



THE PULMO FACE



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OF PULMOCARE & RESEACH**
THE SPECIAL ISSUE

Practice assistance in dealing
End-of-Life Issues :
a consensus statement



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**Practice assistance in dealing End-of-Life Issues:
A consensus statement**

February, 2013, Kolkata

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The preamble:

Last few decades have observed an exponential growth in the development of technology and knowledge in medicine. Keeping abreast with that, the practice of medicine has also changed with the change in attitude to life.

This issue of 'End-of-life care' (EoLC) has, thus, turned a very important one to demand a special attention as the number of elderly population is rising and the quality of possible care has changed with the cost of treatment being hugely escalated in the recent past. The outlook towards the EoLC too has shown a paradigm shift with emergence of areas of conflicts and concerns in every society.

The 'End-of-life-Care' in India has remained largely an issue of contention witnessing, at times, unnecessary stress and financial burden to the family of the sufferer and the community at large. These often create room for misunderstanding the caregivers and even lead to unwarranted reactions from the family and friends of the deceased or suffering patients.

Although the issue remains a dynamic one, we wish to give it a structured shape based on pragmatic and ethical decisions so as to present the caregivers an outline for offering the best possible holistic care to an individual at the 'end-of-life situations'.

Consciously we did not look for any literature or guideline since we wanted to avoid being guided by the minds of others and we felt that our statement should evolve from our experience from the ground reality only. This draft is meant to assist our doctors and the healthcare workers involved in 'End-of-life-care' in their day to day practice where they always try to balance expectations against varied and most often inadequate logistic and infrastructural supports. Very clearly, our motive is to help out our colleagues in the real world situations and we do not wish to indulge in making a "guideline".

In our country in particular, the complexity of the situation has been enormous and one need to take profound precautions to avoid being misunderstood and/ or misinterpreted since both the legal and ethical issues are entangled simultaneously with emotional and economic involvements especially in an end of life care situation leaving aside the question of infrastructural and logistic support. True but sadly, the law of the land is not clear in many areas to deal with the related issues without difficulty. Unfortunately, LAMA (leave against medical advice) or DORB (discharge against risk bond) is a reality for the terminal patients where the physician

often passively allows it for fear of legal hassles. This depicts the weakness of the system and helplessness of the caregiver.

Many important areas may have been left out or in the draft; we wish to apologize for our limitations and hope that the weaknesses can be treated in future.

It will mean a real reward for us if the draft attracts the attention of the concerned people and the intelligentsia of the country to make a change in real life practice.

Dr Parthasarathi Bhattacharyya,

On behalf of the executive committee and the Institute of Pulmocare and Research.

Mode of formation :

- a) Upon decision of making such effort on a co-incident discussion within a few of the members the plan of sitting on a meeting was done. The invitees were limited in number, the attendance was even smaller and in the meeting everyone was allowed to speak to his or her best freely. It was very difficult to come out of a consensus from such free talks and cross talks but one or two of us took the pain to jot down the key points of discussion that rolled down even to the dining table. It was decided that the consensus will not include any reference from existing literature and it will be formed purely on the basis of the experience and opinion of the executive committee.
- b) Accordingly, an outline of a prospective consensus statement was drafted by to of our members separately after the meeting, and this followed free interaction on internet, discussion on telephone, and a few one to one meetings for inputs again. Thus, the draft was edited and re-edited to the present shape.
- c) A second meeting was called for and here we invited people from different other walks of life as teacher, journalist, housewife, legal practitioner, retired persons and others for their inputs. They were handed over with the provisional draft at least seven days prior to the meeting for positive feedbacks
- d) The final draft has been prepared following discussion amongst the members in a second meeting and also considering valuable suggestions from Dr Suhita Chatterjee and Joydeep Sengupta of the department of social studies, IIT Kharagpur. All the executive members signed the draft and separately with details of their assignments.

The Consensus

What is End-of-Life care (EoLC)?

There may be many opinions regarding the definition of the term but we have simplified it in the following-

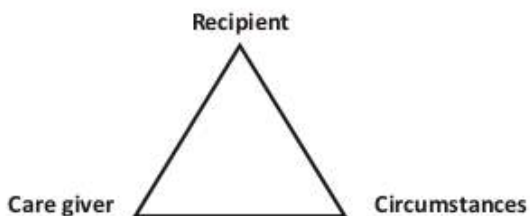
'End-of-life care' EoLC means providing the best possible physical, emotional, and spiritual support to a person in whom a) the putative cause of death, even not imminent, is known and b) in essence, the patient has reached a state of 'no possible return' from the ailment(s) and any attempt of medical intervention is futile.

Such situation demands services that are:

- 1) Appropriate to the age and severity of ailment before initiating and delivering EoLC services. Patient's autonomy to express choice of services also remains an overall ethical issue in the hospital set-up.
- 2) Compassionate by listening and respecting patient's wishes during their last phase of life. Developing greater sensibility to their sentiments that have strong affiliation to their religious sentiments, cultural values and sentiments.
- 3) Cost-effective and
- 4) Long-term and holistic in nature that not only includes the suffering individual, but to the concerned family at large. This involves providing adequate emotional counseling to the dying patient and to the family members before and after death of the patient.

The End-of-life care can be framed involving the three angles of a so called care triangle depicted below.

The care triangle:



The definition of each angle is prepared as:

- a) Care-givers: although the term can be applied to anybody been involved in the patient's treatment; a care giver may be a doctor, a nursing staff, or even a patient's relative individually or as a member of a team, a physician / doctor remains the leader and usually denoted as 'care-givers'.
- b) Recipient: the person receiving the care is the 'recipient'; his or her age, diagnosis, pre-morbid health status, state of the illness, requirement of the details of support, etc. are important areas of concern.
- c) Circumstances: is the situation or setting in which the care is provided. The circumstances can either relate to the recipient as mentioned or it may involve socioeconomic, cultural, emotional, and other issues relating to the recipient and his or her family or it may mean the quality and quantity of the infrastructural and manpower support. Some difficult and uncommon situations may be denoted as 'special' circumstances.

Areas of concern for the care givers:

The following are the areas of concern to a care giver

1. Disclosure of the ailment and the prognosis
2. Assessment of several related issues
3. Arrangements for necessary supports
4. Performing the delivery of the care
5. Making the departure respectful

Elaboration of the individual areas can be done as

1. Disclosure of the ailment and the prognosis: Disclosure means opening the facts about the diagnosis and the likely point of no return from the ailment with possible investigations, interventions, treatment options, the life expectancy, and the mode of demise. The disclosure in its extent and quality depends

upon the subject (sufferer) in concern and the circumstances in consideration. The following issues are very important for disclosure:

- a) **To whom** : A disclosure needs to be done to the patient and / or patient's relatives depending upon the situation. When the patient is unconscious or unable to register or make a communiqué, the patient's family needs to be taken into confidence with subsequent disclosure. On the other hand if the patient is alert, cognitive, and capable to communicate, it needs to be divulged to him or her. In the process, the family in concern may be incorporated to do the job smoothly and effectively.

The issue holds a strong medico-legal importance as well. The detailed procedure of the discussion and disclosure should be written down in the BHT (bed head ticket) and it should be countersigned by a representative of the relatives –better by the closest relative, if possible. For disclosure and further discussion, it is often convenient for the care-giver to choose one or two specific member / members from a patient's relatives and friends who will be consistently attending the doctor and the medical bulletin so that the rest of the relatives can be referred to them for details. Choosing the 'decider' in the patient's family is akin to something like spotting the 'decision power of an attorney', but the disclosure to the decider should be done in the presence of a witness [family member or friend]. A doctor / caregiver should be brief but specific as far as possible. Regarding the disclosure to a patient, one should be extra cautious. It has to be done according to the merit of the case and the circumstantial conditions and one should not hurry. One may not disclose everything at the outset but should set up the ground before disclosure about a serious disease and the consequences and should be cautious that at no stage he or she spoils the hope of the patient. In

course of time the patient comes to know the likely outcome often himself; he should be supported emotionally and the caregivers must behave in a fashion that they are doing best possible. Each case should be dealt with individual merit; it is often difficult to speak the truth on face of the patient but at the same time to suppress it will be an unethical and a wrong course of action. When a patient wants to know the diagnosis and the prognosis with objectivity having background reasons for that (asset management etc.) he or she may be briefed with relatives around.

- b) **By whom** : This remains an important issue; although the physician is expected to divulge all facts and expectations, it is not fair to put the whole pressure on physician solely especially in our country, where doctors are over worked. Moreover at times, doctors are not the suitable people to do the job. This has to be decided on the merit of the situation and preferably a doctor's involvement should be as brief as possible in counseling as far the time management is concerned. Yes, a doctor has to be in the process and he must have support personnel trained in such job. The concerned hospital setting need to involve professional psychologist, psycho-therapist, religious persons, social workers, in the process. Experienced and responsible people from the patients' relatives can also be included in the process to prepare the ground. Unfortunately, in many circumstances, there is no provision to assist doctors during the process of disclosure. Often such experiences are emotionally stressful that inhibit doctors to give more time to treatment. Almost always the treating physician only is expected to speak out the truth regarding a patient's outcome; this demand may be natural but the healthcare infrastructures need to look at this issue seriously to evolve and arrange an effective system to reduce the stress upon the doctor to

prevent compassion fatigue and allow him more time to focus on the overall standard of care. The committee has decided to add a small appendix regarding the role of social workers in the process of EoLC.

- c) **What all to disclose** : The diagnosis, investigations, the prospective treatments, life expectancy, possible mode of demise, and other End-of-life issues including the cost of treatment.
- d) **When and where** : Disclosure can be done at the first consultation or may be delayed for preparing the ground and restricting the emotional overtone and like situations. There cannot be a formula in this regard and this has to be done again on individual merit.
- **The setting** : Acute or chronic in acute setting (either medical or surgical), the issue of disclosure mainly involve the relatives. Since, the prognosis of acute illness is often difficult to ascertain and the patient often remains not in a state to appreciate the details of the impact of the illness, it is very important to divulge the diagnosis and the expectations to the relatives and friends from the beginning and update them intermittently. On the contrary, in a sub-acute (over weeks) or chronic (weeks to months) situation, the patient's wishes need to be addressed preferably in presence of the relatives / friends / attendants.
- **Dealing emotions** : This happens more in acute illness when the relatives and the friends of the sufferer emotionally stressed. Such emotional overtone may lead to problem of disbelief, denial, or even hostility at times towards the entire set-up of care giving. Hence, such difficult situations need to be addressed compassionately and with much more patience. Therefore, choosing right people from the relations / party and gradual disclosure with psychological support may remain the key to success.

- **Circumstantially difficult situations** : When the disclosure of the illness and the possible complication as death can destabilize the family and the friends emotionally, financially, or otherwise. Or there could be situations when a disclosure can lead to outrage of anger and can cause problem of law and order. Hence, it is very important to judge the circumstance in question and act tactfully and ethically to do the job of disclosure as it is essential in the course of treating the patient and the subsequent consequences out of the disease or the treatment. Involvement of experienced colleagues in such situation is recommended.

Another circumstantially difficult situation is when the patient is a minor, or has cognitive limitations for illness or other causes the process of disclosure should take into account the conference with the patient's relatives.

Some practice tips:

- If the disclosure is done to a friend or a relative, it is important to identify the right person for receiving the information with documentation of the fact and the procedure that the disclosure is done; a one or two line statement as 'the basic problem and the prospect of treatment with the no/bleak hope of recovery of (name of the patient) has been conveyed in details to (name of the person receiving the information with address, relationship with the patient)' to be followed by procuring the signature of the said person and that of a witness too. It is better to have a witness from the patient's relations if available or a third party or, in need, or even a hospital staff (in night hours when none else is available).
- In case of severe pain and suffering, the situation should not be considered as circumstantial difficult. Doctors can go on with high dose of sedatives for a length of time. Similarly, brain death should not be regarded as "difficult" and relations need to be declared about them.

- **how to disclose** : The person disclosing must be most humble and gentle, but yet authoritative, bold, and imperturbable. The process should involve a brief but exact description of the illness with the likely prognosis and options of treatment feasible under the circumstances.
- It should be done on individual merit to whom the disclosure should be done and the job can be accomplished through priming by the relatives and friends. It is wise to inform and prime as many persons as possible in single sitting/session. A regular medical bulletin or a public display system (for the conditions of all patients) may be helpful in the process to prepare the relatives before disclosure. It is important to deal each case in individual merit to decide how far to go in priming for disclosure as this bit of effort determines the smooth accomplishment of the rest of the job and helps to avoid a lot of hassles and misunderstandings in future.
- Before making a disclosure, one has to judge regarding the following issues categorically; the place, the person, the time, and the circumstances. All of these are equally important in this regard and none but your experience is the best friend to help you. For junior colleagues, at times, it is wise to refrain from making the final comments but to express the concern regarding the gravity of the likely situation with the likely outcome and call a senior colleague providing him the background and the other details. In such cases, it should be a must to disclose to the senior regarding your impression about the patient and the relations, the briefing that has already been done by you to the relatives so that the senior can deal with the whole situation in a better fashion. Sometimes, the patient's relations can react hostile and in such cases the involvement of senior and experienced colleague is helpful especially from the medico-legal point of view.

- At no point of time, whatever be the situation, it should appear that the caregivers are more concerned with paperwork than treating a patient.

2. ***Assessment of several related issues*** : Before the process of disclosure and the arrangement of the end of the life care, the assessment of the patient and his or her circumstances including the realities as regards his family and social commitments, the likely financial assault to the family etc. are to be assessed. There are issues in the assessment process that appear important for the care and the disclosure as well. They can be listed and elaborated as.

- a) ***Survival chance*** : A possible expected duration of survival needs to be judged whenever possible but divulging an expected period of survival has to be done with caution with adequate flexibility and inclusion of even a very bleak chance of recovery in certain situations especially with illnesses having an infective or metabolic backgrounds. It should be amply cleared that the mean survival, when available for a particular diagnosis or for a particular disease in a particular state (e.g., stage IV cancer of lung) as per the knowledge from literature cannot be applied to a single patient.

Simultaneous assessment of the likely mode of demise is desirable. In case, investigations are available, they should be brought in to convince the party with evidence-if required; using a standard text book for reference may be helpful to convince the relatives.

- b) ***Level of prospective suffering*** : There is no guideline to understand this but, a prospective functional status may be assessed and depicted based on the primary disease and the co-morbidities.
- c) ***Scopes of relief*** : The possible scope of relief for a likely oncoming suffering needs to be thought of and brought into the discussion.
- d) ***Whether that maximum possible has been***

done and communicated : Under a given circumstances the maximum possible care for the sufferer should be done, declared, and reiterated keeping in view the level of possible/affordable / offer able treatment. At the same time, the provision of other supports, if available, at somewhere else should also be stated and, if necessary, elaborated. The party (the patient's relatives and friends) should be allowed, if they wish, to take the patient to another center to avoid misunderstanding. This needs to be documented too if there is real limitation of a center to provide the discussed level of care for a particular patient.

- e) **Assessment of the likely acceptance** : The likely acceptance of the disclosure information needs to be assessed to act properly in the procedure as stated above
- f) **Financial support** : The issue of the expenses needs to be brought into the picture especially in situations of financial constraints for the patient's relatives and alternatives arrangements at the state run institutes or other places should be highlighted to assist the relatives.
- g) **Social support** : Such support to the anxious patient or the relatives is a very important issue. Though not a caretaker's prerogative, it can be subtly dealt with suggestions, assurance, and the participation of the social workers. We have seen that, at times, referring to the God and praying in desperate cases may help to ease the situation.
- h) **Understanding the liabilities of the sufferers** : Though this is not a direct scope of work of the caregivers, the understanding of the liabilities of a patient may help to reassure him properly and mobilizing support for him as a well wisher. Even listening to the liabilities and frustrations of a sufferer may help him to cope up with the destiny. Here again, referring to the 'GOD' may help a distressed mind enormously.

i) **Expectations of the patient** : It is very important to understand the expectations of a sufferer; the system and the caregiver should try honestly to take care of the issues raised by the patient. The medical support can be modified, and the caregivers must inform and insist the system to take care of the non medical expectations.

j) **Others** : There may be other issues relevant in a particular situation and patient; it has to be dealt in individual merit.

Practice point :

- At times we have observed that a written summary or a photocopy of the BHT with the investigations help a lot in the course of disclosure and the end of the life care when these are handed over to the party seeking suggestion from known / unknown colleagues and freely inviting a doctor of the party's choice to see the patient and even allowing the doctor to take part in the process of decision making. In the process, it appears easy to interact with a doctor or an experienced person, if available, from the patient's party than to lay people in most of the time. Such handing over of a document should always be brought to the notice of the hospital management.
- In a difficult situation, the concerned doctor should always maintain a constant liaison with the hospital authority to keep it directly and officially involved in the process and this should be documented at the bed head ticket. At any point, it should not appear that the hospital management is unaware of the developments in the ward or the ICU. It is also the responsibility of the hospital management to take these issues into account seriously but gently enough so that the process does not disturb the very purpose or the spirit of proving the best possible support to the sufferer and the relatives or the people in concern.

3. **Arrangements for necessary supports** : The delivery of the care cannot come out of the

blue; it needs to be facilitated by the entire gamut of other arrangements like, appropriate infrastructure, logistics, and human resource) and such support system has to be functional and available to the caregivers. Ironically and sadly, this area is grossly neglected amidst high expectations of performance (which most often is restricted to the treating physician); even ethical issues often crop up in this area for lack of understanding and adequate support.

Practice point : Here, if asked by the patients' family, the doctor or the caregivers should try to remain as frank as possible to the patient and the relatives to disclose the very available facilities at the outset and express the limitations under a given circumstances to deal with a likely particular crisis. Suggestion, if felt necessary, at this stage to take the patient at the better center is practical and ethical as well. A good communication with the patient and the relatives at every step is important.

Apart, this issue regarding 'arrangement' includes many important things listed below and they should be arranged as best as possible and the doctor or the care giving team should try their best to offer the best possible care in a given circumstances.

- Stay; hospital / home/ others
- Support: basic care / intermediate care/near total care/total care
- Nutrition/ cleaning
- Medication
- Palliation : pain/others
- Possible prevention of complications related to the disease or treatment
- DNR (do not resuscitate)
- Resuscitation arrangements
- Mental and spiritual support

4. Performing the delivery of the care : At times it happens that despite the availability of the

support system, the patient does not get the optimum care. If this comes from the flaw of the delivery system, it should be dealt with firmly and no excuse should be entertained in cases of genuine lapses from lack of involvement and commitment. A dynamic auditing, training, and motivating system has to be kept in place to let the system work. One should not forget the human issues in this job. The physician or a member of the care giving team may suffer from compassion fatigue. It should be the responsibility of the system to take care of the issue. Ideally, the caregivers take the highest stress and highest kind of risk of occupational hazard in the society; they should be highly compensated with respect and remunerations. There is also need for supplementary capacity building of the doctors and other care givers in dealing emotions, communications, etc.

5. Making the departure respectful : This is one of the most important of all in all the 'End-of-life' care universally. It includes not only the offering of physical comfort, mental and emotional support, but also respecting the dying patient / patient in care as a human being till his last breath irrespective of his caste, creed, and religion; one should try all out to imbibe 'empathy' for the sufferer. The process includes efforts to make the end of the life comfortable as well. In this regard, some basic examples are listed below that need attention:

- i) physical pain : analgesic and sedatives
- ii) psychosis, depression, anxiety: appropriate psychotropic care with psychotherapy, behavioral therapy
- iii) Dyspnoea: oxygen and other medications according to the cause
- iv) cardiovascular symptoms: appropriate care
- v) Bleeding, bed sore, mouth ulcer, constipation with abdominal distension, and other problems: appropriate care.

To respect the deceased : After the demise, the caregiver team should always show sympathy to the bereaved family, act to help them to accomplish the formalities at the hospital, try and take proper care of the carcass, and hand over the dead body being cleaned and wrapped nicely with clean cloth. Even beyond, a telephone call from the care giver team after the cremation or the social rites makes it sense

strongly positive and brings a lot of respect and feeling for the care givers. It also makes a positive social impact in favor of the care giver and the infrastructure. Here, the hospital should incorporate an active and effective role of social workers who can do the whole job showing a genuine intention with keeping an effective liaison with the physician in charge.

Appendices

Appendix -1

DNR (do not resuscitate)

- a) **Definition :** It is a voluntary and willful declaration by a 'competent' sufferer or his or her nearest kin / people in case the sufferer is incapable (in coma, dementia, or incapable to take a valid decision about his health) requesting the caregiver not to try resuscitation (CPR) in case of any acute development that can be the terminating event for his or her life.
- b) **When to do :** When the disease state of the patient has reached a state of 'no return' on consensus by more than one doctor and the competent patient or his or her legally responsible kin's / relatives unanimously express the desire to withhold further intervention to prolong the suffering that has been such enormous that mere prolongation of the life span would likely prolong the suffering only.
- c) **How to do :** The process will start following the disclosure and subsequent discussion with the patient or the available responsible relatives (legally responsible). If after learning the fact of a 'state of no return' and or 'futile' prospect of any intervention, the patient or the legally responsible relations spontaneously wishes not to indulge in introduction / enhancement of life support or resuscitative measures, he or she may be allowed to sign a DNR form.

The process will include

- Identification of the patient and
- Documentation of the diagnosis with documentation of the process of disclosure and the discussion (may be audio / video recorded)
- Documentation of the desire expressed by the patient
- Documentation of the presence and involvement of the patient's relatives (preferable)
- Documentation that the DNR has been done under no duress what so ever
- Documentation of the presence of witness

In this regard, the members of the consensus committee referred to an instruction been used in some hospital made in spirit of the judgment of the Honourable Supreme Court of India as **"Patient's family members including the signatory (whose signature is in the admission form) should write in their own language, under no duress about their decisions for DNR (limited /complete) in the BHT stating that they have understood every bit of the doctor's proclamation prior to signing the DNR declaration in the BHT "**

The patient should be asked repeatedly, if possible, in different occasions regarding his thought / mind and the decision before or even after signing the DNR form. This should also get documented.

In case the patient is unable to communicate, and

the relatives are insisting the DNR, it should be and has to be on record and more than one member of the care-giving team need to be involved in the process;

they need to sign the document with more than one witness with one at least from the relatives.

d) When not to follow a DNR?

Such situation can develop very rarely and may be listed as

- i) The basic diagnosis is proved wrong and the outlook appears different than that previously thought of
- ii) The patient / relatives decides to drift from the previous decision and puts it in writing jointly and the decision been endorsed in writing by the previous signatory in particular
- iii) The DNR decision by one relative is challenged by another relative in writing
- iv) When the suspected episode of insult is likely reversible and can be managed well (e.g., hypoglycemia) and the patient may be salvaged
- How far it implies to the doctor and the health care worker if the patient is unable to communicate but the relations want not to respect his expressed desire or if the relatives give DNR request when the patient was

unconscious but has subsequently regained consciousness but yet unable to express the desire.

- Who all should be present in the DNR process?
- To which extent a DNR order is applicable; can it be a restricted DNR as 'do not intubate' or like 'do not resuscitate'?
- What is the present legal status of DNR order in India and what is the officially recommended procedure of DNR?
- What should be the ideal script for a format of disclosure / DNR order?

e) Areas of conflict relating to the DNR order

Incidentally, there are no legal directives for the act of DNR in India. The committee members felt it unfortunate and accept the fact that the paucity of legal provisions has been making the issue difficult to address. They are of opinion that more than an external directive, DNR order can be an in-built process taking shape during the course of patient-doctor interaction. There are evidences of DNR orders in India. However, very importantly, DNR order needs to be evolved as part of the service delivery protocols in a hospital set-up. There are, in fact, many cases where 'witnessed arrest' occurs. A proxy consent or surrogate decision from the family after attending a detailed procedural discussion with the physician or his official proxy can be useful in framing DNR orders.

Appendix: 2

The art of disclosure:

A lot has been discussed under disclosure; the art cannot be taught as mathematics but some guidance can be provided. This is to be done absolutely on the individual merit of each case with unique individualized approach. Two important things are essential before disclosure on the part of a caregiver; they remain as (a) the preparation (b) communication.

a) The preparatory : Actions also assist the communication. This preparation involves the

whole environment of the system in use where the friendly and assuring a congenial ambience created by all level of health care workers (even including the cleaning staff). This needs right recruitment with consistent leaning and attitude building for the HCWs including the supporting staffs. It is also important to take the relatives of the patients in the course of action for the disclosure provided it appears feasible and helpful. A doctor/nursing staff/HCW from a patient's relatives is often helpful to assist the

job.

- b) The communication :** Should be done in a friendly and assuring ambience where the doctor/caregiver will try to understand the patient's mind with all possible efforts being imparted to offer comfort. A casual chat with target to understand the person's mindset, anxieties, liabilities etc. etc. can be immensely helpful in the understanding his outlook and

expectations. We have observed that "God believing" people can often accept things in much calm way than others. Sometimes very objective persons can self-appreciate his status and it becomes easy to communicate the disclosure. The delivery however should be cautious, calculative and may be fragmented into multiple sections. As a primary prerequisite, expression of support and hope will always prevails in the process.

Appendix -3 : The proposed infrastructure

As per the infrastructure issue is concerned, there are mainly two considerations as a) the required infrastructure and b) the available infrastructure. Since, the EoLC issue may involve very sick patients in one hand and apparently healthy individuals on the other; chronic patients in one extreme with acutely ill subjects on the other, the very care may involve support of different kinds and degrees pertaining to different situations in concern.

It appeared important to the consensus committee to lay out some concept of basic infrastructures to address the 'End-of-life-care' in our part of the world. Not all health care infrastructures have similar facilities and trained personnel to address an EoLC. Therefore, it is important for the authority of the healthcare system (management of the infrastructure in concern) to make necessary arrangements for equipments and human resources including specialist physicians and nurses with the requisite competence and experience to deal with 'End-of-life' situations. Immediate operational research is needed to understand the ground reality with the prospect and feasibility of setting up a proper referral chain mechanism among all the hospitals alongside making a coordinated database for enabling the patients move from one facility point to the other as per their choice.

In addition, it is important to make provisions to customize the available guidelines without

compromising the spirit and the quality of the 'End of life' care.

The committee feels that both the facilities and the limitations of an infrastructure should be published or divulged to a sick patient and his or her relatives at the at the time of admission itself especially pertaining to the situation for 'End of life' support so that the patient and/ or their relations can act accordingly with pragmatic expectations.

In short of any defined information, the members have expressed their experience and concerns regarding the paucity of support at the grass root level infrastructures and further articulated that a bare minimum of facilities are needed even at the remotest corner of the country. **The discussion led to a proposal to make the facilities available in three levels of set ups arbitrarily for convenience.**

(see below) It implies again that following such a scheme will ensure at least the basic facilities to be available everywhere and make it a room for death with respect and the minimum satisfaction of being taken care of at any from the view point of the relatives at any corner of the country. The members appreciate that still a huge number of deaths in the country take place in home not by choice, but for compulsions from lack of support structures and

This proposed arbitrary classification of healthcare infrastructures should be reviewed and modified regularly (may be every three years).

The proposed three levels of setups as discussed

a) The proposed basic (grass root) level support

Level	Physical infrastructure	Manpower	Ancillaries
Basic	<ul style="list-style-type: none"> • Cot with provision to prop up • Oxygen • Feeding systems • Basic care support • ECG monitor and defibrillator • Pulse oximeter • Intubation set and ambo bag • Necessary medicines • Medicine tray with emergency medicines • Adequate sterilizing system 	<ul style="list-style-type: none"> • Doctor* • Nursing staff • Trained attendants 	Access to books, video, audio, Access of relatives, social worker, priests, and others to meet for mental support Access for interactions and meeting personal desires Others

b) The intermediate level where the patients are brought as a primary referral point (viz., rural hospital, district level hospitals, and small private hospitals)

Level	Physical infrastructure	Manpower	Ancillaries
Intermediate	<ul style="list-style-type: none"> • Same as the basic level • Emergency cart containing all necessary medicines • Non invasive Ventilator • Pulse generator 	<ul style="list-style-type: none"> • Trained attendants • Nursing staff • Doctor 	Same as the basic level

c) The advanced level (teaching hospitals and private hospitals above 100 beds)

Level	Physical infrastructure	Manpower	Ancillaries
Advanced	<ul style="list-style-type: none"> • Same as the intermediate level support • Non invasive Ventilation and Invasive ventilation access • Pulse generator • Others: advanced support system as ECMO etc • Dialysis/ hemoperfusion • Tracheostomy arrangement • Arterial line and hemodynamic monitoring system • CVP transducer • Swan-gaunz catheter with transducers • Others 	<ul style="list-style-type: none"> • Trained attendants • Nursing staff • Doctor • Intensivists and access to other category of specialists 	Same as the basic level

** The members feel that, though the issue is not in the contemplation of the committee to discuss, in many rural health infrastructures (both public and private), the round the clock availability of doctor /doctors is still a concern. The situation merits urgent attention for improvement.*

Appendix 4:

Regarding the role of a social worker in EoLC

The committee feels that the role of a social worker in the process of EoLC is very important and applies to

- a) Making a rapport with the patient and the relatives to
 - Understand their demand / expectations
 - Capacity to afford
 - Social and logistic difficulties
- a) Making a bridge between the physician and the family members of a patient in concern. The same implies for the hospital authority and the relations,
- b) Taking active part in counseling and selecting the proper representatives from the patients relatives and friends for regular official communication,
- c) Understanding and apprehending in advance

the difficulties in future disclosures and appropriately priming the physician and the hospital management to act accordingly,

- d) Helping the process of disclosure
- e) Helping to act to arrange support for the relatives

Taking care of the situation after the demise that includes making arrangements for proper hand over of the dead-body and showing compassionate gesture on behalf of the system (hospital) and the physician concerned.

The committee is of opinion that the involvement of social workers is a must in any healthcare system and proper education and capacity building of them has to be taken up and reviewed intermittently. A competent and professional social worker can be tremendously helpful and cost effective in the process of an end of life care.

Appendix 5 : Special circumstances

1. When not to allow relatives : the following are the situations when a patient's relatives can be barred to remain in the process of 'End-of-life 'care.

- a) When their presence or involvement appear to pose problem in management
- b) When such presence is not desired by the patient
- c) When such presence may add emotional stress to the patient

These issues remains a physician's prerogative only and needs to be documented by more than one observes especially when such debarring is done despite the request by the relatives etc. and the hospital management must be informed to accomplish the job. Such situation likely to occur rarely and the concerned physician / HCWs will refer the issue to the hospital management immediately to get the system involved in the course of action to assist, guide, and share the responsibilities.

Any bulletin / publication regarding the patient's status shall ideally be done through the hospital

administration only and the direct or immediate caregivers (doctor or nursing staff on duty) should involve the physician in charge and the hospital administration as and when felt necessary and especially at a situation appearing special or exceptional. It is to be kept in mind that the physician or a member of the care-giving team represent the whole system and an action is not a solo act or decision for an EoLC and the hospital administration / management also remains responsible for any unwarranted development. Therefore, sharing the responsibility officially will help to ease ethical and legal pressure upon the caregiver. This kind of sharing responsibility officially simultaneous to acting for the interest of the patient is equivalent to sharing headache and endorsing probably a better care to the sufferer officially.

Conflicts pertaining to a doctor :

At times the diagnosis is written on the patient's face / body or on an investigation as chest x ray. However, confirmation is required to offer

treatment and remain medico legally sound while any invasive procedure (needed to confirm a diagnosis) may be detrimental to a patient. In such circumstances doctors can be at a fix or dilemma. The patient may ask like “doc, shall I survive?” Such question can emotionally affect a doctor who is also a human being.

The consensus committee talked freely on several such issues and came out with a recommendation that a) One should remain as far as neutral to judge such circumstances, b) One should think simultaneously of his/her course of action in the same or similar situation had the patient been a relative/friend of the doctor concern, c) In such cases, the involved physician is desired to express freely his/her opinion without imposing it on the patient or the relations so that they can take a free and willful decision. A statement likes “I would not have done the bronchoscopy had he been my father; however, it is up to you to decide. The risk is high; the procedure is needed to confirm a likely cancer. In case you agree with high risk consent, we will take all possible precautions for the procedure. But despite that, he may suffer or even die as a result of the intervention.” The consent form should contain contents relating to the details of the procedure and the situations having high risk and the fact that a thorough disclosure has been accomplished referring to the identity of the relatives or friends attended to in the family conference for disclosure.

In case of a conflict, the doctor, if possible should involve another person of confidence to discuss and decide his course of action. It is better to share the area of conflict with the patients' relatives as well. Sometimes referring to the practice of other healing acts turn helpful to lessen the conflict or even get a better result. It is easier to tide over the situation with faith on the Almighty God and honest submission of one's intension to Him with prayer for the patient.

The professional job of a treating doctor is distinct and different than any other profession. There is no measurement of the level of involvement and the deliberate acceptance of stress for the welfare

of a fellow being by a care giver; this cannot be scaled for any physical remunerations and in a market driven society, there is always a chance of an overwhelming feeling of being financially deprived if a care giver turns objective in assessing the return compared to his input as practice of knowledge, skill, and sacrifice (spending personal time, and becoming available at odd hours, making him subject to emotional stress and legal or ethical complications etc.) especially in a developing society with huge disparities in earning and social status between people. Therefore, it is important for a physician or any member of a care giving team to remain unperturbed from those issues and prepare him or she to discharge duties to his or her patients as one should do to his parents or kids without expectation of return but with all possible empathy. This is a very difficult job and it, at times, can lead to compassion fatigue. Unfortunately our society, by and large, does not accept or recognize this human demand and fails to reciprocate appropriately. On the contrary, doctors are pointed at and blamed for the deficiencies and the difficulties resulting from the fault of the system. The consensus committee feels that an individual physician and the care giver community at large should keep this issue in mind and try to do their best to get rid of or better to or prevent compassion fatigue at the best of their capacity. Joining sports, clubs, making hobbies and indulging in positive distraction activities may help.

2. When to form a medical board for disclosure :

Board formation with multiple experts (at least three) and different members of a care giving team is recommended when-

- a) the case in concern is really a difficult one to decide by a single physician
- b) when multi-specialty problem is involved
- c) When medico-legal issues are deeply involved with actions having good motive or can arise out of an act done on emergency as an effort to save life especially even with remote chance of reversibility.
- d) When the case in concern is a very special

one (an important personality or VIP in which case divulging an illness and subsequent disclosure can have serious (social, legal, administrative, and other) consequences. Unfortunately, although all lives are of equal value, our society has not ensured the provision of equal treatment for all and equal importance to all such treatments. The committee feels it important to pass this to the colleagues as a practical issue in case of disclosure and 'End-of-life-care'.

3. What to do In case of conflict with the Hospital Management authority/ ICU management team :

There could be rare occasions when the hospital management may get involved in conflicts with a physician or a care giving team as regards the issue of care and arrangements. It has to be kept in mind that such situations should be dealt through mutual discussion and the physician/doctor must try to remain firm in his or her ethical viewpoints remaining scientifically, logically, and conscientiously correct as far as possible (with all efforts, as far as possible, of not making any action that can cause hindrances in the proper functioning of the system). It is preferable that the physician makes a note on the BHT (bed head ticket) or makes appropriate documentations of his or her views with appropriate reasoning with or without citation of scientific evidence. In any such situation, the physician is advised to keep and preserve a copy of the action (may be photograph of the note been put on BHT) for future reference.

The committee intends to advise the physicians to avoid such conflicts and to withdraw humbly from the process, if possible, in case of difficulty to tackle the conflict than to accept something against his or her reasoning and desire.

In case, if it is not possible but to submit, the physician should refer his or her action as per the instruction of the infrastructure authority on record in black and white.

Role of the hospital management:

a) It often appears that in the process of 'End-

of-life-care', the doctor is the sole morally responsible person and the management has nothing to do in the process but to bother for the hospital bill alone. This is unfortunate. Often, a junior doctor is not able to point out at the deficiencies of the infrastructure and seniors could be too busy or engaged in other issues to give attention to them. It is the responsibility of the whole system to offer the best possible care and none in the process can shed off the responsibility. Finally, investment in such area is important as it brings good name and social respect for the institution concerned.

- b) Pointing at a section of workers in the process for any lapse should not be done without objective investigations since such things can bring in unwarranted consequences with involvement of emotional overtones. It is better to have a demarcation of the responsibility at each level. Some members have seen that a hospital issued a notice that the fact regarding the functioning of ventilators should be a visiting physician's duty and sometimes doctors are seen just as medium for the hospital to earn where, often, willingly or unwillingly, a physician turns a party to a likely unwarranted ethical practice. The consensus committee feels that the issue should be addressed separately with adequate background research, but for a physician, it will always remain and conscious effort to remain and practice honestly and ethically.
- c) The infrastructure must understand and act to share the stress and sacrifice of a physician and any member of the care giving team. It is seen that doctors spare their fees for a sick patient but the hospitals do not; rather they charge surcharge etc (service tax) even on top of the profit. The committee feels that this practice is unfair.

The committee wishes to end the draft with a humane appeal the hospitals to reconsider certain costs during EoLC treatments and an appeal to the doctors to inculcate a practice to try EoLC outside ICUs in terminally ill patients where the ICU admissions will unnecessarily burden the family with extra but futile cost of treatments.

Some recommendations:

The consensus committee forwards certain recommendations to make the draft more effective in future with

- a) the involvement of inputs from all walks of life to understand the 'End-of-life care' issues in a better and holistic way; an operational research program can be initiated before editing the draft in future
- b) the incorporations of addressing the issue of organ donation simultaneous to disclosure and procuring the DNR
- c) the listing a set of diseases and declaring them as cut-off points to initiate issues for 'End-of-life care' discussion at a certain and defined stage of a particular disease. Such listing may eliminate a lot of confusion and misunderstanding between the caregivers and the patients' parties. The following diseases are some examples as
 - end stage COPD with respiratory failure
 - advanced malignancy with metastasis
 - Neurological diseases like MND, Alzheimer's, etc. in advanced stage with recurrent complications
 - Very serious injuries from road traffic accidents, violence, abuse, etc. with brain laceration
 - Irreversible hypoxic brain injury
 - Multiple organ failure in sepsis lasting unchanged over 72 hours

End-of-life care issues in ICUs are varied and may be addressed separately in future.

- d) the incorporation of all the issues that are needed to be considered to decide the

degree of support as social, financial, medical etc. and also to demarcate the source of resources for an effective and ideal 'End-of-life care'. The role of the government and NGOs also needs to be elaborated.

- e) the highlighting of the need to incorporate a practical training on the topic in the medical and paramedical curricula for proper capacity building
- f) The consideration of making a specially trained class of HCWs to deal with the issues related to the 'end of the life' care in order to save time pressure for the doctors in view of poor doctor patient ration in the community.
- g) Give a prime focus on extensive advocacy in public domain to sensitize people on EoLC issues. Extensive advocacy through media for mass sensitization program on the issue may change the scenario and help to provide a congenial ambiance proper to ensure easy accomplishment of the DNR orders.
- h) the making of mobilization of resources in appropriate ways

Appeal to the Government:

1. to frame a broad outline for the available support structure for the infrastructure and to implement regular auditing and fixing responsibility for the proper functioning of the support at any level of health care
2. To make a valid guideline with inputs from the different professional bodies to enable the caregivers act properly without conflict and fear of legal hassles. The committee feels it pertinent to put forward a comment in the meeting that goes as ".....but what about the shades of grey that doctors experience in everyday practice? We talk of dignity in death but what are the legal premises of 'end-of-life' care? Where are the fool-proof guidelines?"
3. Legal validation of the issues of euthanasia, DNR, like actions and issuing an appropriate guideline for practice. We just pick up a question raised in a session to exemplify "...If the patient is conscious and oriented and

knows about the terminal prognosis of his/her disease can he/she issue an Advanced Directive about his or her end-of-life care? Who records it? In presence of whom?" Incidentally, at present, 'advanced directives' are not recognized by the legal system in the country. The committee urges to bring the concept of and advanced action plan (advanced directives) as a valid document for End-of-life care and making a necessary guideline to do so.

4. What are the standard expectations and performances of a doctor in dealing with the issue is there a limit to it? A comment was forwarded referring to a particular experience as "...doctors can communicate with relatives about the futility of further expensive treatment which prolongs death rather than prolonging life in a particular grim scenario. The relatives agree without divulging the fact that there is another son in San Francisco. Who can make this decision? Which and/or how many relatives need to sign this declaration? In the presence of whom? What is the legal validity of 'high-risk' consents? Can two doctors authorize a 'do not resuscitate' order on a moribund patient? Or is a third doctor's presence is mandatory? Or also the next of kin?" The committee felt that the Govt. should pool such questions and classify them with experts to deal with each type in a pragmatic fashion to come out with legally sound and yet feasible directives for the doctors.
5. The committee appreciated and feels to express that numerous questions haunt medicine today which has become in some situations victim of its own success. Modern medicine often deploys expensive technology to prolong survival without adding quality to it. Chronic diseases are on rise. Life expectancy is increasing; people conquer tetanus to, die from cancers later. Yet solid legal guidelines are largely non-existent about the 'end-of-life' care issue. The consensus committee urges to express the need a parliamentary debate for

statutes. It thinks that the nation, perhaps, need a technical working committee which will work with the MCI to formulate recommendations with concurrent involvement of our supreme court in this Endeavour. The country needs laws feasible to practice and needs to wake up on issues like 'End-of-life care' and others.

6. Making it legally mandatory to have adequate support structures and personnel in every health-care set ups to assist a doctor and other health care workers adequately for disclosure and other issues related to the 'End-of-life' care.

It is noticed that in India, things change after some huge upsurge of controversy or unwarranted happenings. For issues related to healthcare in particular, things have moved at times only on the verdicts of the Supreme Court of India on public interest litigations (e.g. defining brain death for organ transplantations). This is unfortunate for a democracy like ours where we would expect much faster and proactive decisions from the Government to address such issues before they can often culminate into serious problems.

Thanks and acknowledgement

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ABOUT THE INSTITUTE

The Institute of Pulmocare & Research (IPCR) was born in 2000 as a nonprofit organization with the motto of Research, Education and Patient Care. For the last eleven years the institute has been trying hard to achieve its motto to the best of its capacity despite a lot of logistic constraints.

We have already marked our existence with worthwhile activities. In the research front, we have innovated at least three new therapeutic procedures and have opened up a new horizon in treating a difficult to treat disease IPF (Idiopathic Pulmonary Fibrosis) and two of our manuscript are awaiting to unveil a new chapter in the treatment of obstructive airway disease. We have published the maiden observation that left ventricular diastolic dysfunction in COPD may manifest in myocardial ischemia. There are others areas too where we are trying to bring forth tangible outcome from innovative and operational researches.

We are also active in educational and welfare front. Despite our limitations we arrange significant concession to our patients from our consultation fees and from investigations outside as well. We arrange different training programmes for different categories of health care workers. "Pulmocon" is an annual update of the institute meant to foster education and training on important aspects of pulmonary medicine.

We are recognized by the Govt. of India as a SIRO (Scientific Industrial Research Organization) and have been granted as special provision of IT act through which a corporate or a professional can earn 175% tax exemption on donating to our institute. We are trying to build up our own campus soon-which is under construction at the New Town, Kolkata.

All these have been possible through the constant involvement and zeal of our working members along with the love and affection of all concerned. We solicit your blessings so that we can continue to move on our path.

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