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 67thamongst 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 followed by internal peer review. 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 seven steps**-.

- Step 1: Recognition of "Futility of Further Management" by primary clinician.
- Step 2: Clinicians Consensus on futility of further management.
- Step 3: Early and detailed explanation of prognosis with proper communication and documentation of disclosure by patients and/or family members for withholding life support.
- Step 4: Assessments before initiation of end of life care
- Step 5: Continuous assessment of daily supportive care plan
- Step 6: Documentation of daily progress note
- Step 7: Feedback

The steps of the action plan have been elaborated in the annexure to this document. Templates and format for documentation at various steps have also been described in the annexure. All the terminologies used in this document are in accordance with the ICMR Report on Definitions of terms used in limitation of Treatment and providing Palliative Care at the end of Life.
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.

STEP -1

Recognition of "Futility of further Management"

General Criteria

- Life expectancy expected to be in days to weeks,
- Any condition, where clinicians predicts 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, the specific criteria for futility of further management will be decided by the team of clinicians of the concerned speciality.

STEP-2

Clinicians' consensus on futility of further management

- Consensus on futility of further management and withholding life sustaining treatment should be made by primary clinician and one other clinician of the same concerned speciality not directly involved in the care of the patient.
- If there is no consensus on futility, the situation can be reviewed again after an interval of time.
- Once consensus has been reached, there should be detailed documentation justifying the futility decision (Annexure 2.1). The futility documentation should form part of the patient's medical records and should clearly mention the treatments received so far, the life sustaining methods being currently provided and the life sustaining methods that are being planned to be withheld.
- In case of any dispute, the case can be referred to the Institutional Advisory Committee on End of Life Care (EOLC).
- After consensus on "Futility of further Management", a mandatory referral has to be made to palliative care services.
- Communication of the "Futility of further Management" to the family/caregivers has to be made by the primary clinician in the presence of a palliative care team during a family meeting with documentation.

ANNEXURE 2.1

Recommendation by clinician who is not involved directly in the care of the patient regarding futility of further management

I hereby certify that.....……...bearing Hospital No…… admitted at the 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 medically futile based on following clinical criteria.

……..
……...
……...
……
……

In consensus with the primary care clinician I recommend palliative care referral to facilitate the 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.....

STEP-3

Early and detailed explanation of prognosis with proper communication and documentation of disclosure by patients and/or family members for withholding life support.

Disclosure of Futility of further Management

- The primary clinician 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.
- 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 will be provided.
- At the end of communication the checklist for communication should be filled by communicating team's clinicians (**annexure 3.1**).
- If the patient is mentally capacitated (**annexure 3.2**) to take an informed decision, the patient's wishes for withholding life sustaining support should be recorded and signed (**annexure 3.3**).
- 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 life sustaining treatment will be obtained (**annexure 3.4**).
- If the patient is already on life sustaining measures, e.g. post cardiac arrest patient on ventilators, a separate family disclosure to be signed for not escalating the life sustaining supports and therapies (**annexure 3.5**).

ANNEXURE 3.1

Communication checklist

Language for communication: ……

1	Ability to communicate in _____ language	*Y* □ *N* □
2	Introduction of self and team	*Y* □ *N* □
3	Confirmation of decision makers Name and address checked Main carer noted _____ Others	 *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 …….

ANNEXURE 3.2

Competence to take medical decisions and surrogate decision making

During the process of consenting it is important to determine whether a patient has the capacity to make medical decisions or whether a surrogate should take decisions on his/her behalf.

The capacity for taking healthcare decisions is determined using the four-component model of decision capacity.[1]

A. ***Understanding:*** Refers to the ability of the individual to comprehend the information being disclosed in regard to his/her condition as well as the nature and potential risks and benefits of the proposed treatment and alternatives (including no treatment). In operationalizing assessment of capacity , it is important that the psychologist ensures that he/she is assessing the person's actual comprehension, e.g., as evidenced by an ability to describe the information in his/her own words, rather than the mere ability to parrot-back the words described by the psychologist or to read them verbatim off a printed consent form.

B. ***Appreciation***: Involves the ability to apply the relevant information to one's self and own situation. For example, an individual experiencing an acute manic episode may demonstrate intellectual understanding of what bipolar disorder and mania are, and the risks and benefits of mood stabilizing medications as treatment of acute mania, as well as the risks of forgoing treatment. However, if the very presence of a manic episode (which can include a lack of illness insight) causes an individual with intellectual understanding of bipolar disorder and its treatment to fail to appreciate the personal risks of refusing treatment, he/she might be deemed as incapable on that basis). The same may occur in the context of some forms of acquired brain injury or any other disorders associated with impaired insight.

C. ***Reasoning:*** Refers to the evidence that the person's decisions reflect the presence of a reasoning process, e.g., ability to engage in consequential and comparative reasoning and to manipulate information rationally.

D. ***Expression of a Choice***. It simply refers to the ability to communicate a decision. However, some authors have also emphasized the notion of a “clear and consistent” choice.

---

[1]**Palmer BW, Harmell AL. Assessment of Healthcare Decision-making Capacity.** ***Arch Clin Neuropsychol.*** **2016;31(6):530–540. doi:10.1093/arclin/acw051**

ANNEXURE 3.3

Patient's wishes for Withholding Life Support

I _____ bearing hospital number_____ admitted at the AIIMS NEW DELHI, have a critical/terminal illness where disease modifying treatment options are no more applicable and have complications related to the progressive nature of the disease which is potentially life threatening.

I understand that as the disease is advanced and the general health is poor, I could develop/have developed serious life-threatening complications that could threaten my quality of life. I understand that these complications are seldom reversible. I also understand the futility of life support such as endotracheal intubation, cardiopulmonary resuscitation and aggressive intensive care measures which will cause harm and suffering without any reasonable clinical benefit. Considering these circumstances, my goal of care would be symptom relief, comfort measures and quality of life. I request for the non-initiation of life sustaining measures.

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 any necessary medical and nursing care, pain and symptom relief measures, and supportive and specific nursing care measures as appropriate with the highest priority to maintain dignity and quality of life.
I say that I am making this declaration out of free will and there is no coercion, undue influence and fraud.

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

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 children;
(c) Available Parents;
(d) Available Siblings;
(e) Any other lineal ascendants or descendants of the patient who are present in the hospital and regularly attend to the patient

In case of conflict between surrogate decision-makers at the same level of hierarchy, the case should be referred to the Institutional Advisory End of Life Care Committee.

ANNEXURE 3.4

Family acknowledgement regarding futility of further management and withholding life sustaining management.

We are the family members of the patient……, hospital number……. hereby acknowledge that we have attended the family meeting on the below-mentioned date and time convened by the department of …… on …… at……

In this family meeting, a team of our treating clinicians have explained the advanced and terminal state of the disease. We understand from this family meeting that the benefit of initiating or continuing life-sustaining medical interventions has a higher potential to cause suffering without any reasonable clinical benefit.

After extensive discussion with the treating doctors, I/We have decided and requested the treating clinicians to withhold the life sustaining treatments on behalf of the patient.

We acknowledge that the patient is able/unable to participate in his/her clinical decision making and we the family of the patient are collectively and consensually making treatment decisions for/with the patient.

I/We represent the patient's wishes and state that there is no conflict in the family regarding treatment decision making for the patient.

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:

ANNEXURE 3.5

Family Directive for Non-escalation of Life Sustaining Treatment

I/We understand that our patient _____Ms/Mr/Master_____, bearing hospital number_____ is admitted at the AIIMS NEW DELHI, has a critical/terminal illness where disease modifying treatment options are no more applicable and has life threatening complications related to the progressive nature of the disease.

I/We understand that he/she had developed serious complications [difficulty with breathing asphyxia and cardiac arrest.], which was addressed urgently through cardio-pulmonary resuscitation and advanced life support measures including intubation and ventilation.

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

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

I/ We say that I/We are making this declaration out of free will and there is no coercion, undue influence and fraud.

Relationship	**Name**	**Signature**	**Date /Time**

STEP-4
Assessments before initiation of end of life care

1. Before initiation of End of Life Care, a checklist to be filled (**Annexure 4.1**)
2. The second step is the ratification of the decision to withhold treatment by the Institutional advisory committee on End of Life Care (EOLC) (**Annexure 4.2**).

ANNEXURE 4.1

Checklist for initiation of end of life care

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 advanced 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

ANNEXURE 4.2

Ratification of the decision of withholding life sustaining treatment by the Advisory committee on EOLC.

We hereby certify that ……...bearing Hospital No…… admitted at the AIIMS NEW DELHI, has…….

We concur with the decision of the primary treating clinician and one more clinician not involved in the care of the patient on futility of life sustaining treatment.

We concur with the family/patient decision on withholding life sustaining treatment.

We agree that the decision to withhold life sustaining is done in the best interest of the patient with no coercion, malaise, undue influence or fraud.

We recommend withholding of the life sustaining treatment and recommend palliative care involvement to facilitate end of life care

Place:

Date:

Name & Signature of the EOLC Advisory Committee:

STEP-5

Continuous assessment of daily supportive care plan

i. **Assessments of physical symptoms :**

In Pain	Y N	Able to swallow	Y N	Confused	Y N
Agitated	Y N	Continent (bladder)	Y N	(Record whichever is applicable)	
Nauseated	Y N	Catheterised	Y N	Conscious	Y N
Vomiting	Y N	Continent (Bowels)	Y N	Semi-Conscious	Y N
Dyspnoeic		Constipated	Y N	Unconscious	Y N
Experiencing respiratory tract secretions Y N					
Experiencing any other symptoms (e.g. oedema, itch, etc.) Is a person on a ventilator? Y N					

ii. Clinical decision making & medications

The person has medication prescribed on an "as required"/ prn basis for all of the following symptoms which may develop in the last few days of life:

PHYSICAL SYMPTOMS	DRUGS & DOSAGES	ROUTE
1. Pain		
2. Nausea & Vomiting		
3. Terminal Agitation		
4. Dyspneoa		
5. Respiratory Infections		

Have the following been assessed and discontinued if inappropriate/ causing harm?

	N/A	Continued	Discontinued	Commenced
Routine blood tests				
IV fluids/ antibiotics				
Blood glucose monitoring				
Recording vital signs				
Oxygen therapy				

iii. The person's need for nutrition is assessed and reviewed

Does the person need Clinically Assisted (artificial) Nutrition (CAN)?

Continued Discontinued Not Required

If already in place, which route? - NG/RT PEG/PJ NJ TPN

iv. The person's need for fluids is assessed and reviewed

Does the person need Clinically Assisted (artificial) Hydration (CAH)

Continued Discontinued Not Required

If already in place, which route? - NG/RT PEG/PJ NJ NJ TPN

v. Ongoing assessment of the care plan

DAY: DATE:

Undertake a Team review of this plan at any time if there is an improvement in:

- Conscious level,
- Functional ability, oral intake, mobility, or ability to perform self-care or
- Concerns expressed regarding the management plan from either person, carer or team

This plan must be reviewed daily by one of the EOLC trained doctors

STEP-6

Documentation of daily progress note

Outcomes should be assessed on a daily basis and denoted as "Y" for yes and "N" for no.
If the outcome was not achieved, then an explanation/ comment will be recorded in the progress notes (overleaf).

Timings:						
The person does not have pain						
The person is not agitated						
The person does not have respiratory tract secretions						
The person does not have nausea						
The person is not vomiting						
The person is not breathless						
The person does not have urinary problems						
The person does not have bowel problems (bowels last opened:_____**)**						
The person does not have other symptoms If present record: _____**)**						
The person's comfort food and fluids to support their individual needs						
The person's mouth is moist and clean						
The person's skin integrity is maintained						
The person's personal hygiene needs are met						
The person receives care in a physical environment adjusted to support their individual needs						
The person's psychological wellbeing is maintained						
The person's spiritual wellbeing is maintained						
The well-being of the relative/carer attending to the dying person is maintained						
Signature of the nurse: (Each assessment)						

Progress Notes:		
Record here any comments or observations, particularly if goals are not achieved. Also, any significant events or conversations with clinical staff of carers/ medical review.		
Date/ Time	Comments	Signature

STEP-7
Feedback

Feedback Form:

1. Department under which treatment was going .....
2. Tick to indicate how the following statements reflect your experience

- I/we was/were told about the prognosis Agree Neutral Disagree
- I/ we was / were told about the symptoms expected in last few days or hours Agree Neutral Disagree
- I/we was/were explained about change of goals of treatment from cure to care Agree Neutral Disagree
- Religious/ Spiritual concerns were addressed Agree Neutral Disagree

3. Was it a good and peaceful death?

			Name	Signature
Doctor:	Y	N	.....	.....
Nursing Staff:	Y	N	.....	.....
Primary Caregiver:	Y	N	.....	.....
As per family:	Y	N	.....	.....

Dr. Sushma Bhatnagar
Professor and Head
Department of Onco-Anaesthesia and
Palliative Medicine
Dr. B.R.A IRCH, AIIMS

Prof. M V Padma Srivastava
Professor
Head Department of Neurology
Chief , Neurosciences Centre, AIIMS

Dr. Praveen Aggarwal
Professor & Head
Department of Emergency Medicine at AIIMS

Dr. S.V.S Deo
Professor and Head
Department of Surgical Oncology
Dr. B.R.A IRCH, AIIMS

Dr. D. Bhowmik,
Professor
Department of Nephrology
AIIMS, New Delhi

Dr. Nitish Naik
Professor
Department of Cardiology
AIIMS, New Delhi

Dr. Ambuj Roy, Professor
Department of Cardiology
AIIMS, New Delhi

Dr. T.P Singh,
Chairman, Ethics Committe
AIIMS, New Delhi

Dr. Seema Mishra
Professor
Department of Onco-Anaesthesia and
Palliative Medicine
Dr. B.R.A IRCH, AIIMS

Dr. Rakesh Garg
Additional Professor
Department of Onco-Anaesthesia and
Palliative Medicine
Dr. B.R.A IRCH, AIIMS

Dr. Nishkarsh Gupta
Additional Professor
Department of Onco-Anaesthesia and
Palliative Medicine
Dr. B.R.A IRCH, AIIMS

Dr. Vinod Kumar
Additional Professor
Department of Onco-Anaesthesia and
Palliative Medicine
Dr. B.R.A IRCH, AIIMS

Dr. Sachidanand Jee Bharati
Additional Professor
Department of Onco-Anaesthesia and
Palliative Medicine
Dr. B.R.A IRCH, AIIMS

Dr. Anant Mohan
Professor and Head
Department of Pulmonary Medicine
AIIMS, New Delhi

Prof Randeep Guleria
Director, AIIMS