End of Life Care Principles and Management

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“How people die remains in the memory of those who live on…..”

- Dame Cicely Mary Saunders
Outline the session

- How do we define ‘end of life care’ (EOLC)?
- What is best practice for EOLC?
- What is needed to support the best practice of EOLC?
- What is your understanding about ‘Place of Care’ in EOLC?
- What are the Common Physiological Changes in EOLC?
- What are the main distressing symptoms in EOLC?
- How do we manage these symptoms?
How do we define ‘EOLC’?

The management of patients during last few days, weeks or month of their life, from a point when it becomes clear that the patient is in a progressive state of decline.
What is best practice end of life care?

**Step 1**
Discussions as the end of life approaches
- Open, honest communication
- Identifying triggers for discussion

**Step 2**
Assessment, care planning and review
- Agreed care plan and regular review of needs and preferences
- Assessing needs of carers

**Step 3**
Coordination of care
- Strategic coordination
- Coordination of individual patient care
- Rapid response services
  - GP Assist
  - CNs
  - PCS advice

**Step 4**
Delivery of high quality services in different settings
- High quality care provision in all settings
- Acute Hospitals, Community, Care homes, Hospices and Other in-patient facilities
- Ambulance Services

**Step 5**
Care in the last days of life
- Identification of the dying phase
- Review of needs and preferences for place of death
- Support for both patient and carer
- Recognition of wishes regarding resuscitation and organ donation

**Step 6**
Care after death
- Recognition that end of life care does not stop at the point of death.
- Timely verification and certification of death or referral to coroner
- Care and support of carer and family, including emotional and practical bereavement support

**Support for carers and families**

**Information for patients and carers**

**Spiritual care services**
What is best practice end of life care?

Discussions with patient & family ➞ making plans about EoLC / GoC / PPoC & PPoD

EoLC (End of Life Care)  PPoC (Patients’ Preferred Place of Care)
GoC (Goals of Care)  PPoD (Patients’ Preferred Place of Death)

Start the Discussion Early
Advancing disease
Increasing Morbidity
Last Days of Life
First Days of Death
Bereavement
Follow-up for many Months

Review
Identify needs
Assess need
Implement
Plan

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Advance Care Planning

Advance care planning

- Statement of wishes and preferences
- Advance decisions
- Lasting power of attorney

**Process:**

- The process is voluntary
- The content of any discussion should be determined by the individual concerned

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Where should the end of life occur?

- Preferred Place of Care
- Preferred Place of Death

Most people would prefer to die at home.

Some want to be at health care setting: Hospital or N-Home for safety! ("feeling safe")

Some want to die at home but end up @ acute hospital ("Unable to cope" or "distressing Symptom issues")
Patient Preferred Priorities for Care
[ Preferred Place of Care (PPoC) / Preferred place of Death (PPoD) ]

What is it?

- An advance care plan for people with a life limiting illness who wish to have their choices and preferences recorded in relation to their care and ultimate place of death

- A patient held record which should go with the patient if they are transferred to a different care setting

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Positives of Implementing patient priorities of care

- Empowering for patients ("I’m still in control" & every thing happening according to my wish")
- Opens up vital discussions
- Promotes choice
- Excellent way of lobbying for further resources
- Helps prevent inappropriate transfer to another setting.
- Builds staff confidence and encourages difficult conversations

Support to the staff

- Not everyone finds it easy to have conversations about death and dying
- Staff may need additional support through communication skills training or through mentor or peer support
What are the Common Physiological Changes in EOLC?

- Weakness / Fatigue
- Decreasing Appetite / Food intake / Wasting
- Decreasing Fluid intake / Dehydration
- Decreasing Blood Perfusion / Renal Failure
- Neurological dysfunction
- Decreasing Level of Consciousness
- Terminal Delirium
- Changes in Respiration
- Loss of ability to swallow
- Pain
- Loss of Ability to close the eyes

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What are the main distressing symptoms for patients and family/carers in EOLC?

- Holistic, total care – Not only to the patient but also to family
- All the distressing symptoms need to be addressed to provide comfort/supportive care.

Main Distressing symptoms are:

1. Pain
2. Agitation / anxiety / SOB
3. Nausea
4. Excessive Chest secretions
How do we manage these symptoms?

Pain management in end of life care

- Pain is a symptom that can occur in the last days of life
- Where pain is a pre-existing symptom, measures should be in place to ensure continued effective management during the end of life
- If pain is not a present problem, an intermittent (PRN) analgesic is ordered in anticipation of pain presenting.
- The end of life goal is that the individual be pain free
- Regular assessment is needed
- When pain is assessed, ordered analgesia is administered, and effectiveness determined
- Episodes of pain and its management are documented
1. Pain Management in EOLC

- If more than 3 PRN doses are given in a 24-hour period:
  - regular subcutaneous administration 4 hourly or a continuous subcutaneous infusion via syringe driver may be considered.
  - if already on regular administration the dosage should be reviewed
  - the PRN order is reviewed in line with alterations to regular doses
Other pain management issues

• Keep the individual and/or their primary carer informed about the care strategy

• Ensure that PRN medications are given in response to pain, or in anticipation of incident pain (e.g.: on moving)

• Ensure that the attending doctor is informed of any inadequacies in the pain management strategy

• Remember that any pain experience can be amplified by psychological and spiritual distress

• Maintaining general comfort measures will contribute to the overall management of pain
2. Anxiety / SOB / Agitation

If anxiety / agitation is not a present problem, an intermittent (PRN) anxiolytic is ordered in anticipation of agitation / SOB / anxiety / restlessness presenting during the EOLC period.
SOB / Anxiety / Agitation

**Simple SOB:** ➔ Low dose regular opioid may help

Anxiolytics – Short acting ‘pams’ are helpful  
(Oxazepam, Lorazepam, Alprazolam)

Short acting ‘pams’ can break **SOB ⇔ Anxiety cycle**

Non – Pharmacological interventions (fan)

? Oxygen- no much research evidence

**Agitation / Restlessness:** No reversible Causes.... unable to take orally

➔ 1st line: Midazolam inj sc 2.5-5 mg Q2H or 10mg via S/driver over 24 h
➔ 2nd line: Levomepromazine via S/driver 12.5 -25mg over 24h
➔ 3rd line: Phenobarbital infusion

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3. Death rattle / secretions

- Why secretions are more pronounced in terminally ill patients?

- Drugs: Glycopyrronium / Hyoscine butylbromide (Buscopan)
  
  From research evidence there is no superior drug (same response!)

- Dose?
  - **Glycopyrronium Inj**: 0.2-0.4mg sc stats (max of 2mg/24hr) or S/Driver start with 600mcg – 1.2 mg/24hr
  
  - **Buscopan Inj**: 20mg sc stats (max 240mg/24 hr) or S/Driver  60-240mg/24 hr
4. Nausea / Vomiting

- Many causes & it can be multifactorial
- **Approach:** mechanistic or emaphirical
- **Mechanistic:** Accurate identification of the cause; understanding of pharmacological mechanism and use of most effective drug

<table>
<thead>
<tr>
<th>Medication</th>
<th>Action</th>
<th>Dosage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Metoclopramide</td>
<td>D₂ Antagonist, 5HT₃ at high doses + (5HT₄ - gut)</td>
<td>For Prokinetic Activity (Gastric stasis) 10-20mg qid</td>
</tr>
<tr>
<td>Haloperidol</td>
<td>D₂ Antagonist</td>
<td>For Biochemical Causes (Hypercalcaemia, RF) 0.5 -1mg noite 6mg/24 hr</td>
</tr>
<tr>
<td>Cyclizine</td>
<td>H₁ Antagonist, Anticholinergic antagonist</td>
<td>For Central Causes (Increased ICP) 50mg tds</td>
</tr>
<tr>
<td>Levomepromazine</td>
<td>D₂ + H₁ + 5HT₂ Antagonist + Acetylcholine</td>
<td>Std 2nd due to its multiple receptor activity 6.25mg 25mg/24hr</td>
</tr>
<tr>
<td>Ondansetron</td>
<td>5HT₃ Antagonist</td>
<td>Chemo / DXT related Nausea 4mg tds or 8mg bd</td>
</tr>
<tr>
<td>Others: PPI / Lorazepam / Steroid</td>
<td>PPI → Reflex disease associated N Lorazepam → anxiety induced N/V Steroid → Combination in Chronic N</td>
<td></td>
</tr>
</tbody>
</table>
Comfort measures in EOLC

A number of comfort measures are considered in EOLC.

These include:
- The need for a pressure relieving mattress
- The need for a single room (if an option)

Key comfort care areas are:
1. Positioning
2. Mouth care
3. Eye care
4. Skin care
5. Micturition
6. Bowel care
Mouth care

- The care goal is that the mouth and lips be clean & moist.

- Mouth care is reviewed regularly.

- Moist oral mucous membranes will tend to prevent thirst.

- Local protocols for cleaning mouth and dentures are used

- Avoid alcohol based agents as these can exacerbation “dryness”
Positioning

- The care goal is that a comfortable position be maintained. Frequency of repositioning is reviewed regularly.

- Comfort should take priority over pressure relieving interventions that cause distress.

- Use individual’s “preferred” position as often as reasonable.

- Use PRN analgesia in advance of repositioning when indicated.
Eye care

- The care goal is that eyes are clean and moist
- Eye toilets following local practice are used
- Eye lubrication is indicated if eye is dry
Skin care

- The care goal is that skin is clean and moist
- Avoid products that dry or harm skin
- The need for pressure area care should be balanced against the need for comfort
- Wounds should be managed in the least invasive way (no time to heal)
- If incontinent ensure skin protection products are used
Micturition

- Care goal is that the individual be dry and comfortable. Urinary aids such as pads should be used if resident is incontinent.

- Urinary output is reduced during the last days of life.

- Urinary retention should be excluded if individual becomes restless.

- Catheterisation is only used when it will improve overall comfort.
Bowel care

- The care goal is that the individual is not agitated or distressed by constipation or diarrhoea

- Optimal bowel care prior to the last days of life especially in the presence of regular opioids, contributes to overall comfort
Spiritual / religious / cultural issues in end of life care

☑ Understandings, expectations and practices relating to dying and death vary for each individual

☑ Quality end of life care needs to address what, if any, spiritual, religious or cultural factors are important for each individual and their immediate family during this time

☑ Identified needs are to be recorded and planned for wherever possible
Spiritual / religious / cultural care

- Relevant rituals / processes may apply
  - Pre death
  - At the time of death
  - Post death

- Identifying these and facilitating their adherence will support the individual and their family
Spiritual / religious / cultural care

- Take an individual approach. Avoid assumptions and stereotyping.
- If indicated, facilitate the practice of identified rituals and provision of support.
- Utilise family contacts / resources.
- Negotiate the introduction of other pastoral resources if indicated.
- Exercise cultural awareness and make use of available resources.
Issues around Commencing SD in the Community

- The drug compatibility
- Consider whether prescribed doses are exceeding the maximum volume of the SD?
- SD site issues
Review

✔ If the prescribed medications are ineffective a medical review is indicated.

✔ Escalating doses of opioids Benzodiazepines or anti-emetics are not commonly seen in the last days of life, and should be regarded as an indication for urgent medical review.

✔ Consult with the specialist palliative care service if indicated.
The Key Tasks or 7 Cs

✓ Communication
✓ Co-ordination
✓ Control of symptoms
✓ Continuity out of hours
✓ Continued learning
✓ Carer support
✓ Care of the dying
End Of Life Care is About…

❖ Planning ahead

“Have you seen the pilots checking ‘every thing’ in the Cockpit, before they fly?”

Anticipatory care helps to avoid crisis and enable to:
- Improve support for families and the nursing teams
- Reduce unnecessary hospital admissions
- Achieve patient’s preferred place of care

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