

Case vignette

Case 1

- Mr PP
- 28 yr/M
- Opioid dependent
- Case of DPLD, poor compliant lung, ventilator dependent
- Tracheostomized
- Multiple treatment failures

- Prognosis explained and understood by father, mother and other close relatives
- Patient is conscious, oriented and able to communicate his needs.
- Asks for morphine saying “I am in Pain”

What to do?

- One opinion: Use low potency opioids to avoid withdrawal
- Second opinion: Do not use any opioids- Its poison for him
- Third opinion: Give him what he asks, lets fulfill his last wishes

Case 2

- Mr TS
- 103 yr/M
- Presenting with drowsiness, decreased urine output, hypoxia
- Found to have non-hypercapneic respiratory failure with AKI

- On evaluation found to have Paraproteinemia/Multiple myeloma related AKI
- Intubation denied by Daughter after “asking for consent of intubation”
- But kept on NIV for the respiratory failure
- Family was informed about “BLOOD CANCER requiring Chemotherapy”

What to do?

- One opinion: Give chemotherapy, cause of his “Deterioration” is renal failure and by treating the cause of renal failure he will improve.
- Second opinion: Do not evaluate the paraproteinemia, you won't give any therapy to him at this age.
- Third opinion: What does his daughter want?

Case 3

- Mr RJ
- 68 yr/M
- Case of COPD, CKD, CLD, CAD, type II DM, HTN
- Presenting with worsening type II respiratory failure
- Transferred from peripheral hospital

- Multiple organ failure required- dialysis, ventilation, inotropic support and transfusions
- Sepsis was treated with antibiotics and later underwent tracheostomy
- Baseline status was on LTOT + BIPAP when he was “Apparently well at home”
- Had three intubation in past one and half year

What to do?

- One opinion: How much longer do you want to stretch it?
- Second opinion: Sir he is strong willed man, he had made out of last three intubations, fire all cylinders!
- Third opinion: Since he is VIP, try to do all you can, have you talked to the family?

End of Life care in ICU

DM Seminar

Pawan Kr Singh

Content

1. Advance Directives
2. Medical futility
3. Euthanasia
4. Palliative care
5. Intervention during EOLC
6. Burnout syndrome
7. PGIMER perspective

Part I

Advance Directive

Meaning

- “Advance Directive” are legal documents that allow you to plan and make your end-of-life wishes know in the event that you are not able to communicate.

Advance directives

- Instruction for final hours
- Choices of treatment in different scenarios as pertaining to current health
- Should be used only in cases when subject is not in a state of speaking for himself

Components

- Living Will
- Medical power of attorney

Living Will

- It is legal binding document related to the medical treatment
- In this document it is being described what you want to do, and what you don't want to do in the final hours/days of one's life

Medical power of Attorney

- It is a legal form in which the subject states who can take decisions in one's place when the subject is not able to make decisions for himself, in relation the medical treatment.
- Also known as health care proxy/ health care surrogacy

Advantages of AD

- Makes patient incharge of his body
- Autonomy
- Maintaining dignity in those times
- Dynamic process
- No attorney is needed
- Wishes are made known to every one

Disadvantages

- No one can predict in some cases when one might be needed
- Varies country to country and state to state
- Treating physicians may vary in the interpretation
- Awareness

A few key decisions that are needed

- Life sustaining treatments
- Naso-gastric feeding
- Force feeding
- Inotropes
- Lines
- Dialysis
- Intubation
- CPR
- Resuscitation
- Mechanical ventilation

Indian Scenario

Annexure – 2

[Refer para 13.13 of the report]

THE MEDICAL TREATMENT OF TERMINALLY-ILL PATIENTS (PROTECTION OF PATIENTS AND MEDICAL PRACTITIONERS) BILL

A Bill to provide for the protection of patients and medical practitioners from liability in the context of withholding or withdrawing medical treatment including life support systems from patients who are terminally-ill.

BE it enacted in the Sixty Second Year of the Republic of India as follows:-

Definition

- 'Advance medical directive' also called living will means a directive given by a person that he or she, as the case may be, shall or shall not be given medical treatment in future when he or she becomes terminally ill.

Medical treatment of terminally ill patients bill

- Best interests include medical, ethical, social, moral and other welfare considerations

Incompetent individual

- Less than 16 yrs of age, of unsound mind, unable to understand the information relevant to the informed consent, retain that information's and use or weigh that information as a part of making an informed consent, or unable to communicate that information by any means of language

Medical treatment meaning

- Treatment intended to sustain, restore or replace vital organ functions which when applied to a person suffering from a terminal illness, would serve only to prolong the process to dying and will include....

- Life sustaining treatment by the way of surgical operation or the administration of medicine or the carrying out of any other medical procedure and
- Use of mechanical or artificial means such as ventilation, artificial nutrition and hydrations and cardiopulmonary resuscitation.

Palliative care

- The provision of reasonable medical or nursing procedure for the relief of physical pain, suffering, discomfort or emotional and psycho-social suffering
- Availing reasonable provision of food and water

Refusal of the medical treatment and its binding nature on medical practitioners

- Every competent patient has the right to
 - Withholding or withdrawing of the medical treatment to himself or herself and for the nature of illness to take its course
 - For starting or continuing the medical treatment
 - When a patient communicates her or his decision for the medical practitioner, such decision will be binding of the treatment.

But...

- Before proceeding further to give effect to the decision of the competent patient, the doctor shall inform the spouse, parent or major son or daughter of the patient or in their absence any relative or other person regularly visiting patient at the hospital about the need or otherwise withholding or withdrawing treatment from the patient and shall desist from giving effect to the decision for a period of three days following the intimation given to the said patient's relations

Medical practitioner and his records

- Personal details of the patient i.e. name and address
- Nature of illness
- Treatment being given
- Name of the closest relative to whom communication is being carried out
- Request or the decision of the patient
- Whether it would be in the best interest of the patient or not

Part II

Medical Futility

- Technological advances have enabled medical experts to prolong the lives of terminally-ill patients even when there is no hope for successful treatment
- Thereby introducing debate of futility of medical treatment especially in a resource limited country like ours

The challenge

- Differences in people's perceptions of futile treatment have created many challenges between patients' family members and healthcare professionals regarding continuing or discontinuing treatments

Question is

- 'Is the treatment really futile?'
- 'Who has the right to determine futility (physician, patient, or family members)?'

Modern version of Hippocratic Oath

A widely used modern version of the traditional oath was penned in 1964 by Dr. Louis Lasagna, former Principal of the Sackler School of Graduate Biomedical Sciences and Academic Dean of the School of Medicine at Tufts University

I swear to fulfil, to the best of my ability and judgment, this covenant:

I will respect the hard-won scientific gains of those physicians in whose steps I walk, and gladly share such knowledge as is mine with those who are to follow.

I will apply, for the benefit of the sick, all measures [that] are required, avoiding those twin traps of overtreatment and therapeutic nihilism.

I will remember that there is art to medicine as well as science, and that warmth, sympathy, and understanding may outweigh the surgeon's knife or the chemist's drug.

I will not be ashamed to say "I know not", nor will I fail to call in my colleagues when the skills of another are needed for a patient's recovery.

I will respect the privacy of my patients, for their problems are not disclosed to me that the world may know. Most especially must I tread with care in matters of life and death. If it is given to me to save a life, all thanks. But it may also be within my power to take a life; this awesome responsibility must be faced with great humbleness and awareness of my own frailty. Above all, I must not play at God.

I will remember that I do not treat a fever chart, a cancerous growth, but a sick human being, whose illness may affect the person's family and economic stability. My responsibility includes these related problems, if I am to care adequately for the sick.

I will prevent disease whenever I can, for prevention is preferable to cure.

I will remember that I remain a member of society with special obligations to all my fellow human beings, those sound of mind and body as well as the infirm.

If I do not violate this oath, may I enjoy life and art, be respected while I live and remembered with affection thereafter. May I always act so as to preserve the finest traditions of my calling and may I long experience the joy of healing those who seek my help.

Meaning

- Webster's dictionary: futility as 'serving no useful purpose; completely ineffective or producing no valuable effect' .

Definition

- Medical futility occurs when:
 - 1. There is a goal
 - 2. There is an action or activity for achieving that goal
 - 3. There is a virtual certainty that the action or the activity fails to achieve the goal
- ‘A clinical action which is not performed for achieving a clear goal, and hence, is not useful for the intended patient’

Foundation of this definition

1. The probability of achieving the physiological effects which is supposed for a medical treatment (only physicians can determine it)
2. The probability of achieving the defined goals of a treatment (physicians, patients, and family members can have roles in determining it)

3. The amount of benefit and utility which the intended treatment has for the patient
4. The survival rate of the intended treatment
5. Post-treatment quality of life
6. The cost-effectiveness of the treatment

Steps to determine Medical Futility

- Goals of medicine: Determining whether a treatment is ineffective, useless, or worthless necessitates weighing it against the intended goals
- Effect: Effect is the result of achieving the physiological goals which have been set for a treatment

- Utility: The direct and indirect benefits of treatments for patients, decision upon the futility or non-futility of a certain treatment is sometimes made based on the benefits of that treatment for other people

- Value: For assessing the value of a treatment, not only the probability of achieving the goals, but also the amount of benefit should be taken into account.

Why to give a futile treatment

- Patients'/family members' request and persistence
- Healthcare professionals' personal emotions, beliefs, and attitudes
- Organizational factors and fear over getting involved in medical litigation
- Social, cultural, and religious factors

Consequences of futile treatment

- Suffering for the patient
- Suffering, moral distress, job burnout, job dissatisfaction, and increased turnover among nurses and physicians, and hence, decreased quality of care
- Heavy financial burdens on families, healthcare systems, and societies
- Putting other patients at risk

Part III

Euthanasia

Definition

- The act or practice of causing or permitting the death of hopelessly sick or injured individuals (such as persons or domestic animals) in a relatively painless way for reasons of mercy—called also mercy killing.

Should not be confused with

- Termination or withdrawing life sustaining care
- Providing opioids for symptom relief with compromising over early death

Legal in

- Netherlands
- Belgium
- Colombia
- Luxembourg
- Switzerland
- Japan
- Germany
- Canada
- US states like
Washington, Oregon,
Colorado, Vermont,
Montana, California

Motivations behind asking for mercy killing

- Depression
- Hopelessness
- Concern about loss of dignity
- Loss of autonomy
- Being a burden on the family

What to do when a terminally ill patient requests Euthanasia?

- Deal with competency, clarity
- Open conversation with empathy
- Elucidate the underlying cause of such a request with an open ended question
- Don't be judgmental or endorse an idea
- Educate the patient regarding legal, other options to deal with his emergent needs

Types of Euthanasia

- **Voluntary active:** intentionally administering medications that will cause death with patients consent
- **Involuntary active:** intentionally administering medications that will cause death without patients consent
- **Passive euthanasia:** withholding or withdrawing life sustaining medical treatment
- **Physician assisted suicide:** physician provides medications to a patient that the patient can use to commit suicide

Indian perspective

- Three Landmark cases in the history of Indian justice and their judgments

Aruna Ramchandra Shanbaug vs Union Of India

- Miss Aruna was a staff Nurse working in King Edward Memorial Hospital, Mumbai.
- On the evening of 27th November, 1973 she was attacked by a sweeper in the hospital who wrapped a dog chain around her neck and Molested her
- Due to strangulation by the dog chain she had HIE
- Thirty six years had lapsed since the said incident. She had been surviving on mashed food and could not move her hands or legs.

- The Hon'ble Division Bench of the Supreme Court of India, judgment on March 7, 2011.
- The Court opined that based on the doctors' report and the definition of brain death under the Transplantation of Human Organs Act, 1994, Aruna was not brain dead.
- She could breathe without a support machine, had feelings and produced necessary stimulus. Though she is in a PVS, her condition was been stable. So, terminating her life was unjustified

- She died 6 years later of Aspiration Pneumonia after being on mechanical ventilation for 7 days

Sister Aruna Shanbaug



- In the same Judgment Supreme Court defined and laid down the guidelines of Passive Euthanasia

Pre-requisites of Euthanasia

- The brain-dead for whom the ventilator can be switched off
- Those in a Persistent Vegetative State (PVS) for whom the feed can be tapered out and pain-managing palliatives be added

Section 309

- **Section 309 in The Indian Penal Code. 309.**
Attempt to commit suicide.- Whoever attempts to commit suicide and does any act towards the commission of such offence, shall be punished with simple imprisonment for a term which may extend to one year 1[or with fine, or with both].

P. Rathinam vs. Union of India 1994(3)

SCC 394

- Rathinam is psychologically impaired, mentally retarded teenager tried committing suicide
- He failed in ending his life and landed up in court of law
- He was sent away for one year for jail term

Amendments in the section 309

- Right to live is not equal to right to end life/right to die
- But right to live with dignity does stay equivalent to right to die with dignity

- “A question may arise, in the context of a dying man, who is, terminally ill or in a persistent vegetative state that he may be permitted to terminate it by a premature extinction of his life in those circumstances. This category of cases may fall within the ambit of the 'right to die' with dignity as a part of right to live with dignity, when death due to termination of natural life is certain and imminent and the process of natural death has commenced. “

- “These are not cases of extinguishing life but only of accelerating conclusion of the process of natural death which has already commenced. The debate even in such cases to permit physician assisted termination of life is inconclusive. It is sufficient to reiterate that the argument to support the view of permitting termination of life in such cases to reduce the period of suffering during the process of certain natural death is not available to interpret Article 21 to include therein the right to curtail the natural span of life .”

Part IV

Palliative Care

WHO definition

- “An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.”

- Palliative care improves health care quality in three domains:
 - The relief of physical and emotional suffering;
 - Improvement and strengthening of the process of patient–physician communication and decision-making
 - Assurance of coordinated continuity of care across multiple healthcare settings

Indian Perspective

- Initiated in Gujarat in 1980s
- Under the department of Anesthesiology at Gujarat Cancer and Research Institute
- Indian Association of Palliative Care formed in 1986.
- Professor D'Souza opened the first hospice, Shanti Avedna Ashram, in Mumbai,

Obstacles

- Population density
- Poverty
- Geographical diversity
- Restrictive policies regarding opioids
- Workforce development at base level
- Limited national palliative care policy
- Lack of institutional interest in palliative care

But...

- It is still one of the most neglected fields
- Only 14 Hospice as of now
- All of them by NGOs
- No government support/national policies
- Only sub-group of patients which have been studied belong to psychiatric palliative care.



BHAKTIVEDANTA HOSPICE, VRINDAVAN

Part V

Interventions

Pain management

- Present in upto 36 to 90 % patients
- Causes of pain:
 - Nociceptive pain: localized aching type of pain like metastasis
 - Visceral pain : deep colicky type, or boring type, e.g. pancreatitis or CBB obstruction
 - Neuropathic pain: burning shock like pain, tumor infiltration into brachial plexus

Assessment of pain

- Type
- Periodicity
- Location
- Intensity
- Modifying factors
- Effect of interventions
- Functional impact on patient

VAS



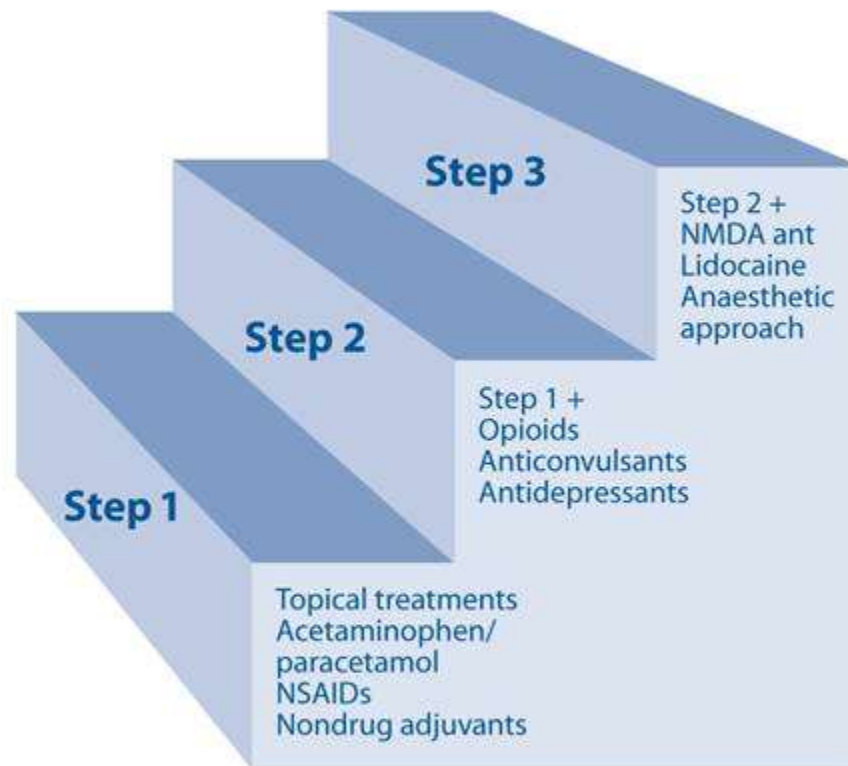
Interventions

- Pharmacological
- Non pharmacological interventions
- Surgical interventions

Pharmacological pains management

- WHO three step approach
- Non opioid analgesics e.g. Ibuprofen, Acetaminophen
- Mild opioids: Codeine,
- Strong opioids: Morphine, Fentanyl,

WHO step ladder



Specific treatment with other modalities

- Radiation
- Zolendroic acid
- Calcitonin
- Nerve blockade

Adjuvant medications

- Non opioids that potentiate the analgesic effect of opioids
- Gabapentin
- Pregabalin
- Carbamazepine
- Topiramate
- Nortryptalline
- Dexamethasone
- Methadone

Key notes

- Predict the onset of pain
- Give the analgesia before the worsening of pain
- Be liberal in dosage
- Titrate the dose
- Inappropriate to start with extended release preparations

- Ceiling effect is for NSAIDs and not opioids
- Do not fear addiction
- Anticipate the adverse effects of opioids and treat preemptively

Constipation

- Present in upto 87.5% of the patients
- Most common cause is use of opioids, use of TCAs, inactivity or poor diet
- Impaction and acute abdomen should be ruled out due to disease process

Intervention

- Laxatives
- High fiber diet
- Enemas
- Manual evacuation
- Prokinetics

Nausea

- Upto 70 % pts
- Localizations is one of the four sites
 - GI
 - Vestibular tract
 - Chemoreceptor trigger zone
 - Cerebral cortex

Other specific causes of nausea are ALF, uremia, hypocalcaemia, bowel obstruction, brain mets, drugs, radiation

Intervention

- Treat the underlying cause
- Dopamine antagonist like Haloperidol
- Metoclopramide
- Dexamethasone
- 5-HT receptor antagonist
- Palonosetron has highest receptor binding affinity
- Lorazepam
- NT1 receptor inhibitors

Dyspnea

- Prevalence 80-90%
- Multifactorial: both organic and functional
- Can be more distressing than the pain
- Does not correlate with objective parameters like po_2 , pco_2 , and respiratory rate
- Potentially reversible causes needs to be ruled out like infection, pulmonary embolism, pulmonary edema, pleural effusion, pericardial effusion, asthma, tracheal compression

Intervention

- Treat the underlying cause unless and until the treatment itself is more uncomfortable than the dyspnea itself
- Opioids
- Benzodiazepines
- Bronchodilators and glucocorticoids
- Oxygen...if that helps
- NIV
- Taking the mind off

Fatigue

- 90%
- Most common cause is the underlying disease process
- Other cases can be dehydration, depression , anemia, hypothyroidism, medications cranial radiation,
- Karnofsky performance status or ECOG is good assessment tool

Interventions

- Treat the cause that is indentified
- Goal is to help the patient and family to adjust expectations
- Behavioral interventions
- Introduction of mild exercise regimens, physical therapy can help in releasing endorphins
- Controlling pain and dyspnea might help
- Dexamethasone, Amphetamins, Methylphenidate

Depression

- Contributes to needless suffering for the terminally ill
- Not limited to only malignant pts but other chronic illnesses too
- Causes can be many: physical symptoms, medications, disease itself, family history of depression

- Assessment: by measuring symptoms like dysphoric symptoms, helplessness, hopelessness, and lack of interest and enjoyment
- VAS can be useful

Intervention

- Treat the other symptoms
- Group therapy, counseling
- Behavioral therapy
- Drugs: psychostimulants work faster
- SSRIS take time
- Dextroamphetamins/methylphenidate should be started at the dose of 2.5 to 5 mg OD/BD

- Side effects of psychostimulants are anxiety, insomnia, paranoia
- Mirtazpine is a promising (SRI) anxiolytic, anti emetic, sedating
- SSRIs, fluoxetine, citalopram and escitaloproam, venlafexime are preferred for the patients who have months to survive

Delirium

- More common in the final hours
- Metabolic causes, paraneoplastic causes, mets, drugs, radiation
- Mostly multifactorial
- Hyperactive delirium >> hypoactive
- MMSE can be used for assessment

Intervention

- Lucidity to say good bye
- Familiar environment
- Laxity in visits
- Reorientation cues
- Haloperidol/ Quetiapine/ Risperidone/
Olanzapine
- Benzodiazepines

Insomnia

- Common disorder in all kind of terminal illnesses
- Medication can be a cause
- Decrease caffeine, pain, night time distractions like monitor alarms
- Mirtazapine, trazodine, zolpidem, BZD

Other social needs and issues

- Financial burdens
- relationships,
- Family caregiver
- Burnouts
- Spiritual needs

The final hours

- Constant communication
- Reassurance to the family
- Minimizing mobilization
- Meeting the spiritual, familial needs
- Allowing the family to be with the patient
- Encouraging to communicate
- Making them understand the inevitable
- Acceptance

Part VI

Burnout syndrome

Definition

- Prolonged response to chronic emotional and interpersonal stress on the job that is often the result of a period of expending excessive effort at work while having too little recovery time.

Prevalence

- 6 to 47%
- Three domains
 - Emotional exhaustion: 25 to 61%
 - Depersonalization domain: 19 to 45.5%
 - Personal accomplishment domain: 6 to 59%

Emotional Exhaustion

- Feelings of being emotionally overextended and exhausted by ones work
- “I feel burned out from my work”

Depersonalization

- Measures an unfeeling and impersonal response towards recipients of ones service, care, treatment or instruction.
- “I don’t really care what happens to some recipients”

Assessment tool

- Maslach burnout inventory

0	1	2	3	4	5	6
Never	A few time a year or les	Once a month	A few times a month	Once a week	A few times a week	Every day

Personal Accomplishment

- Subscale used to assess feelings of competence and successful achievement in ones work with people
- “I have accomplished many worthwhile things in this job”

Symptoms

- Physical Exhaustion
- Low job satisfaction
- Emotional Exhaustion
- Absenteeism
- Helplessness
- Chronic fatigue
- Accident proneness
- Negativism
- Complaining
- Loss of concern for people
- Inflexibility
- Communication difficulties
- Tension
- Powerlessness
- Low morale
- Increase use of drugs and alcohol

Risk factors

- Age: less than 40 yr are at increased risk
- Sex: overall Men are more prone
- Marital status: being single and childless are more prone
- Working experience: lesser the experience people are more prone
- Night shifts: more burnout

- End of life care: more deaths more burnout
- Personality traits: more in people with vulnerable personality
- Organizations factors: association with an ICU research group and having the ability to choose offs was negatively associated

Consequences of burnout

- Coronary artery disease
- Metabolic syndrome
- Depression
- Divorce
- Poor quality of life
- Worse outcomes for patients

Prevention

- Frequent breaks
- Debriefing sessions
- Avoiding risk factors
- Detachments to avoid work and family conflicts
- Physical exercise
- Relaxation therapies.

Part VII

PGIMER guidelines

Definitions

- Brain-stem death: It means the stage at which all functions of the brain-stem have permanently and irreversibly ceased and is so certified in such form and in such manner and on satisfaction of such conditions and requirements as may be prescribed, by a Board of medical experts

- Deep coma in the presence of all of the following:-
 - 1. Chronic, previously-diagnosed and documented advanced, end stage disease.
 - 2. No recognizable and treatable or reversible cause of an exacerbation.
 - 3. No concurrent administration of a hypnotic/sedative/opioid overdose.
 - 4. No hypothermia

Steps

- Proper evaluation of the patient
- Adequately explain and discuss with at least two of the 'next of the kin' of the patient
- The 'next of the kin' should be 'legally competent' individuals
- As per Organ Transplantation Act of India.

- The issues of benefit and burden should be clearly and calmly explained.
- Regarding withdrawing, adequate time (minimum 24 hours) should be given to the family to make a decision.
- The informed and written consent should be obtained in the hospital case-records.

Regarding...

- Ventilator withdrawal: Two methods
 - Immediate extubation.
 - Terminal weaning
- The need to keep the patient in the hospital (or to discharge) should be separately discussed with the family and decided accordingly.

Court interventions:

- There is no unanimity among the next of the kin for further management of the patient for withdrawal of life support, or
- The near relative produces proof of declaration made by the patient while in a sound state of mind and health that he shall not be resuscitated when he goes into irreversible comatose condition
- The attending doctors or team of doctors are indecisive or have differences of opinion of whether or not to continue the treatment

Part VIII

Summary

- Timely awareness of a diagnosis helps in settling issues
- Clarity, straight forwardness in communication is the key
- Help patients to know about Advance Directives and laws related to them
- Break the Bad news as early as possible
- Medical futility exists: uses resources wisely

- Treatment and palliation are the two sides of a coin
- Be firm to speak about futility of treatment
- Treat all symptoms timely
- Help the family prepare for the final Hour
- Prevent Burnout



Inspite of all this... RICU Data

- In last 7 months
- No of patients admitted 65+ yrs of age: 57
- No of those patients Died: 9
- No of patients who went LAMA: 1
- No of patients who were discharged: 46
- Total mortality percentage: 22.6%
- Mortality percentage in this group: 15.7%

Thank you

