How to take care of neurological patients in the last days of life

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Disclosures

- There are no disclosures

Learning objectives

- To be aware of the issues of patients, families and professionals at the end of life
- To be aware of the possible triggers in the recognition of the end of life for neurological patients
- To understand the medication to be given at the end of life
- To be able to discuss the issues that may arise for a neurological patient at the end of life

Palliative care

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

WHO 2002

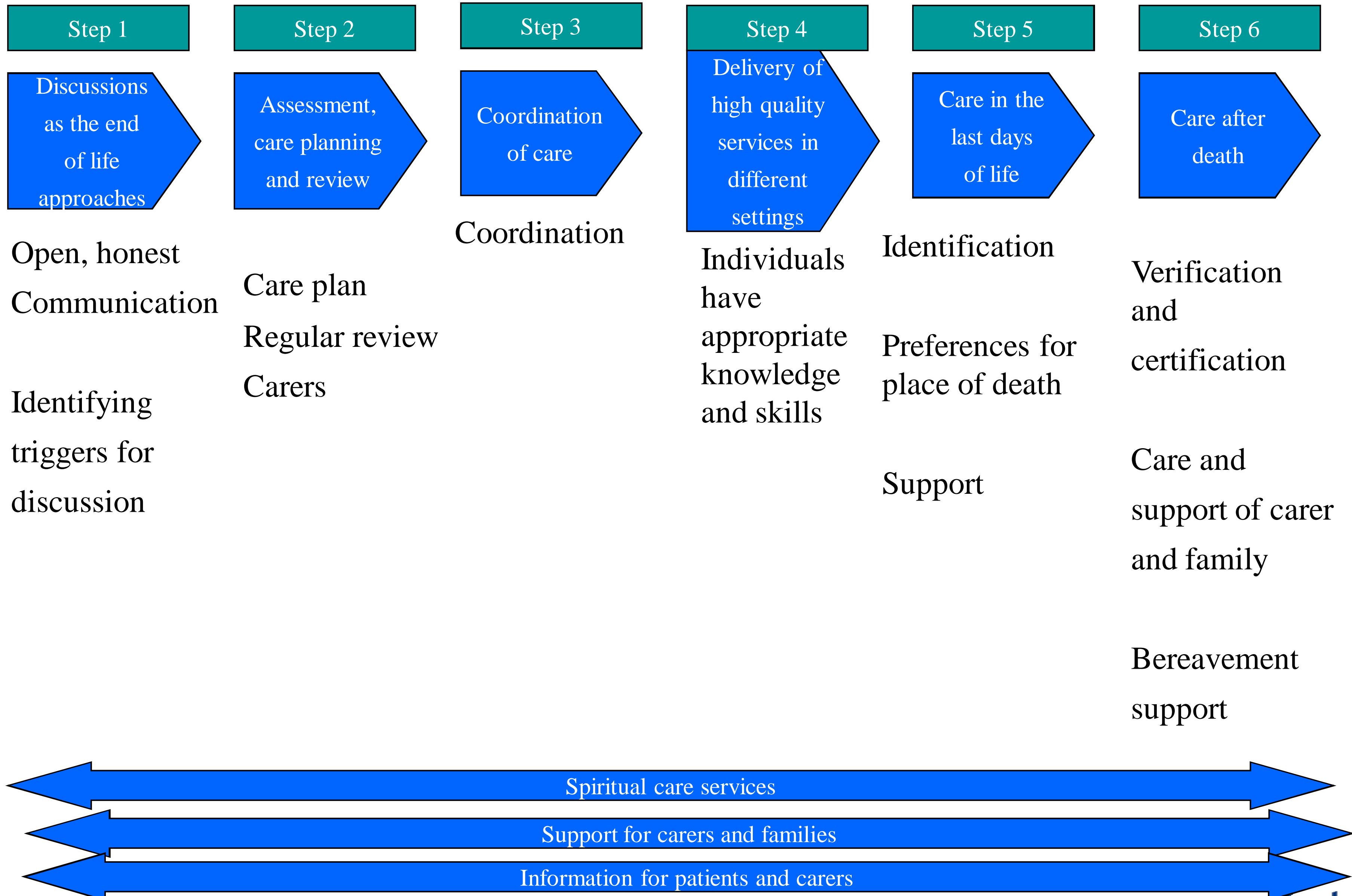
Palliative care aims

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care

End of life care

- When does end of life care start?
- Who is involved?
- How do we discuss with patients?
- How do we develop improved care?

The End of Life Care Pathway



Triggers for end of life care

- Generic for neurological care
  - Patient request
  - Family request
  - Dysphagia
  - Cognitive decline
  - Dyspnoea
  - Repeated infections
  - Weight loss
  - Marked decline in condition

Triggers

- **Amyotrophic Lateral Sclerosis**
  - § **Breathlessness / respiratory failure**
  - § **Swallowing issues**
  - § **Cognitive changes**
  - § **Weakness**

Triggers

- Multiple Sclerosis
  - § Dysphagia
    - Choking attacks
    - Poor hydration and nutrition
  - § Frequent infections
  - § Cognitive decline
    - Reduced communication
  - § Fatigue
    - Profound, reduced response to the environment

Triggers

- **Progressive Supranuclear Palsy**

  Cortico- Basal Degeneration

  - **Dysphagia**
  - **Speech poor**
  - **Weight loss**
  - **Severe pressure sores**
  - **Weight loss**
  - **Psychiatric symptoms**
  - **Medication no longer effective**

Triggers

- Parkinson’s disease
  - Rigidity
  - Pain
  - Agitation / confusion from sepsis
  - Neuropsychiatric decline

End of life care

- Decision making
  - Resuscitation
  - Sedation
  - Hydration / feeding
  - Ventilation
- End of life discussions
  - Euthanasia
  - Is death discussed?

Planning

- Palliative care
  - Specialist palliative care / hospice
  - All professionals
- End of life
  - Advance care planning
- Terminal stages
  - Ensuring comfort
  - Regular review and monitoring of care

Advance care planning

- Advance statement
- Advance Decision to Refuse Treatment
- Lasting power of Attorney
  - Personal Welfare
  - Property and Affairs
- Will
- Funeral plans

Team assessment

- Multidisciplinary
- Multiagency
- Increased need to ensure

  co-ordinated approach

  not overwhelming patients

  carers supported

End of life care

- Symptom control
- Anticipation of crises
- Communication

    Patient

    Family

    Professionals

Recognition of approaching death

- Multiprofessional team have agreed that the

  Patients is dying

  + two of these
  - The patient is bedbound
  - Only able to take sips of fluids
  - Semi-comatose
  - No longer able to take tablets

General principles

- Assess symptoms regularly
  - Team approach
- Assess current medication and discontinue non-essentials
  - Stop statins
- PRN medication available
  - Pain, vomiting, agitation, chest secretions

General principles

- Discontinue inappropriate interventions
  - Iv fluids
  - Oxygen
- Decisions taken to discontinue inappropriate nursing interventions
  - Blood pressure, pulse, temperature
  - Blood tests

Symptoms

- Pain
- Dyspnoea
- Dysphagia
- Incontinence
- Constipation
- Speech problems
- Delirium
- Anxiety / Depression

Family fears

- Dying
  - Symptoms
  - What will happen?
- Death
- Future
  - How will I cope?
- Uncertainty
  - How can I plan?

Patient aspects of care

- Cultural aspects
  - § Ethnic culture
  - § Family culture
- Spiritual aspects
  - § Religious needs
  - § Spiritual issues

Pain

- Oral medication
  - Simple analgesics – paracetamol
  - Codeine based / tramadol
  - Morphine / oxycodone
- Transdermal patch
  - Buprenorphine
  - Fentanyl
- Parenteral medication
  - Morphine
  - Oxycodone

Agitation - Non-Drug Management

- Treat reversible causes
  - Urinary retention
  - Constipation
  - Pain
- Identify and address psychological issues
  - Fear
  - Isolation
  - Spiritual distress
- Suction (rarely needed)

Agitation

- Diazepam / Lorazepam
- Midazolam
- Levomepromazine

- Orally / sublingually
- Rectally
- Parenteral route
  - Injection
  - Subcurtaneous infusion

Anti emetics

- Cyclizine
- Phenothiazines
  - Levomepromazine
- Haloperidol
- Ondansetron

Anti emetics

- Oral
- Parenteral
  - Injection
  - Subcutaneous infusion

Chest secretions

- Anticholinergics
  - Glycopyronium bromide
  - Hyoscine hydrobromide Scopolamine
  - Hyoscine butylbromide

- Parenteral route
  - Injection
  - Subcutaneous infusion

Management of crisis

Preparation

Anticipation

Calm approach

Injection

- Morphine
- Midazolam
- Glycopyrronium bromide

Just in Case Kit – in ALS

Discussion about future plans

Leaflets on death and dying

Box for medication

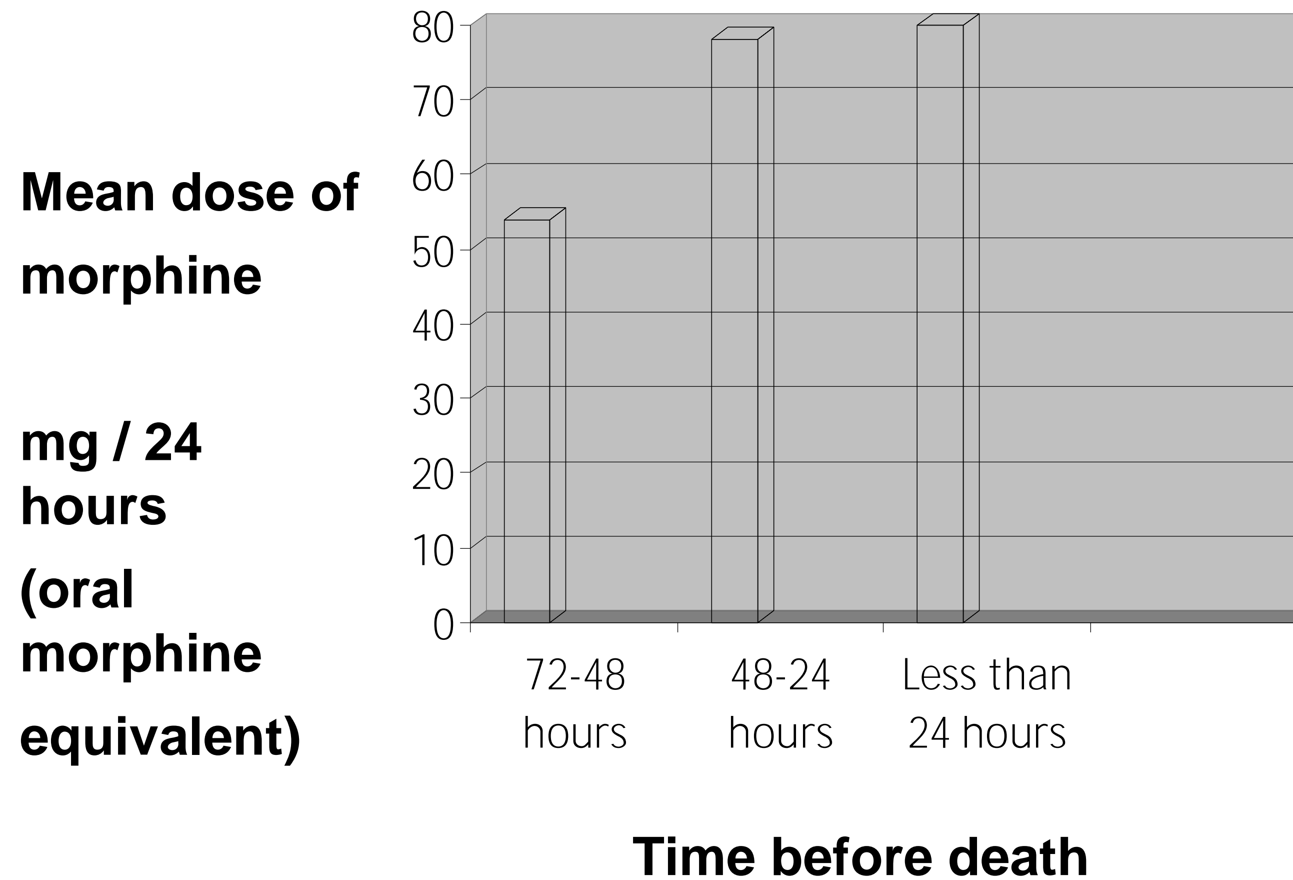
Family carers section

- Rectal diazepam / Buccal midazolam

Professionals

- Injections and syringes

Opioids in last 3 days of life in ALS



Oliver et al 2010

Ethical issues

- Withdrawing treatment
- With-holding treatment

- Examples of life-prolonging medical treatments include:

  IV fluids, enteral or parenteral feeding, antibiotics, CPR, ventilation

Ethical issues

- The primary goal of any medical treatment is to benefit the patient by restoring or maintaining health, maximising benefit and minimising harm

- Treatment that does not provide net benefit to the patient may, ethically and legally, be withheld or withdrawn and the goal should shift to the palliation of symptoms

End of life care in neurological disease

- Assessment of needs
- Attitudes
- Collaboration
  - Neurology
  - Rehabilitation teams
  - Palliative care teams
- Palliative care approach

  / supportive care

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