Dying in today’s world

Prof. Ilora Baroness Finlay of Llandaff
As the light fades

- Dying – yesterday, today and tomorrow
- The changes
- A personal journey in the time of the NHS
## Most common cause of male death:

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- **RTA**
- **Infections**
- **Self-harm**
- **Heart Disease**
Most common cause of female death:

Source: 21st century mortality files, ONS
and 20th century mortality files, ONS
Tuberculosis
1916, 1950s Polio epidemics ... pre-Salk
“You matter because you are you, and you matter to the last moment of your life. We will do all we can, not only to help you die peacefully, but also live until you die.”

Dame Cicely Saunders (1918-2005)
Emotional

Spiritual

Social

Physical
Morphine ‘kills the pain, not the patient’

Toxicity

Breakthrough doses

Pain

4 8 12 hours
Deaths today from:
Cancer   HIV
Morphine availability globally

80% of the world’s dying do not have access to morphine; 6% are children.
Palliative care – developed world

Science of helping dying patients as they die

For most people, dying is not a sudden presence of death, but a gentle absence of life.
What happens as you die of progressive disease

• Increasingly weary
• Often a final burst of energy / activity in last days
• Drowsy and weak
• Slip into a coma
• Breathing slows – may sound bubbly
• Breathing more shallow, pulse weaker
• Colour changes and pulse weakens
• Heart and breathing stop
Recognition that death imminent

• 100% Cancer centre

• 64% General hospital trust

• Warning family?

• Provide appropriate care; stop some interventions
Holme Tower hospice 1987
Core Principles

• Universal access to good end of life and palliative care across Wales 24/7.

• Fairness of service provision, underpinned by high standards in End of Life Care.

• Close integration of services is essential, whether provided by the NHS or by voluntary sector providers.
Palliative care - fairness in Wales:
‘The quality of life gap’
“It is obviously preferable to prevent suffering than to alleviate it.”
Impact of early palliative care

- Temel JS et al NEJM 2010;363:733-42

- Early palliative care for patients with metastatic non-small-cell lung cancer

- Quality of life
- Mood
- Survival (11.6 v 8.9 months, p=0.02)
Early integration of palliative care: randomised trial UK

- Significant benefit in primary outcome, QoL component, 16% better
- Significant survival benefit
- No difference in costs

Higginson et al Lancet Respiratory Medicine, Dec 2014; 2(12): 979-987
Communication Skills - Cardiff Six Point Toolkit

- Comfort
- Language
- Listening
- Question
- Reflection
- Summarising
In place of fear - Listening

Ear

You

Eyes

Undivided attention

Heart
Dignity is having a sense of personal worth

Dame Cicely Saunders 1992
No law against stopping treatment

You cannot be treated against your will

Risks  
Burdens

Benefits

Stop intervention

time
Motor neurone disease (ALS)

'Disease'

dead

Death

CARE

Stop ventilator

time
Euthanasia / physician assisted suicide/ Assisted suicide

Give drug – express intention to kill

'disease' death?

time
Autonomy is relational

Our living and our dying have an effect on those around us

Photo by Sara Burns
Autonomy in decision making

• The involvement of family in the Dutch practice of euthanasia and physician assisted suicide: a systematic mixed studies review
Children

• The way a person dies lives on in the memory of those left behind
**SUPPORTING A CHILD?**

How you can help

**RUNNING A SERVICE?**

Are you a service provider looking for information to help you support children in your area?

CBN supports professionals working with bereaved children and young people, with information updates, key resources and networking opportunities. Find out more about how we can help you.

Find resources

**FIND SUPPORT NEAR YOU**

Search now

**MY STORY**

Young people’s own experiences

**ABOUT BEREAVEMENT**

Find out more about how children grieve

**OUR TWEETS**

Tweets by @CBNtweets

ChildhoodBereavement Retweeted

Kelly Willison

@Kelly_willison

I am in desperate need of a venue that can accommodate 30 children on a Wednesday evening. If you can help or signpost? Thank you x #Trafford area or surrounding
Fears

The future worse than today

Pain

Loss of dignity (mind / body)

Loss of control

Loss of autonomy

Being a burden
A right to die?

- Licensing doctors to assist suicide or inject lethal drugs

- Physician assisted suicide
  Oregon’s ‘Death with Dignity Act’ 1997

- Euthanasia
  The Netherlands ‘Termination of Life on Request and Assisted Suicide Act’ 2001

  Belgium

  Canada MAID
What do you need to make any decision?

1. Accurate information
2. Capacity to take that decision
3. Voluntary
Information – terminal illness?

Diagnostic errors – 5% post-mortems

Prognosis
<6 months is notoriously inaccurate
   “medicine is a probabilistic art”
   “predict in hours or days, but when it gets to months, the scope for error can extend into years”

Cannot foresee death even when imminent

Cancer? Heart disease? MS or MND? Anorexia?

Tallis; RCGP evidene to House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill 2005

Capacity to make decisions

“Mental capacity, written down in law, looks simple. It sounds like something objective".

- MND - 30% cognitively impaired (Assoc Br Neurol)
- Medication / metabolic changes impair capacity
- Desire for death
  - Feeling a burden
  - Depression and hopelessness are mutually reinforcing, independent predictors
  - Major depression (p<.001)
  - 1:6 cleared for PAS (Oregon) had undiagnosed clinical depression “the current practice of the Death with Dignity Act may not adequately protect all mentally ill patients”
Voluntary – societal not clinical

- Pressures - internal or external
  - Fear of being a burden
  - Financial costs of care
- Fluctuating desire for death
- “Compassion”

- Influence of doctor’s attitude
- Normalisation in society becomes expectation
I just want to die

• Are you sure?

• Process request

  • Message = you are right to think that you’d be better off dead

• Stamp of medical beneficence

• What is making today so terrible?

• What can we do to improve today?

  • Message = you are worth me working hard to improve things
Laws and the social dynamic

Laws are more than just regulatory instruments. Laws send social messages.

Embedded in medicine gives stamp of beneficence. PAE makes patient passive recipient.

An ‘assisted dying’ law conveys the message that, if you are terminally ill, it is appropriate to consider ending your life.
Oregon

Figure 1: DWDA prescription recipients and deaths*, by year, Oregon, 1998-2018

*As of January 22, 2019
The watertight Oregon model for assisted suicide is a leaky boat

- **Most diseases become terminal if patients refuse to take the medicine**

- 6-month prognosis is based on an assumption that the illness takes its course without further treatment

Fabian Stahle
21 years data

Time to death 1 minute - 104 hours
(Average 97-439 mins depending on lethal cocktail)

8 awoke (21 yrs data)
1-35 prescriptions / doctor

~ 2,500 England & Wales
Barbara Wagner’s Story

- 64 year old
- Oncologist prescribed palliative chemotherapy
- **Oregon Health Plan** stated chemotherapy is not covered, but... assisted suicide drugs are 100% covered as a “comfort care” measure
  - *Eugene Register-Guard*  June 3, 2008
Reported euthanasia - Belgium 2002-18
Aurelia Brouwers 29 years old

During her last two weeks of life, Aurelia was often distressed and had self-harmed.

"I'm stuck in my own body, my own head, and I just want to be free," she said. "I have never been happy - I don't know the concept of happiness."

83 people were euthanised on the grounds of psychiatric suffering in 2017
Quits regulator committee

• Berna van Baarsen, a medical ethicist, said she could not support “a major shift” in the interpretation of her country’s euthanasia law to endorse lethal injections for increasing numbers of dementia patients.
1 Dutch case prosecution

- Alzheimer’s woman
  - Coffee drugged
  - Restrained while drugs injected
  - Making plans to go out to eat with family that day
  - AD to be euthanized “whenever I think the time is right.” Later, said “But not just now, it’s not so bad yet!”

- Fluctuating capacity

- “overruling the wishes of incompetent patients to live, because a will to live is your basic, fundamental right” Ghislaine van Thiel Utrecht
Canada ‘Medical Aid In Dying’ MAiD

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<td><strong>July 1 - Dec 31, 2017</strong></td>
<td>1525</td>
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<tr>
<td><strong>Total MAID deaths since Dec 10, 2015</strong></td>
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Already pressures to expand to mental illness, mature minors, advance directives

Dr T Lau: Euthanasia in Canada: a cautionary tale
Costs saved on healthcare

- Canadian estimates $35m-139m.
- US > $1000m today.
- “It is certainly plausible and perhaps even likely that budget-minded health care organization managers and their physician-employees would press their dying patients toward exercising [a right to receive a physician's assistance with suicide]”
  Ezekiel J, Battin MP. *NEJM*. 1998;339:167-72
Canada – the lived experience

• **Roger Foley** – disability support arrangements denied but free to pursue medically assisted death

Vulnerable Persons Standard 2008:

• “we can have little confidence that MAiD-related decisions are being appropriately grounded in effective communication especially for patients who have disabilities that affect their communication”
Regardless of your support or opposition to change, if the law were changed to permit assisted dying, would you be prepared to participate actively?  

RCR 2019 - 34% response rate
The law?

- Law is to protect the vulnerable
- Where is the Rubicon re mental illness, suicide prevention, dementia, post-abuse, chronic illness?
- Societal issue, not a medical issue
PAS rejected by 330 votes to 118
(11/9/2015)

- Laws are for public safety
- **Send social messages**
- Can have unintended consequences
Infections

SEPSIS AFFECTS 25,000 CHILDREN EACH YEAR IN THE UK

Layla Astley was just 13 weeks old when she nearly died of sepsis after suffering a water infection.

READ PATIENTS’ STORIES
Sepsis kills 5 people an hour in the UK

**HOW TO SPOT SEPSIS IN ADULTS**
Seek medical help urgently if you (or another adult) develop any of these signs:

- Slurred speech or confusion
- Extreme shivering or muscle pain
- Passing no urine (in a day)
- Severe breathlessness
- It feels like you’re going to die
- Skin mottled or discoloured
How does antibiotic resistance occur?

1. High number of bacteria. A few of them are resistant to antibiotics.
2. Antibiotics kill bacteria causing the illness, as well as good bacteria protecting the body from infection.
3. The resistant bacteria now have preferred conditions to grow and take over.
4. Bacteria can even transfer their drug-resistance to other bacteria, causing more problems.
Resistance of E Coli to fluoroquinolones
India
Deaths Attributable to Antimicrobial Resistance Every Year by 2050

North America: 317,000
Europe: 390,000
Africa: 4,150,000
Latin America: 392,000
Asia: 4,730,000
Oceania: 22,000