Unintended consequences of ‘end of life’ legislation

Prof. Ilora Baroness Finlay of Llandaff

Cicely Saunders lecture 2016
“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  
Nurse, Doctor, Social Worker and Writer  
Founder of the Hospice Movement (1918-2005)
Laws

- More than regulatory instruments
- **Send social messages**
- Can have unintended consequences
Legislation

• Access to Palliative Care Bill 2015
• Mental Capacity Act 2005
• Legislation for Physician Assisted Suicide and Physician Administered Euthanasia
  • Death with Dignity Act – Oregon 1997
  • Termination of Life on Request and Assisted Suicide Act – The Netherlands 2001
Access to Palliative Care Bill [HL]

A BILL

To make provision for equitable access to palliative care services; for advancing education, training and research in palliative care; and for connected purposes.

Baroness Finlay of Llandaff

Ordered to be Printed, 1st June 2015
Do we need legislation for access to palliative care?

• About ½ million deaths per annum
• Reports galore on quality of care
• Quality of death index = UK ranked 1
Why is it needed?

• Health and Social Care Act 2012

NHS reorganisation

“They cut it from 118 quangos to 234, and they reduced the levels of bureaucracy above me from three to 24.” Dame Julie Moore, head of University Hospitals Birmingham, Daily Telegraph Dec 2015

• Clinical commissioning groups responsible – Freedom of information request to 209 CCGs
Phases of illness and need

- **Stable**
- **Unstable**
  - Unexpected
  - Urgent
- **Deteriorating**
  - Expected
  - Non-emergency
- **Dying**
- **Bereavement**
Life enhancing palliative care

Early palliative care for patients with metastatic non-small-cell lung cancer
Temel JS et al NEJM 2010;363:733-42

• Quality of life
• Mood
• Survival (11.6 v 8.9 months, p=0.02)

• Fewer expensive treatments
Early integration of palliative care: randomised trial UK

- **Significant benefit in primary outcome**, QoL component, **16%** better
- Significant **survival** benefit
- **No difference in costs**
Parliamentary and Health Service Ombudsman Report main findings

1. Not recognising dying nor responding to needs
2. Poor symptom control – pain
3. Poor communication
4. Inadequate out-of-hours services
5. Poor care planning
6. Delays in diagnosis /referrals for treatment
Culture, behaviour and training

“staff now no longer appear to feel confident in looking after people who are dying and obviously that is a significant training issue”
Access to Palliative and End of Life Care

“**Round-the-clock access to specialist palliative care** will greatly improve the way that people with life-limiting conditions and their families and carers are treated. This would also help to address the **variation** in the quality of end of life care within hospital and community settings. We also recognise the **value of specialist outreach** services. We recommend that the Government and NHS England set out how **universal, seven-day access** to palliative care could become available to all patients, including those with non-cancer diagnoses.”
Choices review

• Still waiting for a response

What's important to me.
A Review of Choice in End of Life Care

What choices are important to me at the end of life and after my death?

- I want to be cared for and die in a place of my choice
- I want involvement in, and control over, decisions about my care
- I want the people who are important to me to be supported and involved in my care
- I want access to high quality care given by well trained staff
- I want the right people to know my wishes at the right time
- I want support for my physical, emotional, social and spiritual needs
- I want access to the right services when I need them

EXECUTIVE SUMMARY

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The Choice in End of Life Care Programme Board
February 2015
Freedom of information request to Clinical Commissioning Groups 2015

- Few reported number with palliative care needs
- 0.32% lower estimate that 0.75%* of population estimates

*Palliative Care Funding Review, 2011, 355,000-457,000 people have palliative care needs.
Specialist palliative care in hospitals in England

• Face-to-face specialist palliative care:
  • No doctor at any time – 26 (18%) trusts
  • 7 days, 9am-5pm – 37% of sites
  • 24/7 – 11% of trusts

• Out-of-hours telephone advice – most

• Staff education programmes – 96%
  • DNACPR discussions w family – 81%
Where is dying?

- cancer
- dementia
- diabetes
- mental health
- learning disabilities
- maternity care
Palliative care in Wales 2008 – core principle fairness of access
Wales’ palliative care strategy 2008

• Funding formula for core specialist palliative care across all sectors, all ages
• Access to specialist palliative care 7 days a week – advice 24/7
• Electronic Patient Information System (CaNISC)
• National standards & quality measures
• Public engagement
• Research
Duty to commission specialist palliative care

- Point of contact
- Access to medication
- Equipment
- Advice 24/7
- 7 day service
- Admission all hours
- Education
- Research
- CQC inspections
Laws - Mental Capacity Act

- More than regulatory instruments
- Send social messages
- Can have unintended consequences
Mental Capacity Act 2005

1. A presumption of capacity
   • I can make a decision

2. Individuals supported to make their own decisions
   • Do all you can to help me make a decision

3. Unwise decisions
   • Don't assume I lack capacity

4. Best interests
   • Changing clinical scenarios
   • Consulting those important to P

5. Less restrictive option
   • Liberty and security
Unintended consequences?

• Carers feel excluded
• Confidentiality can be used as a barrier to communication
• Assessments take priority over listening
• Deprivation of liberty safeguards bureaucracy
• Advance Decisions to Refuse Treatment are not understood
Children

“The way a person dies lives on in the memory of those left behind”

School children 10% bereaved

• 1/3 lost parent or sibling
• 2/3 lost someone significant

• For every patient think CHILD
  • Is there a child being affected by this death?
Laws – ‘Assisted dying’

- More than regulatory instruments
- Send social messages
- Can have unintended consequences
So what about life ending ...

What is the law now? and is it in need of change?

If so, what would be put in its place?
The Law England and Wales

Suicide is **not** illegal
Encouraging or assisting another person’s suicide is against the law

Refusing treatment is **not** illegal
Acting with the intention of bringing about a patient’s death is illegal

Director of Public Prosecutions guidelines – tests of ‘evidence’ and ‘public interest’
‘Assisted dying’ legislation in action

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

• PAS and euthanasia
  The Netherlands ‘Termination of Life on Request and Assisted Suicide Act’ 2001
What does it involve?

**PAS**
- Patient self-administers
- Barbiturate in massive overdose
- Not soluble - tumbler
  Tastes bitter
- Preload with antiemetic

**Euthanasia**
- Inject short-acting anaesthetic to coma
- May follow with pancuronium
  Patient completely paralysed
  Any distress not visible to onlooker
  Die of asphyxia
This is not sedation at the end of life

• Morphine – oral dose converted to s/c by x0.5
• Midazolam 5-30 mg. if needed for restlessness
• Glycopyrronium or hyoscine
• Antiemetic if already on one (haloperidol 0.5-5 mg)

• **Aim to keep symptom controlled while dying**

• ‘Terminal sedation’ as Dutch protocol: midazolam 60mg+ and/or barbiturate
• No dose titration
• **Aim to keep in coma until death**
It’s not like taking the dog to the vet

Complications

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<th>Country</th>
<th>PAS</th>
<th>Euthanasia</th>
<th>N</th>
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<tr>
<td>Netherlands</td>
<td>Administration difficulties</td>
<td>10%</td>
<td>5%</td>
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<tr>
<td></td>
<td>Vomiting / muscle spasm</td>
<td>7%</td>
<td>3%</td>
</tr>
<tr>
<td></td>
<td>Long time until death</td>
<td>15%</td>
<td>5%</td>
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Oregon PAS N=859

<table>
<thead>
<tr>
<th></th>
<th>PAS</th>
<th>N=859</th>
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</thead>
<tbody>
<tr>
<td>Barbiturate taken to coma</td>
<td>1-35 mins</td>
<td></td>
</tr>
<tr>
<td>Vomiting etc</td>
<td>23</td>
<td>N=530</td>
</tr>
<tr>
<td>Long time to death</td>
<td>Median 25 mins</td>
<td>6 awoke</td>
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</table>


Oregon Public Health Division "Oregon's Death with Dignity Act 2014", Table 1
Oregon’s DWDA

• Adult
• Terminal disease; prognosis <6 months
• Patient is capable, acting voluntarily and has made an informed decision
• Two doctors
• 15 day ‘wait’ from oral request, 48 hours from written request
• Psychiatric or psychological disorder or depression causing impaired judgment - refer for counselling
Oregon’s DWDA

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1. Information

Diagnosis
Diagnostic errors – 5% at post-mortem

Prognosis
<6 months is notoriously inaccurate
“medicine is a probabilistic art”
Even in ‘last 48 hours of life’, 3% improve
We cannot accurately ‘diagnose dying’

House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill 2005

Diagnosing dying: an integrative literature review.
Oregon

Prognosis  <6/12
• 1st application to PAS median 45 days
  (15 to >1,000 days)
• Patient physician relationship median 9 weeks
  (1-1004)

Diagnosis
• 77% cancer 8% MND
• >10% now includes ‘other’
2. Capacity to make decisions

• “Mental capacity, written down in law, looks simple. It sounds like something objective". 
  Hotopf M to Falconer Commission 25 May 2011

• ALS - 30% cognitively impaired  House of Lords Select committee 2005
Oregon - 1 in 6 cleared for PAS had undiagnosed depression

- Prospective study
- 18 patients passed the tests for PAS
- 9 patients took lethal drugs – 3 of these patients had undiagnosed untreated depression

- “the current practice of the Death with Dignity Act may not adequately protect all mentally ill patients”

Ganzini 2008 BMJ
What drives a desire for death?

- **Feeling a burden:** low correlation with physical symptoms ($r = 0.02-0.24$) and higher correlations with psychological problems ($r = 0.35-0.39$) and existential issues ($r = 0.45-0.49$)


- **Depression and hopelessness are mutually reinforcing, independent predictors**


- **Major depression ($p<.001$)**

3. Voluntariness

- Pressures - internal or external
  - Fear of being a burden
  - Financial costs of care
- Fluctuating desire for death
- “Compassion”
  Not all families are loving families
- Influence of doctor’s attitude
- Normalisation in society becomes expectation
Oregon population 3.8m.
Doctors in Oregon (2015 data)

• 2/3 won’t participate Ganzini in Palliative Care and Ethics Eds: Quill and Miller OUP 2014 p270

• Doctor shopping – duration 1-1004 weeks (median 9)

• Referral to psychology / psychairty
  • Expect 10-15%
  • Actual 3.8%

• Don’t know how assessments are done

• 1-27 prescriptions per physician
Oregon – Compassion and Choices

- View themselves as “stewards of the law” evidence to House of Lords Select Committee

Volunteer of Compassion and Choices of Oregon

“The difficulty that I have found in this last client was that their regular doctors and oncologist were not supportive of their process to appeal to this. So we had to find a prescribing physician, and the person, the client, has to see this prescribing physician.” Falconer commission p 269
Dancing on the day she died

• Took her lethal drugs ‘accompanied’ by people from Choice and Compassion

Lovelle Svart--10/28/2007
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
Oregon - scrutiny

- No scrutiny of the quality of assessment itself
- No post-event scrutiny
- No monitoring of unused drug
- Data from reporting by doctor

Oregon death rate from PAS equates to around 2,000 PAS deaths per annum for England and Wales
The Netherlands

• ‘Termination of Life on Request and Assisted Suicide Act’
• No requirement for terminal illness or mental capacity
• Request is 'voluntary and well-considered‘
• Suffering is unbearable, no prospect of improvement
• Aged >16 (12-16 yrs with parental consent)
• Second independent SCEN doctor
Netherlands - 16.8 million population

Notifications of assisted suicide and euthanasia in The Netherlands, 2002-2015

Netherlands

- Illnesses – increase in psychiatric / dementia
- Scrutiny – post-event reporting
  - 5 regional Euthanasia Review Committees
  - Backlog in processing
  - Almost all cleared as being within the law

Netherlands 1 in 26 all deaths are from euthanasia and PAS; equates to about 20,000 such deaths per annum for England and Wales
Theo Bohr

• "In 2007 I wrote that 'there doesn't need to be a slippery slope when it comes to euthanasia. A good euthanasia law, in combination with the euthanasia review procedure, provides the warrants for a stable and relatively low number of euthanasias'. Most of my colleagues drew the same conclusion. But we were wrong - terribly wrong, in fact. In hindsight, the stabilisation in the numbers was just a temporary pause. Beginning in 2008 the numbers of these deaths show a 15% increase annually, year after year".

Daily Mail, July 2014
Belgium – 11.2 million population (6.4 million in Flanders)

Belgium known numbers since 2002

- Total
- Flanders
- Wallonia

Year:
- 2002: 24
- 2003: 235
- 2004: 349
- 2005: 393
- 2006: 429
- 2007: 495
- 2008: 704
- 2009: 822
- 2010: 953
- 2011: 1133
- 2012: 1432
- 2013: 1816
- 2014: 1924
- 2015: 2021

Values:
- Total
- Flanders
- Wallonia

Legend:
- Total
- Flanders
- Wallonia
Belgium

• Many go unreported
• Death rate from euthanasia even higher than in the Netherlands – probably nearer 1 in 23
England and Wales – current law

• Principle
  • Deterrence to malicious intent
  • Prosecutorial discretion – DPP guidance
  • Reflects public attitudes to suicide
  • Harmony with suicide prevention policies
  • Unambiguous clear line

• Social message – ‘you matter because you are you’
Proposals?

• Practice
  • Safeguards not verifiable –
    • Mental capacity
    • Freedom from pressure
    • Settled intent
  • Court agreement = signing off, not an assessment
  • Codes of practice post-legislation = blank cheque
  • Most doctors won’t do it
    • 2015 Medeconnect poll - only 1 in 7 GPs involved in process
• No post-event scrutiny
The Objections Raised

There should be a ‘right to die’.
You can’t be sure you won’t be prosecuted.
Doctors are doing it anyway.
Doctors can’t have open discussions with patients who want to die.
Legalisation is working without problems overseas.
Needs clear evidence that:

The law is dysfunctional / oppressive

What would be put in its place would bebetter

• Not just for some who want their death hastened
• For all, especially the most vulnerable