

Functional Capacity and the Person with Dementia

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Consent and Capacity

- Evolution of consent
- Evolution of capacity
- 'Functional' capacity
- Planning ahead when you have capacity
 - Wills
 - Enduring Powers of Attorney
 - Advance care directives
 - New Assisted Decision-Making (Capacity) Act
- What happens when capacity is diminished or lacking?



Evolution of Informed Consent

1: Consent

- ▶ *Pro corpore mortuoto*: from medieval times - “hold harmless” document to release doctor from responsibility if things went wrong
 - ▶ *Protected the doctor, not the patient*
- ▶ Later came “consent” to treat
 - ▶ 1767 *Slater v Baker & Stapleton*
 - ▶ A doctor set a pts femoral fracture in usual way for that time
 - ▶ Later he re-broke the healing fracture and put the bone in an experimental mechanical device with teeth
 - ▶ Other doctors in court said they usually got consent before intervening
 - ▶ Judge ruled the patient’s consent should’ve been obtained “as part of his duties as a physician”

Consequences of acting without consent

- ▶ **Negligence**
- ▶ **Assault and Battery**
- ▶ **Assault causing serious harm**
 - ▶ Non-Fatal Offences Against the Person Act 1997 IRL
- ▶ *Mohr v Williams 1905, Minnesota*
 - ▶ Consented to operation on right ear, left ear couldn't be examined due to foreign substance
 - ▶ Intraoperatively examined left ear.....worse state than right so operated on left
 - ▶ Brought a suit for \$20,000: damaged hearing, assault & battery as operated on left ear without consent

Consent

- ▶ *Noli me tangere (do not touch me)*
- ▶ Unlawful for a doctor to examine/treat/operate on a patient without their consent
- ▶ Consent is rooted in *autonomy*: that all humans are “free agents”:
 - ▶ “Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without the patient’s consent commits an assault”

*Judge Benjamin Cardozo
Schloendorff v Society of New York Hospital 1914*

The rise and fall of paternalism

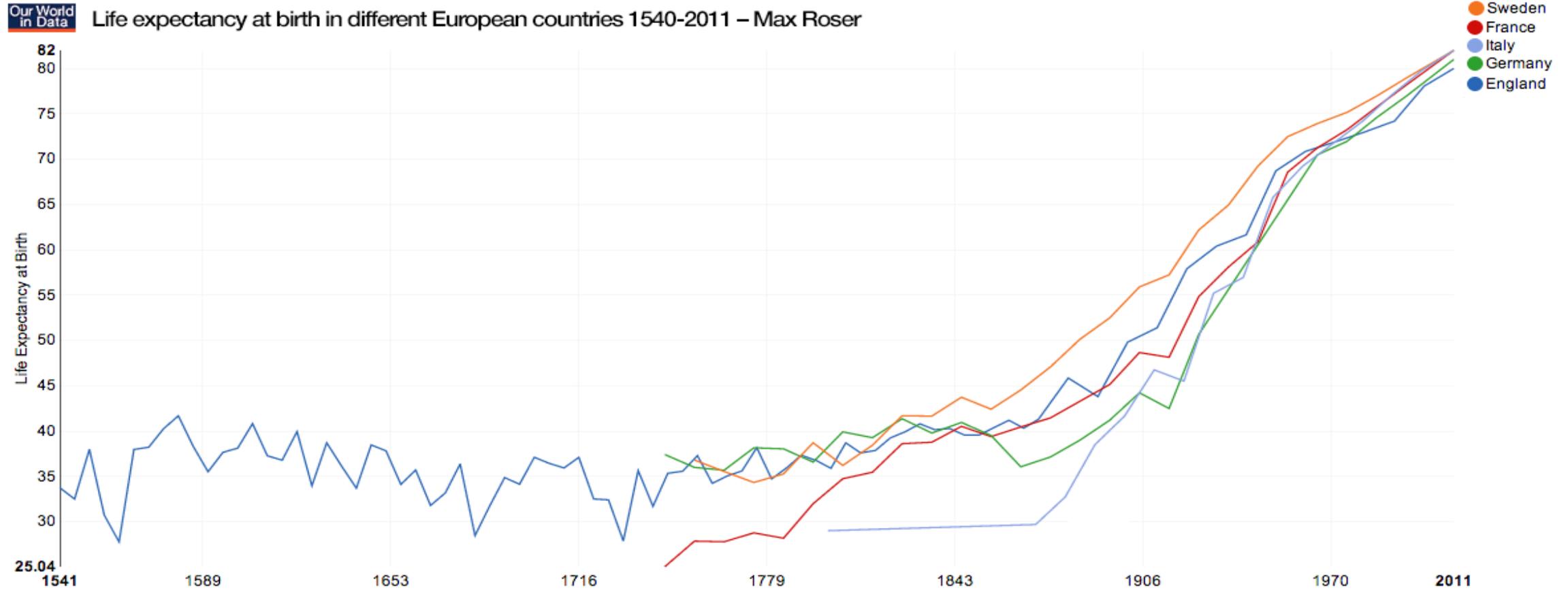
- ▶ Hippocratic Corpus advised:
 - ▶ “concealing most things from the patient, while you are attending him;...turning his attention away from what is being done to him; ... revealing nothing of the patient’s future or present condition”
- ▶ Thomas Percival *Medical Ethics* 1794:
 - ▶ “as misapprehension may magnify real evils, or create imaginary ones, no discussion concerning the nature of the case should be entered into before the patients, either with the house surgeon, the pupils of the hospitals, or any medical visitor.”

Evolution of Informed Consent

2: Informed ...Information

- ▶ Thomas Percival 1803
 - ▶ Patients have a right to truth, but when the physician could provide better treatment by lying or withholding information, he advised that the physician do as he thought best.
- ▶ 19th century view of Holmes in *Currents and Counter-currents in Medicine* 1861
 - ▶ “your patient has no more right to all the truth than he has to all the medicine in your saddle bags”
- ▶ Consent came first.....linking consent with information came later!

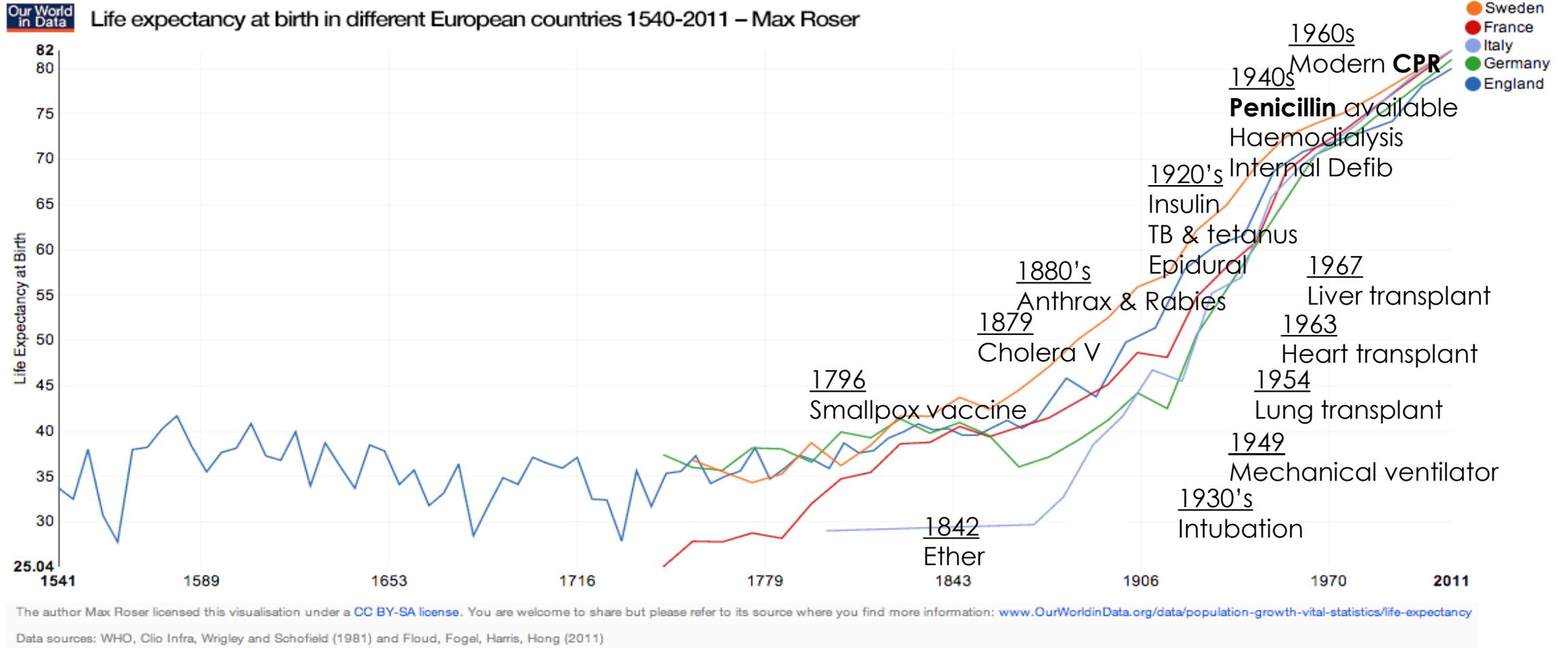
Life Expectancy.....



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Data sources: WHO, Clio Infra, Wrigley and Schofield (1981) and Floud, Fogel, Harris, Hong (2011)

Life Expectancy.....



Evolution of Informed Consent

3: Information & Consent

▶ **Bang v. Charles T. Miller Hospital, 1955**

- ▶ established a patient's entitlement to know inevitable risks or results of surgery.
- ▶ elderly male consented to TURP, but wasn't told of the likelihood of sterility post-op.

▶ **Corn v. French, 1955**

- ▶ Pt advised to undergo a "test" for possible breast malignancy, asked if doctor was going to remove her breast, doctor said "no"
- ▶ Consented to mastectomy without an explanation of the procedure

▶ **Salgo v. Leland Stanford Jr. University Board of Trustees in 1957**

- ▶ Pt awoke paralyzed after aortography, having never been informed that such a risk existed.
- ▶ Failure to disclose risks and alternatives was cause for legal action on its own, reaching further than a case of battery.

Evolution of Informed Consent

3: Information & Consent

- ▶ ***Bolam vs. Friern Hospital Management Committee*** in 1957.....the **Bolam test**
- ▶ **Natanson v. Kline** in 1960
 - ▶ Cobalt irradiation for breast cancer caused pt severe disabling burns
 - ▶ Pt told there were no risks associate with the treatment
 - ▶ Court held the doctor responsible to disclose the risks that a reasonable doctor would provide a patient
- ▶ **Canterbury v. Spence** in 1972
 - ▶ Pt partially paralysed after thoracic spine surgery
 - ▶ Said he had not been informed of such a risk by the surgeon
 - ▶ Court held that the standard for disclosure whould be that which a reasonable patient would want to know.

Paternalism still alive & well in 1960s

- ▶ Oken et al 1961: 219 US physicians,
 - ▶ **90%** of them would not disclose a diagnosis of cancer to patients

16 years later.....

- ▶ Novack et al 1977: 264 medical staff
 - ▶ **97%** of them would disclose a cancer diagnosis
 - ▶ physicians still based decisions on emotionally laden personal convictions

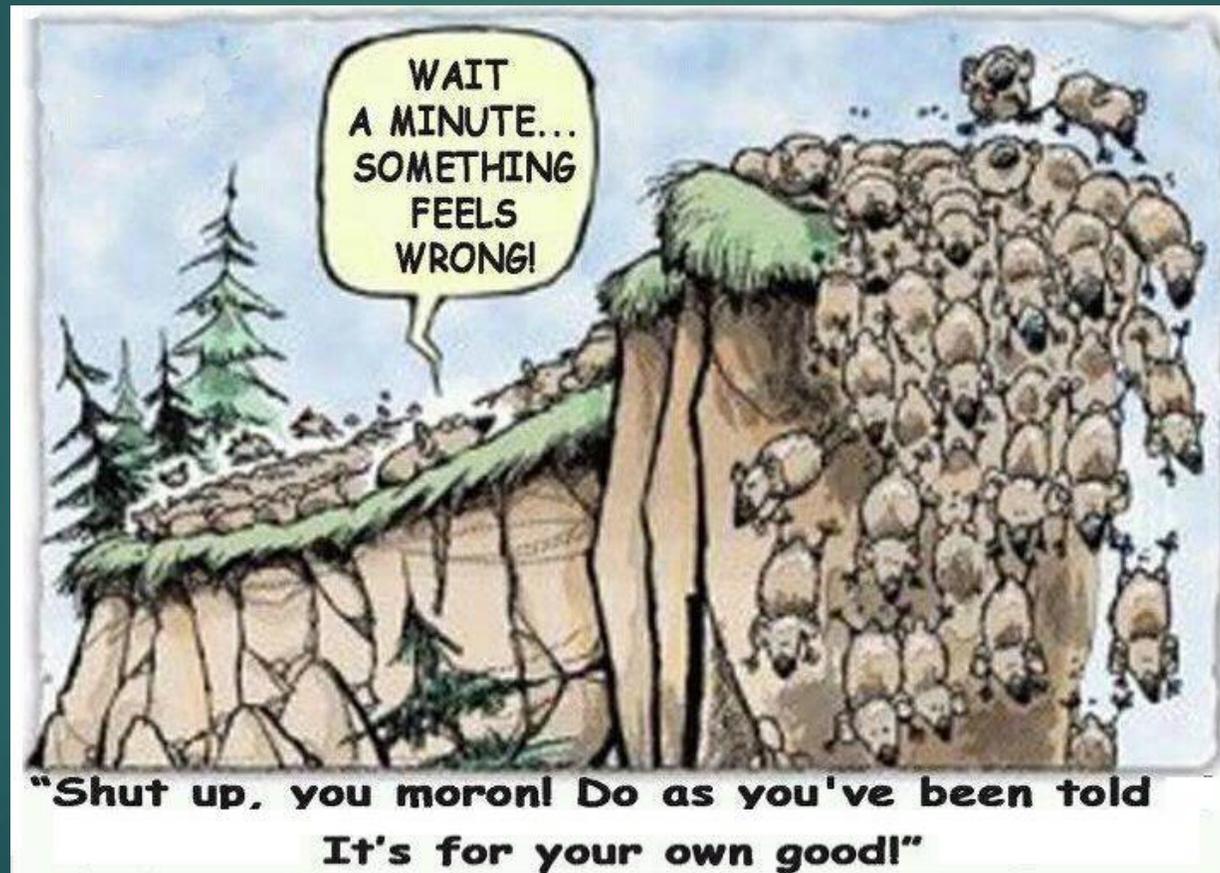
The Influence of the Probability of Survival on Patients' Preferences Regarding CPR

- ▶ 287 elders (mean age 77yrs) in present state.....
 - ▶ **41% wanted CPR** before learning survival likelihood
 - ▶ **22% wanted CPR** after learning survival likelihood
 - ▶ **6% of ≥ 86 yrs opted for CPR still**
 - ▶ **In a chronic illness with life expectancy of < 1 year**
 - ▶ **11% wanted CPR before education Re Survival**
 - ▶ **5% wanted CPR after being told survival chances**
- Distress from CPR discussions in 8% of elderly (O'Keefe, Age Ageing 2001)

Essential Ingredients of Informed Consent

1. Consent must be given (or withheld) **voluntarily**
2. Any decision relating to the giving or withholding of consent should be based on **sufficient relevant information**
3. Consent must be given (or withheld) by a person who has the **legal capacity**, in terms of age and mental competence, to do so.

Capacity Evolution: the “outcome” approach



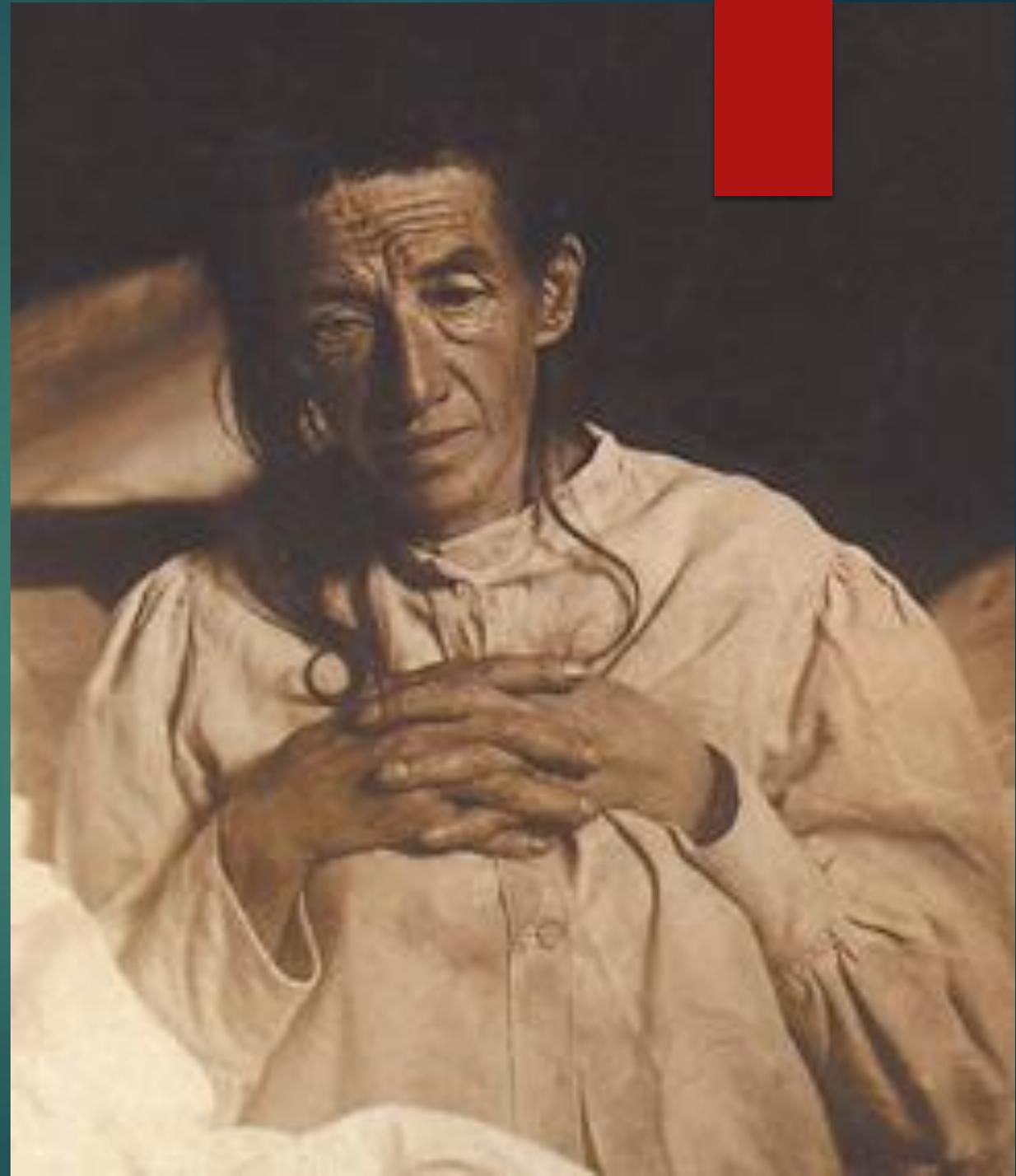
Capacity: The "outcome" approach

“Penalises
individuality &
demands
conformity at the
expense of
personal
autonomy”



Capacity Evolution: The “status” approach

- ▶ Based on diagnosis and disability
 - ▶ e.g. a person in a long-stay psychiatric ward may be automatically denied capacity to make a will or to vote regardless of their actual capability
- ▶ Poor where capacity fluctuates
- ▶ All or Nothing approach
 - ▶ Doesn't respect person's right and capacity to make some decisions



Capacity:

The “functional” approach

- ▶ All adults are presumed to have capacity
- ▶ A person does not lack capacity because
 - ▶ they are old
 - ▶ or indeed because they have dementia
- ▶ Capacity is tied to the decision to be made
 - ▶ e.g. even someone with significant dementia can decide what to have for breakfast
- ▶ The greater the complexity & consequences of the decision the more important capacity becomes.

Functional Capacity: the accepted approach (currently)

- ▶ 'Issue-specific' e.g.
 - ▶ capacity to make a will
 - ▶ capacity to marry
 - ▶ capacity to consent to medical treatment
- ▶ Benefit of involving a proportionate, minimum incursion on an individual's decision-making autonomy

Essential Ingredients of Capacity

- ▶ **Understand and believe** the information relevant to the decision
- ▶ **Retain** that information
- ▶ **Use or weigh** that information to make a decision
- ▶ **Communicate** that decision

Essential Ingredients of Capacity

- ▶ **Understand and believe** the information relevant to the decision
- ▶ **Retain** that information

FOR AS LONG AS IS NEEDED TO

- ▶ **Use or weigh** that information to make a decision

AND.....

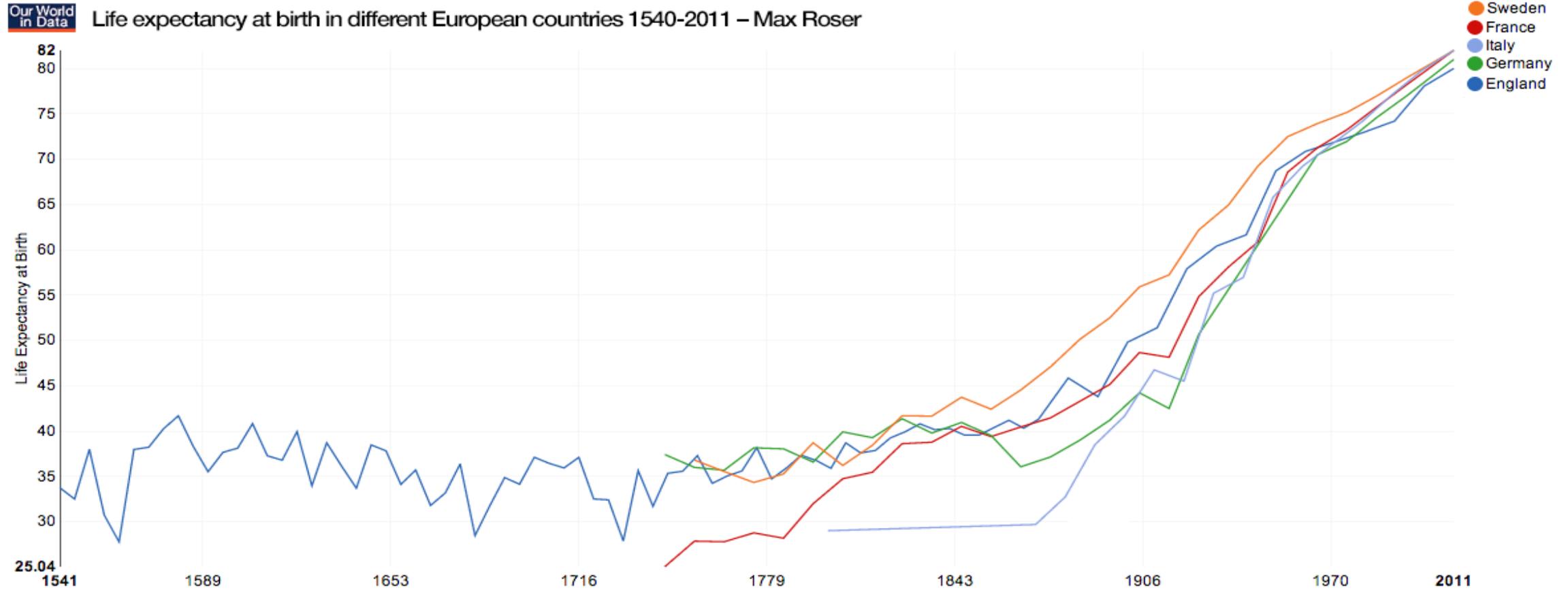
- ▶ **Communicate** that decision

BY WHATEVER MEANS THEY CAN

Essential Ingredients of Capacity

- ▶ **Understand and believe** the information relevant to the decision
 - ▶ Context,
 - ▶ Choices
 - ▶ Consequences
- ▶ **Retain** that information
- ▶ **Use or weigh** that information to make a decision
- ▶ **Communicate** that decision

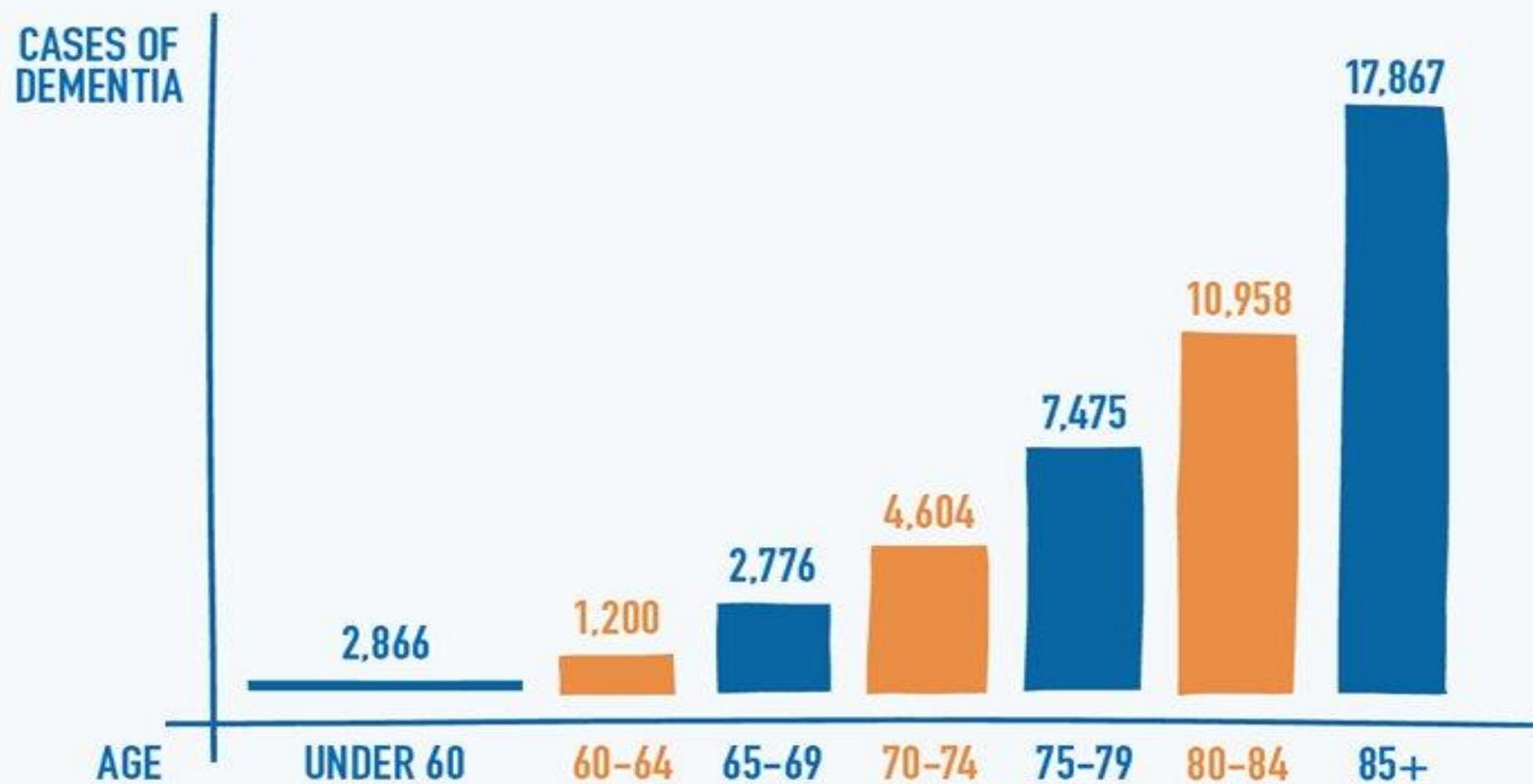
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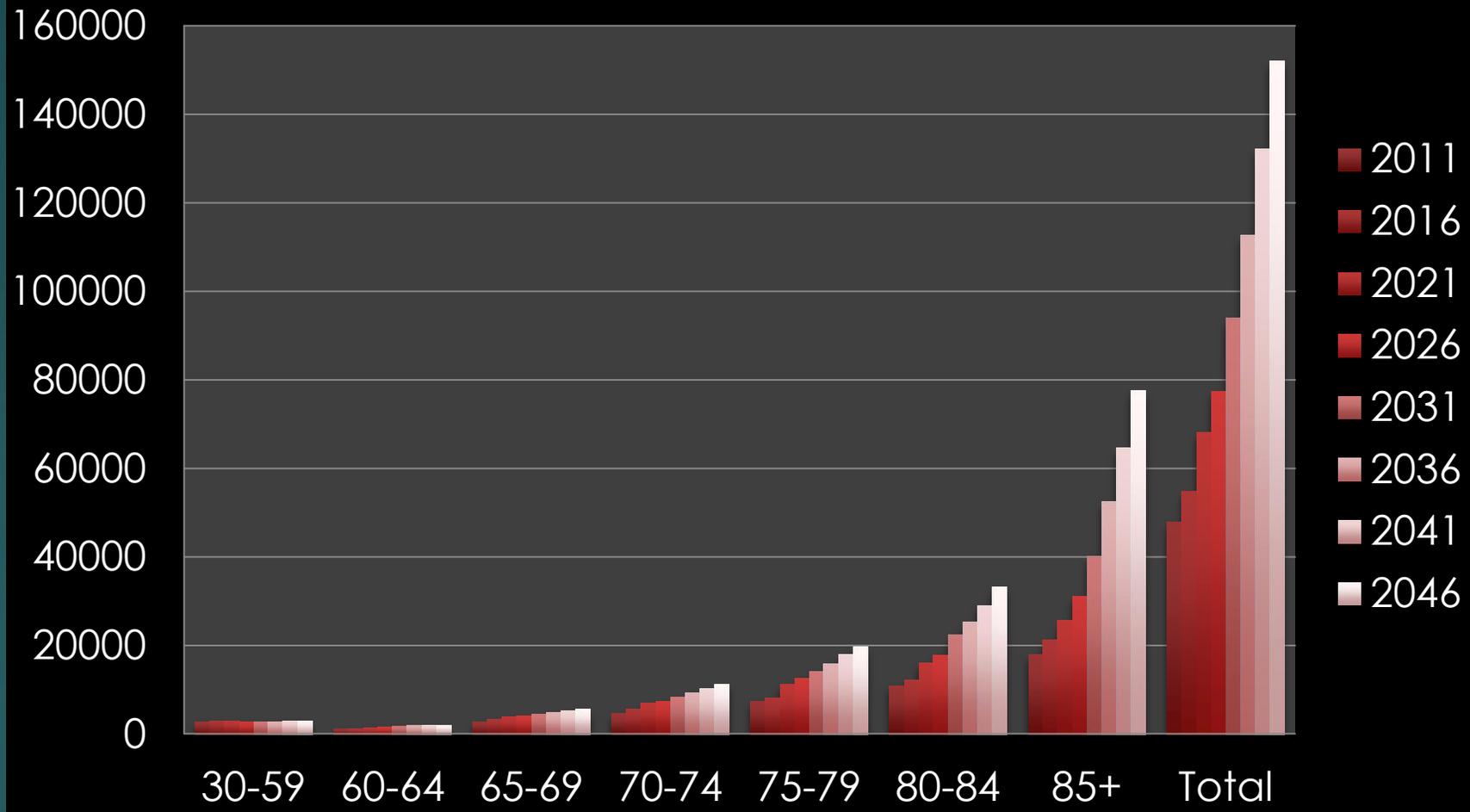
Data sources: WHO, Clio Infra, Wrigley and Schofield (1981) and Floud, Fogel, Harris, Hong (2011)

THE PREVALENCE OF DEMENTIA INCREASES WITH AGE:



Cahill, S. & Pierce, M [2013] The Prevalence of Dementia in Ireland.
Genio Dementia Learning Event

Projected growth in Dementia in Ireland



Estimates based on 2011 census. Projections based on Central Statistics Office (2013) Population and Labour force projections 2016 to 2041 Table 3

Capacity ✓ ?

Planning ahead

- Wills
 - Enduring Powers of Attorney
 - Advance care directives
 - New Assisted Decision-Making (Capacity) Act
-
- What happens when capacity is diminished or lacking?

Diminished Capacity.....optimize it!

- ▶ Research shows that patients' capacity can often be **enhanced** by quite simple steps, such as
 - ▶ breaking down information into smaller 'bites' or
 - ▶ making efforts to talk to patients in a way that they will understand

(Gunn 1999, p.276).

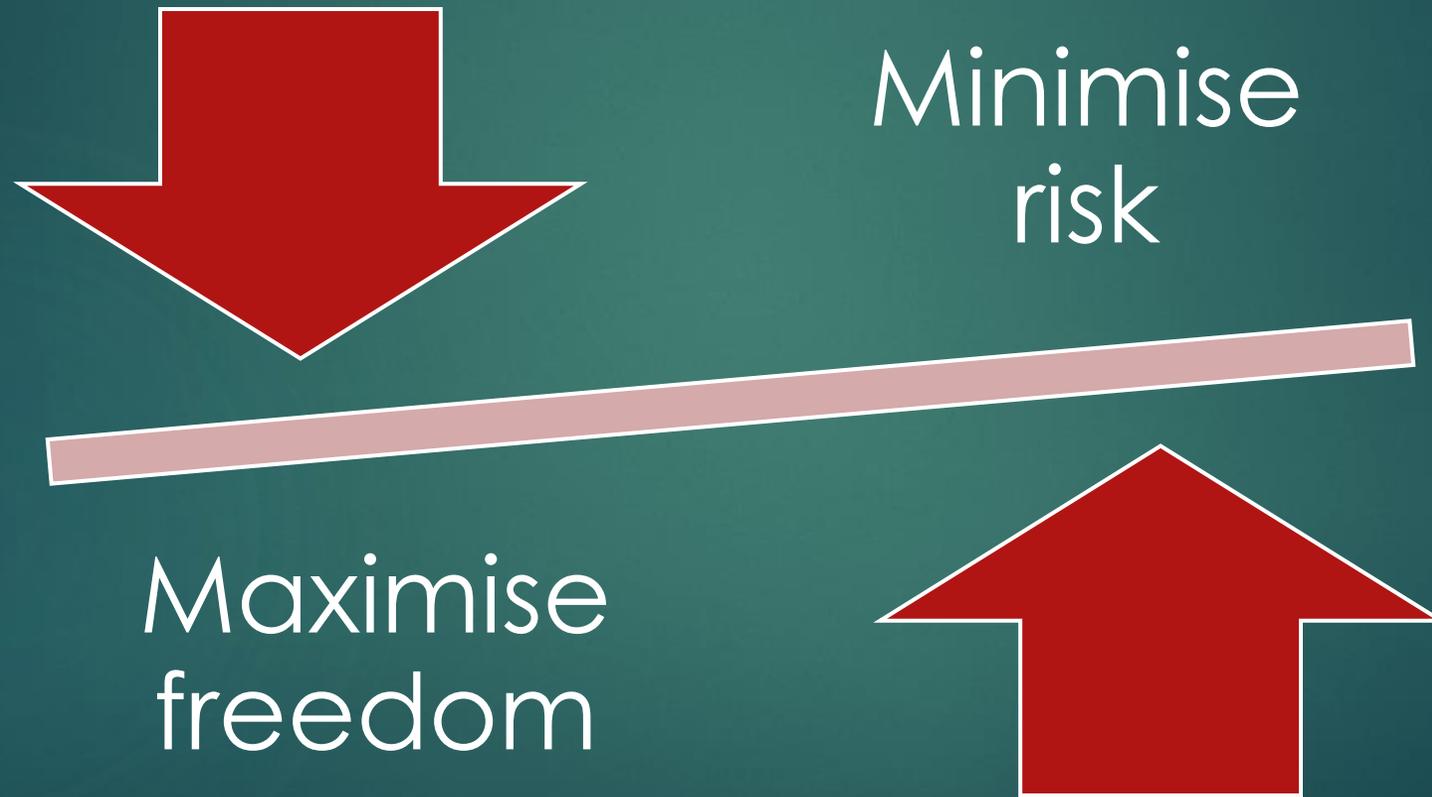
- ▶ This requires time and commitment on the part of health professionals.

Diminished capacity.....inclusion!

Just because a person **lacks formal legal capacity** does not mean that his or her views and preferences can simply be ignored.

- Should still be informed and included in decisions as much as possible.
- Decisions should be made that are consistent with the patient's wishes, values and goals **(substituted judgement)**
- If their wishes are not known, decisions should be made in the patient's **best interests.**

Competing forces in the vulnerable



Intervention

- Advance Care planning program: Let Me Decide (D. W. Molloy)
 - **Educational program for nursing staff**
 - Inviting residents to complete an ACD
 - Assess cognition
 - Educate residents +/- their family
 - Assess capacity to complete an ACD (SIACAD)
 - Complete ACD using LMD or record their wishes (ACP)
 - Standardised form
 - Several copies of form stored in notes for easy retrieval

Time to release staff

Time to release same staff

Retention of trained staff

Trained staff reluctant to take ownership

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Suspicion:

“is there something you know that I don’t”

Moved to introducing LMD at admission and returning to discuss once resident “settled in”

Intervention

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Educational material had to be adapted

Reduced concentration

Reduced cognition

Reduced hearing

Reduced vision

Synopsized, repeatedly

Visual cues

Time consuming

Sometimes issues with which family members involved

Some residents didn't want education but had clear views

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SIACAD

10% had capacity to complete ACD

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Some residents had difficulty imagining a future state that would make them choose differently,

they chose for their current state

LMD pilot study

- Three pilot sites in Cork and Kerry with 287 -> 301 LTC beds
- Annual death rate:
 - BEFORE: 30.3%
 - AFTER: 27.6%
- LTC residents dying in hospital:
 - BEFORE: 9.2% (4.9%, 8.3%, 15.2%)
 - AFTER: 8.4% (1.6%, 7.6%, 20.5%) $p=0.94$
- LTC residents hospitalisation:
 - BEFORE: 80/yr (27.6% of 287 residents) $z=3.96$
 - AFTER: 44/yr (14.6% of 301 residents) **$p<0.001$**
- **LTC residents hospitalised days**
 - BEFORE: 0.54% (1403 hospital bed days/yr) $z=8.85$
 - AFTER: 0.36% (798 hospital bed days/yr) **$p<0.001$**

LMD PILOT study

- EoL care planning for LTC residents who died

	Before		After	
ACD	0/124	(0%)	7/70	(8.6%)
Any EoL care plan	63/124	(51%)	59/70	(84%)
No Care plan	61/124	(49%)	11/70	(16%)

Crisis Decision making avoidance

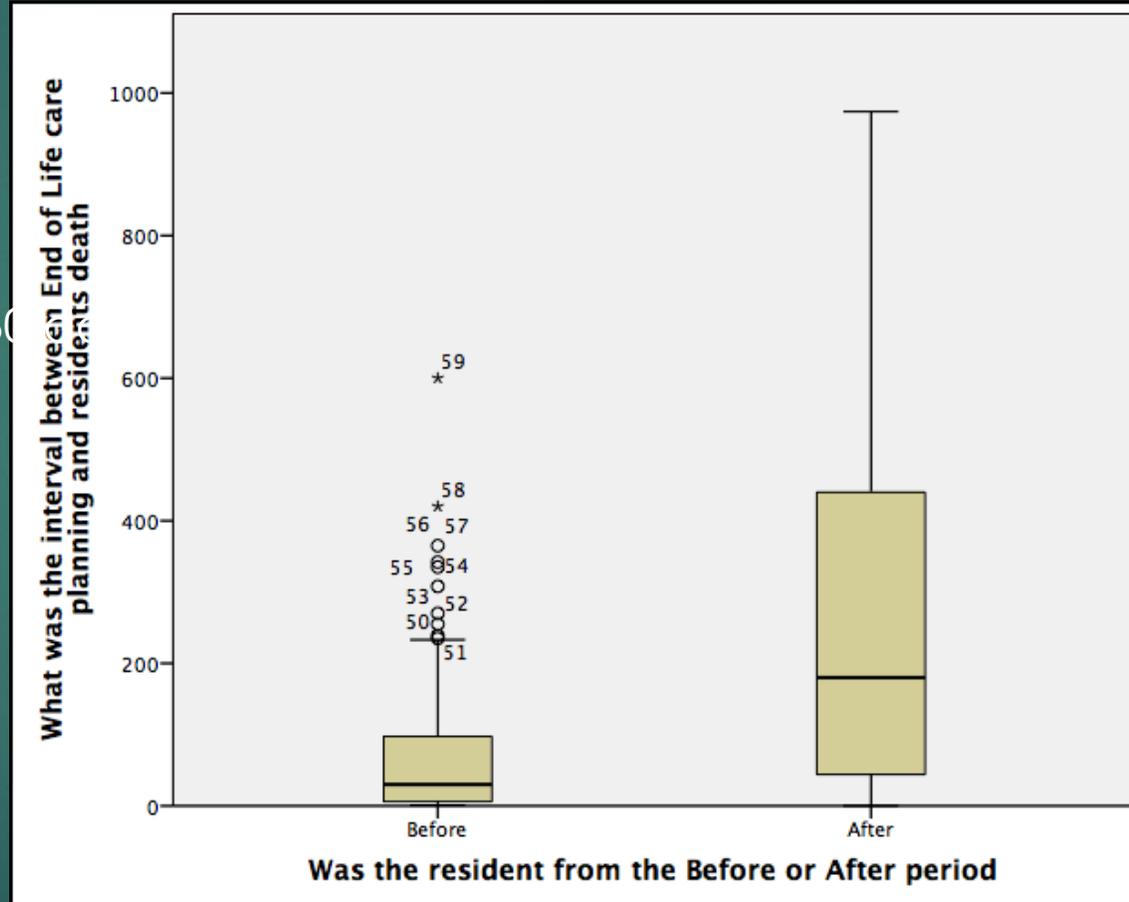
Interval between care planning and resident's death

Before:

Median 30
Mean 92 days
Last week 29%
Last month 51%

After:

Median 180 days
Mean 249 days
Last week 5%
Last month 20%



U=908, z=4.482, p<0.0001, r=0.41

Quality of Care and dying experience

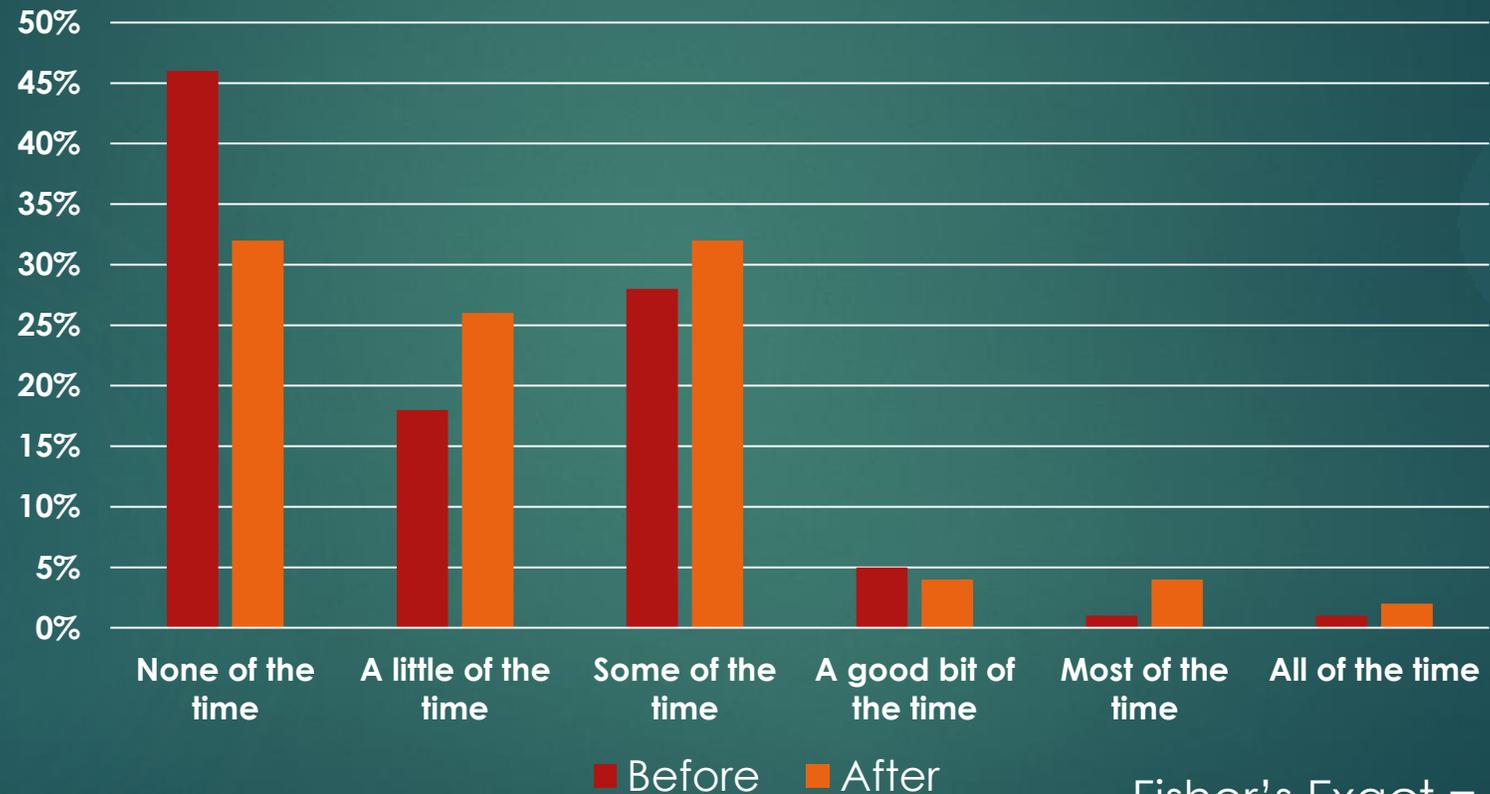


Respect for resident's wishes



Not at the expense of comfort: Pain

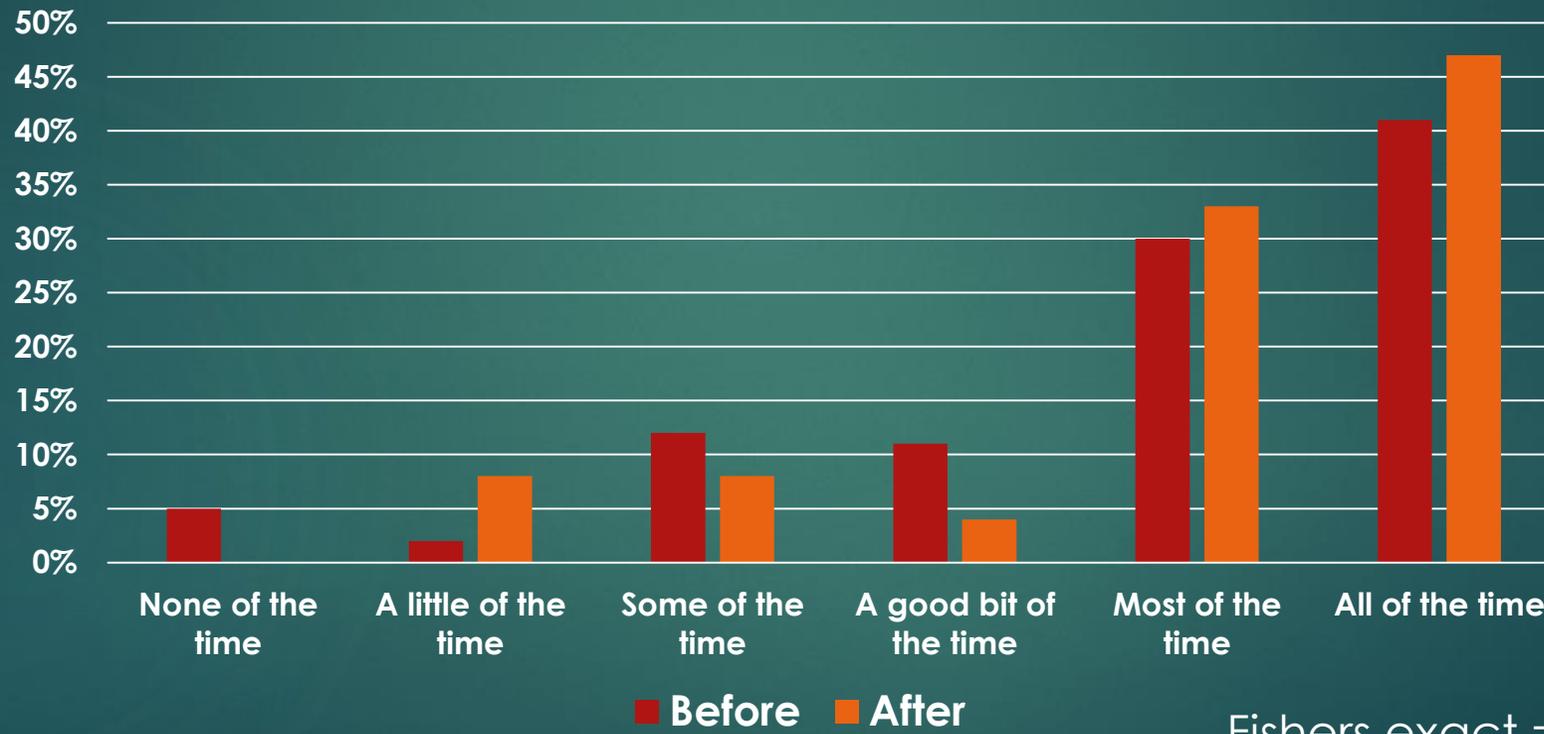
Did your relative have physical pain in their last week?



Fisher's Exact = 4.055
p = 0.556

Not at the expense of comfort: Dyspnoea

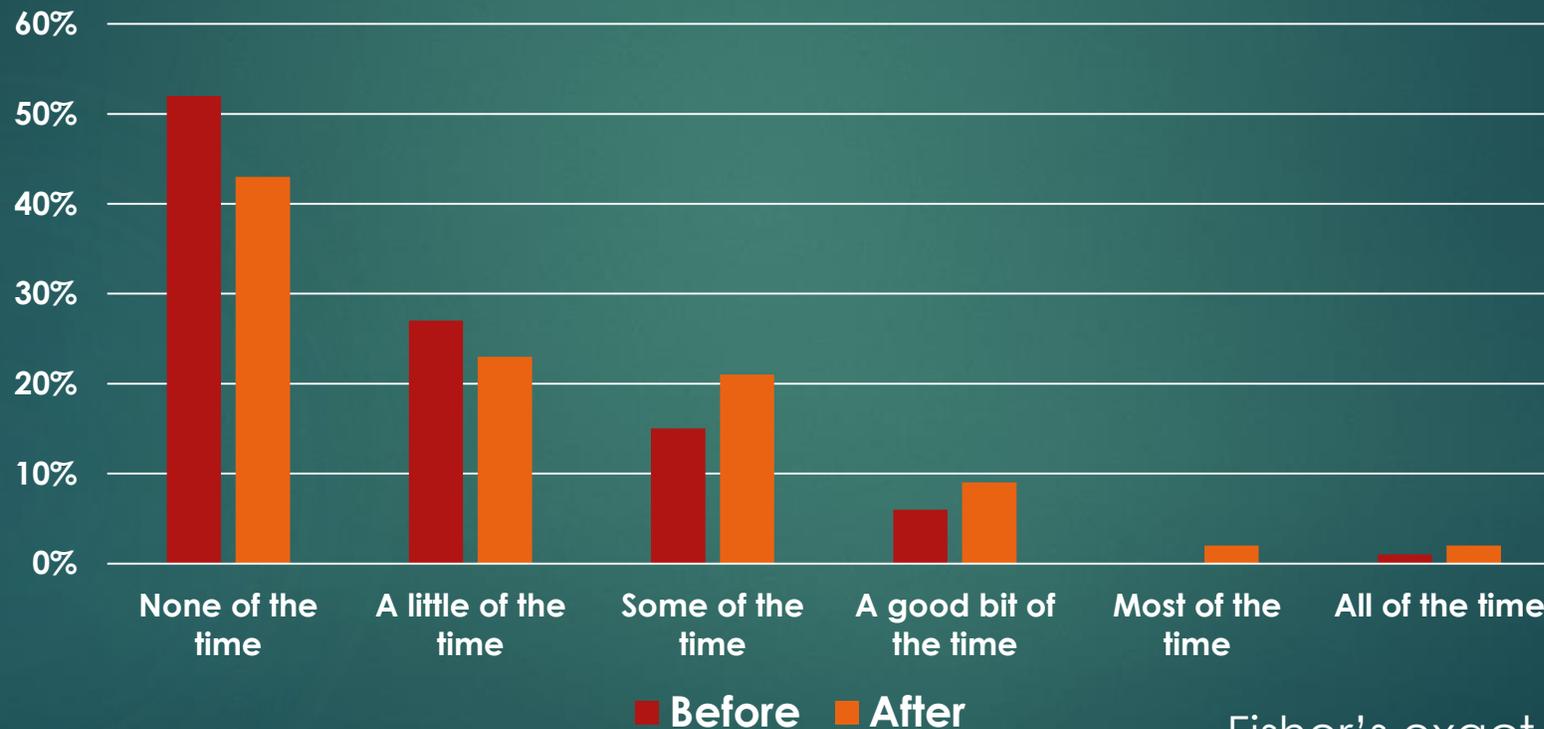
Was your relative able to breathe comfortably in their last week?



Fishers exact = 6.68,
 $p = 0.233$

Not at the expense of comfort: Anxiety

Did your relative seem anxious or afraid in their last week?



Fisher's exact = 4.0
 $p = 0.57$

Sustained initiative?.....July 2017

Worthwhile initiative?

- ▶ **74% had a care plan** (n = 213/291)
 - ▶ Median 914 days (range 44-12291)
 - ▶ After admission: care plan median 263 days
 - ▶ 29% (n=61) were LMD ACD
 - ▶ 62% (n=133) were LMD EOLCP
 - ▶ 9% (n=19) were other formats
 - ▶ Pt involved in at least 46% of care plans (n=98)
 - ▶ Appropriate involvement/pt unable to be involved in 92% of cases,
 - ▶ Pt possibly inappropriately excluded in 1%, documentation unclear in 7%
- ▶ **27% had no care plan** (n = 78/291) ... 8/78 had started
 - ▶ Median 277 days (range 0-3014), Mean LOS 652 days

Thank you