

MY DEATH  MY DECISION

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My Mum



Died December 2015 age 93.

Dementia

In pain from a rectal prolapse.

Doubly incontinent.

Oct 2013

“Make them see sense”

Feb 2015

“All I seem to do is to create problems for myself and other people.”

“I just don't want to go on.”

August 2015

“I feel more frightened than ever before”

“Isn't there anyone who can help me?”

Approaching End of Life

Quantity of Life vs Quality of Life

- We are all living longer
- Heart disease and Cancer are often curable
- Degenerative diseases
 - Dementia: 850,000 in 2015, 1m in 2025. 1 in 6 over 80 yr olds die **with it**
 - Motor Neurone Disease
 - MS
 - ...

Dementia/Alzheimer's is the **leading cause** of death in England and Wales

11.6% of recorded deaths in 2015 1 in 9 of us die **of it**
(ONS Nov 2016)

“A wise man will live as long as he ought, not as long as he can”

Roman Philosopher: Seneca 4BC - 65AD

What is a “Good Death”?

- Free from physical pain.
- Dying in a place of their choosing – often at home.
- Being with close relatives or friends.

- Just going to sleep peacefully and not waking up.
- Dignity – being able to do feeding, dressing, and personal care.
- Still in control of decisions.
- Before loss of basic mental capabilities and identity:
 - Ability to communicate meaningfully
 - Understanding where they are and what is happening,
 - Recognising close relatives, friends, carers.

For SOME people, in SOME situations, it is a medically assisted death

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Medical assistance to die should be an **option** for:

- **Adults** who have...
- **Mental capacity** and
- Suffer from **incurable health problems** resulting in...
- **Quality of life** permanently below the level they can accept
- Provided it is their **own, persistent choice**

- Especially true of the very elderly

Parliamentary Attempts



Faulkner Bill House of Lords 2014

Marris Bill House of Commons 2015

Medically assisted suicide would be permitted for:

- Adults who have...
- Mental capacity and
- Suffer from a terminal illness
- Reasonably expected to die within 6 months
- Voluntary, clear, settled and informed wish to end their life

???

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Rejected at 2nd reading 11th Sept 2015

118 For 330 Against

Parliamentary Attempts



FEELING A BURDEN

IMPROVE PALLIATIVE CARE

NOT NECESSARY

DR / PATIENT RELATIONSHIP

SIX MONTH CRITERION

SAFEGUARDS ILL-DEFINED

SLIPPERY SLOPE

COERCION OF VULNERABLE

DOCTORS OPPOSED

QUALITY OF LIFE

• Re

• Volunt

for 330 Ag

2015

Common Ground

- End-of-Life experience can and should be improved
- Vulnerable people need strong protection from coercion
- Many deserving cases would not be helped by Bill
(because of 6 month clause)
- The issues are complex, difficult and potentially dangerous.

Palliative Care

YES! Improve care for the elderly, incurably ill and dying

BUT we need to be realistic:

- Not always possible to relieve pain sufficiently
- Emotional pain is much harder to palliate
- Dignity may be permanently lost
- Quality of life may still be unacceptable
- Sometimes kinder, more dignified, more compassionate to allow suffering to be ended by hastened death

MPs Main Concerns

1) Fundamental Objections

- Value of Life
- Change in law unnecessary

2) Problems with the Marris Bill

- Protection from coercion
- Six month criterion
- Slippery Slope
- Medical opposition
- Doctor / patient relationship
- Lack of detail in safeguards

Value of Life

- People on all sides value life very highly
- Respect religious and non-religious views through **choice**

BUT

- Value the person - their experience, their reasonable wishes.
- Incurable suffering can make suicide a **rational decision**
- Assisted suicide **option** can **prolong** life and **enhance** quality!

“In refusing dying people the right to die with dignity, we fail to demonstrate the compassion that lies at the heart of Christian values.”

Archbishop Desmond Tutu Oct 2016

Is a Change of Law Necessary?

- People can end their own lives!
Refuse treatment, food & drink ... or worse
- DPP guidelines facilitate ending life in Switzerland BUT
 - People go too soon while they still can
 - If they can afford it
 - A difficult process
 - Unfair to create assisted suicide migrants
- 10x more suicides than Swiss option + unknown failures
- Untenable position if someone asks you to help them die
- Unlikely to face custodial sentence – but unknown.
- UNSAFE – NO independent checks on coercion
- High risk of botched suicide or murder

Is a Change of Law Necessary?

- People can end their own lives!
Refuse treatment, food & drink
- DPP guidelines

Is a Change of Law Necessary?

YES!

**We need to ensure more good deaths,
not facilitate bad ones**

... + unknown failures

... one asks you to help them die

... custodial sentence – but unknown.

... – NO independent checks on coercion

... High risk of botched suicide or murder

But what is the Right Law?

Scope? What situations should it apply to?

- Terminally ill – meaning within 6 months of dying
 - Doctors can't make 6 months prognosis accurately
 - Excludes too many deserving cases
- DIGNITAS criteria?
 - Terminally ill (no time limit), and/or Unendurable and incapacitating disability, and/or Unbearable and uncontrollable pain.

Slippery Slope?

No – **cautious**, one step at a time, gradual change

Each step carefully limited and reviewed by MPs

Compare with how we got the vote:

- Less than 3% in the early 19th C
- Land owners
- Men over 21 and Women over 30
- Men and women over 18

Was that a slippery slope?

Protecting the Vulnerable from Coercion

More detail needed about how this could work

Robust interviewing – appropriate professionals exist

MDMD suggestion:

Record video of patient's explanation of wishes

MDMD suggestion: Extended Advanced Decision

Recorded desire for the **OPTION** of assisted death in the future

Made long in advance

Ideally reaffirmed at intervals until needed

Mandatory if patient considered vulnerable

Feeling a Burden

NOBODY should be **made** to feel a burden.

BUT

- People feel a burden **NOW** – or fear they will in the future if quality of life is permanently unacceptable
- Because of their **illness**
- Especially if they have to make huge demands on their own finances or family carers
- Assisted dying can relieve the feeling of being a burden, contributing to a **good death**.

Doctor Opposition

Doctors conflicted:

Do no harm

Vs

Patient autonomy and desire for good death

NICE guidelines:

“... put the dying person at the heart of decisions about their care, so that they can be supported in their final days **in accordance with their wishes.**”

www.nice.org.uk/news/article/new-guidelines-to-improve-care-for-people-at-the-end-of-life Dec 2015

MDMD suggestions:

Integrate assisted dying into palliative care

OR a new medical specialty for assisted dying

OR DIGNITAS-UK??

Doctor Patient Relationship

Would Assisted Dying damage the relationship?

Could we continue to trust our doctors?

ALREADY BROKEN concerning end of life discussion

Can't talk about assisted dying

No meaningful counselling

People considering Switzerland **frightened** of talking to Dr in case they withhold medical records.

Legalised medically assisted suicide would help restore the relationship.

Where next?

- Open minded new thinking needed on all sides
- Collaboration between Medical professionals, Lawyers, Politicians, Religious leaders...



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Can you help us?:

- Become an MDMD supporter
- Help us develop acceptable, workable proposals
- Talk to your MP, Doctor, friends.
- Share stories of cases which demonstrate the need for a better approach.
- Promote Advance Decisions

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Questions?
Discussion?

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