End-of-Life Care: Consensus Statement by Indian Academy of Pediatrics

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Justification: The right to life has been accepted as one of the fundamental rights in our constitution. Resuscitation is a procedure performed for all patients suffering from cardiac or respiratory arrest irrespective of the clinical condition. There are no legal guidelines defining process to be adopted in situations where resuscitation is unlikely to be useful. There are no guidelines on withdrawal of care or end of life (EOL) decisions, accepted by the Government, judiciary, professionals, academicians or the community.

Process: A National Consultative meet was organized by Indian Medico-Legal and Ethics Association and the Medico-legal group of Indian Academy of Pediatrics (IAP) to formulate the guidelines on 'Do Not Resuscitate' (DNR), and 'End of Life Support'. The meeting was organized on 30th May, 2014 at Ram Manohar Lohia Hospital, New Delhi. The meeting involved professionals from legal and various medical fields as well as administrators, and members from Medical Council of India.

Objectives: To frame the guidelines related to EOL care issues and withdrawal or with-holding treatment in situations where outcome of continued treatment is expected to be poor in terms of ultimate survival or quality of life.

Recommendations: (*i*) DNR or end of life care should not be activated till consensus is achieved between treating team and the next of kin; (*ii*) Consensus within health care team (including nurses) needs to be achieved before discussion with family members; (*iii*) Discussion should involve the family members – next of kin and other persons who can influence decisions; (*iv*) If family members want to include their family physician or a prominent person from the community, it should be encouraged. Similarly if family members want a particular member of treating team, he/she should be included; (*v*) Treating doctors should have all the facts of the case including investigations available with them before discussion; (*vi*) Unit in-charge or treating doctor should be responsible for achieving consensus and should initiate the discussion; (*vii*) After presenting the facts of the cases, family members should be encouraged to ask questions and clear doubts (if any); (*viii*) At the end of discussion, a summary of the discussion should be prepared and signed by the next of kin and the unit in-charge or treating doctors; (*ix*) DNR orders should be reviewed in the event of unexpected improvement or on request of next of kin. Same should be documented; (*x*) DNR orders remain valid during transport.

Key words: *Do-Not-Resuscitate Orders, Euthanasia, Resuscitation, Withholding Life support.*

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Resuscitation is a common procedure performed in hospitals for all patients suffering from cardiac or respiratory arrest. Outcome of resuscitation is better in Pediatric age group than in adults. However, even in children, there are situations where hope for an intact survival is poor. Often, short term recovery and subsequent intensive care inflicts physical discomfort for patients and family alike. Family members also suffer mental and financial agony. This has been appreciated by healthcare providers across the world, and efforts have been made to provide meaningful care and graceful end to life, without painful life pending death for patients and feeling of guilt among the parents and family members.

Definitions

*Euthanasia***:** This word is derived from Greek *Eu* and *thanatos* meaning good death. In medical parlance, it refers to acceleration of death by active intervention to alleviate suffering of a person who is in irretrievable situation. It has been amply clarified that euthanasia is essentially voluntary and any intervention against the will is equivalent to murder [1]. Euthanasia is 'active' when a deliberate intervention is undertaken with the express intention of ending life to relieve intractable suffering, and 'passive' when it involves withholding life support system for continuance of life [2].

*End-of-Life care***:** This refers to care of a person who has received a life-limiting diagnosis. It encompasses all aspects of care till the final outcome and care of mortal remains [3].

*Resuscitation***:** It is the process of restoring the cardiac or pulmonary function back to normal, fully or partially, after a cardiac or respiratory arrest.

Do-Not-Resuscitate (DNR) order: This is a treatment decision taken prior to event of cardiac or respiratory arrest, with the consent of patient, or where that is not possible, proxy consent of next of kin, where care providers will not provide requisite cardio-respiratory resuscitation. This does not preclude, or stop to any degree, normal care and treatment being given to the patient **[**4].

THE LEGAL FRAMEWORK

The Constitution of India, Article 21, provides 'Protection of Life' and 'Personal Liberty'. It states that "no person shall be deprived of his life or personal liberty except according to procedure established by law." However, there have been several expansions of article 21 and in its expanded form it assures the right to live with human dignity. Death is universal but dying in a peaceful and dignified manner would be welcome by every individual.

Some persons interpreted the right to life as including right "not to live" or right to death (*P. Rathinam v. Union of India, JT 1994(3) SC 392*). However in this judgment, while accepting right-to-die, euthanasia was not considered viable and was not permitted. Several other judgments, (*Gian Kaur v. State of Punjab, JT 1996 (3) SC 339; C.A. Thomas Master vs Union of India, Kerala HC, 2000 Cri LJ 3729*) have held that right-to-life as enshrined in constitution article 21 does not confer right-to-death. In a recent judgment on a Public Interest Litigation (PIL), Rajasthan High court two judge bench upheld the PIL and held the Jain religious practice of "Santhara or Sallekhana — a practice of deliberate starvation to death" as unconstitutional, and to treat it as suicide punishable under section 309 [5].

WHY DO WE NEED END-OF-LIFE (EOL) DECISIONS?

There are many situations when patients with irreversible or end-stage diseases (where there is very little chance of recovery) remain, on assisted ventilation for days, weeks or months. This is associated with several conflicts:

1. This results in prolongation of 'vegetative life' that may be a source of misery for everyone, especially for the patient and the family.
2. There is a lowering of 'dignity of death' due to futile invasive procedures and unnecessary treatment.
3. There may not be any chance of improvement or survival leading to wastage of resources.
4. It may be a significant burden for the family or society–physically, financially and psychologically.
5. There may be situation where limited resources may be denied to a more 'deserving salvagable individual' because they are 'in use' for a vegetative individual.
6. In some specific situations, there may be need for withdrawing assisted respiratory support; e.g., in cases of brain-stem death that is certified by a board of medical experts.

In spite of the above situations – which happen quite frequently, especially in intensive care unit (ICU) set-up, cancer patients and in some irreversible chronic conditions – there are no legal guidelines in our country regarding withdrawal of care or EOL decisions. There is also no guideline regarding not to initiate resuscitation in conditions where life may not be meaningful after resuscitation.

PROCESS OF FORMING GUIDELINES

A National consultative meeting was organized at RML Hospital, New Delhi on 30th May 2014, where the participants included experts from various relevant fields like academicians from medical fraternity, practicing doctors, intensivists (adult, pediatric and neonatal), lawyers, persons with both legal and medical qualifications, administrators and members from regulatory bodies. Stakeholders like Government of India, Medical Council of India, social organizations, and legal and medical fraternity were represented. Representation from various medical disciplines included Pediatrics, Anesthesia, Oncology, Cardiology and Intensive care.

The consultative meet had four sessions: First session was on legal issues in relation to end-of-life care, protection of patient rights and rights of medical professional, laws related to right to life and deaths. Presentation included cases dealt by Hon'ble Supreme court including judgments. Second session focused on the issues related to care towards the end-of –life, especially in terminally ill patients. Third session reviewed currently available guidelines and literature on the subject. In last session, issues on various aspects of the topic were discussed. Points agreed upon were reiterated and those lacking consensus were further discussed and a broad consensus was achieved. Summary guidelines were prepared and presented. A writing committee was designated. Draft of the write-up was prepared by two members of the writing committee, and was circulated among all members. Suggestions were incorporated in the final write-up.

END-OF-LIFE CARE

End-of-Life Care is defined by National Council for Palliative Care UK [6] as "Helps all those with advanced, progressive, incurable illness to live as well as possible, until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support."

This essentially means not taking up intensive care in the event of a cardiac or respiratory arrest but does not deny continued care, nutrition by oral or oro-gastric or naso-gastric route, pain relief, physiotherapy and other comfort care. It does not mean abandoning a patient after an EOL Care decision is taken.

Ethical Principles

While taking decisions for EOL in any critically sick patient, four ethical principles must be followed [7]:

Autonomy means an individual's rights of freedom and liberty to make changes that affect his or her life. In the right to self-determination, the informed patient has a right to choose the manner of his treatment. In pediatric and neonatal patients either the parents or a legal guardian can take such decisions.

Beneficence is acting in what is (or judged to be) in patient's best interest. The physician is expected to act in the best interests; his responsibility extends beyond medical treatment to ensure compassionate care during the dying process. The physician's expanded goals include facilitating (neither hastening nor delaying) the dying process, avoiding or reducing the sufferings of the patient and his family, providing emotional support and protecting from financial loss. "The best interest calculus generally involves an open ended consideration of factors relating to the treatment decision, including the patient's current condition, degree of pain, loss of dignity, prognosis and the risks, side effects and benefits of each treatment'' [8].

Non-malfeasance means to do no harm, to impose no unnecessary or unacceptable burden upon the patient. This is subject to varied interpretation, as the same act may be considered as harmful or beneficial depending on the circumstances.

Distributive justice means treating patients truthfully and fairly. Physicians need to take a responsible decision and to make good use of the infrastructure, finances and human resources. The physician may thus provide treatment and resources to one with a potentially curable condition over another for whom treatment may be futile.

In cases of resuscitation of newborn, the autonomy of newborn and to take decision in life threatening emergency situations are both exceptions of general rules of ethics.

Dilemma in EOL Decisions

While dealing with a situation that may warrant EOL care decision or discussion, considering above mentioned principles, dilemma arise in the mind of treating doctor. These may be summarized as below:

Legal dilemma

A reasonable amount of certainty is required to take decisions regarding EOL because the probability of dying is not always clear. In many countries, there are set guidelines about when to initiate EOL discussion; however, we do not have definite guidelines agreed upon by professional bodies. There can be questions in relation to which patients can be ascribed as 'approaching the end of life'. GMC guidelines [9] suggest that if a person is likely to die in a period of one year, he/she may be considered as 'approaching the end of life'.

Ethical dilemma

Ethical dilemma arises when the opinions are at variance; *e.g.* one child or parent of the diseased may have difference of opinion from the other. It may so happen that the diseased person is a minor, but is old enough to understand and his/her opinion is different from parent(s). In another situation, opinion of the parent(s) may be detrimental to the baby.

Most of this dilemma can be solved with clear thought process, involvement of senior most physicians in the team, and good communication with the next of kin. However, in Indian social setup, where everyone wants to do 'the best' till the end for social reasons, it may still be difficult to achieve consensus among family members. In such situation, DNR or EOL should not be activated till consensus is achieved.

DO NOT RESUSCITATE

Do Not Resuscitate (DNR) is a clear concept in most developed countries [10]. It does not involve withdrawing life support system where a patient is already on ventilator or inotropes. It also does not involve discontinuing routine care like oxygen, nutrition, fluids (oral intravenous). DNR is like any other treatment decision, and must be adequately documented and communicated to all team members for effective implementation. In India, so far we do not have a clear

legal guideline and accepted method of documentation of DNR [11].

There are two more terms used in this relation; 'withhold LST (Life-sustaining Treatment Measures)', and 'withdraw LST'.

Witholding LST: LST, especially ventilation, central line placement and renal replacement therapy, require consent. Except in the event where none from family is available, and clinical condition of the patient is life-threatening, these should not be initiated without consent. While obtaining informed consent, it is required to inform the patients or attendants about the possible outcome, need or futility of the intervention, what can be expected as a result of such intervention and the cost likely to be incurred (where applicable – likely to be paid by the family) in the process. The same should be documented. Only after such informed consent, if the patient or relatives insist on continued intervention, these should be undertaken. Care should be exercised that refusal of such consent should not result in dilution of basic care to the patient and judgmental statements are not made by the staff working in the unit, which can result in feeling of guilt.

Withdrawing LST: Withdrawing life sustaining treatment is more difficult. It should always be done with clear and repeated discussion till parent(s) or next of kin understand the consequences and concur with the actions being taken and have given written consent for the same. Discussion should involve senior member of the medical team, preferably unit in - charge or the treating doctor. The withdrawal of support should never be done to facilitate use of equipment for another patient who may be potentially salvagable. This should never be used as an argument for counseling for withdrawal of support. The principles and components of 'good death' have been elaborated in ***Box* 1**. These have been modified from the guidelines of Indian Society of Critical Care Medicine and Indian Association of Palliative Care [14, 15].

Box 1 PRINCIPLES OF GOOD DEATH

- To understand the possible time of death
- To be in control of the situation at the time of death
- To die with dignity and privacy to the extent desired
- To be able to get pain relief, control over other symptoms and care including hospice care where available
- To be able to choose the place of death
- To have access to desired information and expertise
- To have access to support required including spiritual and emotional support
- To be able to decide about the presence of near and dear ones and who share the end
- To be able to issue advanced directive ensuring that one's wishes are respected*
- To avoid pointless prolongation of life

* Such provisions do not exist in India. At present, there is an appeal admitted to the Supreme Court on the issue of allowing advance directive.

Modified from Reference number 14 and 15

Clinical Aspects of DNR

Who are the candidates for DNR?

It can be said that situations where resuscitation is not likely to lead to prolonged and useful survival, are the candidates for DNR **(*Box* 2).**

Who are not the candidates for DNR?

DNR should not be activated where:

- patient is unable to pay for advanced care
- the outcome is doubtful (may or may not improve situation)
- there is conflicting opinion among the family members
- responsible next of kin is not available for discussion
- written consent is not available

Box 2: WHO ARE THE CANDIDATES for DNR

- Where life sustaining treatment is likely to be ineffective or futile.
- Where patient has prolonged unconsciousness which is unlikely to recover.
- Where patient has a terminal condition for which there is no definitive therapy.
- Where patient has a chronic debilitating disorder where burden of resuscitation far outweighs the benefits.
- Where medical treatment appears futile. Futile medical treatment is generally defined as "where treatment is useless, ineffective or does not offer a reasonable chance of survival" [12].
- Such other factor that may be unique to the patient e.g., where patient has made an informed living will to refuse CPR [13].

Box 3 WHAT IS DONE AND WHAT IS NOT DONE IF DNR IS ACTIVATED [14]

Even with DNR orders, a health worker will provide basic support in the form of:

- Clear airway
- Provide Oxygen
- Position for comfort
- Splint
- Control bleeding
- Provide pain medication
- Provide emotional support
- Contact hospice or hospital (as hospice facility is hardly available in India)
- With DNR orders, a health care worker is not required to
- Perform chest compressions
- Insert advanced airway
- Administer Cardiac resuscitation drugs
- Provide ventilator assistance including noninvasive ventilation
- Defibrillate

What is done and what is not done if DNR is activated [16] is listed in ***Box* 3**.

DNR Issues in Neonates

Neonates are in a special situation with respect to resuscitation and DNR orders. A clinician may face this situation right at the time of birth or subsequently during treatment. At the time of birth, condition of the baby may be anticipated or may not be anticipated and arise suddenly. Like in all other situations, social, emotional and cultural environment would affect DNR decisions.

Decisions at the time of birth

At the time of birth, two broad situations may demand a decision. First is a baby with congenital anomaly or anomalies that are incompatible or may be compatible with life, but the expected quality of life may be poor or a big drain on resources of family/society. Second situation is where the birth weight and gestational age is such that survival, especially intact survival, may be almost impossible. Where congenital anomalies are known before birth and the time permits, DNR decisions should be discussed with parent(s) and other family members, sometimes elders from society including religious leaders or family physician. If family desires that the baby should be resuscitated and subsequently reassessed for the status with respect to survival and treatment options, this must be honored. Where family agrees with DNR decision, it may be implemented if the baby is found to have expected situation/problem. The decision of DNR may be reversed if doctor finds baby's condition to be different from what was antenatally expected. This should also be explained to parent(s) during discussion on DNR.

Where there had been no opportunity for discussion with parents, baby should be resuscitated fully except in gross anomalies that are incompatible with life *e.g.*, anencephaly [17] or prematurity that is not compatible with life. Decision on prematurity depends on period of viability. With improving survival of babies with lower gestational age [18,19] definition of period of viability has become more difficult. This decision should be based on local survival data and possibility of intact survival in a given setup. However, as a general norm, it can be said that 24 weeks gestation babies are regularly surviving [18] in many centers in our country where tertiary care facilities are available and therefore any baby above this gestation age must be resuscitated in such centers. In centers where tertiary care facilities are not available, babies below 28 weeks gestation are not likely to survive. In such a situation, subsequent management options should be discussed with parents and a decision to resuscitate may be taken based on feasibility of transfer to a tertiary care neonatal unit. It would be prudent to attempt 'in utero' transfer in such situations.

Decision in neonatal units

DNR issues faced in neonatal units are qualitatively same as faced in other intensive care units. However, frequency of congenital anomalies in neonatal units is high and is a prominent reason for a DNR order. In a study from Oman [20], lesions that will not allow meaningful survival (18 of 39) and lesions incompatible with life (15 of 39) were the reasons for a DNR order. Gestational age related reason (below 24 weeks gestation) was present in only 3 of 39 babies where DNR orders were given. This study also highlighted that parents were more comfortable accepting non-initiation of ventilator support (14 of 20 cases where it was proposed) than withdrawal of ventilator support (2 of 19 cases). In this study, 36% of deaths were preceded by a DNR order. This is far less than some of the western studies [21] where the frequency was as high as 68%.

In India, there are hardly any studies on this subject. However, wherever facilities for neonatal care are sparse, the requirement will be more and criteria for DNR order should be customized. While customizing and documenting these criteria, one should be cautious that lack of resources or inability to pay is not a criterion for

DNR decisions in neonatal units, just as they are not in other intensive care units.

Whereas tertiary neonatal intensive care units can use a gestational age criteria of 24 weeks, others like special care neonatal units being setup in district hospitals should use a gestational age cut-off of 28 weeks. Lesions incompatible with life or compatible with poor quality life are the criteria for all neonatal units to follow. It is strongly recommended that each unit should document its own criteria for DNR decisions.

Criteria for Brain Death in Children and Neonates

The diagnosis of brain death is often difficult but essential for counseling, more so while initiating discussion on withdrawal of support. The diagnosis of brain death is based on clinical examination and apnea test conducted twice at an interval of 24 hours for neonates and 12 hours for children beyond 1 month to 18 years of age. Wherever possible, $PaCO_2$ of 20 mm/Hg above the baseline should be documented. There is no role of ancillary tests like electroencephalography (EEG) or radionuclide scan for assessing cerebral blood flow for the diagnosis of brain death–either in neonates or children [21-23].

Counseling

Preparation

Preparation for counseling involves unanimity in the health care team on appropriateness of DNR decision in the given circumstances [24]. Decision to invoke DNR order should first be discussed in the treating team including nurses [24]. Once agreed upon within health care team, further steps to initiate a discussion with the parents/ patient or 'next of kin' should be undertaken.

Team needs to decide on competence of the patient to take a decision, in which case discussion should involve patient himself, unless he/she expresses his/her unwillingness to discuss matter related to death [24, 25]. Where patient is not found competent, members of the family need to be taken into confidence and a next of kin should be identified. In Indian context, often the decision makers are not parents. They may be grandparents, local elders from community or other relatives. These persons must be included in the discussion process. In Indian social scenario, family may desire to include even a family physician or a doctor not working in health care facility where patient is currently being treated [26]. This should be permitted as it is more likely to be helpful rather than a hindrance in taking appropriate decision. Pending such discussion, a DNR order should not be invoked and resuscitation carried out. However, finally only parents should be requested to sign on the papers.

Health care team leader (usually unit in charge or treating doctor) should be aware of all details about patient illness. The records related to patient's illness, including the progress notes, must be reviewed. It may be helpful to keep complete records of the patient, so that the progress (or lack of it) can be discussed based on clinical notes and investigation rather than being seen as the personal opinion of the treating physician.

It is a good social practice to formally introduce the members of health care team. This helps all concerned in understanding each other's perspective and help in breaking ice initially. Discussion should be initiated with the information on patient's illness (past and present), treatment being offered, future plan and benefits or futility of treatment and prognosis. Presence of a living will (though not really prevalent in Indian scenario) should be enquired about. The family members may be asked "what the patient would have done in such a scenario if he/she would have been competent. That may provide a clue to the attitude of the patient (and may be the person replying) towards life or death. This may help the 'next of kin' in decision-making.

Responsibility

It is difficult and stressful to undertake a conversation about death even for experienced clinicians [25,27]. Therefore, usually the senior most doctor (*i.e.*, consultant in charge of the case) should take the responsibility for initiating and completing this discussion [28,29]. However, there may be situations where another member of the health care team has developed an excellent rapport with the patient. This may be junior doctor in the team or even a nurse. In such cases, responsibility may be given to that member and (s) he/she should be supported by other members.

Family and Social Issues Specific for Indian Situation

It is imperative for the counseling team to try and understand the social dynamics and identify the decision maker. In case of an old patient, an assessment of conflict of interest among family members should be explored. It is a common scenario to find that one person agrees with the decision of DNR and other(s) do not. In such situation, it is avoidable to press for the agreement, and it is prudent to call for another session. In Indian scenario and that of other developing countries, where hierarchy of community still exists, it may not be possible to give consent out of free will despite constitutional freedom to do so [26]. Financial issues may be involved, where the person responsible for the payment wants such a

decision whereas others resist [30]. One such situation is where a newborn is delivered and is being taken care of at maternal grandparents' cost. In these situations, it is not unusual to find a family member in agreement with the prognosis and futility of intensive treatment but out of social pressures and culture of 'doing best possible till the last' do not want to discontinue treatment [27]. Such situations should be handled with gradual re-enforcement of clinician's viewpoint and discussion on financial involvement in such situation may be of help, especially where the cost of hospitalization is to be borne out-of-pocket of an individual.

Another area of potential conflict can be where parents (or relatives where parents are not available) ask for abandoning treatment. Female gender of the child may confound this situation. In many parts of our country, first baby is delivered at maternal grandparents' place and at their cost. Here the father and relatives from his side may continue to press for continued treatment whereas maternal side that is bearing the cost of treatment may be more amenable to suggestions on DNR. Where doctors do not agree to DNR decisions, it should never be accepted based on suggestions of parents or relatives. In view of hierarchy of decision-making, which give first right to parents, no decision should be taken against the wishes of the father/mother of the baby.

Hierarchy for decision making [31-35]

There is no description of hierarchy for decision making; in Indian situation, only guidelines available on hierarchy are for inheritance of property. Though not meant for clinical decision-making, they do provide some guidance for similar situation [34] **(*Box* 4).** However, the hierarchy for consent in various situations (*e.g.,* emergency treatment, clinical research) are clearly defined in some other countries and are logically acceptable for decision-making with respect to DNR decisions as well.

Box 4 HIERARCHY FOR DECISION-MAKING*

1. Patient him(her)self so long he/she is competent.
2. Advanced health directive (will seldom be available in actual practice in India).
3. Enduring Guardian (In India, there is no law that recognizes this kind of arrangement. Therefore, this becomes invalid in Indian scenario)
4. Guardian
5. Spouse
6. Child
7. Parent
8. Sibling (who maintain close contact)
9. Unpaid provider of care
10. Anyone who maintains close contact

**Same hierarchy could be valid for consent in situation of DNR*

Process of Consent and Documentation

The process of taking consent involves preparation for discussion. All options in relation to possible alternative treatment strategies should have been discussed within the medical team and agreed upon [24,25,28]. It is useful to have privacy and uninterrupted time for discussion. Sensitivity and empathy are of paramount importance to achieve desired goal. Initiation of discussion should be by elaborating patient's current condition, which should be followed by a discussion on caregiver preference. Information provided should be free of jargon, in simple terms, and in language that relatives can understand. Uncertainties should be explained and also the fact that in the event of a cardio-respiratory arrest, there will not be enough time for discussion. Any distressing signal, verbal or in body language should be addressed. Realistic hope should be provided that is honest but not blunt. Realistic goals of care that is to be continued should be explained. Questions should be encouraged to clarify the situation. This also helps in assessing the mindset of the relatives.

Finally, after the discussion is over, a summary of the discussion should be documented **(*Box* 5).** If DNR is agreed upon, the order should be placed in the case records and the healthcare team should be informed of the same.

Review of DNR Orders

Every DNR order, even where it seems final, should be reviewed at predefined interval and continuation of DNR orders should be documented in the case records at least once in week [25]. However, patients' relatives may request review of the DNR orders. In such case, fresh documentation of discussion and decision taken should be documented. Another reason for revoking the DNR orders could be an unexpected improvement in patients' condition. Where a DNR order is revoked, the reasons for the same should be documented and informed to the relatives, preferably the same people who were present at initial discussion. It is of importance to note that if a patient is being transferred to another facility for care of the patient, DNR orders remains valid. However, it would be a good practice to re-communicate the same to the relatives.

EUTHANASIA

A detailed report was submitted to law ministry in 2012 regarding feasibility of making legislation on euthanasia, taking into the account of earlier 196th report of Law

commission of India [2]. Supreme Court of India laid down the law on the subject of passive euthanasia in relation to incompetent patients who are in persistent vegetative state or in irreversible coma or of unsound mind. For safeguard purpose and to avoid misuse of law, permission from High court will be required before executing passive euthanasia. This law will continue till parliament makes a law on this subject that is now long pending. The commission supported passive euthanasia that is withdrawal of life support measures to dying patients which is different from euthanasia and assisted suicide. The bill entitled "The Medical Treatment of Terminally ill Patients (Protection of Patients and Medical Practitioners) Bill 2006" outlines safeguards to be maintained by attending doctors while taking such a decision.

Permission shall be sought from the jurisdictional District Court/High Court (wherever the latter has original jurisdiction) where treatment is being given to the patient, where the patient is in a persistently vegetative state and chances of revival seem remote. However, according to report of Law commission of India, 2012, Supreme Court has laid the guidelines to seek high court's opinion as mandatory whenever any decision of withdrawal of life support is to be undertaken. The high court then should seek the opinion of three medical experts' committee and also put on notice the close relations and in their absence, the next friend of the patient and the state.

There is also a need to formulate policies on comfort care before death, palliative care and pain relief in terminally ill patients and nutrition policy of these patients.

Box 5 A CHECKLIST FOR THE SUMMARY OF DISCUSSION ON DNR

- Name of the patient:
- Regd. No:
- Diagnosis:
- Prognosis:
- Names of persons involved in discussion:
- Likely outcome of CPR: Unsuccessful
- Preference of the patient: Against CPR/ Undecided / Not Known
- Views of the "person responsible": Against CPR/ Undecided / Not Known/ Wants CPR
- Reasons for decision of DNR / Not advising DNR:
- Goals of treatment: Palliation/ Symptom relief/ Recovery from present episode of illness
- Consultant Responsible for DNR order: Dr……..
- Review Date: dd/mm/yyyy
- Remarks (if any)

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Note: The guidelines may not be long lasting and will change with time. Significant legal issues may arise in the future and hence the guidelines may need revision. The guidelines are not mandatory or binding and the treating team may utilize the prevalent laws to make a decision.

REFERENCES

1. Viela LP, Caramelli P. Knowledge of definition of euthanasia. Study with doctors and caregivers of Alzheimer disease patients. Rev Assoc Med Bras. 2009;55:263-7.
2. Passive Euthanasia- A relook: Law Commission of India 2012. Available from: *http://lawcommissionofindia.nic.in/reports/report241.pdf.* Accessed May 15, 2017.
3. Irish Hospice Foundation Definitions. Available from: *http://hospicefoundation.ie/about-hospice-care/definitions/.* Accessed May 15, 2017.
4. Lofmark R. Do-not-resuscitate orders: Ethical aspects on decision making and communication among physicians, nurses, patients and relatives. Available from: *http://lup.lub.lu.se/search/ws/files/5599819/1693395.pdf.* Accessed May 15, 2017.
5. Nikhil Soni Vs Union of India. Civil WP No. 7414/ 2006 Rajasthan High Court. Available from: *https://indiankanoon.org/doc/173301527/.* Accessed May 15, 2017.
6. Commissioning End of Life Care- National Council for Palliative Care. Initial actions for new commissioners. Available from: *http://www.ncpc.org.uk/sites/default/files/AandE.pdf.* Accessed May 15, 2017.
7. Mohanty BK. Ethics in palliative care. Indian J Palliat Care. 2009; 15:89–92.
8. Passive Euthanasia – A Relook- Report no 241. *Available from: http://lawcommissionofindia.nic.in/reports/report241.pdf.* Accessed May 15, 2017.
9. Treatment and Care towards End of Life. Good Practice in decision making. GMC Guidelines 2010. Available from: *http://www.gmc-uk.org/static/documents/content/Treatment_and_care_towards_the_end_of_life_-_English_1015.pdf* . Accessed May 15, 2017.
10. Chen J, Flabouris A, Bellomo R. The medical emergency team system and not-for-resuscitation orders: results from the MERIT study. Resuscitation. 2008;79:391-7
11. Salins NS, Pai SG, Vidyasagar M, Sobhana M. Ethics and medico-legal aspects of "Not for Resuscitation". Ind J Palliat Care. 2010;16:66-9.
12. Mason JK, Laurie GT. Mason and McCall Smith's Law

and Medical Ethics. 8th ed. Oxford: Oxford University Press, 2011.p.476.
13. Mcquoid-Mason DJ. Emergency Medical Treatment and 'Do Not Resuscitate' orders: When can they be used? South African Med J. 2013;103:1-7.
14. Myatra SN, Salins N, Iyer S. End of Life Care Policy: An integrated Care Plan for Dying. Indian J Crit Care Med. 2014;18:615-635.
15. Macaden SC, Salins N, Muckaden M, Kulkarni P, Joad A, Nirabhawane V, *et al*. End of life care policy for the dying: Consensus position statement of Indian Association of Palliative Care. Ind J Palliat Care. 2014;20:171-81.
16. Emergency Care Do Not Resuscitate order. State of Wisconsin. F-44763 (Rev 08/2015). Available from: *https://www.dhs.wisconsin.gov/forms/f4/f44763.pdf*. Accessed May 15, 2017.
17. Kattwinkel J, Perlman JM, Aziz K, Colby C, Fairchild K, Gallagher J, *et al*. Part 15: Neonatal Resuscitation: 2010 American Heart Association Guidelines for Cardio-pulmonary Resuscitation and Emergency Cardiovascular Care. Circulation. 2010;122:S909-19.
18. Tyson JE, Parikh NA, Langer J, Green C, Higgins RD. Intensive care for extreme prematurity- moving beyond gestational age. N Engl J Med. 2008;358:1672-81.
19. Kong XY, Xu FD, Wu R. Neonatal mortality and morbidity among infants between 24 to 31 complete weeks: A multicenter survey in China from 2013 to 2014. BMC Pediatr. 2016;16:174-81.
20. da Costa DE, Ghazal H, Al Khusaiby S. Do not resuscitate orders and ethical decisions in a neonatal intensive care unit in a Muslim community. Arch Dis Child Fetal Neonatal Ed. 2002;86:F115-9.
21. Mathur M, Ashwal S. Pediatric brain death determination. Semin Neurol. 2015;35:116-24.
22. Sekar KC. Brain death in the newborns. J Perinatol. 2007;27:59-62.
23. Tejedor Torres JC, Garcia AL. Making ethical decisions of limiting vital support to critical newborns. Ann Esp Pediatr. 1997;46:53-9.
24. Clayton JM, Hancock KM, Butow PN, Tattersall MHN, Currow DC. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. Med J Australia. 2007 (suppl);186: S77-S108.
25. Treatment and Care Towards the End of Life: Good Practice in Decision Making. General Medical Council 2010. Available from: *http://www.gmc-uk.org/End_of_life.pdf_32486688.pdf.* Accessed May 15, 2017.
26. Kumar NK. Informed consent: Past and present. Perspect Clin Res. 2013;4:21- 25
27. Mani RK, Amin P, Chawla R. Guidelines for end-of-life and palliative care in Indian intensive care units: ISCCM consensus ethical position statement. Indian J Crit Care Med. 2012; 16:166-81.
28. Emanuel EJ, Fairclough DL,Wolfe P, Emanuel LL. Talking with terminally ill patients and their caregivers about death, dying, and bereavement: is it stressful? Is it helpful? Arch Intern Med. 2004; 164:1999-2004.
29. Schachter L. Talking with terminally ill patients and their caregivers about death, dying, and bereavement: Is it stressful? Is it helpful? Arch Intern Med. 2005;165:1437.
30. Jindal SK. End of life care: A curricular and practice need. J Postgrad Med Edu Res. 2012;46:117-21.
31. Consent: Patients and Doctors Making Decisions Together. Available from: *http://www.gmc-uk.org/static/documents/content/Consent_-_English_0414.pdf*. Accessed May 15, 2017.
32. Guidelines for Withdrawal of Treatment of Irreversibly Critically ill Patients on Assisted Respiratory Support. Available from: *http://pgimer.edu.in/PGIMER_PORTAL/AbstractFilePath?FileType=E&PathKey=ME NUFILES_PATH&FileName=Guidelines04Mar2011152342.pdf*. Accessed May 15, 2017.
33. Consent to Treatment Policy for the Western Australian Health System 2011. Available from: *http://www.health.wa.gov.au/circularsnew/attachments/1135.pdf.* Accessed May 15, 2017.
34. Jiloha RC. Mental Capacity/Testamentary Capacity. Indian Journal of Psychiatry Clinical Practice Guidelines 2009. Available from: *http://www.indianjpsychiatry.org/cpg/cpg2009/article9.pdf.* Accessed May 15, 2017.
35. Mental Capacity Act: Code of Practice. Available from: *http://www3.imperial.ac.uk/pls/portallive/docs/1/51771696.PDF*. Accessed May 15, 2017.

ANNEXURE

List of Participants of National Consultative Meet

Shri Rao Narender Singh, Hon'ble Health & Medical Education Minister-Haryana; Ajay Khera (Deputy Commissioner), MOHFW-GOI, SP Yadav (Member, MCI); RK Mani, Adv MC Gupta, Adv PN Tiwari, Adv. Sushil Gupta, KK Aggarwal, Rishi Bhatia, AS Jaggi, Sudhir Mishra, Kanya Mukhopadhyay, Satish Tiwari (Founder President IMLEA); Rajendra Bangal (Professor, Forensic Medicine & Medicolegal Expert), Balraj S Yadav (Joint Secretary IAP-IYCF), Anjan Bhattacharya, Awadh Pandit, Mugdha Tapdiya, SP Kataria (Professor Radiotherapy, Safdurjang), DV Saharan, Pushpa Bishnoi (Civil Surgeon), Anant Mohan (Professor, Medicine AIIMS), Vishesh Kumar (WHO), Dr Sanjay Wazir (Consultant, Neonatologist), Lata Bhat, VK Goyal, TBS Buxi (Consultant Radiologist, SGRH), Mukul Tiwari, HK Kar (Director RML Hospital), Ashish Jain, Pankaj Garg.