Guidelines for End of Life Care, AIIMS, New Delhi

A "Good Death" is the right of every dying patient. In the UK, a world-wide survey was done for quality of death in 2015 and India was ranked 67th amongst 80 countries. With this background, this document for implementation of "Guidelines for End of Life Care, AIIMS, New Delhi" was developed by task forces from various disciplines of healthcare.

The review was done by designated experts from various disciplines nominated by the Director. The aim of developing this document was to develop practical procedural guidelines to identify the terminal stage of illness, ensure care at all levels – physical, emotional, social and spiritual, to minimize the symptoms and enable dignified dying process for chronically and terminally ill patients.

The document includes the following four steps-

1. Establishment of "Futility of further management" by the physicians.
2. Consensus among all the caregivers on "futility of further management" and initiation of best supportive care pathway.
3. Initiation of End of Life Care (EOLC) pathway.
4. Symptom management and on-going supportive care till death.

The steps of the action plan have been elaborated in the document. It has also been summarized in a flow diagram (**Figure 1**) at the end of this document.

These guidelines are meant to guide physicians in navigating end of life situations and should be read along with all applicable laws, rules and regulations concerning such situations. AIIMS recognises that these guidelines are a work in progress and is committed to ensuring that they respond to developments in the law and international and national best practices with regard to end of life care.

1. Establishment of "Futility of further management"

"Futility of further management" should be recognized initially by primary physicians based on some general as well as disease specific criteria.

General Criteria

- Life expectancy expected to be in days to weeks,
- Any condition, where clinicians predict a very low chance of meaningful survival and purposeful life,
- Post-cardiac arrest status with poor neurological outcomes,
- Brain dead patients, who are not suitable for organ donation.

Speciality specific criteria for futility of further management:

In different specialities, (i.e., critical care units, pulmonary medicine, paediatric medicine, neurology, neurosurgery, oncology etc.) the specific criteria for futility of further management will be decided by the team of clinicians of the concerned speciality considering the disease specific details.

Once the futility of further management has been identified by the primary clinician, the same must be confirmed by another clinician of the same speciality who is not directly involved in the care of the patient. After this consensus on futility of further treatment a mandatory referral has to be made to palliative care services. The consensus among the clinicians must be documented in proper format **(Enclosure 1).**

2. Consensus among all the caregivers on "futility of further management and initiation of best supportive care pathway"

Four basic steps should be followed to reach a consensus:

I. **<u>Assess the mental competence of the patient for taking an informed decision</u>:**

Check for the ability to understand, appreciate, reasoning and expression of choices. If a patient is not found to be mentally capacitated to give a valid informed consent, a surrogate decision maker should be identified.

II. **<u>Identify the responsible Surrogate decision makers</u>:** If the patient does not have the capacity to make healthcare decisions or is unable to participate in the healthcare decision making, the process of decision-making rests on patient surrogates, which is usually the patient's family who makes the medical decision in consultation with the treating team in best interests of the patient.

If there are no documented surrogate decision makers, the hierarchy for surrogate decision makers will be as follows:

(a) Spouse or *de facto* spouse or a partner with whom the patient has a relationship in the nature of marriage or a friend of long standing who regularly attends to the patient in the hospital;
(b) Available Adult Sons & Daughters;
(c) Available Parents;
(d) Available Adult Siblings;
(e) Any other lineal ascendants or descendants of the patient who are present in the hospital and regularly attend to the patient

III. Proper communication to disclose the "Futility of Further management" and options for best supportive care

The primary clinician along with the palliative care physician and nursing officer should communicate to the patient and/or all concerned family members together in a meeting. The communication should take place in a language, with which they are comfortable. The communicating team must introduce themselves to all the family members present in the meeting.

- Communication should include explanation related to the terminal nature of illness with emphasis on the following
  - ✓ Short life expectancy
  - ✓ Burden versus benefit of further aggressive management
  - ✓ Option of end of life care as an alternative
  - ✓ Change of goals of treatment from cure to care
  - ✓ Symptoms expected in last few days or hours and their comfort measuring strategies
  - ✓ Clarification of any myths or misunderstanding regarding illness and treatment.
  - ✓ Recheck and ensure the understanding of prognosis and process of EOLC among all the caregivers.
- At the end of communication the checklist for communication should be filled by communicating team's clinicians **(Checklist 1)**.

IV. Documentation

If the patient is mentally capacitated to take an informed decision, the patient's wishes for withholding life sustaining support should be recorded and signed **(Enclosure 2)**.

If the patient does not have the capacity to make informed decisions, then once consensus amongst all family members is established, a written disclosure of futility of further treatment and withholding or non-escalation of life sustaining treatment to be obtained **(Enclosure 3)**.

3. Initiation of End of Life Care (EOLC) pathway

Once consensus for initiating EOLC is achieved among all the caregivers and physicians, palliative care physician must ensure all the prerequisites have been adequately addressed (**Checklist 2**).

4. Symptom management and on-going supportive care till death

- Daily assessment of the patient to be done for holistic palliative needs, e.g. psychological, spiritual along with symptoms management at the end of life (e.g., pain, breathlessness, delirium, vomiting)

- Daily supportive care plan and treatments given should be documented for all in-hospital EOLC **(Enclosure 4).** Any change in plan (Care to Cure) must be documented.

- If patient is already not on any life sustaining support, patient / surrogate decision makers may be given option for home based / hospice based care.

Enclosure 1

Establishment of futility of further management by clinicians

I hereby certify that .....……..…….... with UHID No. …… admitted at AIIMS, New Delhi suffering from …… is being reviewed for futility of further management. I feel that initiating or continuing life-sustaining treatment in this patient is futile based on following clinical criteria.

……..
……..
……..
……..
……..

In consensus with the primary care clinician I recommend palliative care referral to facilitate good end of life care for this patient.

Place:

Signature of the Clinician: (along with seal)

Signature of the Primary Clinician

Date:

Date:

1. ……

1.....

Enclosure 2

Patient's wishes for Withholding Life Support

I _____ with UHID No. _____ admitted at AIIMS, New Delhi, have a critical/terminal illness where disease modifying options are no more applicable.

I understand that my general health is poor.

I also understand the futility of life supportive measures such as endotracheal intubation, cardiopulmonary resuscitation which will cause suffering without any reasonable benefit.

My goal of care would be symptom relief, comfort measures and quality of life.

I hereby request you to allow natural death in the event of cardio-pulmonary arrest i.e. (no external chest compressions, no intubation, and no chemical or electrical cardio version)

I understand that signing this document would not deprive me of required medical and nursing care, pain and symptom relief modalities, and nursing care as appropriate with the highest priority to maintain dignity of life.

I say that I am making this declaration out of free will and there is no coercion.

Name of the patient		**Signature**	**Date /Time**
Doctor/Department			

Enclosure 3

Family acceptance regarding futility of further management & withholding or non-escalation of life sustaining treatment

I/We the family members of the patient …… with UHID No. ……. acknowledge that we have attended the family meeting convened by the Department of …… on …… at……

I/We have been explained regarding advanced state of illness. We understand that the benefit of initiating life-sustaining medical treatment has the potential to cause suffering.

I/We have decided and requested the doctors to withhold life sustaining treatments on behalf of the patient.

I/We understand that signing this document would not deprive our patient of required medical and nursing care, pain and symptom relief modalities, and nursing care as appropriate with the highest priority to maintain dignity of life.

I/We hereby request you to allow natural death in the event of cardio-pulmonary arrest i.e. (no external chest compressions, no chemical or electrical cardio version).

I/We represent the patient's wishes and there is no conflict amongst the family members regarding the decision.

Signatures of the family members attending the meeting

S. No.	Name	Age	Relationship	Signature

Signature of the clinicians conducting the meeting

S. No.	Name	Designation	Signature

Date and Time: Place:

Enclosure 4

Documentation of daily progress note for in hospital care

Date (Time)						
Conscious (Y/N)						
Pain (Y/N)						
Breathlessness (Y/N)						
Oral secretions (Y/N)						
Nausea & vomiting (Y/N)						
Bowel problem (Y/N) If yes mention_____						
Bladder problem (Y/N) If yes mention_____						
The person's personal hygiene needs are met (Y/N)						
Patient's psycho-spiritual needs addressed (Y/N)						
Caregiver's psycho-spiritual needs addressed (Y/N)						
Any change in goals of care (Y/N)						

Y= Yes N= No

Date/ Time	Special remarks	Signature of the nursing staff :

Checklist No 1: Disclosure of Prognosis and futility of further management

Language for communication: ……

1	Ability to communicate in _____ language	*Y* □ *N* □
2	Introduction of self and team	*Y* □ *N* □
3	Confirmation of decision makers (Patient/ Caregiver) Name and address checked Surrogate decision maker noted _____	*Y* □ *N* □ *Y* □ *N* □ *Y* □ *N* □
4	Insight into condition assessed Awareness of diagnosis and prognosis	*Y* □ *N* □ *Y* □ *N* □
5	Prognosis discussed Goals and Plan of care explained and discussed	*Y* □ *N* □ *Y* □ *N* □
6	Understanding of prognosis and plan of care checked	*Y* □ *N* □
7	Religious/spiritual needs assessed/ offered	*Y* □ *N* □
8	Option for organ donation discussed with family and /or patient where appropriate	*Y* □ *N* □

Signatures:

JR/SR …….. Faculty……..

Date …….. Date …….

Checklist No 2: Initiation of EOLC

All potentially reversible causes of patient's condition excluded	Yes	No
Consensus among clinicians involved in the treatment	Yes	No
Patient is able to take part in the decision making	Yes	No
Patient is aware of irreversibility of his/her condition	Yes	No
Any advance directive available	Yes	No
Family is able to take active part in decision making	Yes	No
Family is able to comprehend fully about irreversibility of the patient's condition	Yes	No
Family meeting documented	Yes	No
Family consensus and agreement of futility of further management	Yes	No
Family explained about further course of care plan	Yes	No
Guidance and Care Plan for the Dying explained and initiated	Yes	No
Organ harvesting planned	Yes	No
Place of Care opted by patient / caregiver	Hospital/Home/Hospice	

Signatures:

Palliative Care Team: Primary Care Team:

1…… 1……..

2…….. 2……..

Date: Date:

Figure 1. Summary of End-of-Life Care Execution Pathway