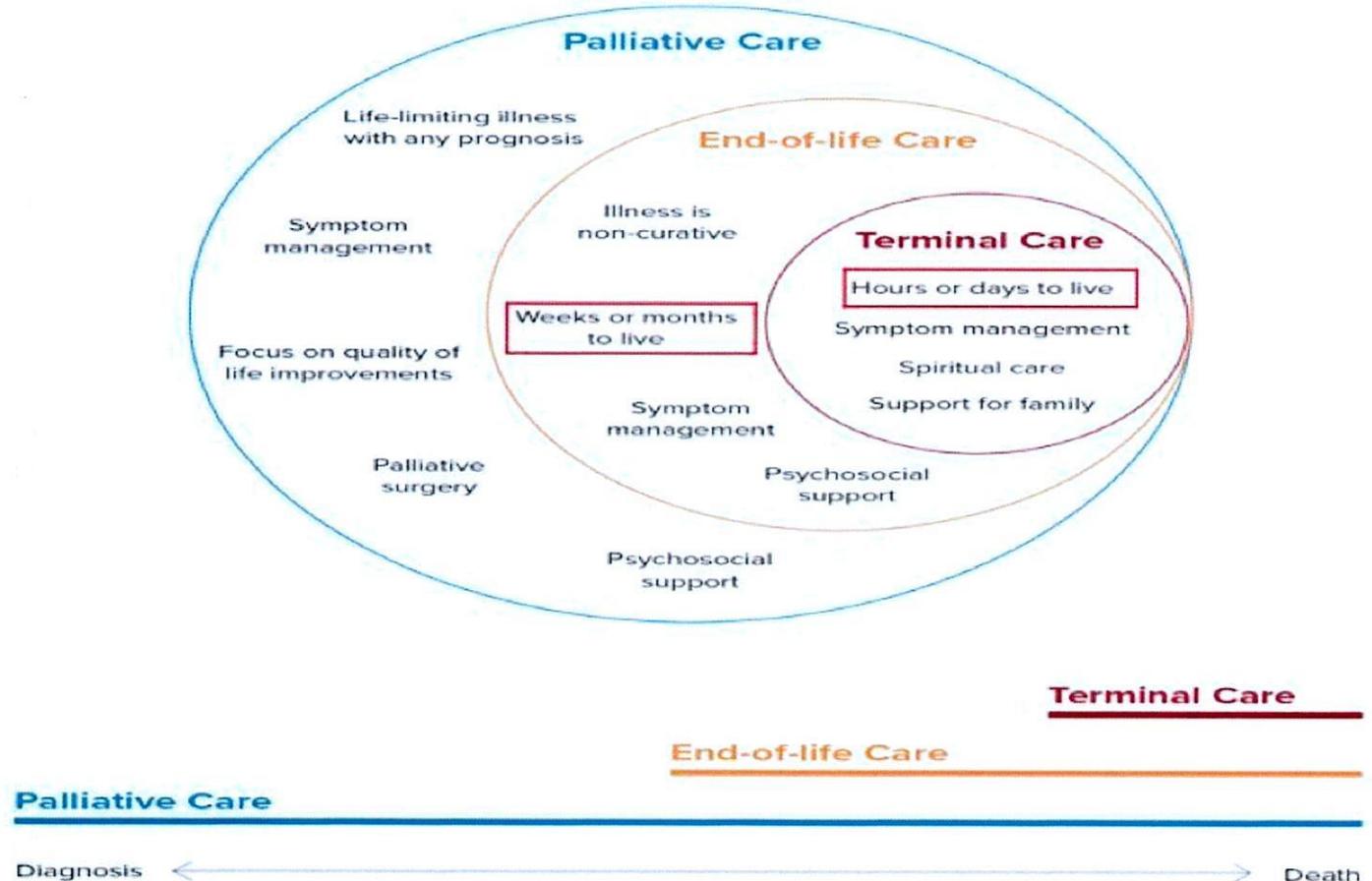
**Policy Title:** Operational and Management Policy and Guide for Adults with Terminal Illness.

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### 3. Definitions:

- 3.1 **Terminal Illness:** Is the advanced disease state from which there is no expectation of recovery.
- 3.2 **Palliative Care:** An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and correct assessment of pain and other problems, physical, psychosocial and spiritual.
- 3.3 **Best Supportive Care:** It is the care meant to maintain the patient's quality of life and alleviate suffering with treatments that are symptom-focused rather than disease-focused.
- 3.4 **ELC: End-of-Life Care:** The care of a person during the last part of their life when it has become clear that the person is in a progressive state of decline. The life expectancy is weeks to months (less than six months).
- 3.5 **Terminal Phase (Imminent Death):** The period of irreversible decline in functional status before death. The terminal phase lasts from hours to days.



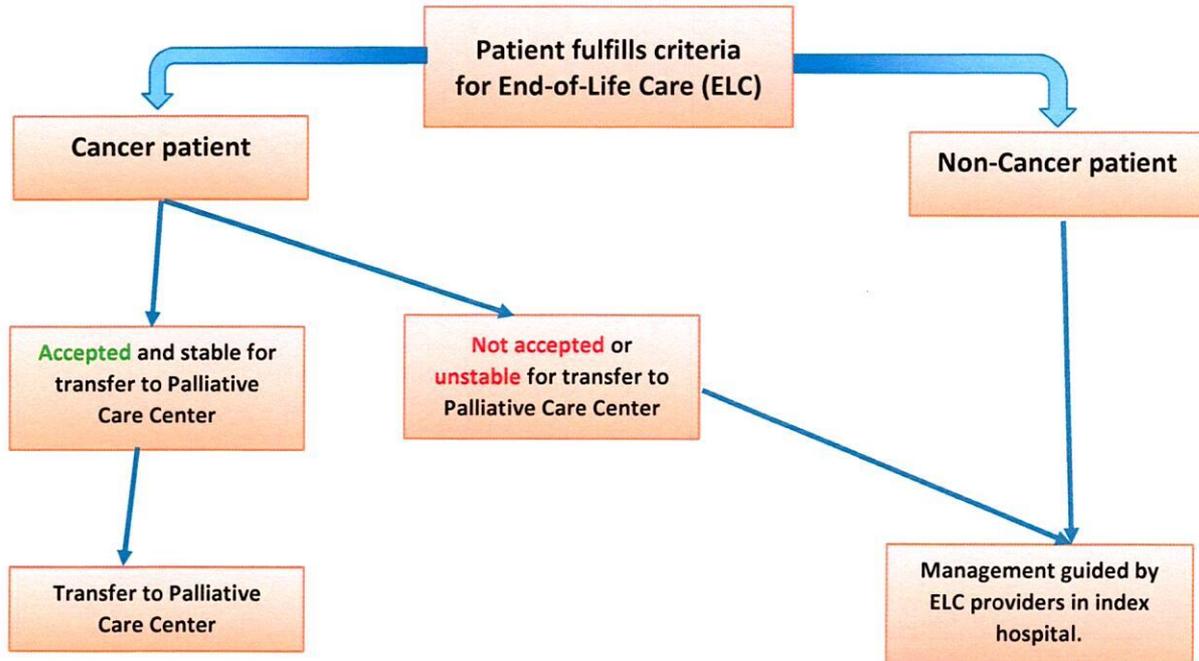
3.6 **MOH:** Ministry Of Health.

3.7 **Index hospital:** General or specialized MOH hospital that the patient was admitted to and is residing in at the time he / she is deemed for end-of-life care.

3.8 **Attending Physician:** Any physician of the rank of Specialist, Senior Specialist or Consultant.

- 3.9 **Treating Physician:** Any physician who oversees the direct care of the patient in the index hospital.
- 3.10 **PPSv2:** Palliative Performance Scale (PPSv2) version 2.
- 3.11 **ECOG:** Eastern Cooperative Oncology Group.
- 3.12 **ROSC:** Return of Spontaneous Circulation.
- 3.13 **ELC: End of Life Care Providers:**
- 3.13.1 An 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.
  - 3.13.2 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. Internal Medicine Department, Cardiology, Hepatobiliary Surgery and/or Anesthesia/ICU Department, etc.).
  - 3.13.3 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.
- 4. Requirements / Criteria 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:
    - 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 (using scores like: PPSv2, Karnofsky, ECOG). **(Refer to appendix).**
    - 4.3.4 Current clinical status.
    - 4.3.5 Prognosis.
    - 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 Documented agreement (by the patient/legal guardian) that the patient will be provided with end-of-life care.
      - 4.3.8.1 If the patient incapacitated, no next of kin available and/or no contact numbers available in the country, the documentation of 2 attendings and a legal guardian as per MOH-policy should be provided.
      - 4.3.8.2 Please refer to the **management guide for ELC** -section: Approaching patient and family for end-of-life care **(refer to appendix).**
  - 4.4 **Please refer to the management guide for ELC** -section: General indicators for deeming patient end-of-life care **(refer to appendix).**

## 5. Pathway for consultation and care for end-of-life care:



## 6. Special considerations for end-of-life care management:

6.1 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).

### 6.2 Ventilatory Support in End-of-Life Care.

6.2.1 **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.

#### 6.2.2 Patients **not** on mechanical ventilation:

6.2.2.1 Please refer to the **management guide for ELC** -section: Symptoms management for dyspnea (**refer to appendix**).

6.2.2.2 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.

6.2.2.3 If the patient and or his legal representative(s) decide **against** ventilatory support, the treating physician (or the delegated ELC provider) should document the wishes and acquire a signed informed consent. And thereafter follow article 6.2.2.1.

6.2.2.4 The mechanical ventilators settings and adjustments will be followed by the anesthesia/ICU team or any physician with airway and mechanical ventilation competency.

### 6.3 Hemodynamic Instability:

6.3.1 **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 guide on ELC for pain, sedation, delirium etc. accordingly).

6.3.2 **Patients who are hemodynamically unstable but not on vasopressor support**

6.3.2.1 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.

6.3.2.2 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.

6.3.2.3 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.

6.4 **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 guidelines for the inpatient set below.

## 7. References:

- 7.1 World Health Organization. Definition of palliative care. 2002. Available from <http://www.who.int/cancer/palliative/definition/en/>. Accessed March 1, 2021.
- 7.2 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.
- 7.3 Oxford textbook of Palliative Medicine, 4<sup>th</sup> edition (2010).

## 8. Appendix:

- 8.1 Symptoms management guide.
- 8.2 Functional Status Scores.
- 8.3 Patient and Family Conferences (Counseling).

**Policy Title:** Operational and Management Policy and Guide for Adults with Terminal Illness.

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### 1. Symptoms management guide

- For the detailed symptoms guide, kindly visit the following link  
<https://www.dropbox.com/s/ap50ytbsbrv0nhw/Detailed%20Symptoms%20Guide-%20finalised.pdf?dl=0>
- For the brief symptoms guide version, kindly visit the following link  
<https://www.dropbox.com/s/kuuen3ykwr4vi0m/Quick%20Symptoms%20Guide-%20finalised.pdf?dl=0>

### 2. Functional Status Scores

Palliative Performance Scale (PPSv2) version 2 <sup>2</sup>						
PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level	
Stable	100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
	90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
	80%	Full	Normal activity with effort Some evidence of disease	Full	Normal or reduced	Full
Hospice Appropriate	70%	Reduced	Unable to do normal job/work Significant disease	Full	Normal or reduced	Full
	60%	Reduced	Unable to do hobby/housework Significant disease	Occasional assistance necessary	Normal or reduced	Full or confusion
	50%	Mainly sit/lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or confusion
	40%	Mainly in bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or drowsy +/- confusion
	30%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Normal or reduced	Full or drowsy +/- confusion
	20%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Minimal to sips	Full or drowsy +/- confusion
	10%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Mouth care only	Drowsy or coma +/- confusion
	0%	Death	-	-	-	-

**Policy Title:** Operational and Management Policy and Guide for Adults with Terminal Illness.

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**Rev. date:** 5/11/2027

## ECOG performance status

Grade	Description of patient
0	Fully active, able to carry on all predisease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light housework, office work
2	Ambulatory and capable of all self-care but unable to carry out any work activities; up and about more than 50% of waking hours
3	Capable of only limited self-care; confined to bed or chair more than 50% of waking hours
4	Completely disabled; cannot carry on any self-care; totally confined to bed or chair
5	Dead

### KARNOFSKY PERFORMANCE STATUS SCALE DEFINITIONS RATING (%) CRITERIA

Able to carry on normal activity and to work; no special care needed.	100	Normal no complaints; no evidence of disease.
	90	Able to carry on normal activity; minor signs or symptoms of disease.
	80	Normal activity with effort; some signs or symptoms of disease.
Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.	70	Cares for self; unable to carry on normal activity or to do active work.
	60	Requires occasional assistance, but is able to care for most of his personal needs.
	50	Requires considerable assistance and frequent medical care.
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.	40	Disable; requires special care and assistance.
	30	Severely disabled; hospital admission is indicated although death not imminent.
	20	Very sick; hospital admission necessary; active supportive treatment necessary.
	10	Moribund; fatal processes progressing rapidly.
	0	Dead

**Policy Title:** Operational and Management Policy and Guide for Adults with Terminal Illness.

**Effective date:** 6/11/2025

**Rev. date:** 5/11/2027

### 3. Patient and Family Conferences (Counseling)

#### Purpose:

To ensure patients and their family (when appropriate) are involved in decisions about care, treatment and services provided.

To provide guidance on conducting patient and family conferences.

#### Definitions:

**Family Conference:** A meeting among the patient, family and health care team to facilitate communication about the plan of care, transition or discharge plan, and patient and family goals and resources. Most conferences are held to prevent or address communication issues and to resolve identified or anticipated issues.

Family and carers of all patients admitted to palliative care unit must be aware that in palliative care patients resuscitation is often inappropriate and futile if deterioration is due to their primary disease.

Patient, family and carers must be aware that being labelled for best supportive care by the primary doctor, makes him uneligible for further disease modifying therapy and it became futile to have any investigations to monitor the primary disease status (either imaging techniques or laboratory work up).

All discussions with the family regarding advanced care plans and resuscitation's futility should be well documented. Refer to (APPENDIX F: Patient/Family Conference Record)

**Multi-Disciplinary Team (MDT) Meeting:** A formal or informal meetings of health care professionals involved in the care of a patient to communicate and or develop the plan of care where the patient and family are not present. Patients have an interdisciplinary, individualized, documented care plan that is based on the assessed needs of the patients.

#### Responsibility:

Treating attending Team/ Palliative team

#### Procedure

1. Indicators for Family Conference and Multi-Disciplinary Team (MDT) Meeting:  
Patient or family presents one or more of the following indicators for a conference

**TABLE 1. INDICATORS FOR PATIENT / FAMILY CONFERENCE AND MDT meeting.**

Patient/ Family Conference (May also indicate need for care conference)	MDT meeting:
<input type="checkbox"/> Change in patient status/ changing goals of care, initial referral to palliative care.	<input type="checkbox"/> Complicated and difficult to manage symptoms.
<input type="checkbox"/> Health care provider / family miscommunication of conflict.	<input type="checkbox"/> Need for coordination among multiple specialties.
<input type="checkbox"/> Unusually long length of stay.	<input type="checkbox"/> Health care team disagreement.
<input type="checkbox"/> Differing messages from family members	

**Policy Title:** Operational and Management Policy and Guide for Adults with Terminal Illness.

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**Rev. date:** 5/11/2027

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- Boundary conflicts.
  - Family conflict or mistrust of caregivers
  - Alternative sites of care are indicated.
  - Health care providers need information about patient/family cultural and spiritual beliefs.
  - Ethical dilemmas e.g. cessation of some treatment(s), artificial feeding, need for referral back to primary services for more disease targeted treatments etc.
  - Patient and/ or family seen as "difficult"
  - Acute or chronic mental health condition complicating plan of care
- 

2. Requesting an MDT or a Patient/ Family Conference:

- a. Any member of the Palliative Care Team may suggest a care conference.
- b. This typically occurs during rounds or interdisciplinary discussions. All members of the palliative care team are responsible for identifying the need for a conference.
- c. The consultant designates a member of the team to be responsible for organizing the conference and inviting team members.

3. Attendance:

- a. The patient, family and any others that patient wishes to invite.
- b. Attending and consulting physicians, nurses and other team members involved in the care or whose expertise is needed.
- c. Spiritual Advisor, social worker, rehabilitation therapists and pharmacists.

4. Preparation for the Meeting:

Some members of the team may need to meet prior to the conference to:

- a. Discuss need and purpose.
- b. Make sure the right people are at the table.
- c. Identify lead physician to present medical information from all services.
- d. Identify goals.
- e. Resolve or identify team conflicts around plan of care. All parties need to be at the team conference, if involved in conflict.
- f. Come to consensus on plan of care.

5. Facilitator's Role:

Facilitator's roles can vary depending on group facilitation skills of attendees and relationship with the patient and family. Facilitator may include any of the disciplines. Facilitator's tasks include:

- a. Facilitates introductions.
- b. Explains purpose and goals of conference.
- c. Reviews ground rules.
- d. Asks patient and family to identify their questions, concerns and goals.
- e. Invites review of medical status.
- f. Facilitates discussion among those present.
- g. Clarifies understanding, especially of medical terminology.

**Policy Title:** Operational and Management Policy and Guide for Adults with Terminal Illness.

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- h. Summarizes discussion, identify follow-up and document in progress notes.
6. Format of Conference:
- 6.1. Set atmosphere for collaborative respectful discussion.
- 6.1.1. Discusses purpose of and need for patient/family conference.
- 6.1.2. Identify goals and desired outcomes of family conference.
- 6.1.3. Identify family needs and wishes.
- 6.2. Provide setting for discussion of diagnosis, implication of illness and treatment options.
- 6.3. Identify current and anticipated issues and stressors.
- 6.4. Identify resources among patient, family, staff and community that can support patient and family coping.
- 6.4.1 Explore and identify hopes and goals beyond elimination of current issues. This frequently cannot be addressed until feeling about presenting concerns and problems have been expressed.
- 6.4.2 Document follow-up in progress notes.