END OF LIFE CARE AFTER STROKE

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End of life and the dying process

- **End of life** – is used to define a particular time frame and when likely to die within next 12 months
- **Palliative care** – focus is on relief of pain and other symptoms experienced from or during the illness or disease. The goal is to improve quality of life by increasing comfort, promoting dignity and providing a support system to the patient and those close to them.
- Timeframes in the dying process

**The End of Life**

- At risk of dying in 6 – 12 months, but may live for years **Disease(s) Relentless** Progression is less reversible
- **Months** 2 – 9 months **Change Underway** Benefit of treatment less evident Harms of treatment less tolerable
- **Short Weeks** 1 – 8 weeks **Recovery Less Likely** The risk of death is rising

**Dying Phase**

- **Last Days** 2 – 14 days **Dying Begins** Deterioration is weekly/daily
- **Last Hours** 0 – 48 hours **Actively Dying** The body is shutting down The person is letting go

The Leadership Alliance for the Care of Dying People (2014)

There is limited research on end-of-life care for patients dying from stroke.
Last weeks and days – managing the dying patient (1)

Important considerations

• The Leadership Alliance for the Care of Dying People (LACDP) has identified five priorities for care of the dying person:

1. The possibility of death is recognised and communicated clearly; decisions are made and actions taken in accordance with the person’s needs and wishes, and these are regularly reviewed and decisions revised accordingly.

2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.

3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.

4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion.
Why?

- Stroke is a leading cause of death; 1 in 20 within 72 hours, 1 in 7 will die in hospital and between 20% and approx 30% of people die within 30 days of a stroke.
- High-quality palliative and end-of-life care are advocated for patients not expected to recover from stroke.
- Only about 50% of people who have a stroke survive to five-years.
- Identify those most at risk of dying, and gradually integrate palliative care.
- Holistic and anticipatory care will be of benefit to patients and their family carers;
- Predicting the prognosis after acute stroke can be challenging and may account for the low proportion of people with stroke identified for end-of-life care in hospital and community settings. RCP 2016
- Reduce futile treatments, medications, or unsuccessful resuscitation attempts; help more people die how and where they choose.
PALLIATIVE CARE

- **Palliative care** is the management of patients with progressive, far-advanced disease for whom the prognosis is limited and the focus of care is quality of life.

- **During the last days of life**, it is important to redefine the goals, as previously present symptoms may increase and new symptoms may appear.

- **Symptom assessment** is important.

- Many patients and families fear worsening of symptoms as death approaches and may need reassurance that such is not necessarily the case.

- **Many dying patients display** signs of retained respiratory secretions, sometimes called the “death rattle” ([Ellershaw 2001](https://www.ellershaw2001.com)). Although this is often disturbing to family members, it is unclear whether patients themselves find it distressing.
End of Life Care

- There is no evidence that opioids or sedating agents, when reasonably and properly administered at the end-of-life, hasten death (Campbell, 2004).
- While it is reasonable to treat pain or dyspnoea presumptively, the goal should not be simply to reduce the respiratory rate per se; it is just one of a number of possible markers of distress.
- Oxygen administration may also relieve dyspnoea via mechanisms other than by raising oxygen saturation (Watanabe, 2000).
End of Life Care

- Because families are understandably distressed at witnessing delirium in the dying person, they may benefit from emotional support from clinicians.
DYING WITHOUT DIGNITY

- Dying without dignity report (2015) as a result of investigations into complaints about end of life
- Not recognising that people are dying, and not responding to their needs leading to poor care and distress.

Main Themes

1. Not recognising that people are dying and not responding to their needs
2. Poor symptom control
3. Poor communication
4. Inadequate out of hours service
5. Poor care planning
6. Delays in diagnosis and referrals for treatment
RECOGNISING THE DYING PATIENT

- **Signs**
  - Profound weakness
  - Gaunt, Cachexia
  - Drowsiness
  - Disorientation
  - Diminished oral intake
  - Poor concentration
  - Skin colour changes
  - Temperature change in extremities
RECOGNISING THE DYING PATIENT

- Barriers
  - Hope
  - No definite diagnosis
  - Unrealistic or futile goals
  - Disagreement in the team about patient’s condition
  - Failure to recognise key signs and symptoms
  - Poor communication
  - Concerns about withdrawing or withholding treatment
  - Fear of fore shortening life
  - Cultural and spiritual
  - Medico-legal concerns
Mazzocato et al. found a high prevalence of certain symptoms among dying stroke patients **dyspnoea** (81%) and **pain** (69%), **mouth dryness** (62%), and **anxiety** (26%)

Ntlholang et al. identified **respiratory secretions** as a main palliative care symptom in patients dying of stroke

The symptoms with the highest prevalence were: **dyspnoea** (56.7%), **pain** (52.4%), **respiratory secretions/death rattle** (51.4%), and **confusion** (50.1%)

Symptom management is essential in palliative care and before you can take further action to relieve a symptom, it has to be identified and assessed.
PRINCIPLES OF SYMPTOM CONTROL

- Anticipation - can problems be nipped in the bud
- Understanding the natural history of the disease
- Awareness of patients' psychosocial circumstance
- Identification of risk factors
- Assessment and reassessment
- Do not assume that just because patients are not complaining of symptoms they do not have them
- Knowledge, skills, and attitude of the MDT is key
Managing pain is satisfying

Over 80% of pain can be controlled with straightforward medication

Often not achieved

Physical and emotional experience-why me, fatigue, isolation, depression, hopelessness

Replace oral to another route
**Which medications**

- **Pain**: morphine? oxycodone? fentanyl
- **Agitation**: midazolam? First line Levomepromazine
- **N&V**: Cyclizine, metochlopropamide, haloperidol?? Brain mets, seizures, parkinsons
- **Respiratory Secretions**: Glycopyrronium 1st line as less sedation, hyocine
<table>
<thead>
<tr>
<th>Symptom</th>
<th>Medication options</th>
<th>Starting dose</th>
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<tbody>
<tr>
<td>Pain</td>
<td><strong>Normal renal function</strong></td>
<td>2.5 mg S/C, PRN, up to hourly</td>
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<td></td>
<td><strong>Impaired renal function</strong></td>
<td>25 µg S/C, PRN, up to hourly</td>
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<td>(eGFR &lt;30 mL/min)</td>
<td>100 µg S/C, PRN, up to hourly</td>
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<tr>
<td>Agitation</td>
<td><strong>No delirium</strong></td>
<td>2.5 mg S/C, PRN, up to hourly</td>
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<td><strong>With delirium</strong></td>
<td>0.5–1.0 mg S/C, PRN, up to hourly</td>
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<td></td>
<td>Add haloperidol or levomepromazine</td>
<td>12.5 mg S/C, PRN, up to hourly</td>
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<tr>
<td>Nausea</td>
<td>Cyclizine</td>
<td>50 mg S/C, 8 hourly/PRN</td>
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<td><strong>Alternative</strong></td>
<td>6.25 mg S/C, 6 hourly/PRN</td>
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<td></td>
<td><strong>Chemical cause</strong></td>
<td>1.5–3.0 mg S/C, daily</td>
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<tr>
<td>Respiratory tract secretions</td>
<td><strong>Alternative</strong></td>
<td>20 mg S/C, PRN, up to hourly</td>
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<td><strong>Or</strong></td>
<td>400 µg S/C, PRN, up to hourly</td>
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<td>Hyoscine butylbromide</td>
<td>200–400 µg S/C, PRN, up to hourly</td>
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<td>Hyoscine hydrobromide</td>
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<tr>
<td></td>
<td>Glycopyrronium</td>
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<tr>
<td>Breathlessness</td>
<td><strong>Alternative</strong></td>
<td>2.5 mg S/C, PRN, up to hourly</td>
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<tr>
<td></td>
<td>Morphine</td>
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<td>Midazolam</td>
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eGFR, estimated glomerular filtration rate; PRN, as required; S/C, by subcutaneous injection.
ANTICIPATORY MEDICATION

- PRN
- Expect to see a result in 15 mins
- Not all patients will require
- Pain, N&V, Agitation, Respiratory secretions
- Rule out reversible causes
- Syringe driver useful but is not necessary for all patients
Terminal Restlessness

- Distressing to patient and family
- Medication toxicity
- Organ shutdown and associated with metabolic changes
- Pain
- Urinary or faecal retention
- Dyspnoea and related hypoxia
- Sepsis
- Psychosocial and spiritual distress
MANAGEMENT

- Assessment and symptom control
- Watch for non verbal signs
- Mouth care
- Eye care
- Compassionate care
- Communication
ETHICAL ISSUES

- Nutrition and hydration
- At the end of life a person may become hydrated and there is no moral or legal obligation to continue to administer and clinically assisted hydration or nutrition if they are having no beneficial effect
- Common area of concern to relatives and MDT
- If the patient wants to drink they should be assisted to do so
- Some patients may not feel like it
- The body cannot utilise the nutrition
- Help families to understand this.
- To give or not to give iv fluids – may reduce thirst in some – good mouth care does just as good
- The patient is dying from their disease not from thirst
- Who are we treating the patient or their family or us.
- Seems like we are not just letting the patient die
- On the other hand increases incontinence and restlessness from a full bladder, increases pulmonary oedema, makes death less natural, may delay or prevent discharge home
**Ethical Issues**

- Essential ethical principle that the clinician must put the best interest of the patients first.

- When a person lacks capacity to make such a decision, this should be made by the doctor in consultation with the patient’s family.

- The patient may have already have made their wishes known by a binding Advanced Decision to refuse treatment.
**People in the Last Year of Life**

- 90% of patients die from a previously diagnosed condition.
- The Gold Standards Framework Prognostic Indicator can help recognition of the end of life.
- For patients who are older and frail or have advanced progressive disease, prognostic factors could include:
  - a ‘No’ answer to the question ‘Would I be surprised if the patient were to die in the next 12 months’
  - two or more unplanned admissions in the last 6 months
  - poor or deteriorating performance status
  - persistent symptoms despite optimal therapy
  - secondary organ failure arising from an underlying condition.
While the provision of a *private room may not always be possible* because of a sudden and unexpected decline in the patient’s’ condition, or through lack of availability, *it should be given the highest priority* for the sake of the patient, relatives and carers, and other patients on the ward.

Where the wishes of the patient are known in respect of the environment in which they die, these should be respected. This may include the playing of music, provision of flowers, pictures, or anything else which can reasonably be accommodated for their comfort and emotional well-being.

Relatives and carers of loved ones who are deteriorating to the point that they might die soon should be able to access their loved one freely outside normal visiting times to enable them to be together at this important and difficult time.

During this time the medical and nursing staff should be able to build a rapport to help and support the family members through a difficult
You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully but also to live until you die.
REFERENCES

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- http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4742254/#pone.0147694.ref031
- RCP End of life 2016