End of life care

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A talk by Associate Professor Amanda Walker from onthewards conference discussing the practicalities of end of life care, warning signs that a patient is dying, what to consider, say, be, and chart as a doctor.

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About Amanda Walker

Amanda Walker is a Specialist in Palliative Medicine. She is also working as a Senior Clinical Advisor at the Australian Commission on Safety and Quality in Healthcare. Furthermore, Amanda has worked at the NSW Clinical Excellence Commission developing programs addressing diagnostic errors and end of life care. She has previously worked as a clinician, educator, and administrator in South Western Sydney.

End of Life Care

With Associate Professor Amanda Walker, Specialist in Palliative Medicine, Clinical Director, Australian Commission on Safety and Quality in Care, Sydney, Australia

Introduction

Death is inevitable
Warning signs: most people have some warning that something is catching up with them
What's important for the patient?
The practicalities of end of life care:

What to consider
What to say
What to be
What to chart

1. What to consider?

- What people need in End of Life Care
    - Release from symptoms
    - Caring environment
    - Expert care
    - Assurance that they won't be abandoned

- Individual preference: Sometimes what we would choose is not what someone else may choose
- What we perceive vs. reality:
    - Patient's will sometimes muster up all their strength to see their doctor
    - We get a different view of a patient than reality
- One Chance:
    - Only one chance to get this right
    - Lifelong ramifications of poor care to family or friends
- Could they be supported to die at home?
    - Do they have family and friends who can care for them 24 hours a day supported by palliative care nurses?
    - Do they have access to 24-hour specialist advice?
    - Is there a local Doctor who is available to visit them at home and provide a death certificate if we are sending them home to die?
    - Have we sorted out the medications that they might need in a route that they can actually absorb So, we need to plan for the fact that they lose the oral route
    - Have we talked through with patients and families about what to expect so they understand that someone is going to be bed bound for 24 hours a day and needs serious support?

2. What to do?

- Tips for a palliative care consult:
    - A brief summary of the disease
    - What are the current or proposed treatment options?
    - What's the home situation?
    - Are there issues with capacity?
    - What's important to the patient?
    - Are there family conflicts?
    - What have they been told?
    - Current symptoms?
    - Have limits of care been established?
    - Best Estimate of Prognosis
- Listen to nurses
    - They spend more time with the patients than we do
    - They see functional changes close-up
    - If they are worried – you should be worried
- We need to recognise dying
    - Prognosticating is hard
    - SPICT tool – the Supportive and Palliative Care Indicators Tool
- Symptom control

- The key = understanding the pathophysiology and treating the mechanism of the symptom
    - E.g. Back pain in cancer: pathological fracture vs. strap muscle spasm. One needs opioids and NSAIDs, the other needs benzodiazepines.
- Analgesia:
  Opioid conversion (from oral to subcut)
    - NSW – 2:1
    - Victoria – 3:1
    - Elsewhere – follow local protocol
    - Actual estimate – 2.4:1
- Restlessness – see what to chart
- Secretions/Rattly Breathing – see what to chart

- Rationalise medications
    - Stopping all non-essential medications:
        - Antihypertensives
        - Lipid Lowering Agents
        - Antihyperglycaemic: Target = BSL 5 – 20 – avoiding symptoms from hypo and hyperglycaemia.
- Planning for subcut medications
    - Patients eventually lose the ability to swallow
    - Be prepared to change all medications to subcut when this happens

3. What to be?

- Be Present:
    - Bear witness to suffering by listening, by showing respect and kindness.
    - This time is the patient's time
    - Put aside assumptions
- Be kind to yourself:
    - Talk to friends, family, colleagues, nurses, social workers, pall care doctors about your experience – they will all think better of you for expressing how you're feeling
- Be prepared:
    - Plan for the loss of the oral route
        - Saf-T intima line – ensure it is inserted in areas where patient will absorb medications (e.g. no oedema)
        - Syringe Drivers: get help from the Palliative Care Service and don't turn them off

- Be practical:
    - Basics – support nursing staff
        - Mouth care
        - Pressure care
        - Eye care
        - Incontinence care
- Be there for complexities:
    - Examples of the terminal catastrophe.
    - Arterial Blow
    - Out/Exsanguination
    - Perforated Viscus
    - Respiratory Distress
    - Status Epilepticus
- Other complexities:
    - Agitated patient – look for pain, dyspnoea, urinary retention and faecal impaction.
    - Terminal Delirium
    - Terminal Restlessness

4. What to say?

- General principles
    - “I find the more upfront I am, most people are appreciative of that.”
    - Most patients aren’t surprised by diagnosis
- Prognosticating:
    - Don’t give numbers
    - Relate to rate of progression: changes occurred over days, weeks or months – prognosis is likely days, weeks or months respectively
- Resources:
    - PREPARED Model – CEC/HETI guide for clinicians in NSW – how to talk to people about end of life care and what they want in the last days. It’s been developed by the CEC and HETI here in New South Wales and it can give you the words to use.
    - New South Wales Clinical Excellence Commission website – Last Days of Life Toolkit
- New South Wales guardianship hierarchy (in order):
    - Appointed guardian
    - Most recent spouse with continuing relationship
    - Unpaid Carer providing care
    - Children

- Signs of dying:
    - Loss of interest in food or fluid.
    - Spending more time asleep
    - Changes in responsiveness
    - Less energy to interact.
    - Changes in breathing pattern
    - Rattly breathing
    - Circulatory change: either cooler or warmer
- Things to say to family:
    - Patient can still hear us.
    - Invite families to care for patient
        - Massage pressure points
        - Syringe Fluids
        - Mouth Care
    - Look after themselves: sleep, food and care when driving
- 7 important words: “She is so sick she could die”, or “he is so sick he could die.”

5. What to chart?

- General Principles
    - Changing to subcut route
    - Cancel unnecessary meds
    - PRN medications for terminal care
- PRN Medications
    - Antisecretory
    - Medications – Glycopyrrolate or Hyoscine
      Analgesia – Morphine or Hydromorphone
        - Breakthrough: 1/6th total daily dose
        - Hydromorphone: 5 times stronger than morphine
    - Anxiolytics – Clonazepam
    - Antiemetic
- Active Treatment
    - Time limited trial of therapy
        - Allows you to set the expectations

6. Summary

- In summary:
    - Recognise and acknowledge dying.
    - Adjust your treatment plans accordingly
    - Have appropriate discussions with patients and relatives
    - Evaluate and prepare for the mode of death
    - Address the physical symptoms that are present and any existential distress and its manifestations
    - Support nurses to provide excellent end of life care
- So perfection is our goal but excellence will be tolerated
- Consider a career in palliative medicine
- If in doubt: ask for help
    - National Standards: every patient in NSW must have access to a Pall Care doctor over the phone

Related Blogs

- Palliative care consult guide
- A day in the life of a palliative medicine advanced trainee

Related Podcasts

- Palliative care and crisis medications
- Palliative Care
- End of life care

Tags: #analgesia,#communication,#death,#end of life care,#end of life management,#Geriatrics,#guardianship,#kindness,#limits of care,#medications,#palliative care,#palliative care consult,#palliative medicine,#PREPARED Model,#signs of dying,#SPICT tool,#treatment plan