Dying - and the end of life care of frail older people'

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Overview of lecture

- The visible process of dying
  - Recognising dying
  - Peripheral shutdown
  - Central shutdown
- The invisible process of dying
  - Exiting the body
  - Panorama of life
  - Expansion of self
- Weave in various quotes /literature to emphasise ‘dignity in dying’ in frail older people

‘But that the dread of something after death,
The undiscovered country from whose bourn
No traveller returns, puzzles the will
And makes us rather bear these ills we have
Than fly to others that we know not of.’

[*Shakespeare*: Hamlet: Act 1, Scene 3]

The Care of the Aged, the Dying and the Dead (Worcester, 1940)

- The process of dying is a progressive not a simultaneous failure of vital organs
- In the majority of cases there is ample warning
- The importance of being devoted to the patient/resident rather than the disease (p.vi)
- Nurses role versus that of doctors in the care of the dying
- Dying itself is not painful

The Visible Process of Dying

I. Recognising Dying
II. Peripheral Shutdown
III. Central Shutdown

i Recognising dying (week/s to live)

- **Importance of recognising dying if we are going to manage the last days of a person's life**
  - Spending more of the day asleep rather than awake
  - No longer interested in eating
  - Drinking insufficient amounts
  - There is multidisciplinary/family agreement that further investigations and treatment is futile
  - In the opinion of the caring team the person is believed to be dying
  - The person themselves may tell you they are dying

Care of the dying person

Mouth care is of utmost importance

- as long as the person can swallow – give small amounts of water
- As death approaches increasing frequency BUT smaller amounts
- Piece of damp gauze in mouth with crushed ice – water evaporates without risk of choking. Patient must be on their side [NB – do **not** use lemon/glycerine swabs]
- Vaseline to lips

- **Regular turning**
  - To counteract 'stiffness'
- **Importance of 'being with' & explaining what is going on to both the person and family/friends**

"Dignity in dying is…..dying without a frantic technical fuss and bother to squeeze out a few more moments or hours of biological life, when the important thing is to live out one's last moments as fully, consciously and courageously as possible"

[David Roy, *Ethics & Aging*. 1988]

ii Peripheral Shutdown – day/s to live

Person may have day/s to live

- Pinched nose
- 'Death rattle' – inability to cough up tracheal secretions
- Laboured breathing – gently raise on soft pillows
- Bluish and cold extremities / mottling
  - Don't feel cold
    - restlessness often caused by heat

Care of the dying person

- Assess and manage any symptoms
- Importance of a FAN
- Keep a LIGHT on in the room
- As sight and hearing fail – the dying only see what is near & hear what is spoken almost in their ears.
  - Keep outside noise to a minimum
  - Play soothing music

Guidance

'Anticipatory medication' guidance

This guidance is for symptom control in the last days of life for very frail older people dying in care homes who do not have specialist palliative care needs. Frail older people are defined as 'aged over 75 years with the presence of multiple chronic diseases' (Kinley et al, Anticipatory end of life care medication for the symptoms of terminal restlessness, pain and excessive secretions in frail older people in care homes. *End of Life Journal*, 2013, Vol. 3, No. 3)

PAIN		
Dying itself is not painful but some older people who have required regular oral analgesia will require a substitute when they can no longer swallow. All residents should have access to analgesia.		
Drugs to choose from	**Dose**	**Frequency**
Paracetamol suppositories **or**	0.5-1g	prn 4-6hrly (maximum 4g/24hrs)
s/c Morphine (see overleaf for equivalents)	1.25-5mg	prn (4-6hrly)*
When a resident already has a transdermal analgesic patch (buprenorphine or fentanyl) these must be continued. 'prn' analgesia should also be available.	See 'Guide to dose equivalents for morphine' on next page (patches take up to 24hrs to become fully effective)	
TERMINAL RESTLESSNESS		
If a resident has been on long-term anti-psychotics or anxiolytics and is now unable to swallow seek specialist advice		
Drugs to choose from	**Dose**	**Frequency**
Diazepam rectal solution eg Stesolid **or**	5-10mg	prn
s/c Midazolam **or**	2.5-5mg	prn (1-4hrly)
s/c Haloperidol**	0.5mg	prn
SECRETIONS		
To prevent excessive tracheal secretions. If the 'rattly' chest is due to end-stage pneumonia an anticholinergic is unlikely to work, consider repositioning the resident (this may be in the recumbent position).		
Drugs to choose from	**Dose**	**Frequency**
s/c Glycopyrronium	0.2mg	prn (4-6hrly)
s/c Hyoscine Butylbromide (Buscopan)	10-20mg	prn (4-6hrly)
OTHER SYMPTOMS		
NAUSEA AND VOMITING		
Drugs to choose from	**Dose**	**Frequency**
s/c Haloperidol** **or**	0.5mg	prn
i/m Cyclizine (can be painful) **or**	25-50mg	prn (8hrly)
Domperidone suppositories	10mg	prn
BREATHLESSNESS		
Drug	**Dose**	**Frequency**
s/c Morphine	1.25mg	prn (4-6hrly)
Caution is required when prescribing as many residents will have renal impairment * 'prn' medications can be repeated once within an hour if the first dose was not effective ** Avoid completely in residents with Lewy Body Dementia and/or Parkinson's		

St Christopher's Hospice Clinical Guidelines

Kinley, Stone & Hockley (2013)

Anticipatory end-of-life care medication for the symptoms of terminal restlessness, pain & excessive secretions in frail older people in care homes. *End of Life Journal*, Vol 3(3): 1-6

"Dying with dignity is.....dying in the presence of people who know how to drop the professional role mask and relate to others simply and richly as a human being"

[David Roy, *Ethics & Aging*. 1988]

iii Imminent dying ['central shutdown']

– hour/s to live

- Thin and thready pulse
- Breathing becomes 'shallow'

"Even when only watchful waiting is needed, the physician [nurse] must not underrate the help that his mere presence may afford in steadying and comforting both the dying patient and the family. When apparently doing nothing, he yet may be doing much:

They also serve who only stand and wait"

[Worcester 1940]

‘Medicalisation of dying’

+

taboo of death

….causes people to block engaging with the ‘instinct of dying’ in humanity

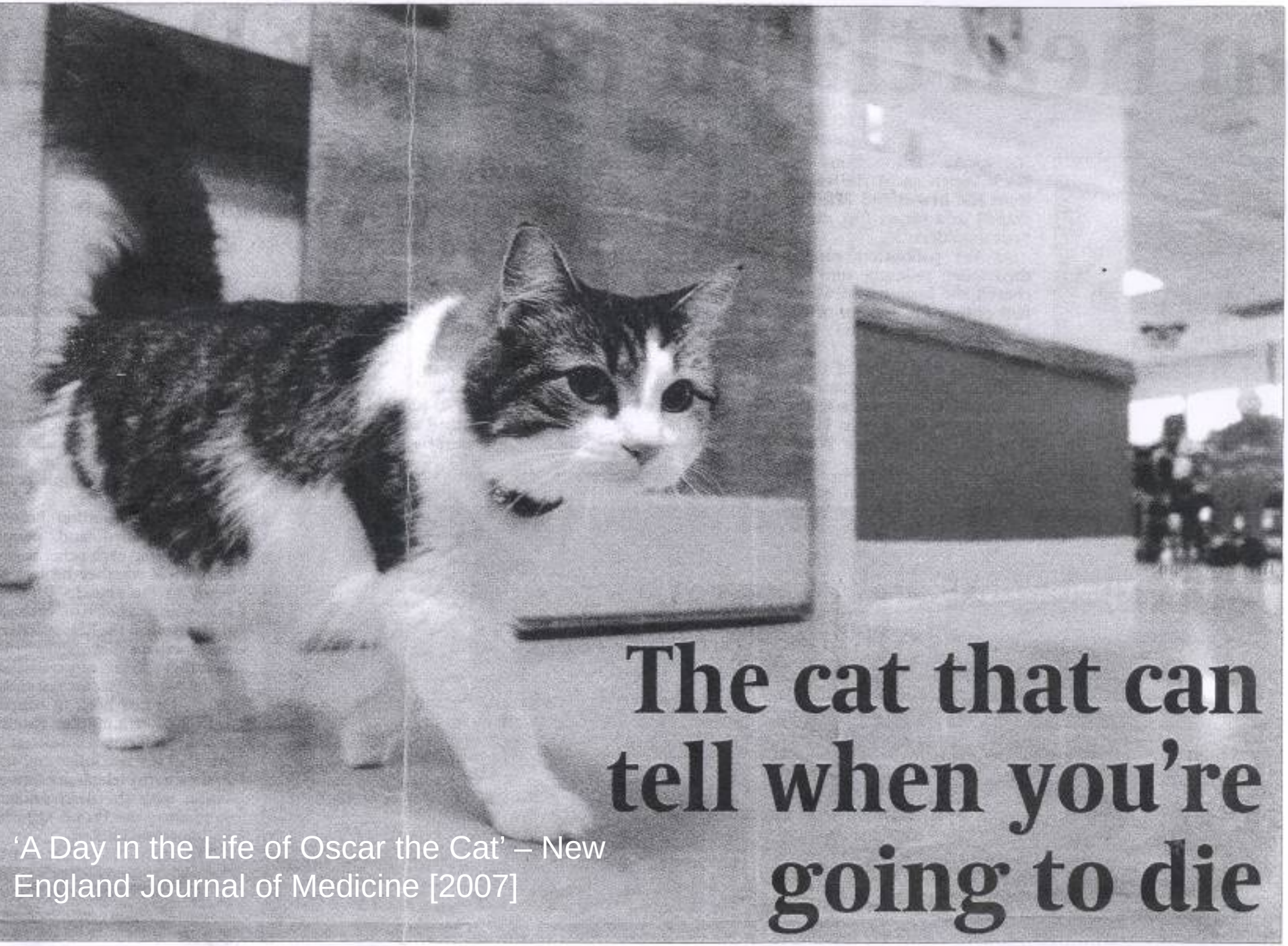
The invisibility of dying

" I have lived all my life with an embarrassment of squirrels in my backyard....I have never seen anywhere a dead squirrel"

Thomas Lewis (1974)

cited in:

Principles of Practice of Nursing by Henderson & Nite (6th ed.)
Ch: 'Death & Dying'



'A Day in the Life of Oscar the Cat' – New England Journal of Medicine [2007]

…use of symbolic language to indicate preparation for a journey when dying (Final Gifts, Callanan & Kelley 1992)

"He's here but I need a ticket"

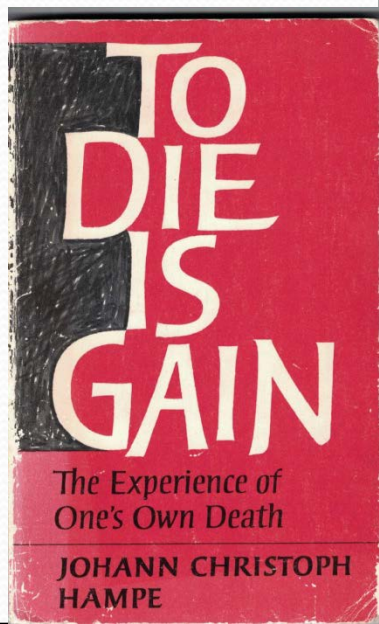
"I went but the door was closed"

[Strachan House NH, NHM – 2003]

Illustrating three aspects of the invisible process of dying

- The escape/exit of the self
- The account rendered by self
- The expansion of self

[Hampe, 1970]



Exit of the Self – i

‘A time to be born and a time to die’

[Ecclesiastes 3 v.2]

Themes from narratives…

‘Choosing to go’ – Mrs Mc

‘Permission to go’ - Cathy

‘Being accompanied in the going’ - Sylvia

Account Rendered by Self – ii

- NDE – 'near death experiences'
  - people report out of body experiences – looking down on the body or seeing themselves at different ages [Hampe, pg 52]
- In actual dying, people do not seem to experience leaving their bodies, rather they remain in their body but aware of two existences [Callanan & Kelley, 1992]

Expansion of the Self – iii

Heightened or other consciousness

- Mrs A, 78yrs stroke - hadn't spoken for 2 years [Pittendreich NH, Edinburgh]

- DAD's experience of the last hours of his life
  - Wonderful scenes
  - 'I have come to understand everything……. I just want to go onto the New Heaven '

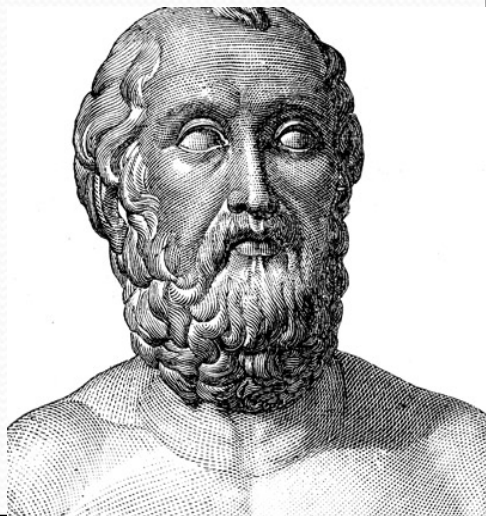
After death

- TIME to be respected viz a viz the body of someone who has died
  - Relatives
  - The mind is often very active to the point of death

‘To fear death, gentlemen, is no other than to think oneself wise when one is not, to think one knows what one does not know. No one knows whether death may not be the greatest of all blessings for a man, yet men fear it as if they knew that it is the greatest of evils. And surely it is the most blameworthy ignorance to believe that one knows what one does not know.’

Socrates/Plato, *The Apology*

424 - 347 BCE



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Hampe J C (1970) *To Die is Gain*. London: Darton, Longman & Todd

Roy D (1988) Ethics & Aging: trends and problems in the clinical setting. In: *Ethics & Aging.* Eds: J E Thornton & E R Winkler. The University of British Columbia Press

Henderson V 'Death & Dying'. In: *Principles of Practice of Nursing* Eds: V. Henderson & G. Nite (6th ed.)

The Death of Ivan Ilyich [Tolstoy, 1960: 153]

Callanan E & Kelley P (1992) Final Gifts. Poseidon Press: New York