End of Life Care
&
Ethical Dilemma

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Overview

- What is End of Life Care?
- How is EOLC provided?

What is EOLC?

1. Care in the last few days of life?
2. Care during the last few hours of life?
3. Care during the last one year of life?
4. Same as palliative care?

Definition of EOLC

End of life care is a multidisciplinary team approach towards total care for people with advanced, progressive, incurable/life-limiting illness so that they can live and die as well as possible and involves after death care and bereavement also.

The process of care is not just limited to the person who is dying but extends to his/her families and caregivers.

? Last 12 months of life

? Weeks to hours before death

Does it matter?

What is EOLC [1,2,3]?

GMC/NICE

- When patients are likely to die within the next 12 months or in those whom death is imminent (few hours or days)

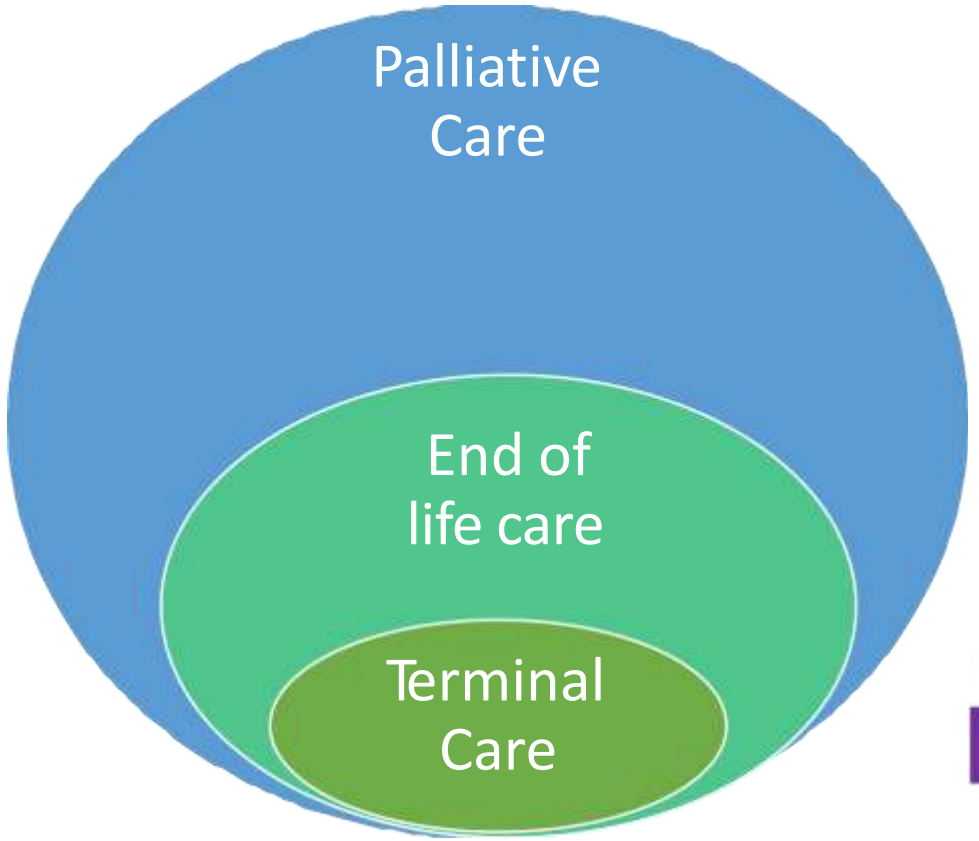
USA

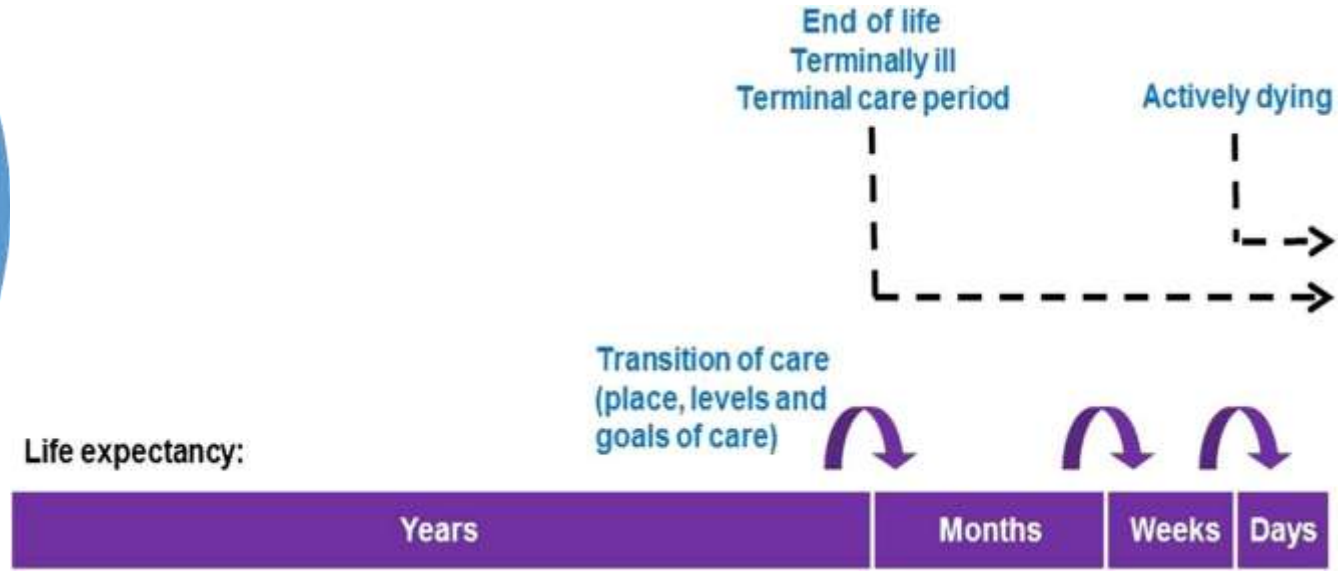
- The last 6 months of a patient's life (insurance)

ICMR

- An approach that shifts focus of care to symptom control, comfort, dignity, quality of life and dying rather than on treatments aimed at cure or prolongation of life

Not all Palliative Care is EOLC [2]





Objectives of EOLC

- Good EOLC is a human right, and every individual has a right for peaceful and dignified death
- To achieve a 'Good Death' for any person who is dying, irrespective of the situation, place, diagnosis or duration of illness.
- Emphasis on QoL and QoDD

What is Good Death

- **To know when death is coming**, and to understand what can be expected
- Retain control of what happens
- **Be given dignity and privacy**
- Have adequate symptom control
- To have choice and control over where death occurs
- **To have wishes respected**
- To have control over who is present and who shares the end
- To be able to leave when it is time to go **and not to have life prolonged pointlessly**
- **Family should not carry the guilt that they have not done their best.**

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Srinath's Story

- Mr Srinath,a **77-year old patient with. CVA, HTN, T2DM. Has right-sided hemiplegia. Has been bed bound for the last two years**
- Being cared for by his 70 year old wife and children,one son&a daughter
- **He has not been eating and been withdrawn since the last 15 days**
- He looks gaunt and pale and **has lost significant weight**
- **His peripheries are cold, skin very dry, low volume pulse**
- His bed sore is oozing pus and foul smelling
- Every time he is moved, **he grimaces in pain**
- **His urine output has reduced**
- **He has altered consciousness**
- **His wife is with him and very worried. They arrive at the hospital**

The normal pathway to dying

- Shifted immediately to the ICU. **Started on IV antibiotics, IV fluids, catheterized, NGT insertion for feeding, repeated blood tests and monitoring of vitals**
- Initially improves but condition worsens in 3 days
- **He is hypotensive and started on ionotropes**
- His renal parameter are deranged and he is advised dialysis
- **for theEscalation of antibiotics is done infection**
- He developARDS, started mechanical ventilation
- **Family is confused and stressed, but daughter says, "Please do everything you can"**
- "**We are doing everything we can". "Condition is serious".**
- On D9 – Cardiac arrest – CPR initiated with ROSC
- **D10 – On ionotropes, ventilatory support and dialysis**
- ***"We need to do everything we can."***
- **D12 – Arrested twice but resuscitated**
- **Srinath was declared dead on D14 after failed attempts at resuscitation**

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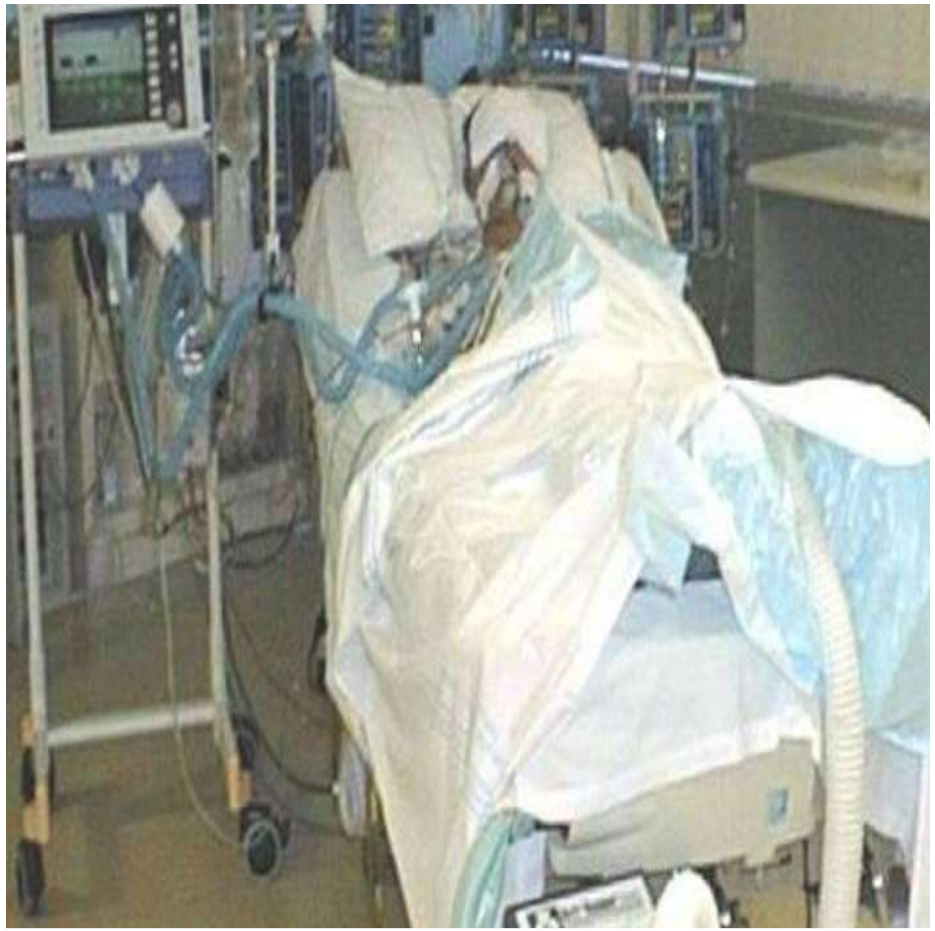
How do most people die? [6,7,8]



- In ICU
- 50% of hospitalised patients shifted to ICU before death.
- with a threat to comfort,dignity&connectedness.
- 58.17lakhs death due to NCD,cancer being a part of it(**2016**)
- **78% of patients** left the hospital against medical advise(LAMA)
- Receive inappropriate interventions – those who die in hospital.

  80.5% of Indians were self-paying – enormous economic burden
- 55% goes below poverty line for this health care cost.

  Neither the public nor the HCP are well aware about the concept of EOLC process.

Quality of EOLC in India [4,5]

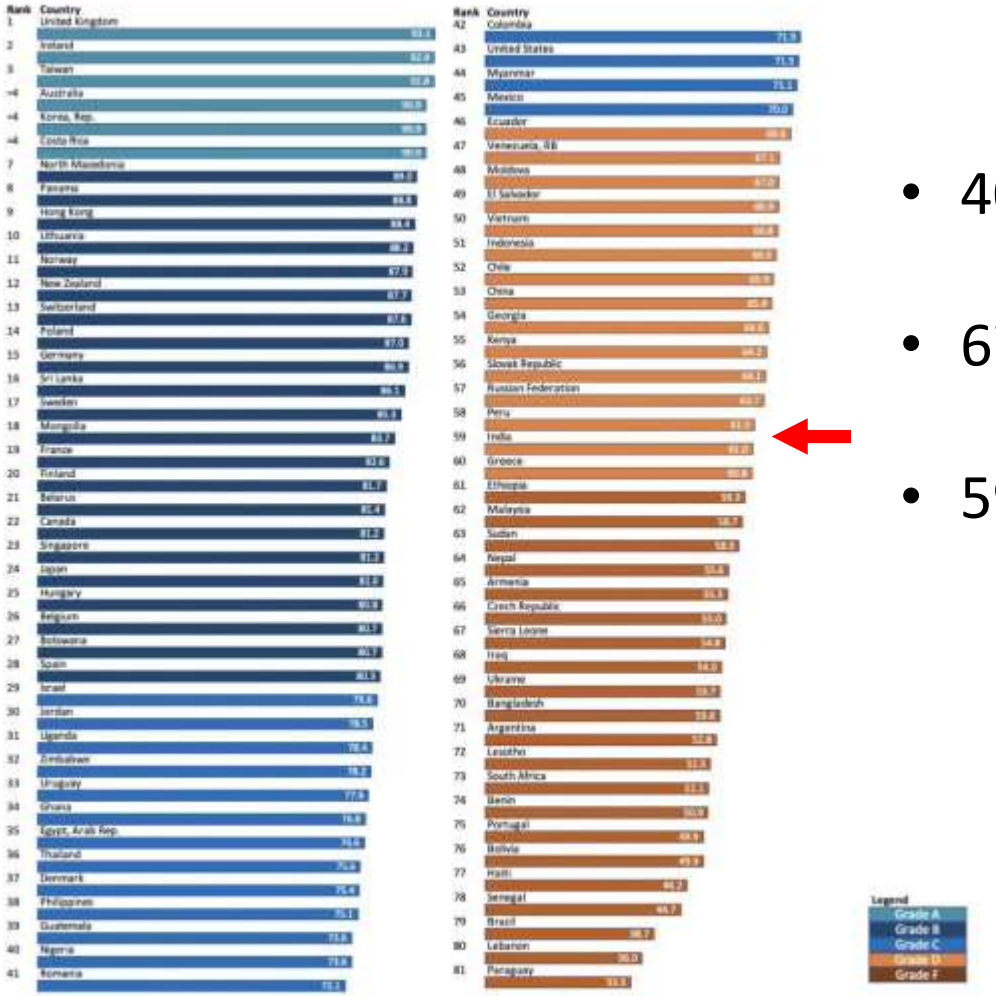
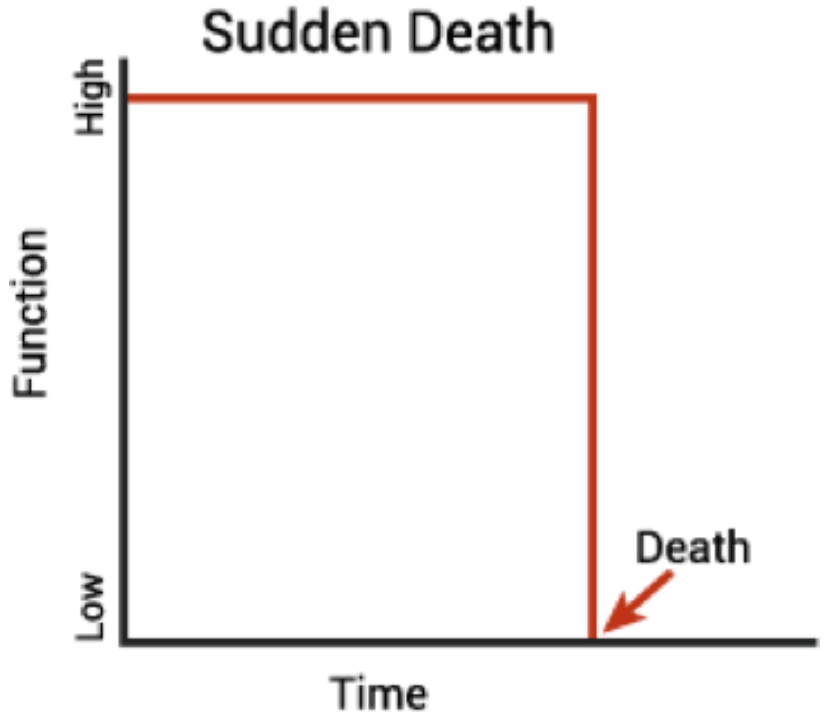


Fig. 3. Rankings of countries (and Hong Kong and Taiwan) based on input from country experts.

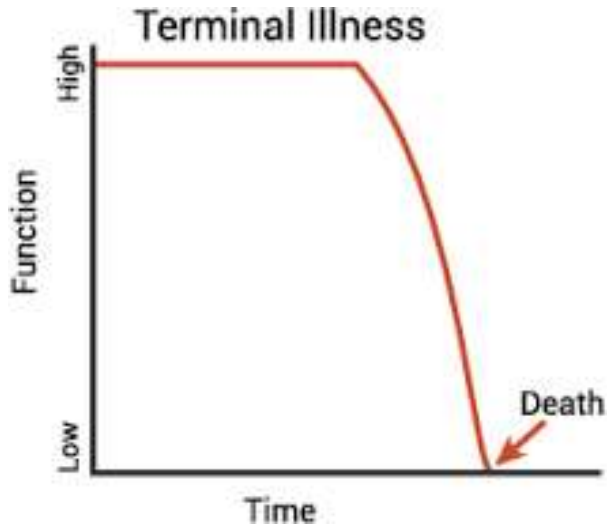
- 40/40 – 2010
- 67/81 – 2015
- 59/81 – 2021

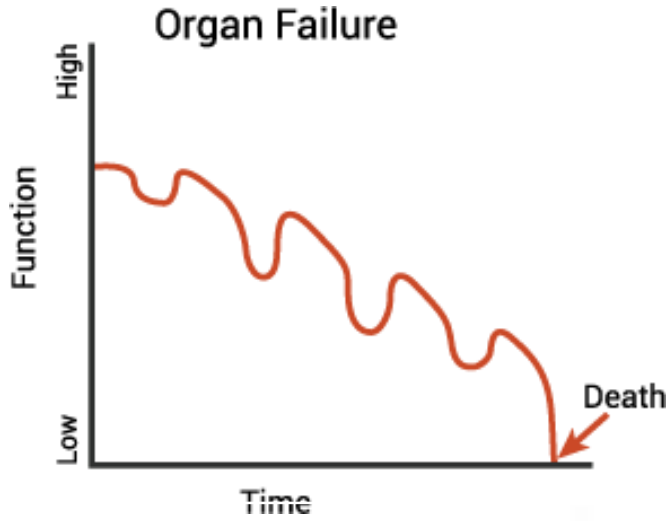
Trajectory of Dying [15]

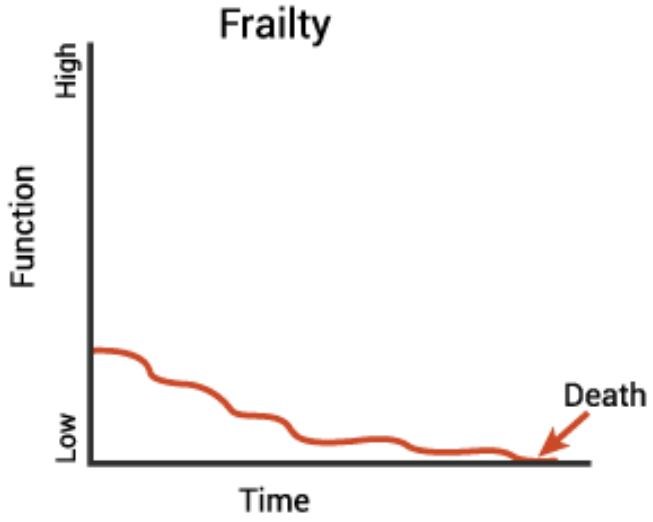
Not everyone is as blessed



Trajectory of dying [15]







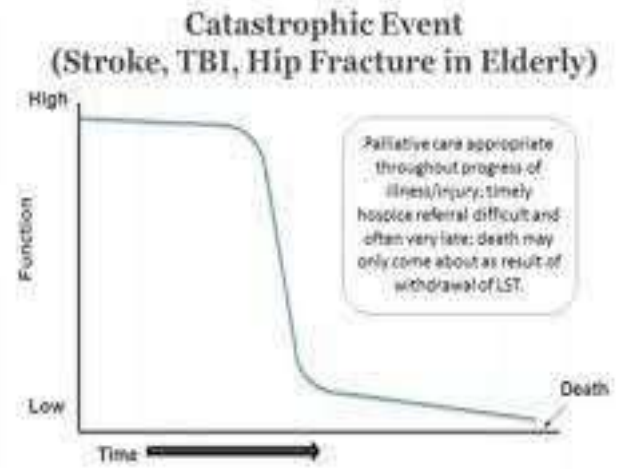
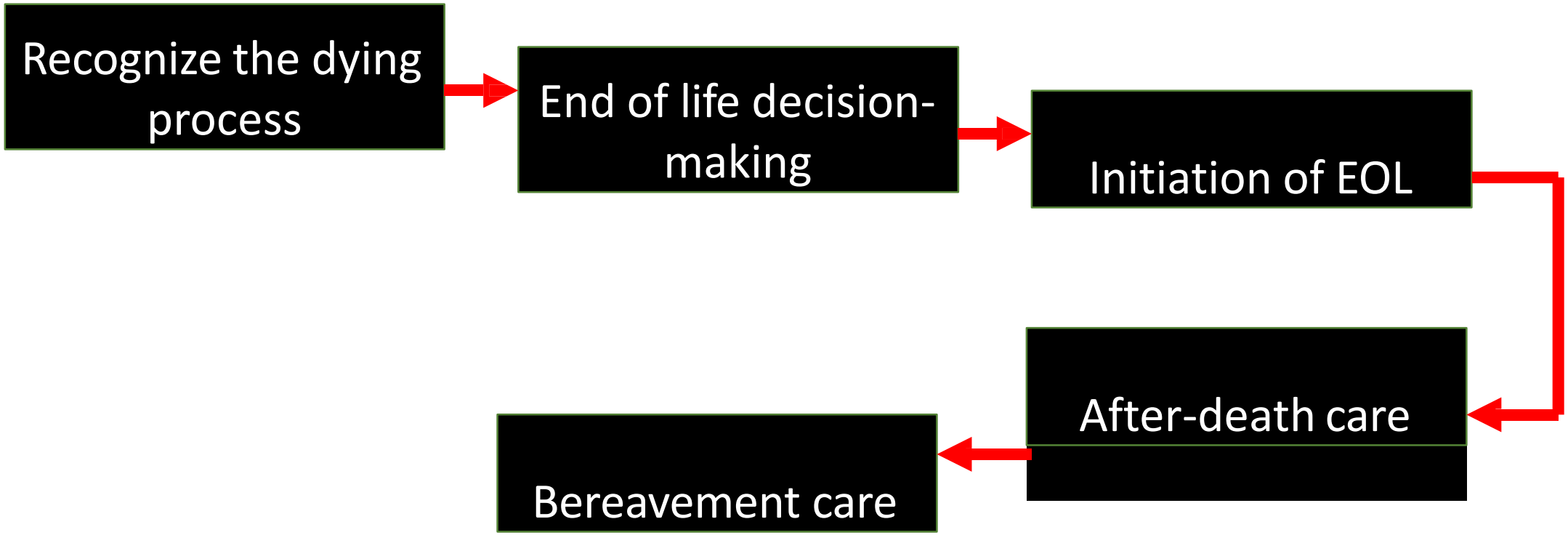


Figure 5: Catastrophic Event Trajectory (reprinted with permission of the author from Ballentine, 2013).

Steps of EOLC [9]



Steps of EOLC [9]

Recognize the dying process

Recognizing EOL [10, 11]

Gold Standards Framework Proactive Identification Guidance

Step 1 **The Surprise Question**

For patients with advanced disease of progressive life limiting conditions - Would you be surprised if the patient were to die in the next few months, weeks, days?

- The answer to this question should be an intuitive one, pulling together a range of clinical, co-morbidity, social and other factors that give a whole picture of deterioration. If you would not be surprised, then what measures might be taken to improve the patient's quality of life now and in preparation for possible further decline?

If the answer is "No", initiate the conversation about end of life care

Step 2 General Indicators

Are there general indicators of decline and increasing needs?

- Decreasing activity – functional performance status declining (e.g. Barthel score) limited self-care, in bed or chair 50% of day) and increasing dependence in most activities of daily living
- Co-morbidity is regarded as the biggest predictive indicator of mortality and morbidity
- General physical decline and increasing need for support
- Advanced disease - unstable, deteriorating complex symptom burden
- Decreasing response to treatments, decreasing reversibility
- Choice of no further active treatment
- Progressive weight loss (>10%) in past six months
- Repeated unplanned/crisis admissions
- Sentinel Event e.g. serious fall, bereavement, transfer to nursing home
- Serum albumen <25g/l

Functional Assessments

Barthel Index describes basic Activities of Daily Living (ADL) as 'core' to the functional assessment. E.g. feeding, bathing, grooming, dressing, continence, toileting, transfers, mobility, coping with stairs etc .

PULSE 'screening' assessment - P (physical condition); U (upper limb function);
L (lower limb function); S (sensory);
E (environment).

Karnofksy Performance Status Score
0-100 ADL scale .

WHO/ECOG Performance Status
0-5 scale of activity.

Step 3

Specific Clinical Indicators - flexible criteria with some overlaps, especially with Those with frailty and other co-morbidities.

a) Cancer – rapid or predictable decline

Cancer

- Metastatic cancer
- More exact predictors for cancer patients are available e.g. PiPS (UK validated Prognosis in Palliative care Study). PPI, PPS etc. 'Prognosis tools can help but should not be applied blindly'
- 'The single most important predictive factor in cancer is performance status and functional ability' - if patients are spending more than 50% of their time in bed/lying down, prognosis is estimated to be about 3 months or less.

b) Organ Failure – erratic decline

Chronic Obstructive Pulmonary Disease (COPD)

At least two of the indicators below:

- Disease assessed to be severe (e.g. FEV1 <30% predicted)
- Recurrent hospital admissions (at least 3 in last 12 months due to COPD)
- Fulfils long term oxygen therapy criteria
- MRC grade 4/5 – shortness of breath after 100 metres on the level o confined to house
- Signs and symptoms of right heart failure
- Combination of other factors – i.e. anorexia, previous ITU/NIV resistan organisms
- More than 6 weeks of systemic steroids for COPD in preceding 6 months.

Heart Disease

At least two of the indicators below:

- CHF NYHA Stage 3 or 4 - shortness of breath at rest on minimal exertion
- Patient thought to be in the last year of life by the care team - The 'surprise question'
- Repeated hospital admissions with heart failure symptoms
- Difficult physical or psychological symptoms despite optimal tolerated therapy.

Renal Disease

Stage 4 or 5 Chronic Kidney Disease (CKD) whose condition is deteriorating with at least 2 of the indicators below:

- Patient for whom the surprise question is applicable
- Patients choosing the 'no dialysis' option, discontinuing dialysis or not opting for dialysis if their transplant has failed
- Patients with difficult physical symptoms or psychological symptoms despite optimal tolerated renal replacement therapy
- Symptomatic Renal Failure – nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload.

General Neurological Diseases

- Progressive deterioration in physical and/ or cognitive function despite optimal therapy
- Symptoms which are complex and too difficult to control
- Swallowing problems (dysphagia) leading to recurrent aspiration pneumonia, sepsis, breathlessness or respiratory failure
- Speech problems: increasing difficulty in communications and progressive dysphasia. Plus the following:

Motor Neurone Disease

- Marked rapid decline in physical status
- First episode of aspirational pneumonia
- Increased cognitive difficulties
- Weight Loss
- Significant complex symptoms and medical complications
- Low vital capacity (below 70% of predicted using standard spirometry)
- Dyskinesia, mobility problems and falls
- Communication difficulties.

Parkinson's Disease

- Drug treatment less effective or increasingly complex regime of drug treatments
- Reduced independence, needs ADL help
- The condition is less well controlled with increasing "off" periods
- Dyskinesias, mobility problems and falls
- Psychiatric signs (depression, anxiety, hallucinations, psychosis)
- Similar pattern to frailty- see below.

Multiple Sclerosis

- Significant complex symptoms and medical complications
- Dysphagia + poor nutritional status
- Communication difficulties e.g. Dysarthria + fatigue
- Cognitive impairment notably the onset of dementia.

c) Frailty / Dementia – gradual decline

Frailty

Individuals who present with Multiple co morbidities with significant impairment in day to day living and:

- Deteriorating functional score e.g. performance status – Barthel/ECOG/Karnofksy
- Combination of at least three of the following symptoms:
  - weakness
  - slow walking speed
  - significant weight loss
  - exhaustion
  - low physical activity
  - depression.

Stroke

- Persistent vegetative or minimal conscious state or dense paralysis
- Medical complications
- Lack of improvement within 3 months of onset
- Cognitive impairment / Post-stroke dementia.

Dementia

There are many underlying conditions which may lead to degrees of dementia and these should be taken into account. Triggers to consider that indicate that someone is entering a later stage are:

- Unable to walk without assistance and
- Urinary and faecal incontinence, and
- No consistently meaningful conversation and
- Unable to do Activities of Daily Living (ADL)
- Barthel score <3.

Plus any of the following:

- Weight loss
- Urinary tract Infection
- Severe pressures sores – stage three or four
- Recurrent fever
- Reduced oral intake
- Aspiration pneumonia.

It is vital that discussions with individuals living with dementia are started at an early to ensure that whilst they have mental capacity they can discuss how they would like the later stages managed.

Was Srinath in EOL?

Was Srinath in EOL?

- Would you be surprised if Srinath was to die in the next few months, weeks, or days?

No

- What are the general indicators of decline in Srinath's case?

- Decreasing activity, Physical decline and need for continuing support
- Comorbidity, advanced disease, decreased reversibility
- Weight loss, low serum albumin

- What are the disease-specific indicators of decline in Srinath's case?

- Stroke-related – dense paralysis, lack of improvement with 3 months of onset, medical complications
- Deteriorating functional score, weakness, weight loss, exhaustion

Imminently Dying [2]

Symptom Criteria

- Last few hours or days of life (3-16 days)
- Physiological changes that indicate irreversible decline (at least 4 present)

Early signs	Late signs
Sedation/Agitation (RASS ≤ 3)	Decrease response to stimuli – verbal and visual
Palliative Performance Scale ≤20%	Non-reactive or sluggishly reactive pupils
Dysphagia for liquids	Cheyne-stokes breathing/apnea episodes
Decreased oral intake	Respiration with mandibular movement
Exacerbation of other symptoms	Grunting of vocal cords, death rattle
Social withdrawal, fatigue, disinterest in food and drink	Cold peripheries, low volume pulse, peripheral cyanosis, hypotension
	Decreased urinary output <100 ml in 12 hrs

Was Srinath Imminently Dying?

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Steps of EOLC [9]

Recognize the dying process → End of life decision-making

End of life decision-making

Consensus – Medical Team

Communication – Honest and Empathetic

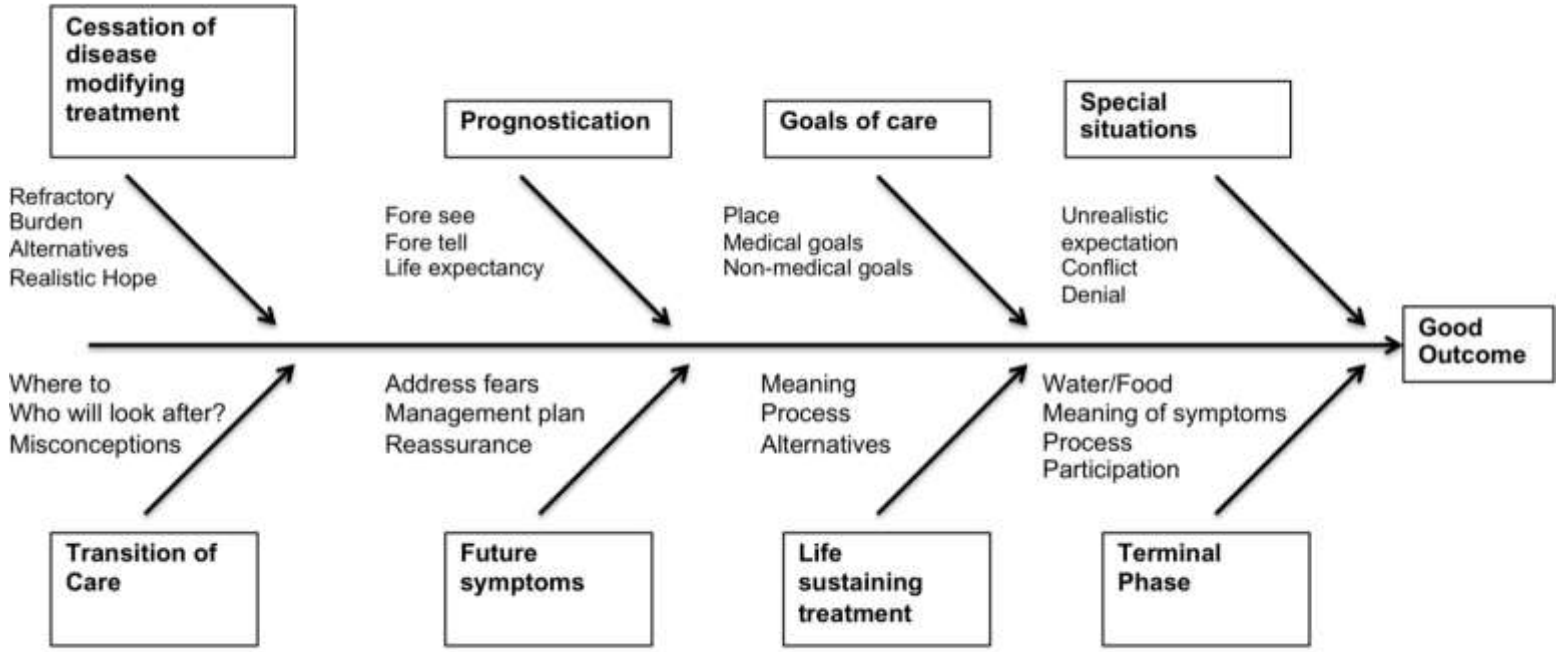
- ✓ Family/Caregivers are informed, educated and supported about prognosis
- ✓ Preferred place of care and death is identified
- ✓ Caregivers are involved and empowered to provide EOLC
- ✓ Goals of care: Discussion on treatment options and advance care planning
- ✓ Level of care: From primary physician to PC teams
- ✓ What to expect – symptomatology. **Emphasize on the uncertainty**

Continuity of care

Discussion on after-death protocols

Clear & transparent documentation

Advanced Medical Communication



Serious-Illness Conversations

- Honest Communication
- Active listening
- Acknowledge emotions
- Explore Concerns and Preferences
- Shared decision-making
- Compassionate communication

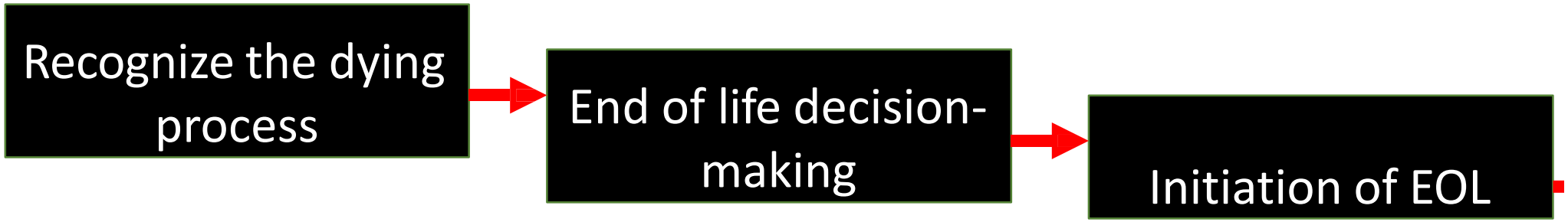
Life-sustaining treatment

- Life-sustaining treatment comprises of any medical treatment that artificially supports or replaces, a body function essential to the life of the person.
- Cardiopulmonary resuscitation (CPR), endotracheal intubation, mechanical ventilation, vasopressor therapy, parenteral or artificial enteral nutrition, dialysis, blood products, antibiotics, and intravenous fluids
- Treatment that does not provide net benefit to the patient may, ethically and legally, be **withheld** or **withdrawn**
- The goal of medicine then shifts to the palliation of symptoms

EOL Decision-making in Srinath

- Referral to palliative care. Documentation of goals of care by the primary team
- Family meeting with Mrs. Srinath and daughter and son (Telecounselling)
- Prognosis explained. Wife and daughter supported through grief.
- PPC/PPD discussed – Home. LLST discussed and documented. Copy given.
- Nursing care at home arranged. Local doctor and local hospital contacted for coordination of care. Goals of care discussed with the local team. Communication channel established
- Anticipatory prescription given
- The nurse and the caregiver empowered regarding further management
- After-death care explained
- Daughter moved in with the mother. Son travelling to be with them
- Daily review

Steps of EOLC [9]



Initiation of EOLC [9]

- Relief of end-of-life symptoms
- Review of existing medical/nursing care
- Review medication chart – stop unnecessary medications
- Routine investigations – stop that which may not benefit
- Continued communication
- Psychosocial support to patient, family, caregivers
- Spiritual care aligned to patient and family expectations

Symptoms in EOL [11]

- Pain
- Restlessness/Agitation (Delirium)
- Respiratory secretions
- Nausea & Vomiting
- Breathlessness
- Constipation
- Loss of appetite
- Fatigue
- Dry membranes
- Incontinence

- Psychological
  informational
  Emotional Grief
  - Isolation/Loneliness
    Fear/Anxiety
  - Saying goodbyes
- Social/Financial/Family
- Practical Issues
- Spiritual/Religious
- Existential

Principles of EOL symptom management [2, 9]

- Frequent assessment and review
- Anticipate symptoms
- Ensure accessibility of medications
- Ensure round the clock and prn orders are written
- Liberal use of prn medication and rapid readjustment of background dose
- Route of drug delivery should be reliable and least invasive
- Refractory symptoms need palliative sedation

Managing Pain in EOL [12, 13]

- Change to a reliable route – Oral/IV/SubQ/Rectal
- Increase background dose
- Rapid titration with liberal PRN dosing
- Unconscious patients can also experience pain
- Frequent review

Beneficence and Doctrine of Double Effect

Table 4 Revised card for Nonverbal Pain Scale

	0	1	2	Score
1. Face	No particular expression or smile	Occasional grimace, tearing, frown or wrinkled forehead	Frequent grimace, tearing, frown or wrinkled forehead	
2. Activity (movement)	Lying quietly, normal position	Seeking attention through movement of slow cautious movements.	Restless activity and/or withdrawal reflexes	
3. Guarding	Lying quietly, no positioning of hands over areas of body	Splinting areas of the body, tense	Rigid, stiff	
4. Physiologic I (vital signs)	Stable vital signs, no change in past 4 hours	Change over past 4 hours in any of the following: SBP >20 HR >20 RR >10	Change over past 4 hours in any of the following: SBP >30 HR >25 RR >20	
5. Respiratory	Baseline RR/Spo_2 Complaint with ventilator	RR >10 above baseline or 5% ↓ Spo_2 Mild asynchrony with ventilator	RR >20 above baseline or 10% ↓ Spo_2 Severe asynchrony with ventilator	
Revised Nonverbal Pain Scale (NVPS)			**Total**	

Abbreviations: HR, heart rate; RR, respiratory rate; SBP, systolic blood pressure; Spo_2, oxygen saturation as measured by pulse oximetry.
[a] Reprinted with permission of Strong Memorial Hospital, University of Rochester Medical Center, Rochester, New York, developer and copyright holder of the scale.

Managing Dyspnea in EOL [2, 9]

- Most common and distressing symptom
- Non-pharmacological measures as tolerated
- Aggressively pursue comfort
- Remain onsite till patient comfortable
- Continuous infusion and prn

Pharmacological measures

- Opioids: Morphine: 2.5 – 5 mg PO q6h – q4h
- Benzodiazepines: Lorazepam: 0.5 – 1mg PO/SL q1h - q2h
- Palliative Sedation: Inj. Morphine 30mg /Inj. Fentanyl 150-300mcg and Inj. Midazolam 15mg- 60mg SC/IV over 24hours

Managing Oral Secretions [2, 9]

- Noisy breathing in 50% of dying patients
- Strong predictor of death (48% in 24 hours and 76% within 72 hours)
- Type 1: Predominantly salivary
- Type 2: Bronchial secretions that cannot be coughed up and swallowed
- Non-pharmacological : Positioning, oral care, avoid hydration, reassurance
- ? suctioning

Table 4. Medications for the Treatment of Excessive Oropharyngeal Secretions in End-of-Life Care

Medication	*Dosage (as needed)*
Atropine ophthalmic 1% drops	1 or 2 drops sublingually every 6 hours
Glycopyrrolate (Robinul)	1 mg orally or 0.2 to 0.4 mg subcutaneously or intravenously every 4 hours
Hyoscyamine (Levsin)	0.125 to 0.5 mg sublingually or subcutaneously every 4 hours
Scopolamine transdermal patch	1 or 2 1.5-mg patches applied every 72 hours

Managing Delirium in EOL [2, 9,14]

- Challenging
- Multifactorial
- Non-pharmacological measures
- Pharmacological measures
  - Antipsychotics: Haloperidol
  - Benzodiazepines(hyperactive/agitated delirium): Midazolam
  - Inj. Haloperidol 20 mg and Inj. Midazolam 30 mg as a continuous infusion (intravenous/subcutaneous) in 24 hours

	Dosage			Observations
Drug	Induction	Rescue	Maintenance	
Levomepromazine	12.5–25 mg	12.5–25 mg	5 mg/h SCCI-IV	>300 mg*/ day + MDZL
Midazolam	5–10 mg	5–7.5 mg	1.5–2 mg/h SCCI-IV	>200 mg*/ day + LMPZ
Propofol	1–1.5 mg/kg	50% induction dose	2–3 mg/kg/h IVCI	No mix with other drugs
Phenobarbital	200 mg IM	100 mg	60–100 mg/h SCCI	No mix with other drugs

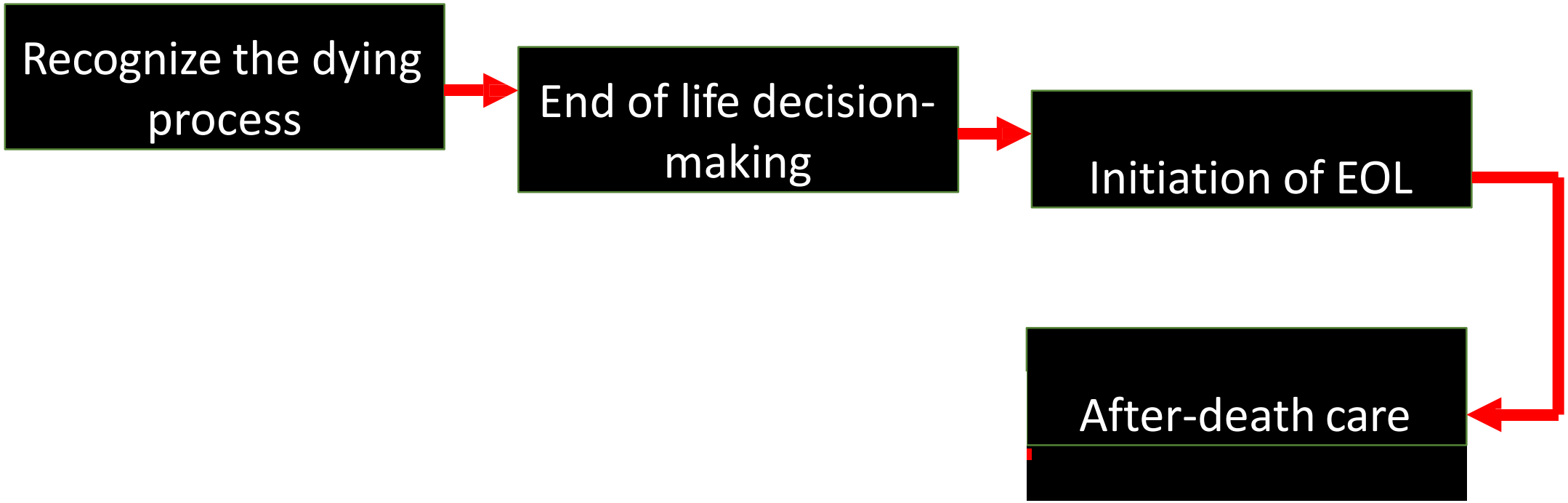
Emergency Situations in EOL

- Stridor
- Seizure
- Hemorrhage
  - Benzodiazepines - reduce anxiety & control seizures
  - Antiepileptics if indicated
  - Midazolam: 2- 5 mg slow iv/sc, if iv is not available
  - Lorazepam: 0.1 mg/kg IV, not faster than 2 mg/ minute
  - Diazepam: 10 mg rectally, if iv is not available
  - Dark coloured towels and bed clothes - reduce visual impact of bleeding
  - Psychological support for the patient and the family

Nursing in EOL [2, 9]

- **Care of pressure areas**
  - Silent pressure points – NG tubes, Masks, etc.
  - Pressure reducing mattress
- **Skin care**
  - Avoid soiling and talcum powders
  - Gentle massaging of pressure points
  - Moisturizers
- **Avoid too rigid turning regimes**
- **Oral care**
- **Bowel/Bladder care**

Steps of EOLC [9]

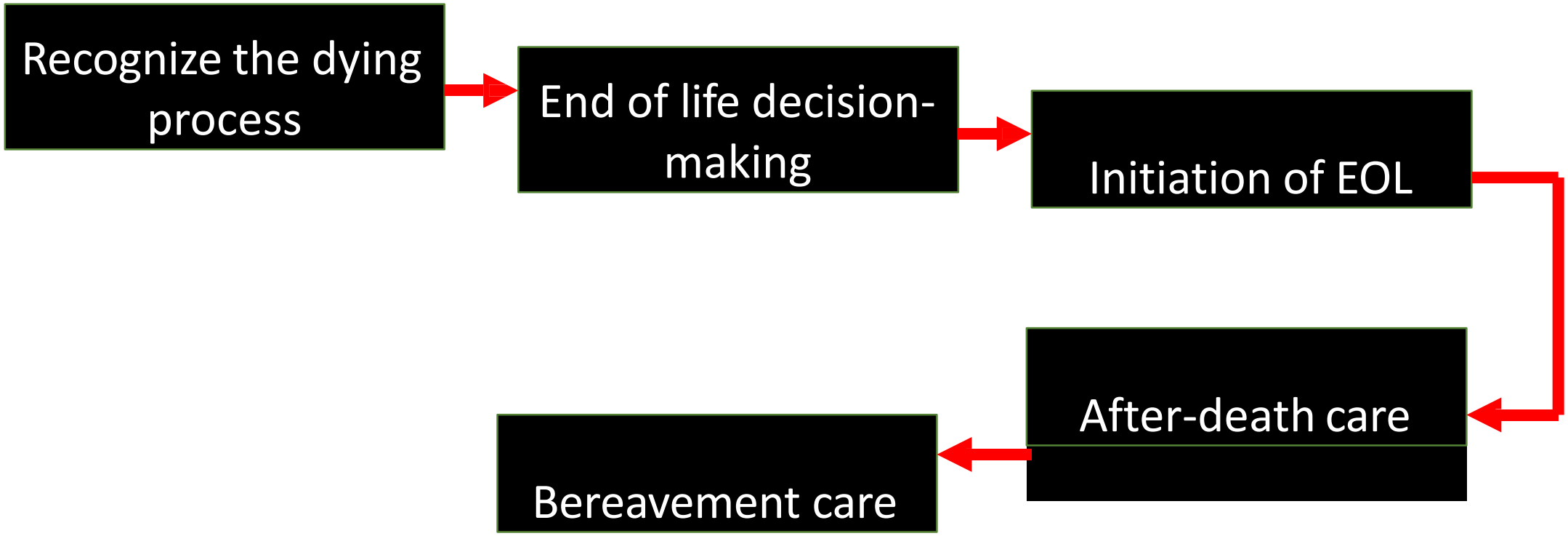


After death care [2, 9]

Culturally appropriate and sensitive after death care should be provided to all the dying patients irrespective of the situation or the setting

- Information about the death is communicated early and sensitively to the family
- The primary team is informed
- Body laid out in the culturally appropriate manner
- Provide presence and support to the family
- Privacy and space to the family
- Timely and correct verification and certification of death
- Timely and dignified transfer of the deceased from the hospital

Steps of EOLC [9]



Bereavement Care [2, 9]

- Identify families/caregivers who are very likely to need bereavement support
- Bereavement visit for all patients under your care
- Bereavement support groups for those at-risk
- Identify complicated bereavement – refer to mental health professionals
- Grief and bereavement of the healthcare workers

Ethics in EOLC

Determining Patients Best Interest

- Autonomy
  - What does the patient and family want? Respect for patient wishes
- Beneficence
  - Is the treatment being offered to benefit to the patient?
- Non-maleficence
  - Is the treatment being offered likely to cause patient more harm?
- Fair allocation of societal resources
  - Avoid futile treatment
  - Withhold or withdraw life-sustaining treatment when clinically indicated

ETHICAL DILEMMA AT EOL

- Nutrition/IV fluids
- Life sustaining treatment
- Doctrine of double effect (palliative sedation for refractory symptoms)

Take Home Points

- Good death is possible
- The onus is on healthcare providers to start the process
- Patient symptoms well controlled
- In their preferred place of care with fewer crises
- Families are prepared, informed, and empowered
- Caregivers feel involved, supported, and satisfied
- Healthcare team feel confident and develop a sense of teamwork

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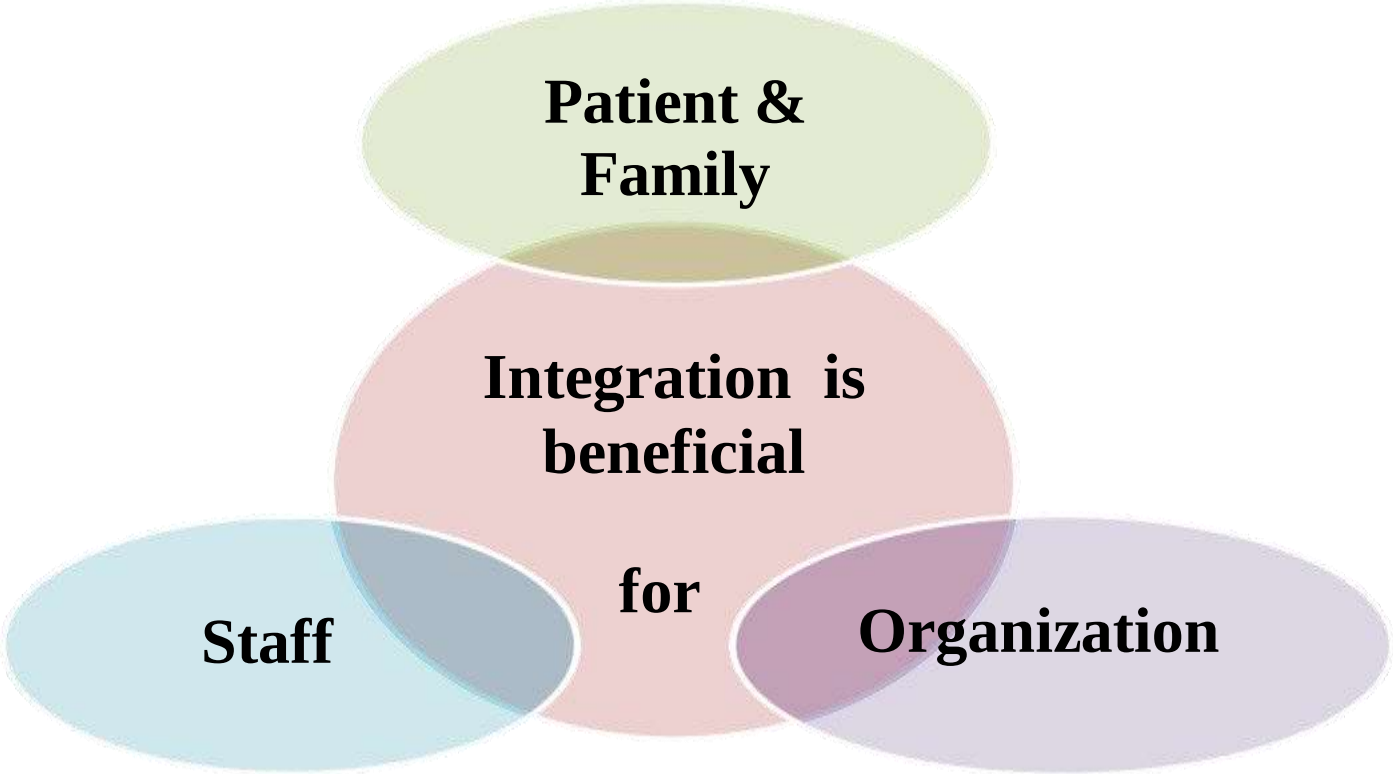
Benefits of Integration of Palliative Care

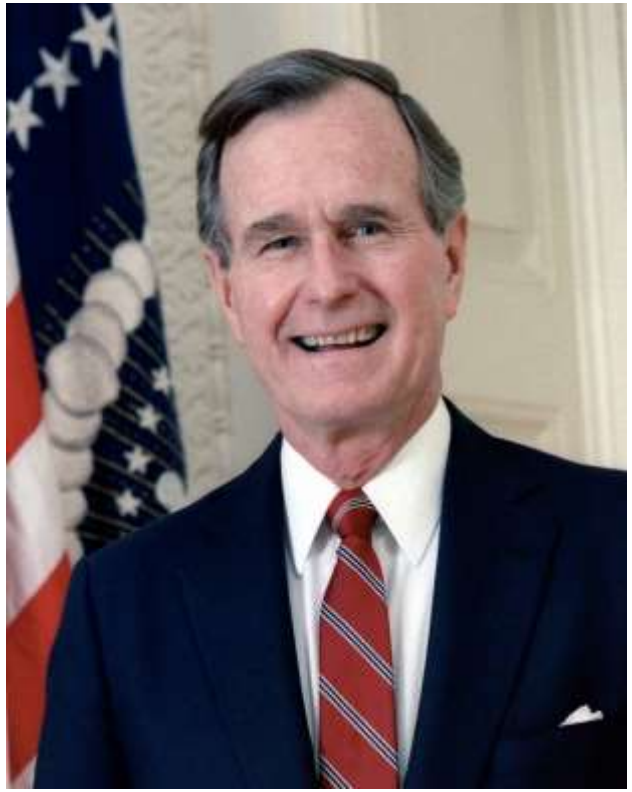


WHAT CAN YOU DO ?

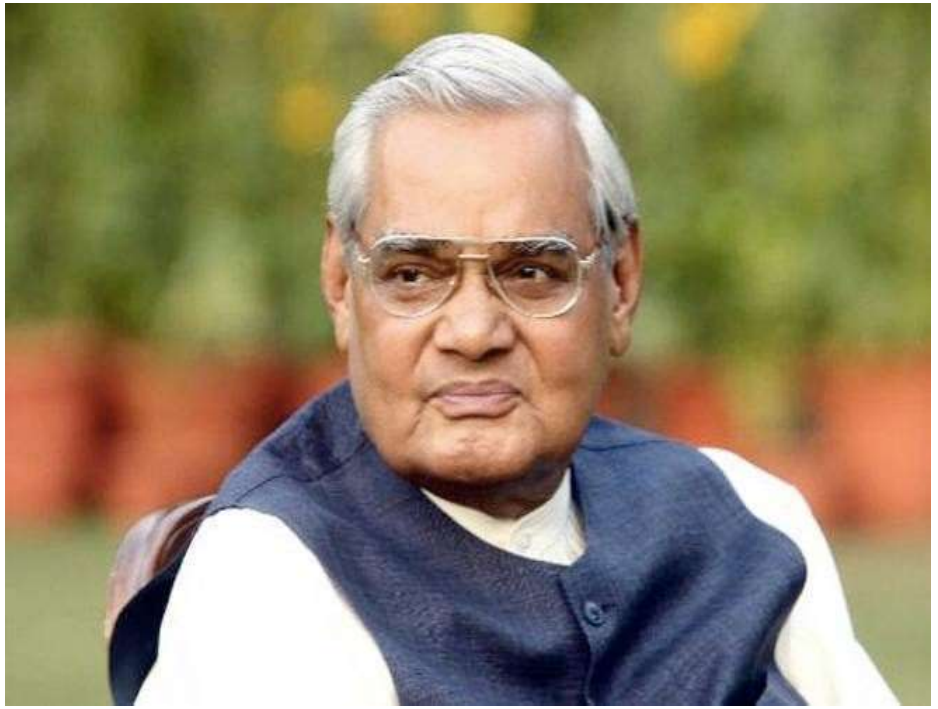
- Talk – create awareness
- Help NGOs establish PC in your area
- Guide friends , relatives, community
- Support them get information
- Help them make joint decisions
- Complete own ACP and directives
- Talk, talk, talk
- Last Aid, Death Cafes are concepts worth emulating

Progress in Medicine

Died on Nov 30, 2018
94 years
Vascular Parkinsonism



Died on Aug 16, 2018
93 years
Major Stroke and Aphasic for 9 years, Vascular Dementia



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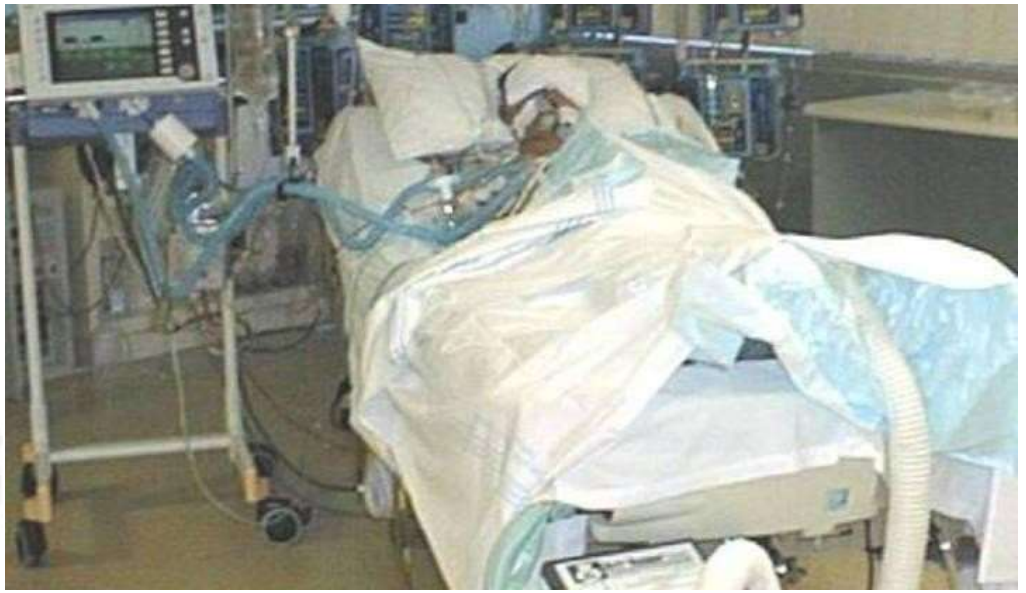
The choices we make…

Dignified…with family

Distressing…lonely



Q/A

- Palliative care is end of life care- T/F
- Discussion on EOLC should begin just before death- T/F
- Family members should be included in care process- T/F
- Patients and family preferences is the priority- T/F

Q/A

- What is the ideal place to die?

Home

Hospice

ICU

Hospital ward

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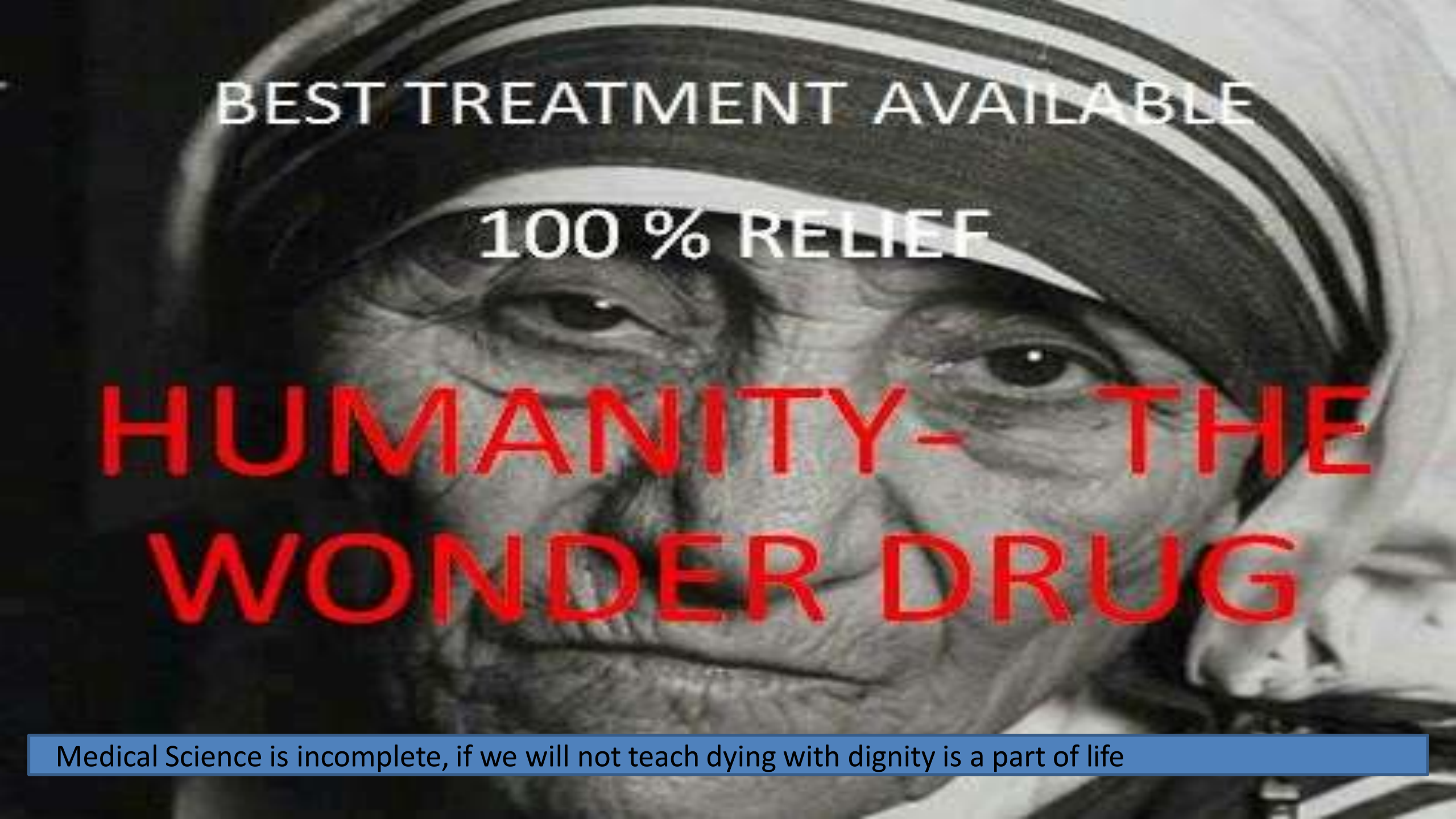

Medical Science is incomplete, if we will not teach dying with dignity is a part of life