DYING SAFELY IN AN ACUTE HOSPITAL

Australian & New Zealand Society of Palliative Medicine – Medical & Surgical Update for Palliative Medicine Physicians
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“I did an unusual thing this year, I decided to make a New Year’s resolution. It’s quite simple really. My resolution is to stay out of hospital.”

Jim Murrant, Journalist. March 2013
JIM MURRANT

• Referred to Palliative Care
• PRIME AIM – health and quality of life – NOT CURE
JIM MURRANT

- On home $O_2$
- Empowered to manage his own symptoms
- Tests returned to normal
“I had lost the energy to write, which was tragic ……….. But now it has come back. Witness this article.”

Jim Murrant, Journalist. March 2013
MOST PEOPLE WOULD PREFER TO DIE AT HOME

JAMA 1995;274:1591
CONVEYOR BELT TO INTENSIVE CARE

- Ambulance
- Emergency department
- Hospital ward
- Intensive care
MEDICALISATION OF THE DYING PROCESS
SOME DRIVERS

• Dying is frightening
• Lack of community support for the dying
• Societal expectations (media)
• Difficult to be 100% certain
• Because we can, we do
• Litigation
HOSPITAL DOCTORS

• Single organ specialists
• Reluctance to discuss death/dying
  – Cure orientated
  – Incrementally adjusting their own organ
  – Lack big picture
  – Time-consuming
  – Defeat/embarrassment
  – Don’t understand limits of my specialty and therefore:

  CANNOT MAKE THE DIAGNOSIS OF DYING
THE INEVITABILITY OF AGEING, DYING AND DEATH

Objections but I will merge them
APOPTOSIS

Your life span is encoded at conception
APOPTOSIS

- In the past apoptotic potential has rarely been reached
- Apoptosis gradually made one more prone to disease and physical misadventure
- Now cocooned by technology
- Modern medicine maximises potential and ICU often surpasses it
BUILT IN OBSOLESCENCE

Similar to computers
PALLIATIVE CARE

Often working at the end of the apoptotic potential
DIAGNOSIS OBSESSSED

- Training
- Dialogue and communication
- DRGs – billing and performance indicator
- Dictates how we die
Nelson Mandala has been admitted to a hospital’s ICU with a lung infection. He is in a critical condition.
Nelson Mandala is dying of old age and frailty. Of all the people in the world who has the courage, acceptance and dignity to face this, it is Nelson Mandala.
The system is not being honest with Nelson Mandala. The same system is not being honest with our society as a whole.
AGEING = CO-MORBIDITIES

<table>
<thead>
<tr>
<th>Condition</th>
<th>Associated Problems</th>
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<tr>
<td>Type 2 DM</td>
<td>Dementia</td>
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<tr>
<td>HTN</td>
<td>Skin cancer removal</td>
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<td>Cholesterol</td>
<td>Muscle bulk loss and falls</td>
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<tr>
<td>IHD</td>
<td>Decreased kidney, liver and genital function</td>
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<td>CVA</td>
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<td>COPD</td>
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DYING

Often not the acute ‘diagnosis’ which determines outcome but the underlying sum of the chronic conditions – as yet unquantifiable

eg urinary tract infection or ‘pneumonia’
The diagnosis of dying often trumps the sum of all the other ‘diagnoses’ that come with age

Not allowed to write ‘old age’ as a cause of death
DEFINING MEDICINE

• Organised around disease and organs
• Not around normal ageing and dying
AGEING AND DYING

Are the result of the body’s function decreasing – becoming frailer
FRAILTY

Collecting diseases (or age related conditions)
FRAILTY

Multidimensional syndrome characterised by loss of physical and cognitive reserves that leads to increased vulnerability and adverse outcomes
FRAILTY SCORES

Very fit → terminally ill
eg 3 or more of:

- Decreased grip strength
- Self-reported exhaustion
- Weight loss >4.5 kg/yr
- Slow walking speed
- Slow physical activity
FUTILITY

• FRAILTY – (RESERVE)
• Interacting with acute disease largely defines FUTILITY
DYING IN ACUTE HOSPITALS
MYTH

Doctors know how to diagnose dying and understand the limits of modern medicine
RAPID RESPONSE SYSTEMS or MEDICAL EMERGENCY TEAMS

- Rapid recognition and response to the seriously ill in a hospital
- In most hospitals around the world
- Reduces mortality and cardiac arrests by about one-third
- Also rapidly detects patients at the EOL, previously not recognised
DIFFICULTY DIAGNOSING DYING

- One-third of all MET calls are for EOL issues
- Multicentre, international study

CCM 2012: 40; 98-103
MYTH

Hospitals are good places to die
DIFFICULTY MANAGEING DYING IN HOSPITALS

- Physical symptoms (pain, SOB) not treated
- Inappropriate active management
- Poor communication
- Mixed messages
- Failure to address emotional and psychosocial needs

*Inter J Cl Practice 2009;63:508*
MEDICAL TORTURE

‘- causes suffering without benefit

J Palliat Med 2011;14:122
INTENSIVE CARE MEDICINE

- $4000/patient/day
- 1980 6 beds
- 2012 60 beds
20% of all deaths in the US occur in ICUs

CCM 2004;32:638
INTENSIVE CARE MEDICINE

• Intensive care creep
• Limited role initially
• Now, anyone who is seriously ill
• You have to pass through being seriously ill on the way to ‘natural’ dying
GOING TO HOSPITAL / ICU TO DIE IS NOT SOMETHING WE PLANNED / WANTED – IT JUST HAPPENED
HIGH TECH MEDICINE

• Expensive
• Increases life expectancy
• HOWEVER – mainly affects the circumstances, mode and timing of death
MANIPULATION OF THE DYING PROCESS

The dying process can be interrupted at any stage by modern technology – its application or withdrawal.
PATIENTS IN ICU
DIE A CAREFULLY ORCHESTRATED DEATH
MANIPULATION OF THE DYING PROCESS

- Death is a transitional process

INTENSIVE CARE

- MANIPULATE UP – prolonging dying by temporarily supporting some of the dying organs
- MANIPULATE DOWN - withdrawal and withholding when no progress is being made
AN EXERCISE IN INTENSIVE CARE

REPLACE
Heart
Lungs
Kidneys
Gut
Adrenals

DON’T NEED
Limbs
Bladder
Spleen
Genitals

NEED
Liver
?Head
PALLIATIVE CARE

- Palliative chemotherapy
- Palliative radiotherapy
- Palliative surgery
- “Palliative intensive care”
WHAT CAN THE SPECIALTY OF INTENSIVE CARE OFFER THE DYING?

• Some will have death delayed by hours → days → weeks
• Some will die in general wards after ICU
• Some will go home to slowly die in a cruel way
• Some will be cured and live a productive and good quality of life
“3 months in ICU
Sent home weak and debilitated.
Lost his business and house.
Moved in with sister
…but he survived and most don’t”

Gawande ‘The Checklist Manifesto’
 Boundaries between being old, sick and dying have been obscured by us
DEATH IS A NON-NEGOTIABLE MEDICAL DIAGNOSIS – although different rates of tissue death

DYING IS ALSO A MEDICAL DIAGNOSIS – although different rates of dying tissues
“SHARED DECISION”
– MODEL
A CONSENSUS JOURNEY
SEEKING CONCENSUS WITHOUT ASKING FOR PERMISSION
SOME PERSONAL LESSONS
KNOWING ABOUT DIFFERENT CULTURES, RELIGIONS, NATIONALITIES, ATTITUDES AND BELIEFS AROUND DEATH
BE COMFORTABLE WITH SILENCES
USE PLAIN SPEECH

“This is a very serious situation. We are doing everything possible, but I think that he/she may die during this illness.”
SOME LESSONS

• “Tell us a little about …. None, of us got to know her/him
• Alleviate guilt
• Understand anger and blame
• Consider dying at home
PRACTICAL APPROACH

• I’m almost sure that he hasn’t got the strength to survive this
• But to be 100% sure why don’t we do everything possible for 24hrs
• I know he’s a fighter and we will give him every chance
• However, I also know he would not us to put him on any machines when there is no hope.
• Even though he may not live I can promise you that he won’t suffer.
WHITE LIES

• We are doing everything possible (that is appropriate).
• I don’t mention ECMO, organ transplant, IABP, dialysis or ventilation if I don’t think they are appropriate.
• Working in intensive care, I always have to be honest with you
• It’s not my decision. It’s not your decision. It’s his.
PALLIATIVE CARE BED IN ICU

TRANSFER TO HOME
WHERE TO NEXT?
DEATH IS MOST COMMON HEALTH EVENT

2.5 million die/year in the US

JAMA 2012;307:997-1098
PROJECTED DEATHS 2030

- <10% die at home
- >90% in institutions

AUSTRALIAN DEATHS

• 150,000 / annum
• 50% were expected and amendable to palliative care

MJA 2011;194:1
LAST 12 MONTHS OF LIFE
– IN PATIENTS SUITABLE FOR
PALLIATIVE CARE

• 96% SPENT SOME TIME IN HOSPITAL
• Hospital admission – 7.8 days
• 70% had at least 1 ED visit
• 62% were in hospital on last day of life

MJA 2011;194:1
DRAMATIC INCREASE IN EMERGENCY AMBULANCE SERVICE – ESPECIALLY IN THE ELDERLY

MJA 2011;194:1
ACTIVE MANAGEMENT AT EOL BY PHYSICIANS

• Half chose comfort care for themselves

BUT

• Half of those recommended active treatment for their patients

Arch Int Med 2010;171:630
“Please don’t let me die like this!”
THE CURRENT WAY OF DYING

• People are forced into the way we manage conventional illness
• Complex issues dealt with expensive and often inappropriate ways
• Medicalisation of the dying process
FUTURE

• Currently – wasteful and inappropriate health care delivery
  ➢ unsustainable health care costs
  ➢ demoralise families

• Lobby groups for drugs, hi-tech devices and hospitals

• No lobby group for better overall care eg carers
END-OF-LIFE CARE

• Research not funded by drug or equipment companies

• When did you last see the “Morphine rep”? 
MOVING PALLIATIVE CARE CENTRE STAGE
PALLIATIVE CARE

• End-stage cancer
• End-stage non-cancer
• End-stage life – independent of simplistic diagnoses frailty and old age
PALLIATIVE CARE

• Operating on a referral basis
• Operates within the confines of the medical hierarchy and the way we have been doing things for over a century
• Needs to more explicit about not being just another medical specialty but a service constructed around patient needs
PALLIATIVE CARE

Referers:

Often cannot diagnose dying
Often get the timing wrong
Difficulty identifying reasons for referral
Evidence to suggest they manage dying poorly
PALLIATIVE CARE

• Move from being a referral service to a fully integrated and early service made available to all patients
PALLIATIVE CARE

- STANDARDISED recognition of appropriate patients (uncertainty)
- LINKED response by service
- Hard to go wrong if system is built around the patient’s needs
Diplomacy, politics and conformity with the medical hierarchy usually trumps patient care
PALLIATIVE CARE

Leaders and managers of complex systems integrated into health care and the way we live
PALLIATIVE AND INTENSIVE CARE

- New boys on the block
- Team approach
- Strong nursing base
- Expanding role
- Not just another medical silo
- Pushing boundaries and redefining roles (Tim)
MOVING PALLIATIVE CARE INTO CENTRE STAGE

HOME ➔ Ambulance (Oregon Model) ➔ ED ➔ HOSPITAL ➔ ICU

“Hospice-type concept"

Connected to early patient detection systems

24 hour palliative care – urgent
- Placement
- Take over or share care
WIN / WIN

- Radically reduce health expenditure
- Provide better/more appropriate end-of-life care
MEDICAL EPOCHS

- Curative medicine
- Preventative medicine
- End-of-life care
A NEW TYPE OF HEALTH SYSTEM IS NEEDED

- GP 24 year old with slow to resolve ‘flu
- ED 50 year old pedestrian hit by car
- Hospital 45 year old for removal of bowel cancer

REALITY - Old patients with multiple co-morbidities who are nearing end-of-life and who have caring issues
WHAT IS THE MOST DIFFICULT ETHICAL DILEMMA FACING SCIENCE TODAY?

Sir David Attenborough: How far do you go to preserve an individual human life?

Stephen Hawkins: That’s a good one, yes.

The Weekly Guardian 24.09.2010 page 26