End of Life Care

For MO

STRUCTURE

Provider + Process = Outcome

Primary Healthcare Provider

End of Life Care

Good Death

QUALITY OF DEATH IN INDIA

62	Bulgaria	30.1
63	Kenya	30.0
64	Romania	28.3
65	Sri Lanka	27.1
66	Malawi	27.0
67	India	26.8
68	Colombia	26.7
69	Ukraine	25.5
70	Ethiopia	25.1
71	China	23.3
72	Botswana	22.8

CASE STUDY 1

- Mrs. Sharma, 66 year old
- Care-givers: Son/daughter in law, Unmarried daughter
- Advanced Ca ovary, post Chemotherapy 2 courses
- Inoperable Malignant bowel obstruction

GOOD DEATH – WHAT DO PATIENTS WANT ?

- Control over pain and other symptoms
- To understand that death is nearing and to know what to expect
- To have **access to information** and **special needs**

GOOD DEATH

- Respecting personal preferences
- To have choice and control over **place** of death
- To be able to leave when it is time to go and **not to have life prolonged pointlessly**
- To not die alone
- To strengthen relationships
- To have dignity and privacy
- To not be a burden

GOOD DEATH

- Patient and family were fully aware of disease statusand prognosis
- Better coordination of care
- Quality of life and death
- Completing unfinished tasks
- To have wishes respected
- Leaving a legacy

TO DIE AT HOME..

CASE STUDY 2

- Mrs. SB, 66 Yrs
- Unmarried daughter, cares son / daughter in law
- Advanced Ca ovary, post CT
- Inoperable Malignant bowel obstruction,
- Advised intravenous nutrition, opted for subcut and home care
- Fell ill around Diwali
- Letter to her family to be read on her “teeya”
- No Shraaddh feast

GOOD DEATH

- To know when death is coming, and to understand what can be expected
- To be able to retain control of what happens
- To be afforded dignity and privacy
- To have control over pain relief and other symptom control
- To have choice and control over where death occurs

- To have access to information and expertise of whatever kind is necessary
- To have wishes respected and have access to any special needs
- 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

WHAT ARE THE COMPONENTS OF GOOD DEATH?

Pain and symptom management	Control of current pain and physical symptoms Reassurance
Clear decision making	Communication and clear decision. Empowering the families
Preparation for death	Helping patients know what they could expect Help to plan for the events that would follow after their deaths.

Completion	Meaningfulness at the end of life and dealing with faith issues, life review, resolving conflicts
Contributing to others	Contribute for the well being of the others, legacy
Affirmation of the whole person	Affirming the patient as a unique and whole person not the disease perspective, but in the context of their lives, values, and preferences

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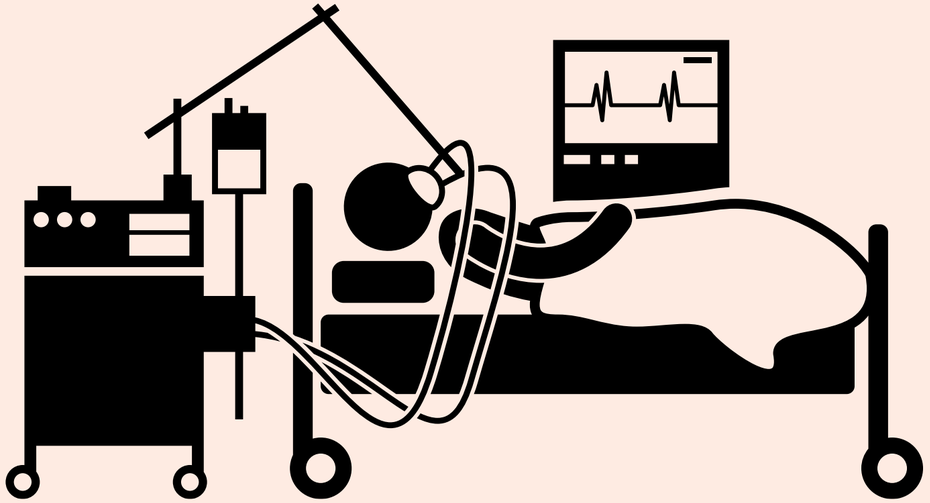
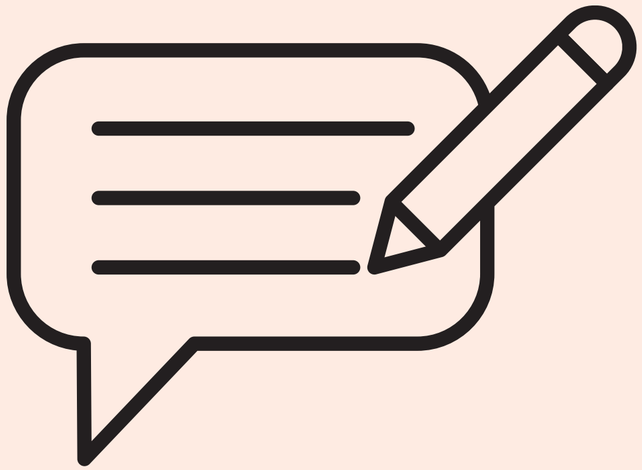
10 KEY ELEMENTS OF CARE FOR THE DYING PATIENT



- Recognition that the patient is dying
- Communication
- Spiritual care
- Anticipatory prescribing for symptoms of pain, respiratory tract secretions, agitation, nausea and vomiting, dyspnoea
- Review of clinical interventions in the patient's best interests

- Hydration review,
- Nutritional review, including commencement or cessation
- Full discussion of the care plan with the patient and relative or career
- Regular reassessment of the patient
- Dignified and respectful care after death

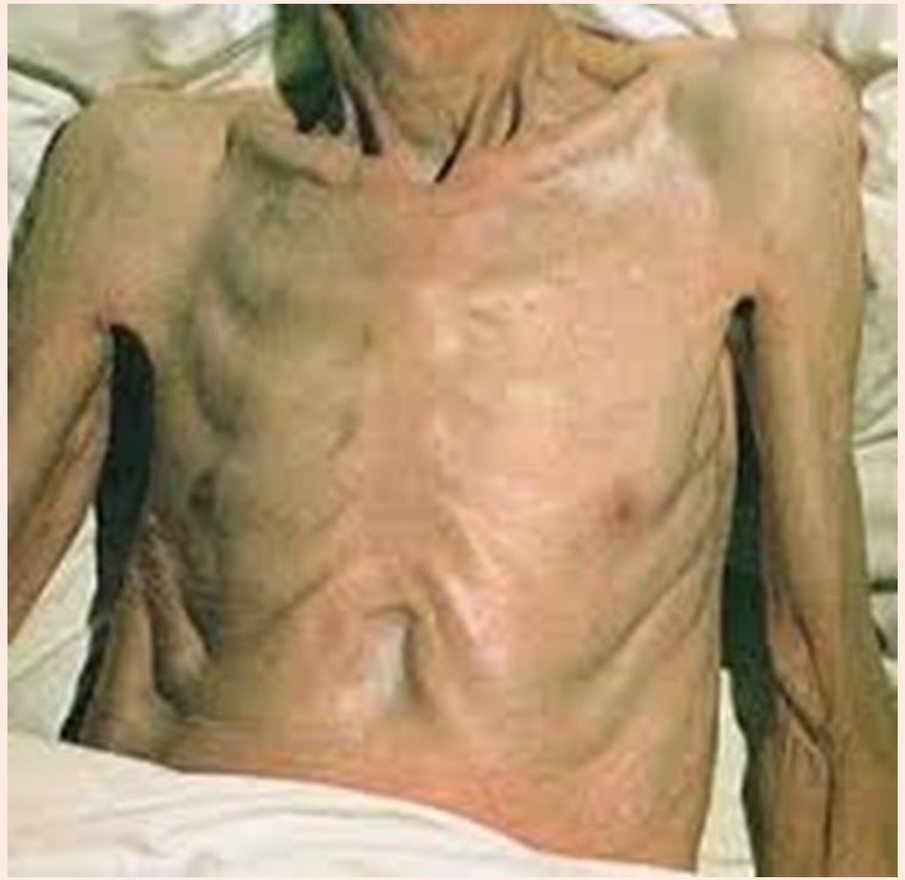


Editorial - Best care for the dying patient: J.E Ellershaw, Mayur Lakhani
BMJ 2013;347:f4428 doi: 10.1136/bmj.f4428 (Published 12 July 2013)

RECOGNISING DYING

- The peripheries gets cool and clammy
- May get mottled, grey mouth and conjunctiva get dry
- The pulse gets weaker
- Blood pressure gradually falls
- disorientated in time, place and person

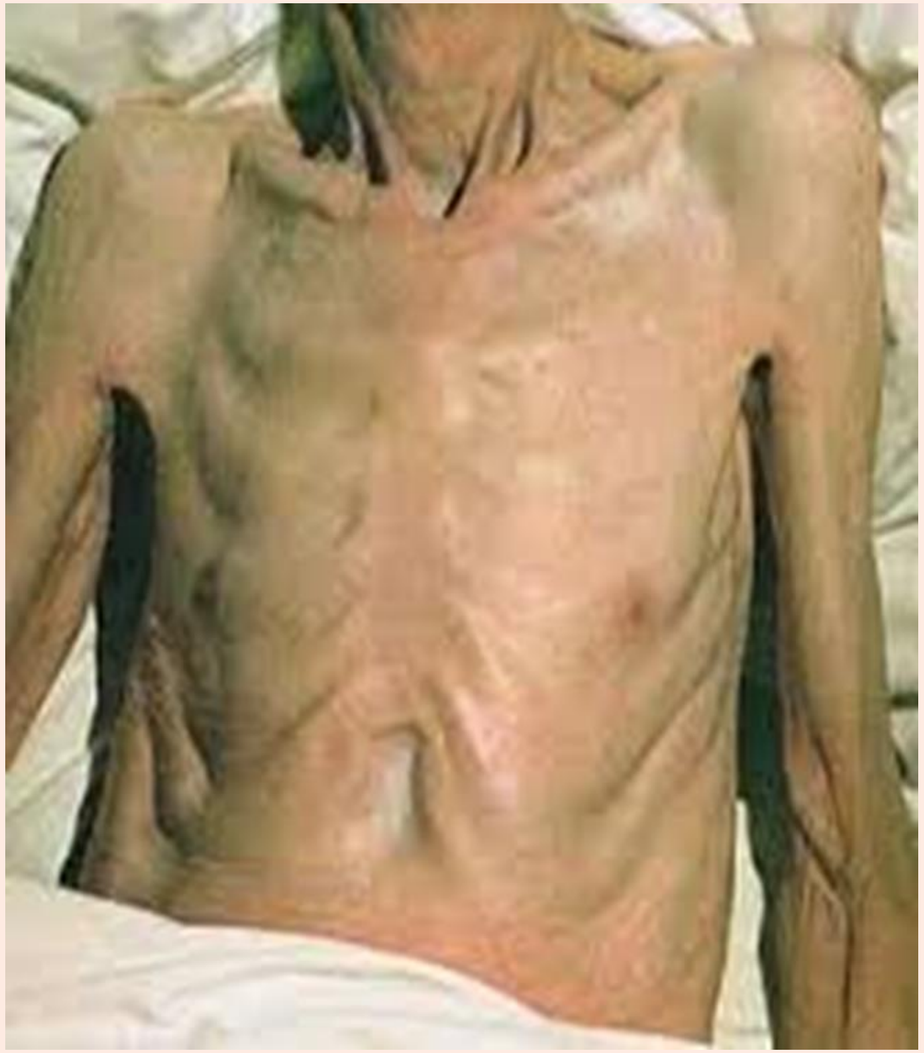
- The face may be gaunt,
- patient is cachexic
- Profound weakness/patient is bed bound/needs help for all activities
- Decreased Intake of food and fluids
- Difficulty swallowing
- Decreasing urine output



- Inspiration shallow, slow and gradually irregular, may vary in depth Cheyne Stokes pattern
- Gradually duller, cannot concentrate
- Decreased spontaneous verbalization,
- Interacts less with people and usually loses consciousness
- Loss of sphincter control

TERMINAL PHASE - SYMPTOMS

- Pain
- Dry mouth
- Noisy, moist breathing
- Breathlessness
- Restlessness & confusion
- Nausea & vomiting
- Severe haemorrhage
- Seizure



BEREAVEMENT SUPPORT

Slide objective: How to provide ongoing emotional support to the bereaved families?

- Who are very likely to need bereavement support ?
- support groups run by medical social workers and volunteers
- counseling and psychotherapy-based treatments

PRINCIPLES OF EOLC SYMPTOM MANAGEMENT

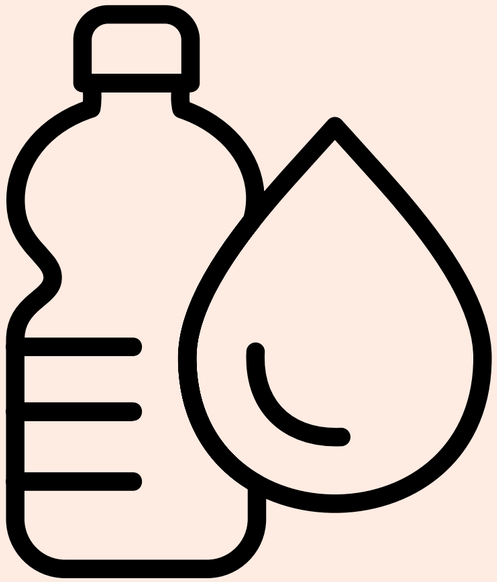
- Symptoms assessed at least two times a day.
- anticipatory prescription
- Access and availability of essential medications.
- Medications and doses prescribed carefully
- response to treatment should be frequently reassessed
- Rescue /SOS/prn/meds

- Route of drug delivery should be: most reliable, least invasive and convenient
- Empower/Educate the family and caregivers to participate in symptom management and care process
- Consider palliative sedation when symptoms are refractory to adequate and aggressive palliative care

CLINICALLY ASSISTED NUTRITION AND HYDRATION

- Clinically assisted (artificial) hydration and (artificial) will not be of benefit and decisions about their use should be individualized and made in patient's best interest

- Symptoms of thirst / dry mouth are often due to mouth breathing or medication / oxygen therapy and good mouth care, frequent wetting of mouth will alleviate symptoms of thirst.



How to address the family's demand for hydration and nutrition at EOL?

- If hydration or nutritional support is in place,
- review rate/ volume / route according to individual need
- Avoid complications related to overhydration and parenteral nutrition at EOLC
- IV antibiotics at EOL should be rationalized and judiciously prescribed as it may not confer any additional benefit during EOLC

WHEN TO CONSIDER PALLIATIVE SEDATION?

- Palliative sedation is defined as medication-induced sedation that is administered, without intending to cause death, utilizing a non opioid drug to control intolerable symptoms that are refractory to conventional treatment in patients with advanced and incurable disease whose death is imminent (death expected in hours or days)

- Common conditions where Palliative Sedation is considered is intractable pain, intractable dyspnea

MANAGING INTRACTABLE SYMPTOMS: PALLIATIVE SEDATION

- Symptoms are refractory to pharmacological and non-pharmacological options
- Death is imminent in days or weeks
- Additional treatments are unlikely to bring relief
- Aggressive palliative treatment has failed to control symptoms
- Goal is relief of distress of symptom
- Not enough time to try a potential non- sedative approach – impending death

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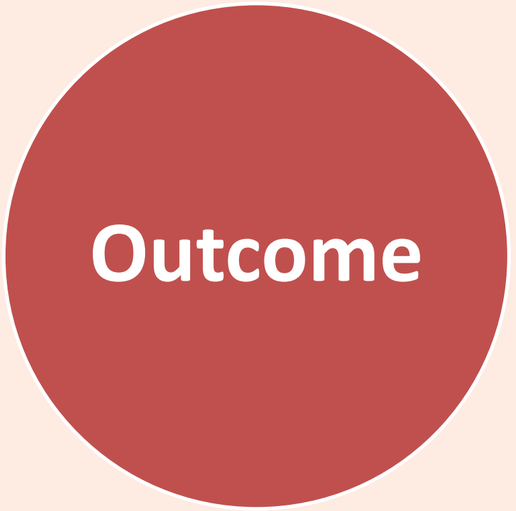


Good Death

PROVIDER

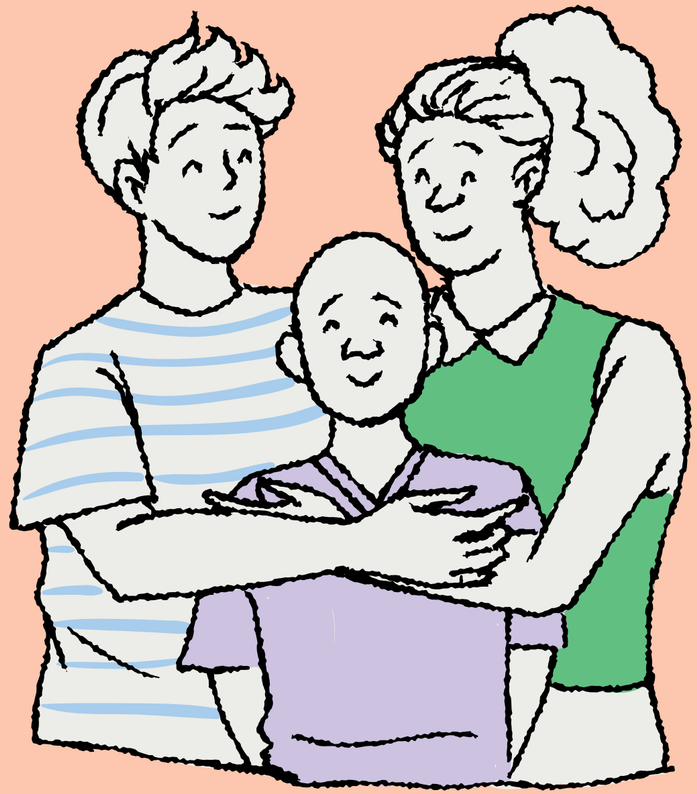
- Important aspects relating to provider’s attitude and communication towards end of life
- Discuss end of life communication:

ACTIVE ANDQUALITY OF LIFE PASSIVE EXERCISE

- Very subjective perception
- Reflects gap between expectation (hopes, ambitions, dreams) and reality (recurrence/short life span)

THE LAST DAYS: COMMUNICATION - FAMILY SUPPORT

- Explain what is happening and what is likely to happen
- Anticipate and prepare
- Listen, be available
- Answer questions
- Assure that symptom control will continue
- Address religious concerns: communion, tulsi
- Fulfill wishes of patient



COMMUNICATION - PATIENT

- Hearing is often preserved for a long time
- Decreasing level of consciousness Communicate with the patient as though he/she can understand
- Encourage family members to express affection and intimacy

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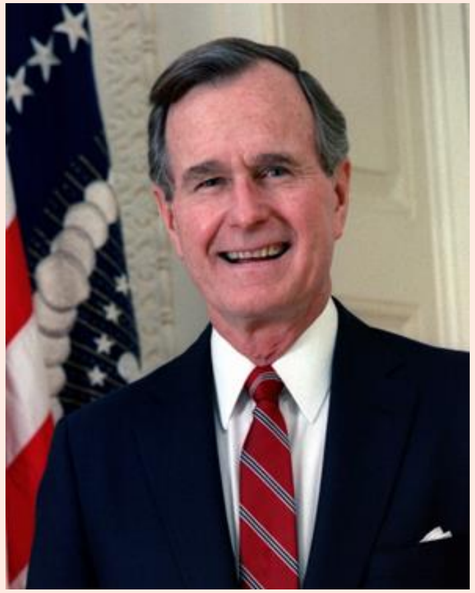
HIPPOCRATIC OR HYPOCRITICAL

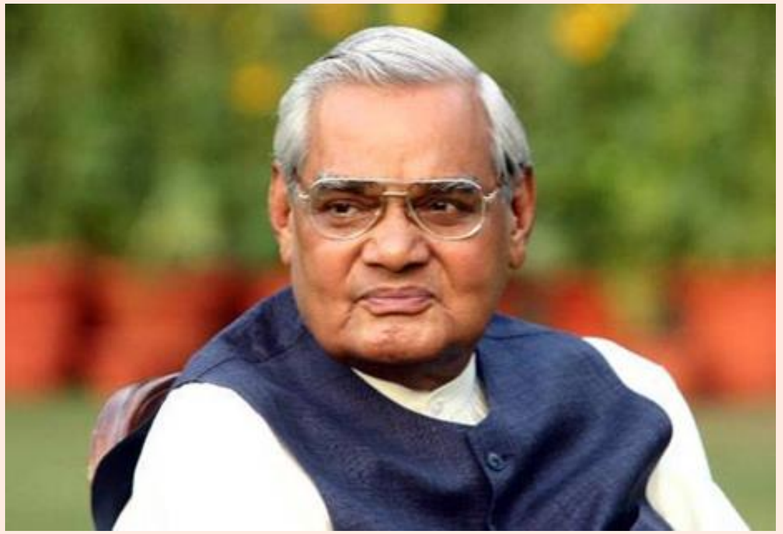
END OF LIFE CARE IN INDIA: RECENT ADVANCES 2018 - 19

Died on Nov 30, 2018
94 years
Vascular Parkinsonism



President George Bush Sr
Died at home with family besides him

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



Prime Minister A B Vajpayee
Died on a ventilator alone – 2 months in ICU

Thank You