POLICY ON END OF LIFE CARE

1. PURPOSE

To identify the **emotional, psychological** and **spiritual/religious** needs of dying patients and their families.

2. DEFINITIONS AND ABBREVIATIONS

2.1 End of life – Patients who are unlikely to recover. Period of time marked by disability or disease that is progressively worth until death.

2.2 Palliative Care – WHO defines Palliative acre as the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems. The goal of palliative care is achievement of best quality of life for patients & their families.

2.3 Brain dead: As per the Organ transplantation Act, 1994 brain death is defined once a patient meets all these listed criteria:

- Absence of corneal reflex
- Absence of spontaneous respiratory movements
- Absence of pupillary reflex
- Absence of Doll's eye movement
- Positive Modified apnea test
- Metabolic parameters are normal
- Absent cerebral blood flow on Transcranial Doppler
- Positive caloric test

A patient is declared dead only after examination by 2 neurologists or a team of 1 neurologist and 1 anesthetist, to be repeated after 6 hours.

2.4 Life sustaining treatments - Usually but not limited to, artificial ventilation, invasive airway access, invasive vascular access, ionotrope medication, antibiotics and intravenous infusions are considered Life Sustaining treatments.

3. RESPONSIBITY

Nurses, Doctors

4. SCOPE

Hospital wide

5. POLICY

5.1.1(a) Patient Centered Goals:

- Identify patients who require end of life care.
- Document all criteria for end of life care.

5.1.2 (b) Family Centered Goals:

The clinical team (Doctors, Nursing personnel, Counselors) must strengthen their own relationship with the patient's loved ones by:

- Facilitating ongoing communication among family members, and members of the care team.
- Shared decision making between health team and patient/family have to be made and family's consent documented in patient case sheet.
- Supporting families, and caregivers including grief, and follow-up services.

5.1.3 (c) Special Issues in Communicating with families near the time of death:

- Arrangements for the last wishes of patients or request of family members
- Notification of Death.
- Organ Donation
- Paperwork & discharge formalities

5.2 As per the Indian Law, no patient can be denied any form of medical treatment. This includes Cardio-Pulmonary Resuscitation (CPR). Hence, all patients shall receive CPR in case of a Cardio-Pulmonary Arrest.

The Indian Law likewise does not allow withholding of life sustaining treatment from any patient. Hence, all patients shall be given maximum medical care as per the Law of the land. No medical/surgical treatment with be withheld unless the relative give negative consent.

An attending physician or his designee has no right to advise/order for "DNR" or "withdrawal of cardiopulmonary support".

The procedure for an End of life (EOL) order in these patients shall follow the following steps:

5.3 Patient is declared brain dead by 2 Neurologists or 1 neurologist and 1 anesthetist, by strictly applying Brain Death criteria.

5.4 The Primary Consultant shall be responsible for discussing EOL (end of Life) issues with the family members

5.5 The Consultant shall ensure the participation of as many immediate family members as possible, in the discussion.

5.6 The Consultant shall inform the nurse and duty doctors taking care of that patient regarding EOL status.

5.7 All other terminally ill patients shall receive CPR in case of a Cardio-Pulmonary Arrest. The Senior Consultant / Consultant shall convey this to the patient and family.

6.0 Procedure –

6.1 Objectives of end-of-life care

- To achieve a "good death" for any person who is dying, irrespective of the situation, place, diagnosis, or duration of illness
- Emphasis on quality-of-life and quality of death
- Acknowledge that good EOLC is a human right, and every individual has a right to a good, peaceful, and dignified death.

6.2 Personnel Role-

Personnel Role	**Responsibility**
Nursing services	• Coordinates and review care plan. • Ensure nutrition, hydration, and artificial feedings, enteral / parenteral, continue high quality supportive care. • Makes intermittent visits, based on patient needs. • Educate staff and families. • Maintain communication to fulfill plan of care and inform each other of changes in care plan.
Physician Services	• Provide for unmet medical needs related to terminal diagnosis. • Provide palliative care.

	○ Alleviate pain and primary and secondary symptoms using appropriate analgesics ○ Provide hydration. ○ Address ancillary needs. ○ Reassess often.
Medical Social Services, spiritual counseling, dietary counseling	• Provide spiritual, emotional, nutritional counseling. • Frequent communication with family regarding treatment decisions. • Emotional and spiritual support.

6.2 Guidelines –

- Every reasonable effort will be made to relieve pain and other undesirable physical symptoms.
- Emotional, spiritual and personal suffering will be identified, addressed & discussed.
- Prime determinant of every decision will be to make patient comfortable & pain free (if technically feasible) and will also ensure that the attendants are not distressed unduly by the terminal event that will affect the patient.

Patient who have deteriorated to a state such that life is near its end will be cared for as under –

- The relatives will be **informed** politely and clearly about the deterioration and the present scenario.
- There should be multiple counseling sessions of adequate duration.
- The precipitating cause of such an event will be **explained** to the patient.
- **Exception will be made** to visit the patient in ICU at least once when patient deteriorates.
- Family must be given adequate time and opportunity to ask questions and to express their views and emotions.
- Possibility of death should be discussed along with the medical and palliative treatment options.
- It might be useful to remind the family that death is inevitable and medical science cannot offer cure in all situations.
- Decisions may be taken in a step wise manner through discussions until the picture becomes clearer to the family.
- Conflicts may be resolved through improved communications, deferring decisions, seeking second opinions, or a psychologist's consultation.
- Details of communications between the medical team and the family should be documented accurately and completely.

- Terminal care may be offered in ICU, or in other area of the hospital in keeping with the wishes of the family.
- The optimal dose of opiates is determined by increasing the dose until the patient's comfort is ensured.
- Upon death, Next of Kin of patient will be informed about the demise and will be allowed to see the body.
- Medico-legal implication if any will be explained.
- Death certificate will be prepared.
- All invasive lines, ET tube etc will be discontinued and removed.
- Dead body will be cleaned, wrapped in white sheet & placed in body bag (if required).
- Due respect will be given to deceased during handling.
- The body is sent to mortuary and then handed over as per policy.
- Patient should be allowed to every opportunity to experience spiritual meaning and fulfillment & performance of un-obtrusive bedside religious services or rites should be encouraged.(If technically feasible)
- The declaration of the terminal event (death) of the patient should be always communicated to attending family members by the physician in attendance.

If person is diagnosed brain dead:

- Organ donation counseling is given, if condition permits. If it is accepted, then patient is shifted to PGI under maximum care after confirmation from PGI team.
- If does not accept, organ donation, treatment and utmost care will be continued till clinical death.
- No invasive airway device or monitoring line will be removed in hospital premises.
- Any extra requirement of invasive devices or surgery can be withheld after document negative consent.
- CPR can be withheld after consent.

If person is critically ill,

- For relieving the pain initially non sedative opiods are given, then sedative opiods.
- Negative consent for ventilation/invasive monitoring will be considered.
- No withdrawal of artificial airway or stoppage of ventilator will be allowed relative will be encouraged for lama

6.3 Initial assessment and Reassessment of Dying Patient-

- Document the information supporting the team's opinion that the patient is dying.
- Make a plan, in consultation with patient if possible, and involving their relative if appropriate.
- Identify and relevant decisions made in advance.
- Decide about any relevant monitoring/investigations/ interventions.
- Assess symptoms and agree options for symptom control.
- Explore the patient and relative/ care's understanding and concern about the situation.
- Identify the patient's current wishes, beliefs, values and spiritual needs.
- Discuss and agree with patient and their relative (s)/ carer(s) the option regarding hydration and feeding.
- Confirm and document the plan of care and the conversations that have taken place.
- Ensure that any medication or equipment that may be required has been prescribed, is available and has been discussed with the patient and their relative/carer.
- Medication must be prescribed subcutaneously on an as required basis for symptoms that commonly occur at the end of life (pain, agitation, nausea/ vomiting, breathlessness etc).
- Regular reassessment of patients should be done regularly to have their treatment and care needs re-evaluated and addressed. There needs to be a regular communication with patient and their families.
- At least once a day medical assessment and reassessment and 4 hourly nursing assessments should be done.

DEATH AND DYING: SPIRITUAL GUIDELINES in case the attendants request for the same Some cultural/religious observations involve special rituals such as washing and draping of the body. This is usually performed in the hospital area and may take some time (up to 2 hours). Talk to the family to find out what special arrangements may need to be made

	Preparing for death	**Imminent death**	**After death**	**Burial/cremation**
HINDUISM	Hindus will want their family present. They may wish to lie on the floor. They may read from their holy books and sing hymns.	A priest may be requested by a Hindu family. A dying patient should be given Ganges water and a relative may place a Tulsi leaf in their mouth. The name God should be recited.	Do not remove jewelry or religious objects. The family should be allowed to wash the body.	Cremation Only children under three years are buried.

SIKHISM	A dying Sikh, or their relatives, may wish to recite hymns and prayers from their holy book.	A Sikh should die with the name of God, Waheguru being recited. Some may want Amrit, holy water, in their mouth.	Cover the body in plain white sheet. Do not trim any hair. The 5Ks should remain on the body. Relatives may want to wash the body.	Cremation
ISLAM	Family and friends will recite passages from the Qur'an. A dying Muslim should face Mecca (Southeast).	The declaration of faith (shahada) is recited. The dying patient should be helped to respond 'I bear witness that there is no God but God and Muhammad is his Messenger.	Non Muslim should not touch the body with bare skin. The body must be kept covered. It should be washed by a person of the same sex.	Burial
CHRISTIANITY	Some Christians recite prayers; others may request a religious leader. Some will want to be anointed with holy oils by a minister/priests.	A chaplain, minister or priest may be requested to give holy communication, or recite the prayer of commendation.	Some relative may wish for the body to be blessed and the prayers of the dead said. Relatives may wish to say special prayers, place the deceased hands together and place a cross on them.	Both
BUDDHISM	A dying Buddhist needs peace and quiet. They may wish to see a religious lead or monk. They may chant passages of scripture.	A Buddhist needs to die with a clear and conscious mind. They may refuse pain killers. Someone may chant to bring peace.	There are no specifics, this is based upon culture. Ask the family for advice.	Both, according to Local tradition.

Scope of Palliative care in End of Life care-

- Relief of end of life symptoms such as pain, dyspnoea, delirium, respiratory secretions.
- Review of existing care protocols (Medical/Nursing).
- Review of medication chart and stopping unnecessary medications.
- Stopping routine and unnecessary investigations that may not contribute to the process of care.
- Continued communication throughout the process.
- Counseling regarding optimal hydration and food intake.
- Psychosocial support to patient, family and caregivers.
- Meeting special family requests (religious/spiritual/cultural).

Documentation –

- End of life care should be documented in patient file.
- Communication with patient/family about the diagnosis, prognosis of disease should be done and the same should be documented. *(Family Counseling record)*
- Documentation should be done of the evidence that end of life care symptoms were identified and managed properly, resuscitation status, Allowing natural death and End of life care management plan*. (Progress Sheet)*

6.4 END OF LIFE CARE

Signs of End of life / Chronic illness	**Remedial actions to be taken by**
Dry Mouth • Cracks in the side of mouth • Tongue is dry and cracked with deep furrows.	• Use a mouthwash *without* alcohol. • Use a wet wash cloth to moisten the mouth. • Apply Vaseline or lip balm to the lips several times daily. • Use saliva substitutes.
Sore Throat and Mouth • Verbal or facial expression of pain in his/her mouth or throat. • Verbal or facial expression of pain	• Offer soft foods at room temperature. • Avoid spicy, acidic, hard or crunchy foods. • Apply Vaseline or lip balms. • Use lots of liquids.

Taste and smell changes • "Nothing tastes good" • Odors bother him/her • Makes a face when food is served.	• Avoid food with offensive odors (Ginger/garlic/onion) • Remove any lid from the plate prior to serving food. • Offer cold or room temperature foods. • Provide good oral hygiene frequent throughout the day and night. • Do not expose the patient to food odors during preparation.
Diarrhea	• Avoid food that causes diarrhea. • Check for incontinence and clean skin immediately after incontinence episode. • Check for fecal impaction with overflow incontinence. • Use barrier cream as directed.
Nausea and Vomiting	• Avoid physical activity after eating. • Avoid foods likely to aggravate nausea such as fatty, greasy, sweet foods, strong odors.
Constipation	• Chart the frequency of bowel movements. • Increase dietary fibers as tolerated. • Increase fluid intake to 2-3 liters per day, as tolerated. • Increase physical activity.
Other Physical and clinical symptoms	To be managed as per patient physical/clinical condition.

7.0 Implementation- All Hospital Staff will be trained on this. Regular training sessions of doctors, nurses, counselors are taken for the implementation.

8.0 Policy cross linkages- nil

9.0 Attachments – nil