The last days of life ……

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- "I'm not afraid of dying, I just don't want to be there when it happens"
  - Woody Allen

Palliative Care…

is an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of an early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

World Health Organisation 2003

Palliative care

- Suffering
  - physical
  - emotional
  - spiritual
  - psychosocial

A Good Death

- A death which is purposeful and allows for resolution and reconciliation
- Consistent with the persons ideals as well as clinical, cultural and ethical standards
- Absence of avoidable suffering
- In accordance with patient and families wishes

- Palliative Care principles applied throughout the patients disease process will allow the patient not only to live well but also to die well

End of Life Care

- Last opportunities
- Last chance for health professionals to get it right
- Closure

Key Principles of Palliative Care

- **NEVER** true that nothing can be done
- The family and the patient are the unit of care
- Patient's priorities are paramount

Misconceptions regarding Palliative Care

- Misconceptions regarding Palliative Care
  - Only for end of life care
  - Only for cancer patients
  - Automatic commencing of opioids
  - Means all active interventions will be stopped

Difficulty diagnosing dying

Death is not a failure but a reality

Death is perceived as a failure by health care workers and the public

Life at any cost

Not wanting to "give up" –team or patient/family

- unrealistic expectations
- poor communication

NFR

- medical decision

- Diagnosing dying is important
- Change the emphasis of care from cure to comfort

- Surprise question…….
  - "Would it surprise you if your patient died in the next 12 month?"

- "How long will I last?"
  - Residual renal function
  - Patient expectations

Last 48 hours of life

- Every patient and families experience will be different
- Never presume what is the worst thing
- Ongoing assessment

Contexts of Dying with ESRD

- Sudden death usually of cardiovascular origins
- Withdrawal from dialysis (driven by the patient or after major sentinel event)
  - Fluid overload
  - Uraemia
  - Hyperkalaemia

Contexts of Dying with ESRD

- Death while on a conservative pathway- non dialysis pathway

Advanced illness

- Profoundly weak
- Essentially bed bound
- Drowsy for extended periods
- Disorientation for time/limited attention span
- Disinterest in food/fluids
- Difficulty swallowing medications

Decreasing appetite/food intake

- Fears: "giving in", starvation
- Reminders:
  - Food may be nauseating
  - Anorexia may be protective
  - Risk of aspiration
  - Clenched teeth express desires/control
  - Help family find alternative ways to care

Decreasing fluid intake…

- Oral rehydrating fluids
- Fears: dehydration, thirst
- Remind family, care givers
  - Dehydration does not cause distress
  - Dehydration may be protective

Decreasing fluid intake …

- Parenteral fluids may be harmful
  - Fluid overload, breathlessness, cough, secretions, incontinence
  - Importance of mucosa,conjunctiva care

Communication with the unconscious patient

- Distressing to family
- Assume patient hears everything
- Include in conversations
- Give permission to die
- Touch

Medications for comfort

- Prescribe in anticipation
- Consider route of administration
- Rationalising unnecessary medications

Pain

- Fear of increased pain
- Assessment of the unconscious patient- persistent vs fleeting expression
  - Grimace, moaning
  - Incident vs pain at rest
  - Distinction from terminal delirium

Management of Pain

- Hydromorphone 0.25-0.5 mg 4/24 s/c
  - Titrate as required
  - Route of administration
  - Regular V PRN
  - Remembering that other opioids may accumulate in renal failure causing myoclonic jerks, profound narcosis and respiratory depression

Management of agitation

- Assess for reversible causes
  - If conscious Haloperidol 1-2mg daily po/sc
- Clonazepam 1-2mg BD S/C or S/L
- If unconscious
  - Midazolam 2.5-5mg 2-4/24 prn S/C
  - Midazolam infusion 10-20mg over 24 hrs

Management of Myoclonus

- Clonazepam 1-2mg BD S/C or S/L
- Midazolam infusion 10-20mg over 24 hrs

Management of dyspnoea

- Hydromorphone 0.25-0.5mg 2-4/24 prn
- Titrate as required

- Lorazepam 0.5-1mg S/L TDS prn
- Midazolam 10-20mg S/C in Syringe driver or Clonazepam 0.5-1mg BD S/C or S/L

Management of Nausea and vomiting

- Haloperidol 0.5-1mg BD s/c as starting dose
- Titrate as required
- Maxalon 10mg TDS s/c

Respiratory Secretions

- Glycopyrrolate 200-400mcg 2-4/24 s/c prn

Key elements of the renal end of life pathway

- Discussion as death approaches
- Assessment, planning and review of care needs
- Delivery of high quality care in different settings
- Coordination of patient centred care
- Care in the last days of life

As death approaches

- Discuss
  - Status of patient
  - Realistic goals of care
  - Plan of physician
  - Reinforce signs, events of dying process
  - Family support