

Clinical Update in Palliative Care

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**Government
of South Australia**

SA Health



Outline

- > Palliative care versus End-of-Life care
 - Symptomatology vs psychosocial/spiritual care
- > New medications and novel uses
- > Advance Care Planning/Directives
- > End of life Pathways/Liverpool Care Pathway
- > Governance & Models of Care for Spec Palliative Care
 - Consultation liaison vs Inpatient palliative care units vs Home care
- > Home care/Death at home
- > Interface with generalists and general practice
- > Euthanasia and physician-assisted death
- > Palliative care research in Australia



WHO Definition of Palliative Care

- > 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 early identification and impeccable assessment and treatment of pain and other problems physical, psychosocial and spiritual.

WHO definition



Within specialist palliative medicine a tension between

> Symptomatologist

OR

> Holistic care

- Dying as an 'opportunity for integration and healing'
- Spirituality



Components of a Good Death

- > Observations of patients, families and providers
 - Pain and symptom management
 - Clear decision making
 - Preparation for death
 - Completion
 - Contributing to others
 - Affirmation of the whole person

Steinhauser et al, Annals of Internal Medicine, May, 2000

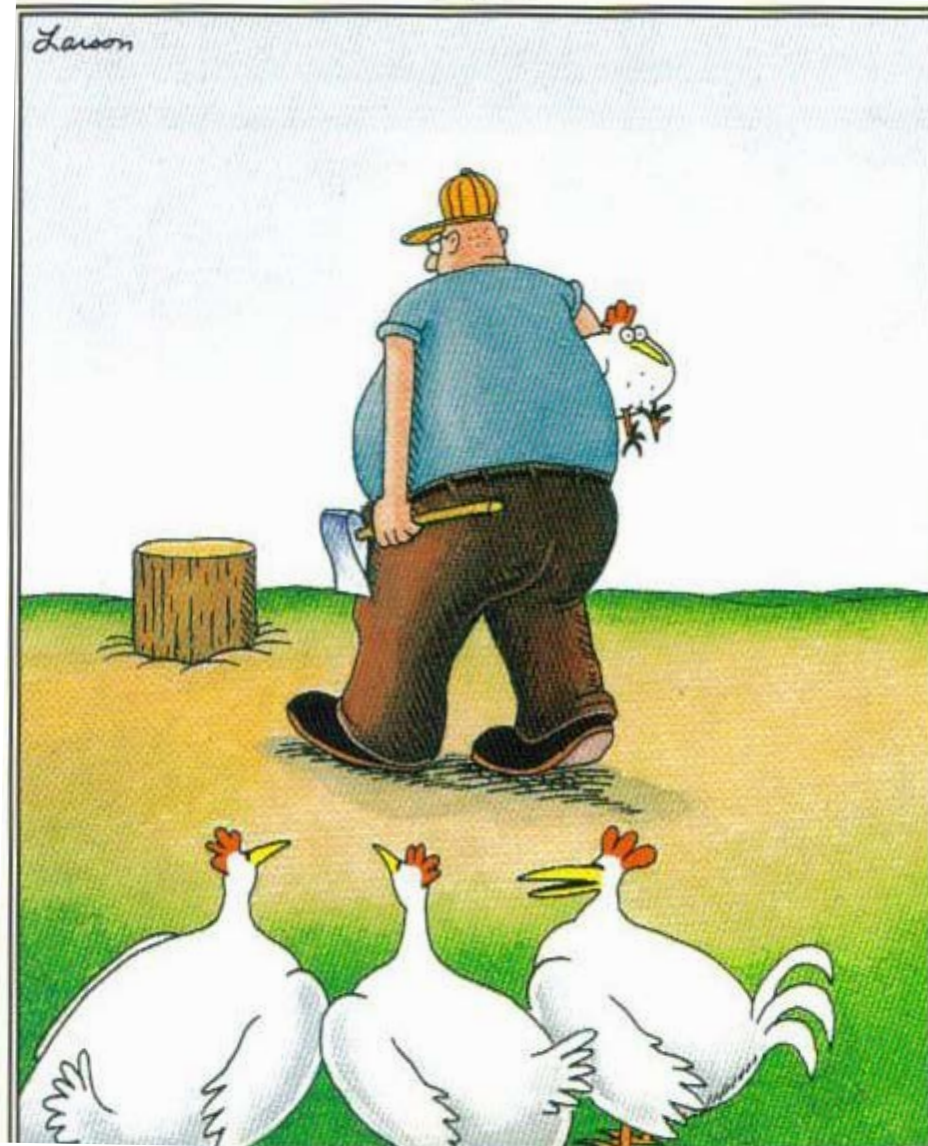


Is palliative care becoming end-of life care

- > Feels like “palliative care” is less used and more reference to “end of life”
- > What or when is “end of life”?

“Well, when it’s my
turn, I just hope I go
quietly. ...

You know – without a
lot of running around.”





Medications new or changed


- > Oral fentanyl
 - *Abstral* sublingual tablets
- > Oral ketamine
- > Ketamine's place in palliative care pain management
 - Hardy et al, Fallon ??
- > Lower opioid dosing
- > Increasing recognition of pain poorly non-responsive to opioids
- > Increasing use of Methadone
- > Neuropathic agents



Advance Care Directives

- > National Framework
- > South Australia has the first legislation
- > Other states following but with a great variety of different terminologies

- > Values and wishes
- > Substitute Decision Makers
 - Stand in the person's shoes
- > Hierarchy of responsible adults
- > Binding refusals

- 
- > Challenges of medical profession understanding binding refusals if context appropriate i.e. must be followed
 - > Community engagement with the process
 - > How to have good guidance in the completion
 - > How to know one exists
 - ?Patient held electronic record
 - > Feels like ACD is the “answer to all our questions”



End of Life Pathways

- > Liverpool Clinical Pathway
 - UK outcry re inappropriate patients and ending of life prematurely
 - tied to KPIs, to funding
 - Lack of senior clinical assessment re eligibility and review
- > Australia no apparent “outcry”
- > Still used in some places but generally being phased out
- > Development of other end of life clinical pathways
- > No evidence of similar problems

- > NICE Guidelines to make patient-specific pathways and anticipatory orders



Governance



Where is specialist palliative care located

- > Tertiary care
 - Integrated cancer centres
 - General medicine
 - Medical subspecialties
 - Subacute services
- > Primary care
 - Community health
 - Within community nursing
 - In General Practice
- > Alone
 - Does not fit in to any



Tertiary care

- > Increasing emphasis on providing consultation liaison rather than direct care
- > More involvement in the complex and difficult
- > Tension between continuity of care and volume of workload

- > “Palliative care is everybody's business”




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BUT IS IT?


- 
- > BUT also increased pressure for more deaths at home
 - > BUT
 - > Is specialist palliative care ONLY for
 - Complex issues or Unmet need
 - To increase home death rates
 - Increasing pressure for General Practice to be increasingly involved



Home

- > Belief that home is always best
 - Is this home care, home death
- > Increasing pressure to facilitate home death
 - May be desired
 - Many do not want this
- > Not necessarily BEST
 - Symptom control
 - For family
- > What are the community supports to enable this

- 
- > BUT is home always best
 - > Is it safe?
 - > Changing role of family to becoming personal carers
 - Not always best
 - Financial implications

- 
- > BUT is home always best
 - > Is it safe?
 - > Changing role of family to becoming personal carers
 - Not always best
 - Financial implications
 - > Clearly NOT



Inpatient Palliative Care Units

- > Acute inpatient Palliative Care Units
 - Short length of stay
 - Reducing death rates
- > Hospice
 - In tertiary care
 - Community/primary care
 - Stand alone
 - Charitable sector
- > Hospice versus RACF
 - PA toolkit
 - ?resourcing/staffing




How can palliative care be “everyone’s
business”



Palliative approach


- > Patient centred care
- > Symptom management
- > Communication
 - Clear
 - Sensitive
 - Appropriate

- 
- > But doesn't all health care aspire to be patient-centred?
 - > Surely all medical care addresses patients' symptoms
 - > How good is our communication ability?
 - > Can you learn to be a better and more effective communicator?
 - > What drivers are there for generalist clinicians to gain, maintain and improve communication abilities?



General Practice

- > What is a general practitioner
 - Special interests may not be PC
- > Model of care and remuneration
 - Fee for Service/Practice Incentive Payments
 - Corporate practices
- > Home visits
- > Afterhours
- > Phone contact
- > Palliative care specific issues
 - General practice opting out, being deskilled or bypassed
 - Direct oncology to palliative care referrals
- > Call for “palliative care to be EVERYONE’S business”

- 
- > Mantra that home is always best
 - Is this home care, home death
 - > What are the community supports to enable this



Changing patient profile

- Longer duration from diagnosis to death
- Older population
- New side-effect profiles of anti-tumour therapies
- More non-malignant disease
- Different symptom profiles
- Multi-organ failure management



Implications

- > Risks of long term opioids
- > Greater recognition of pain that is poorly responsive to opioids
- > More conservatism re opioid dosing
- > More combination therapies
 - Opioid combinations
 - Adjuvants
- > Neuropathic pain

Can opioids cause harm?

> Yes

- Excessive
- Toxic me
- Opioid-in
- Possible
- Testoste



"If you remember, I did mention possible side effects"



Euthanasia and Physician-assisted death

- > Netherlands
- > Belgium
- > Oregon and other states USA
- > Canada
- > Frequent attempts at legislation in Australia



Euthanasia and Physician-assisted death

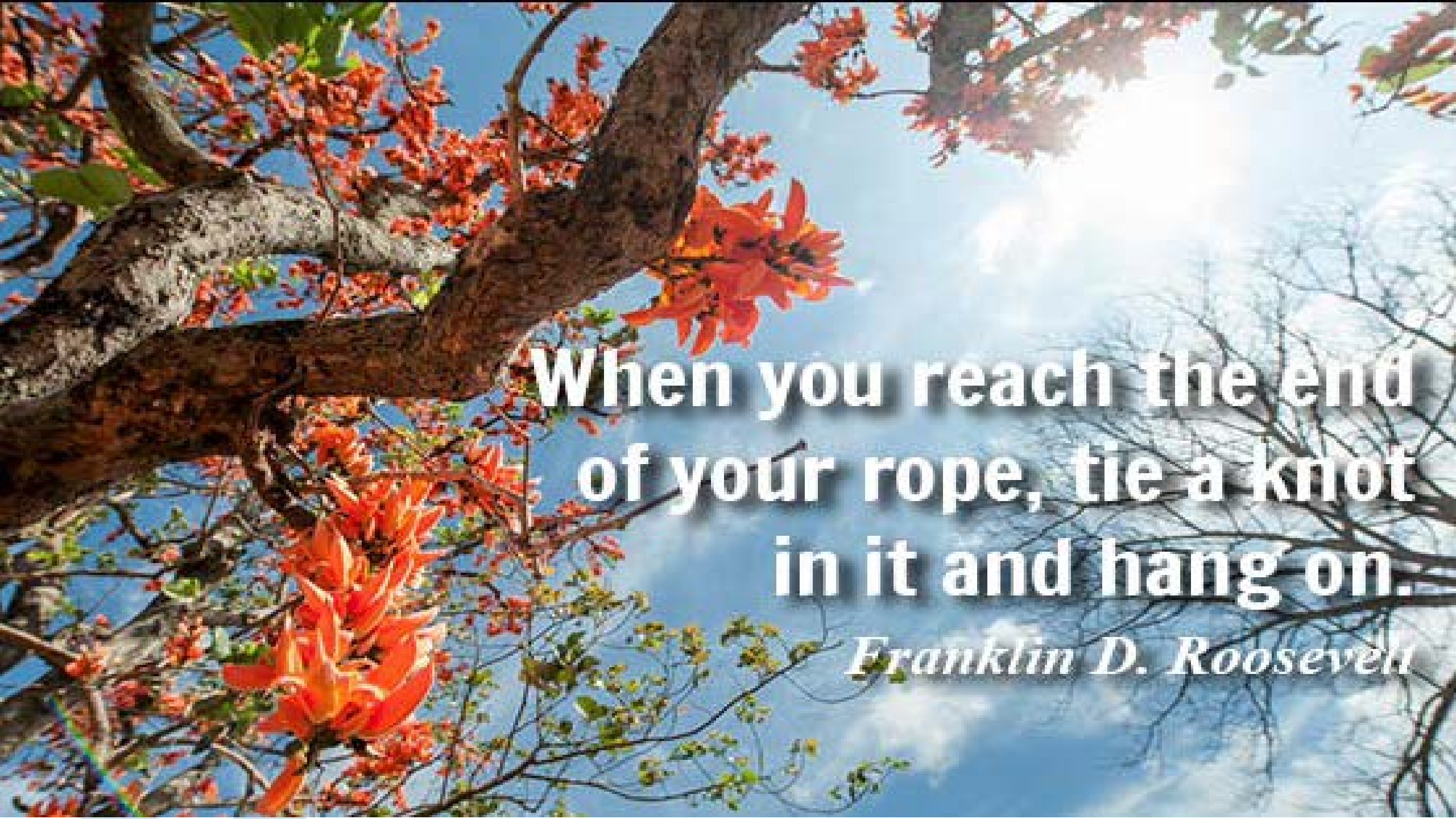
- > Shift in argument from autonomy AND compassion to
- > Focus just on patient autonomy
- > So is euthanasia part of palliative care clinical provision?
- > Why are doctors needed at all?
 - Refusal of USA physicians to be involved in lethal injection of death row criminals
 - Increasing dis-ease in Dutch physicians with increase in autonomy-based arguments and development of End-of-Life clinics → less role for medical evaluation



Research

- > Continuing and developing large body of research from all areas of Australia
 - Notably PaCCSC and Flinders Uni lead by Prof Currow

- > Commonwealth funded projects
 - CareSearch
 - Educational needs in acute hospitals
 - PCOC
 - PCC4U and PEPA
 - AIHW
 - PCA
 - Respecting Patient Choices



**When you reach the end
of your rope, tie a knot
in it and hang on.**

Franklin D. Roosevelt