

Ethical Aspects of Advanced Care Planning for Dementia

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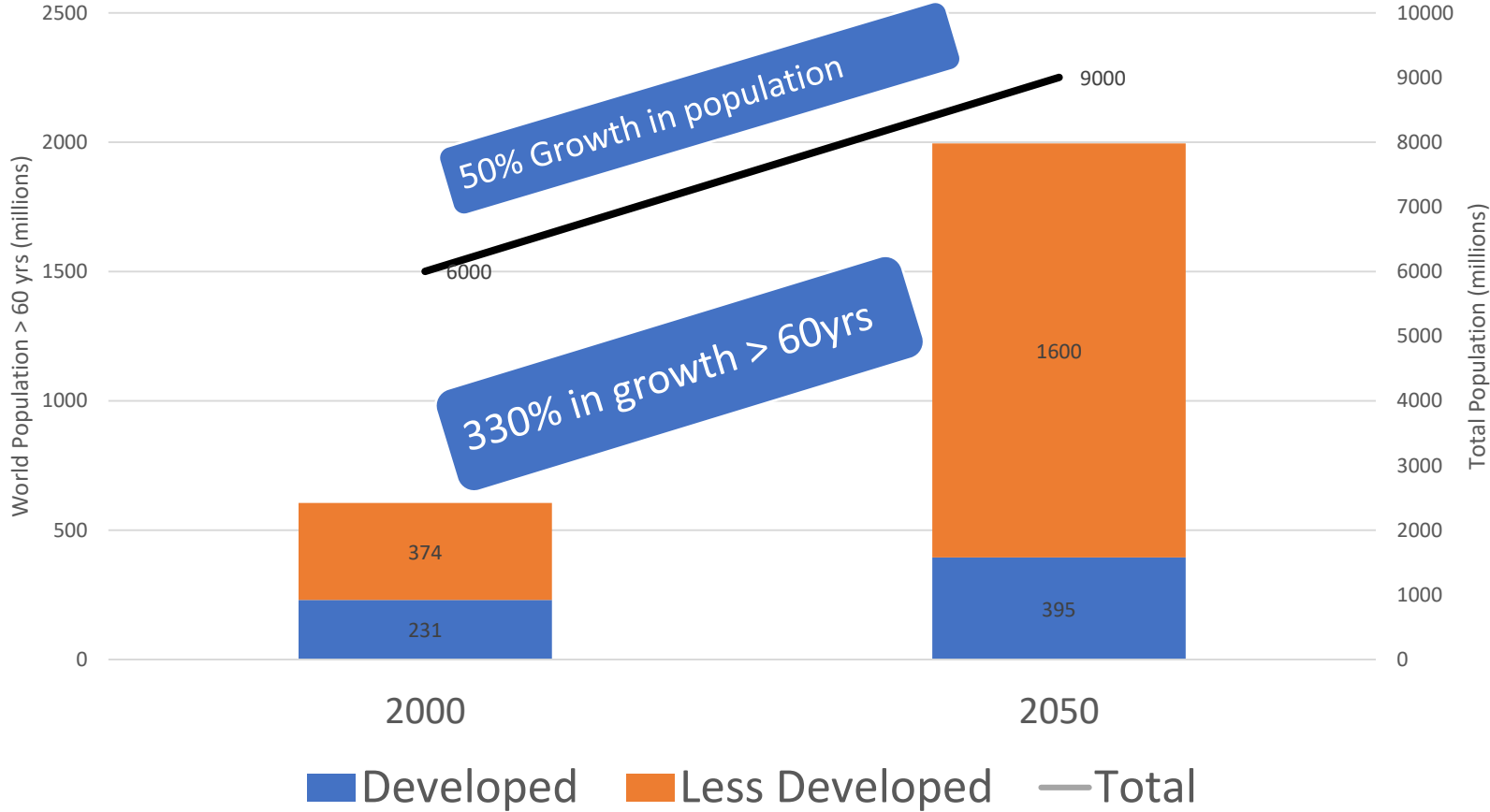
lgeffen@sifar.org.za

SA Academy Family Physicians

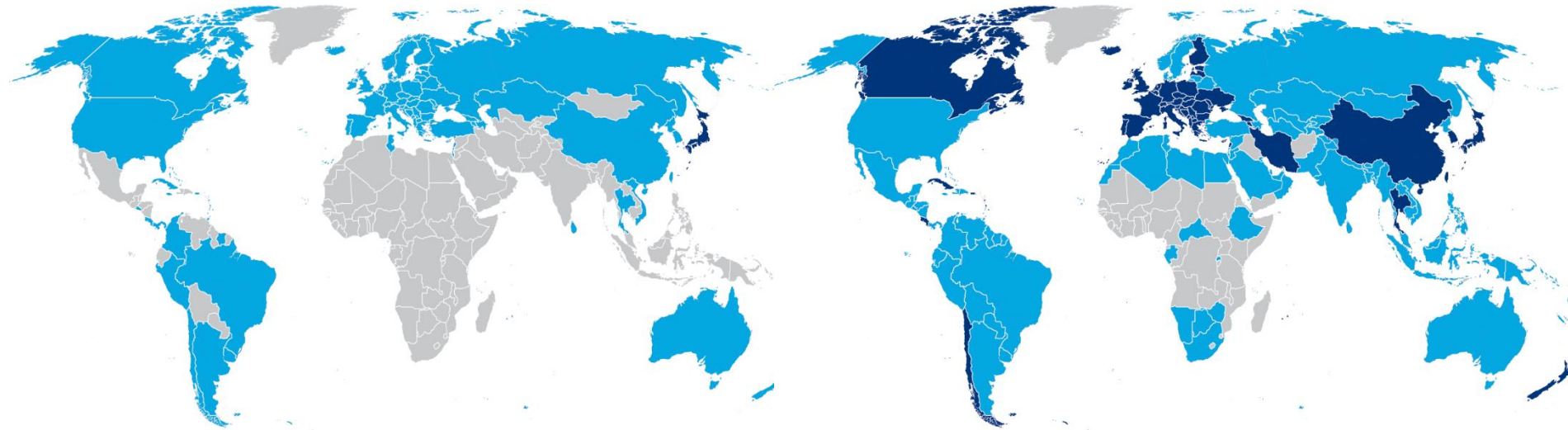
21st National Family Practitioners Congress

26 August 2018

Distribution of World Population > 60yrs old by Development Region 2000 & 2050

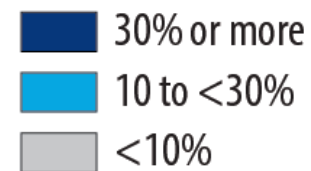


Populations are getting older



2015

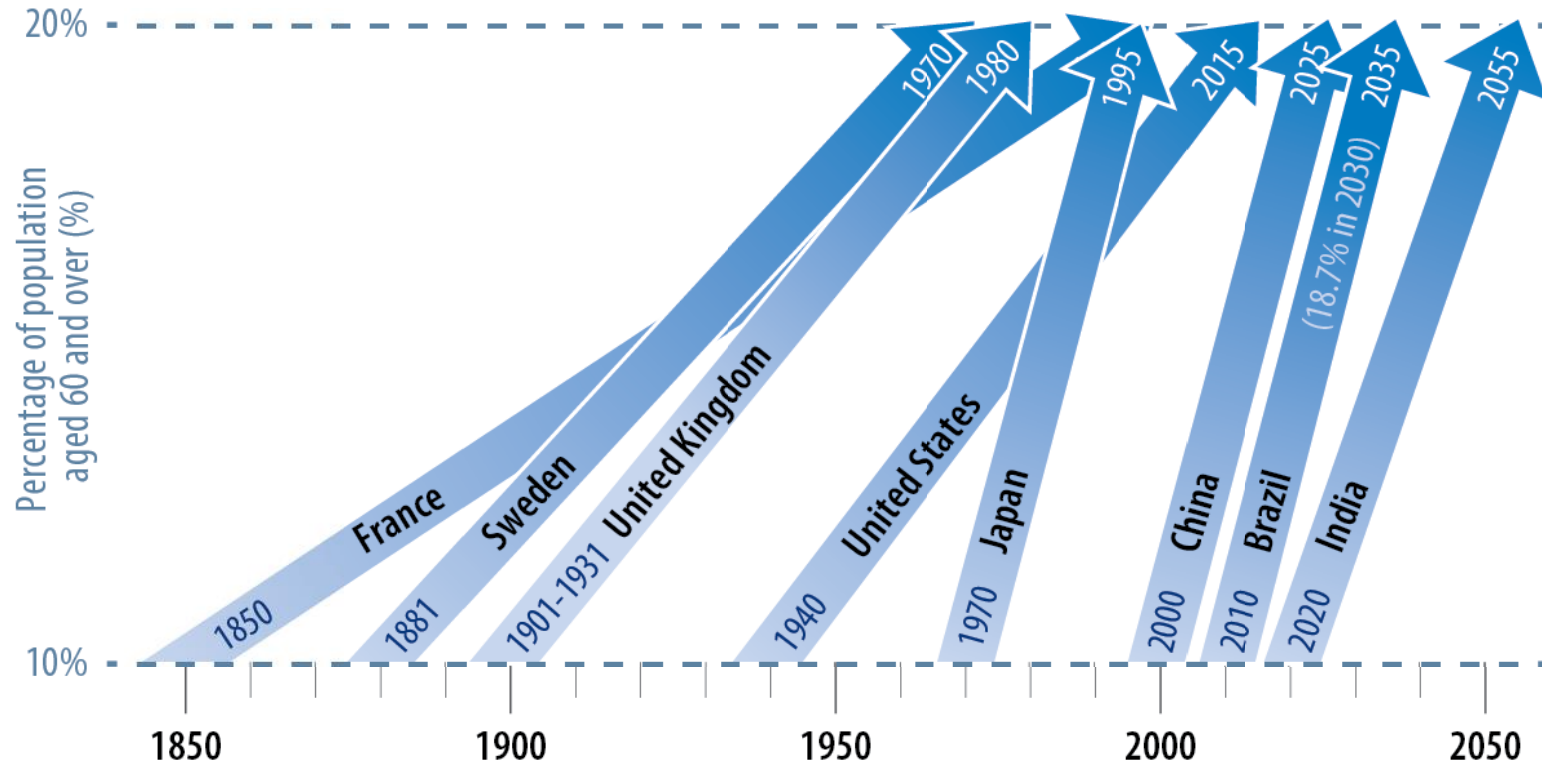
Percentage aged
60 years or older:



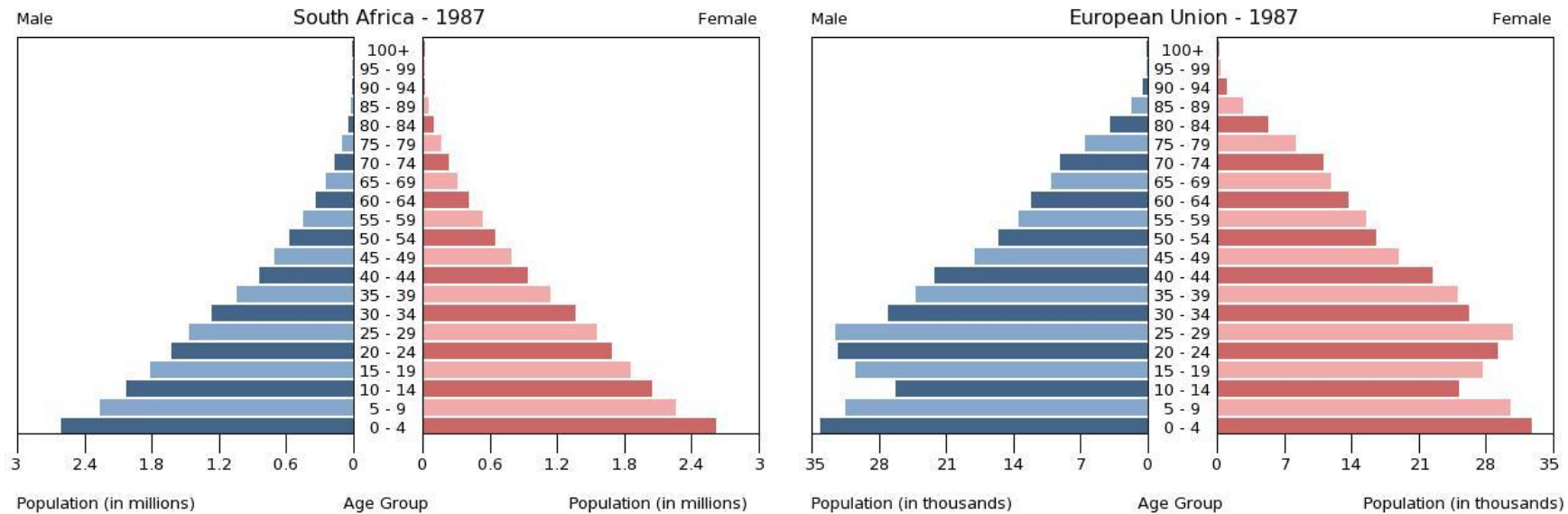
2050

Population ageing is happening much more quickly than in the past

Time for percentage of population
older than age 60 to double

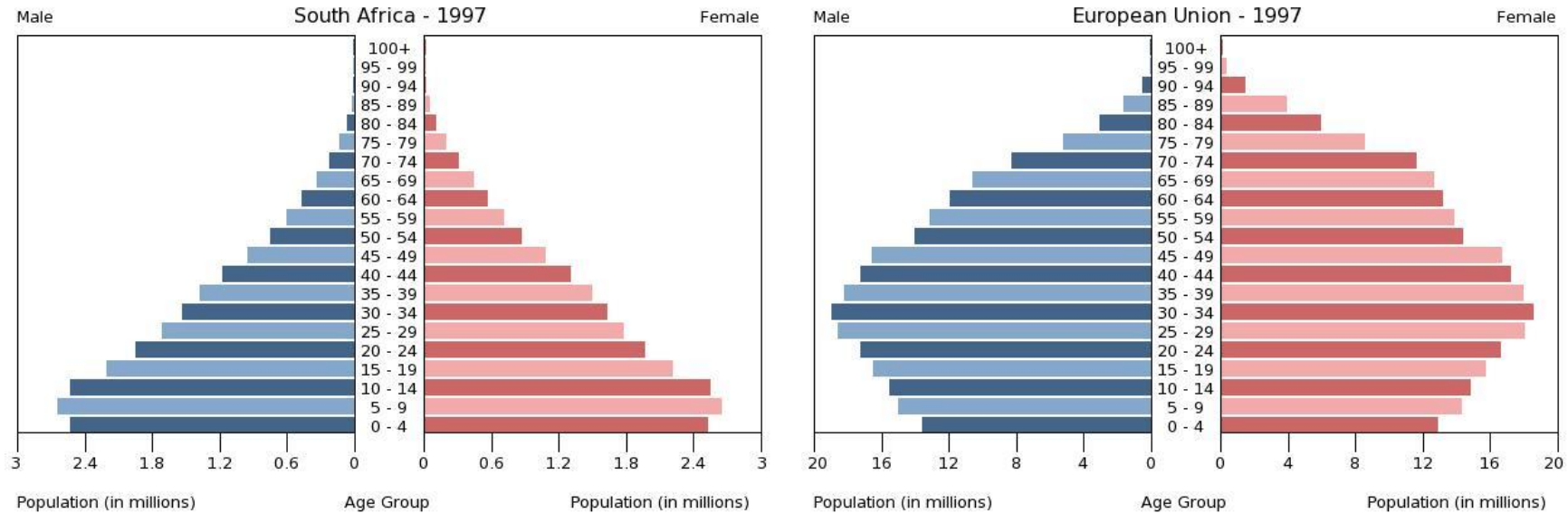


The Ageing Population 1987 - 2047

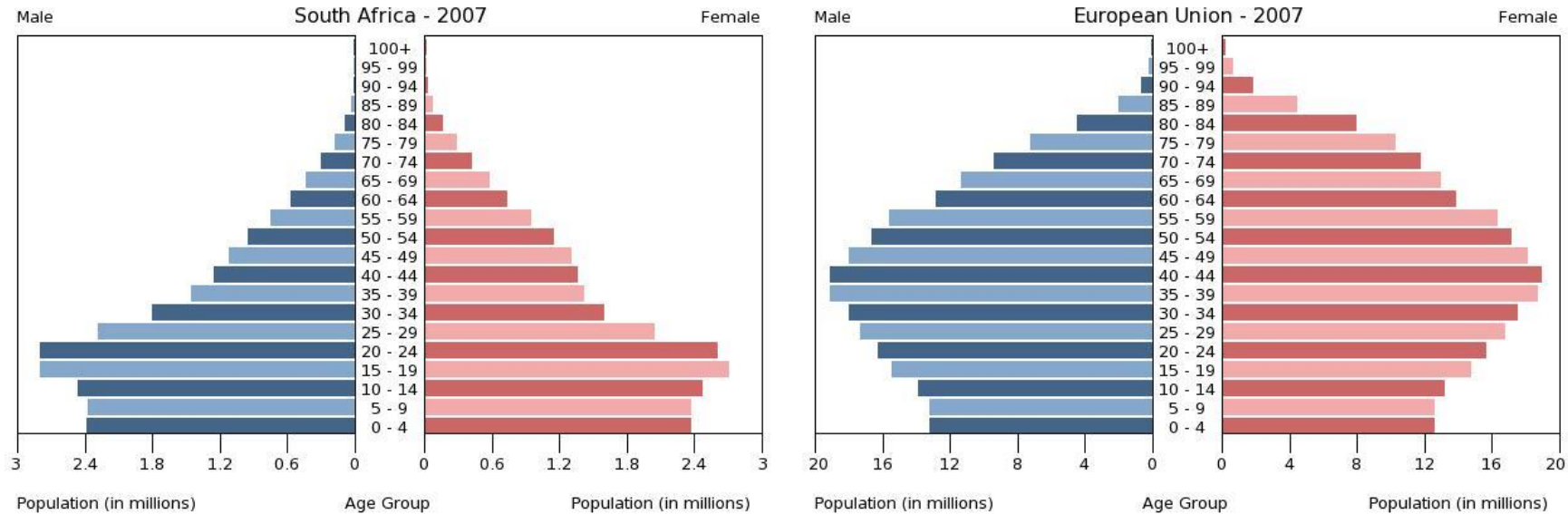


<http://www.census.gov/population/international/data/idb/informationGateway.php>

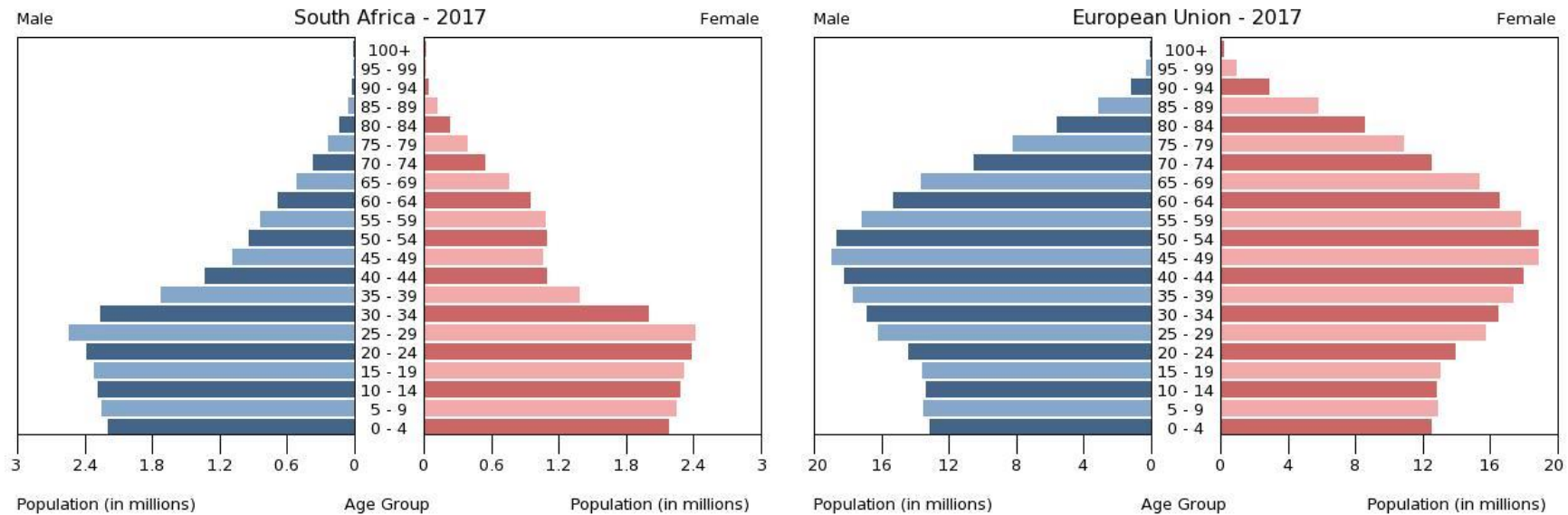
The Ageing Population 1987 - 2047



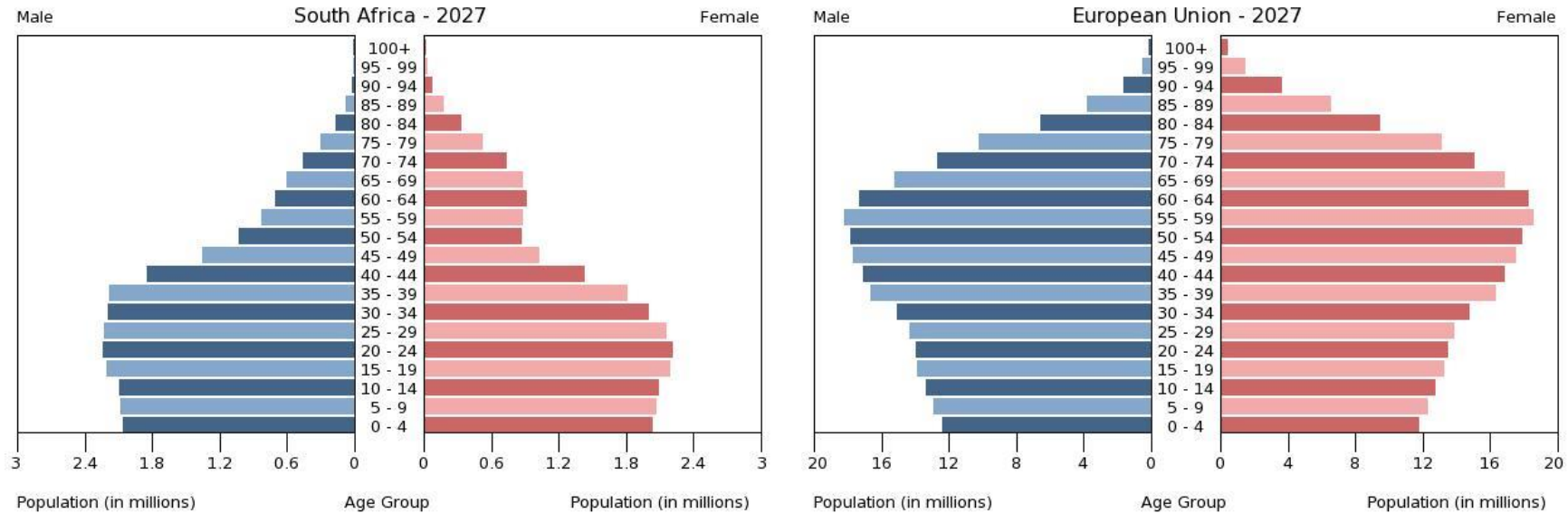
The Ageing Population 1987 - 2047



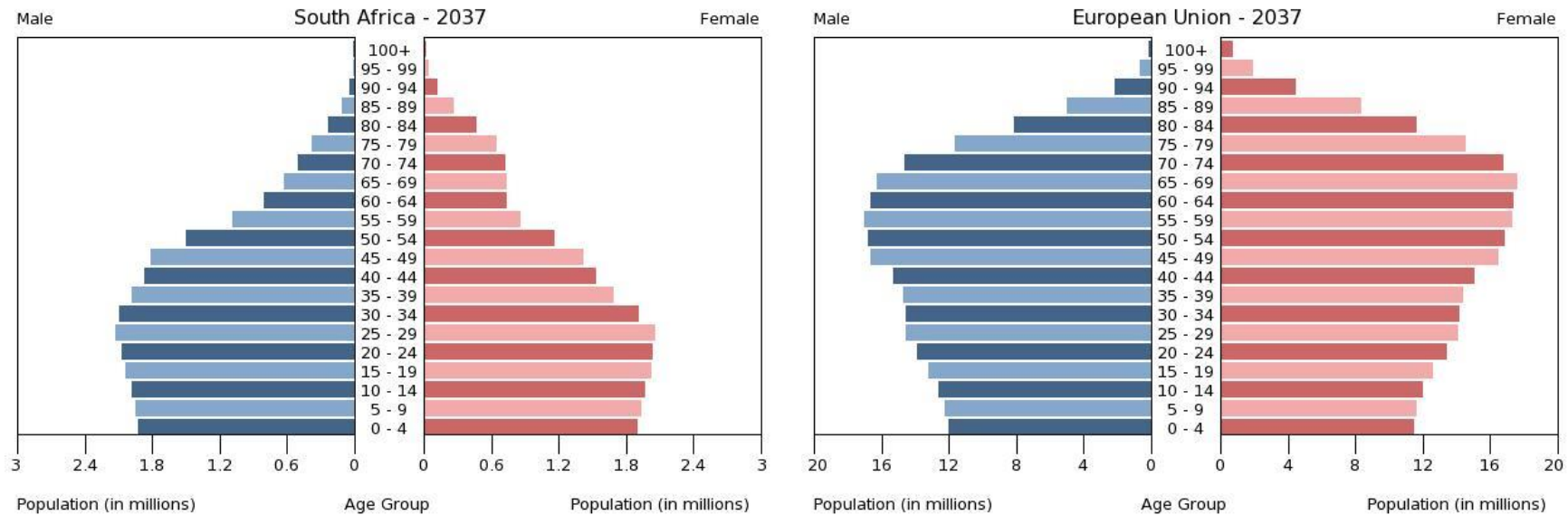
The Ageing Population 1987 - 2047



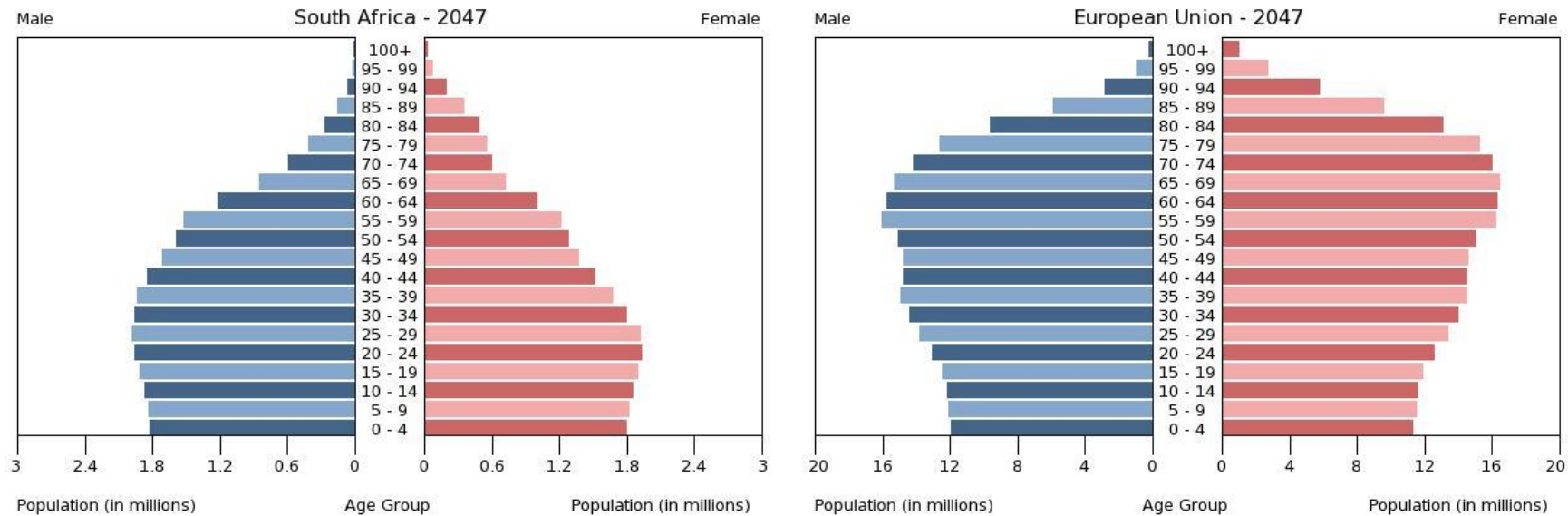
The Ageing Population 1987 - 2047



The Ageing Population 1987 - 2047



The Ageing Population 1987 - 2047



United Nations

A/RES/46/91



General Assembly

Distr. GENERAL

16 December 1991

ORIGINAL:
ENGLISH

A/RES/46/91
74th plenary meeting
16 December 1991

46/91. Implementation of the International Plan of
Action on Ageing and related activities

The General Assembly,

Declaration of the Rights of The Elderly

UN Resolution 46/91



- Independence
- Participation
- Care
- Self Fulfilment
- Dignity



REPUBLIC OF SOUTH AFRICA

GOVERNMENT

VOL. 378

NO. 17678

The Constitution

OF THE REPUBLIC OF SOUTH AFRICA, 1996

18 December 1996

President has assented to the
published for general infor-

stitution of the Republic of South Africa,
1996.

Chapter 1 – Founding Provisions

1. The Republic of South Africa is one, sovereign, democratic state founded on the following values:
 - (a) Human dignity, the achievement of equality and the advancement of human rights and freedoms.
 - (b).....
 - (c).....



Government Gazette

REPUBLIC OF SOUTH AFRICA

Vol. 497 Cape Town 2 November 2006 No. 29346

THE PRESIDENCY

No. 1098

2 November 2006

It is hereby notified that the President has assented to the following Act, which is hereby published for general information:—

No. 13 of 2006: Older Persons Act, 2006.

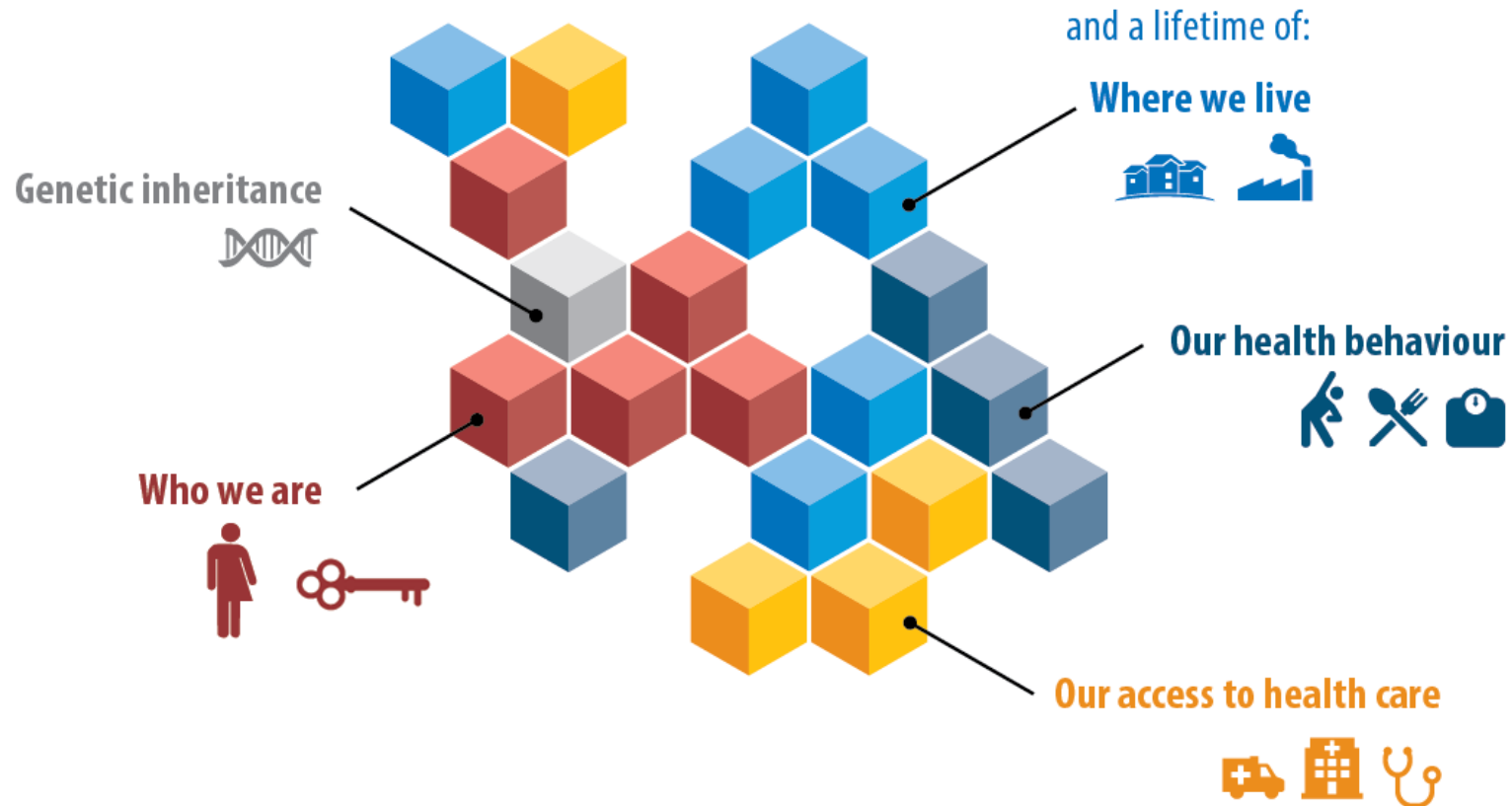
Older
Persons Act
13 of 2006

Older
Persons Act
13 Of 2006

- To deal effectively with the plight of older persons by **establishing a framework aimed at the empowerment and protection of older persons** and at the **promotion and maintenance of their status, rights, well-being, safety and security**; and to provide for matters connected therewith.

Health in older age is not random

What makes us age differently?



People are living longer

60 years

+20 years



How these extra 20 years can be spent...



... It all depends on HEALTH



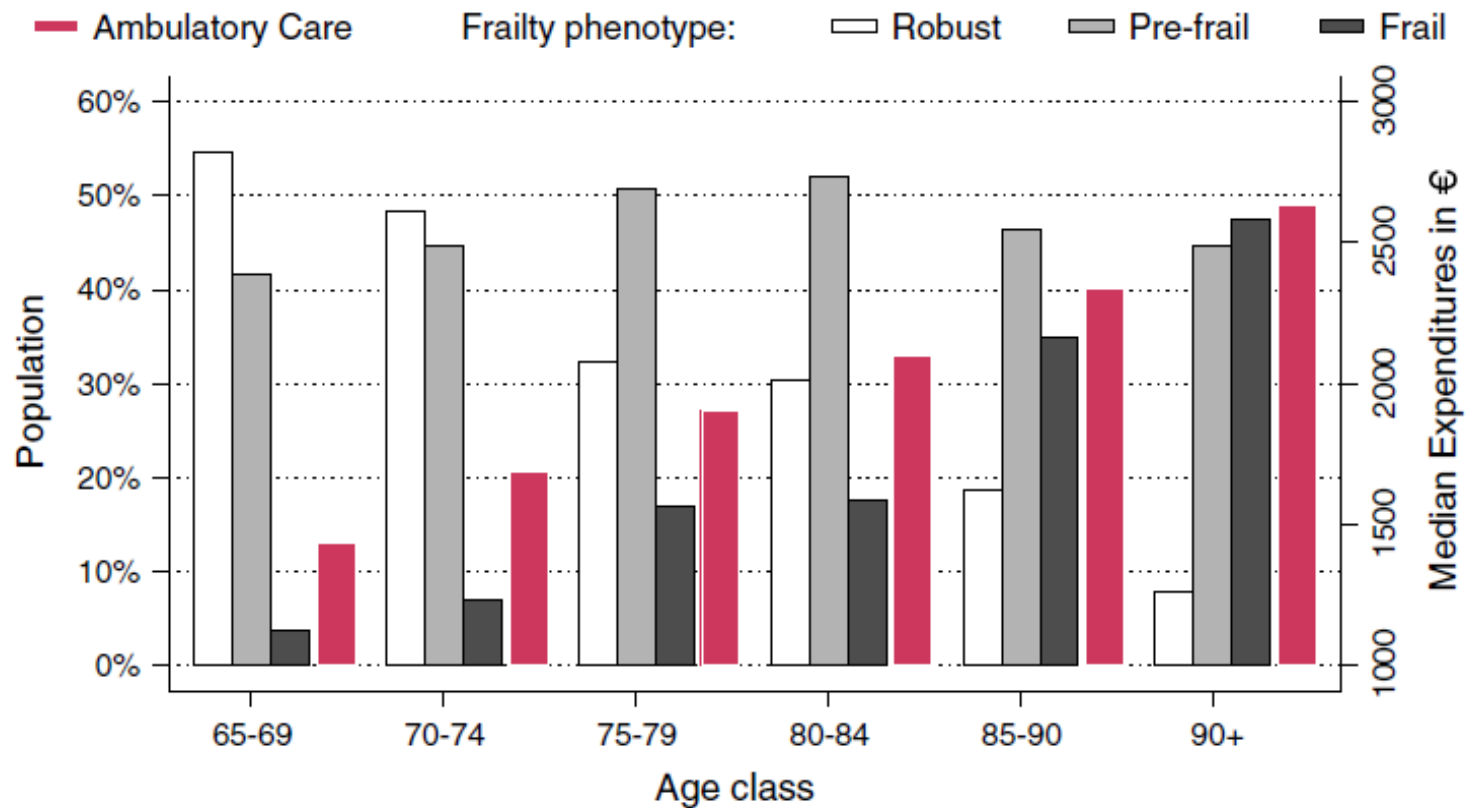
Improving care at the
end-of-life
has been identified as a
global public health priority

Older persons & Burden of Disease

- Cognitive impairment
- Frailty
- Comorbidities
 - Hypertension, DM, Musculoskeletal disorders, COPD
- Poor quality of life
 - Loneliness, declining functional ability
- Hospitalisation

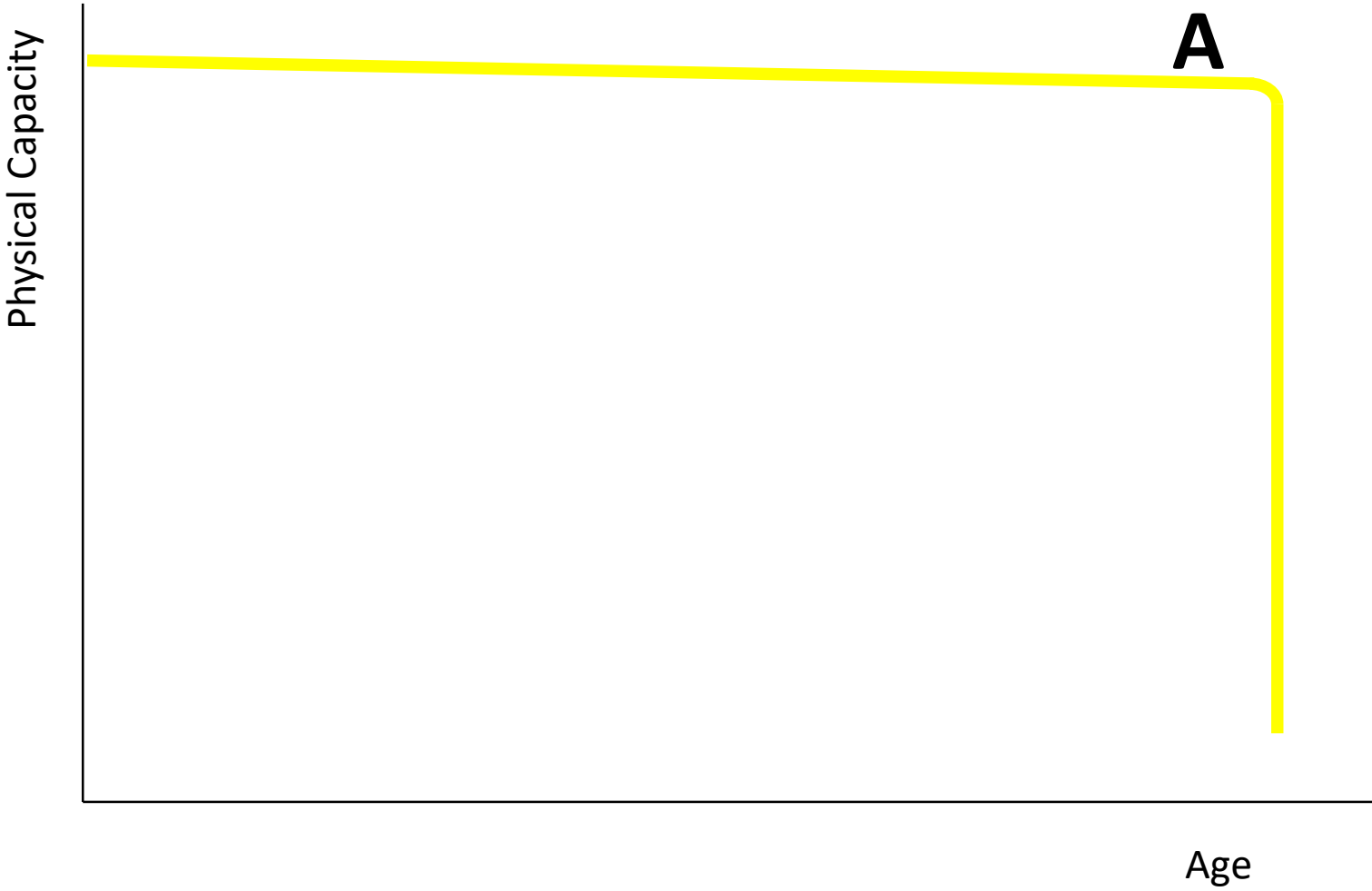
Frailty

Health Care Expenditures & Prevalence of Frailty by Age Class – France 2012

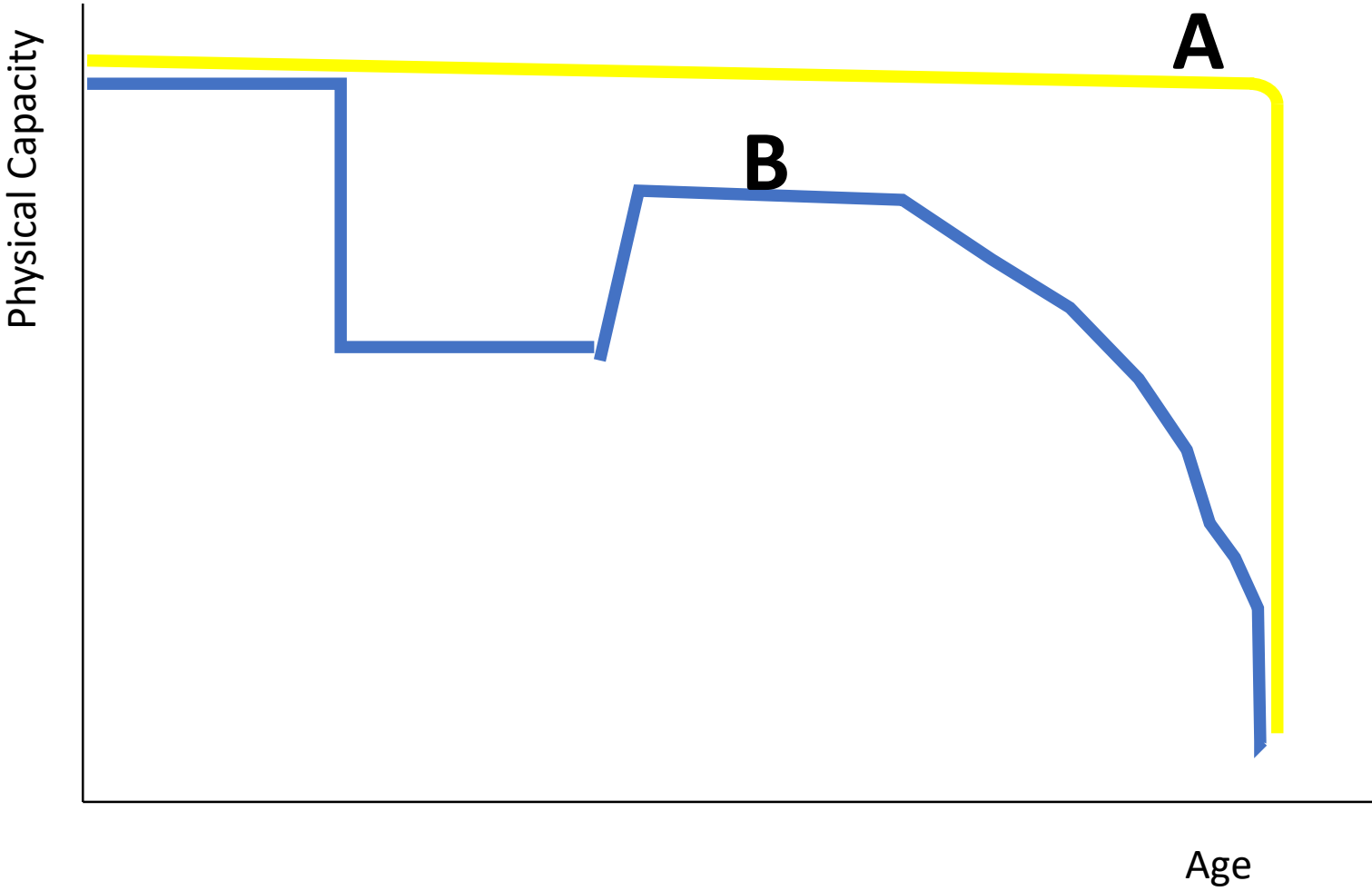


Sirven N, Rapp T. The cost of frailty in France. Eur J Health Econ. 2017 Mar;18(2):243–53.

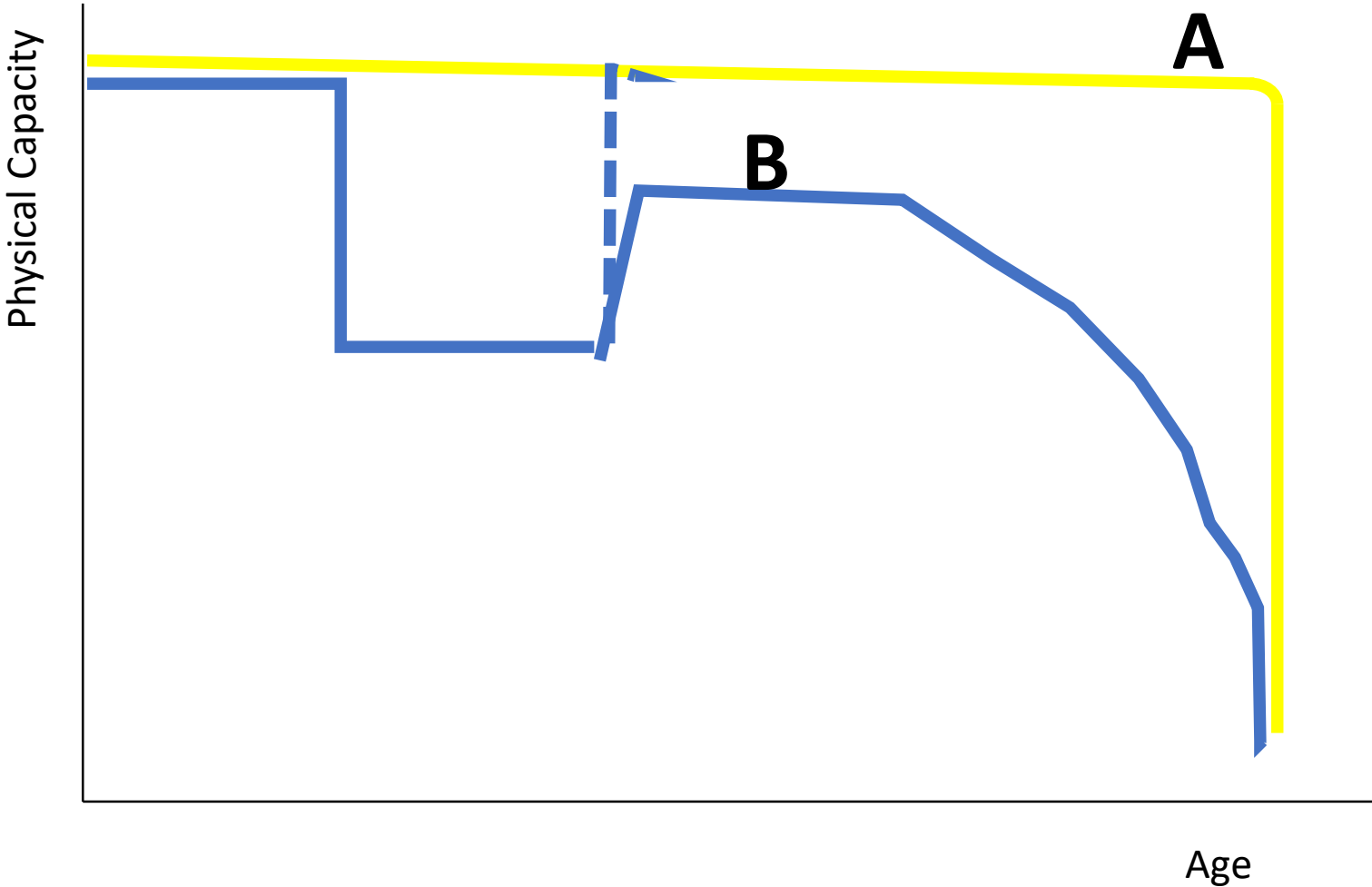
Hypothetical Trajectories of Physical Capacity



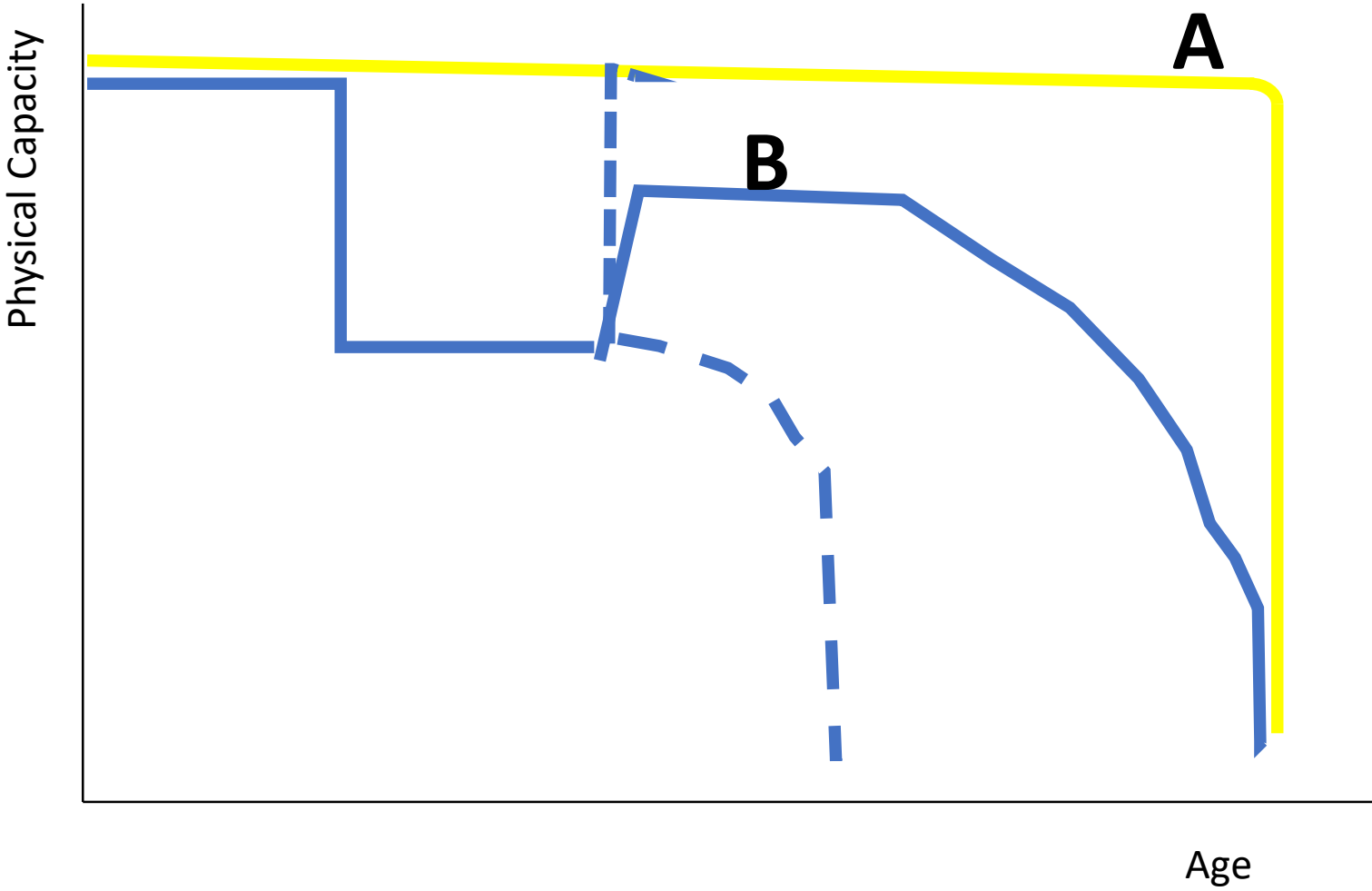
Hypothetical Trajectories of Physical Capacity



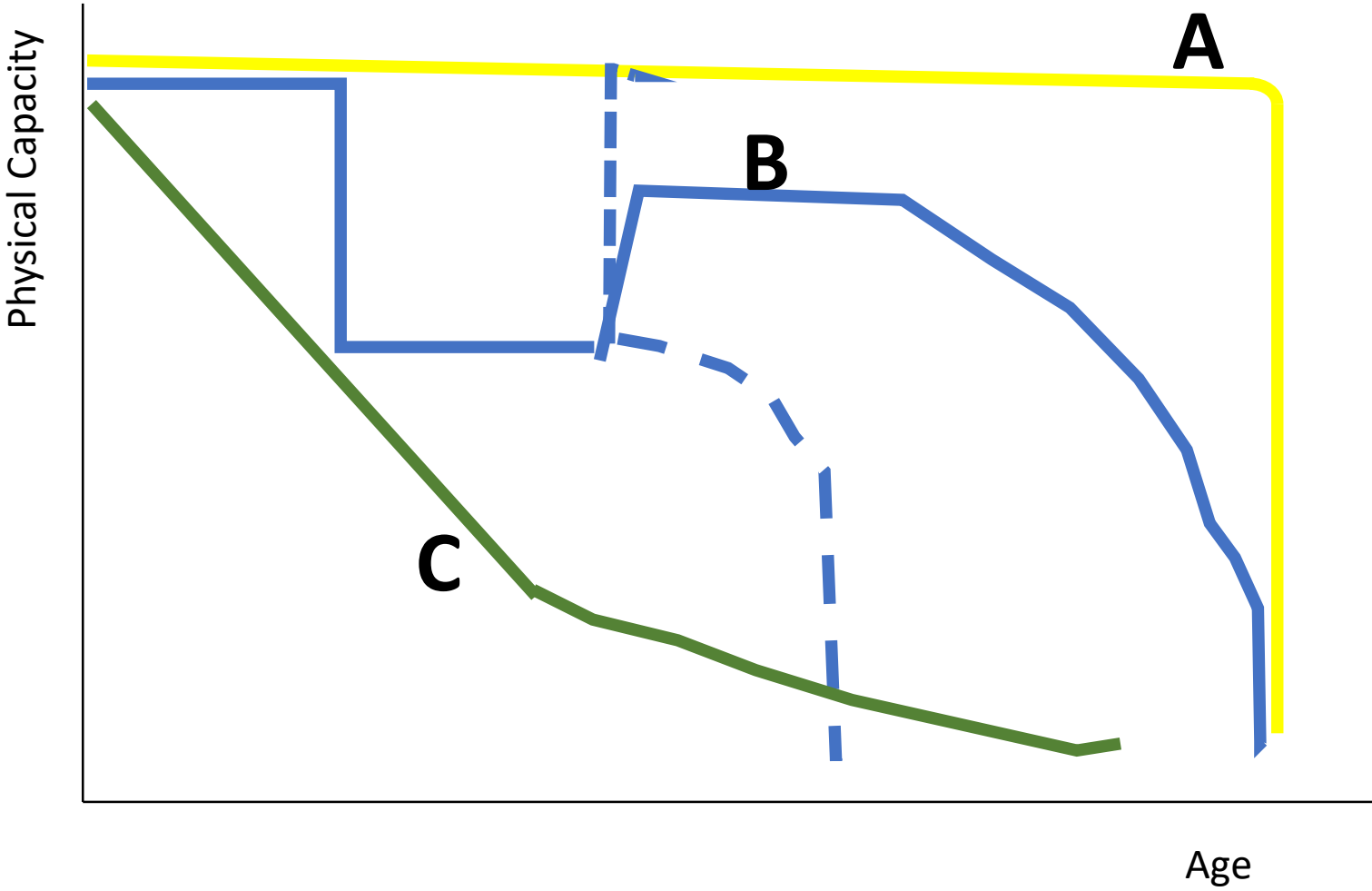
Hypothetical Trajectories of Physical Capacity



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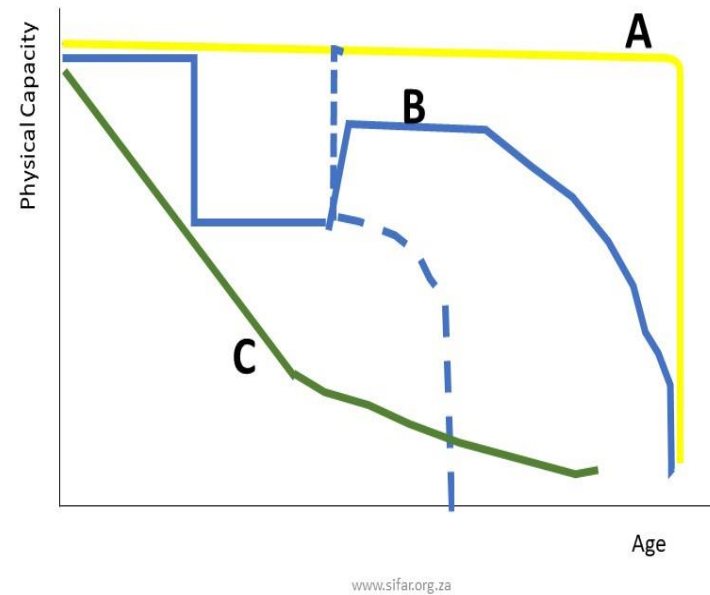
Hypothetical Trajectories of Physical Capacity



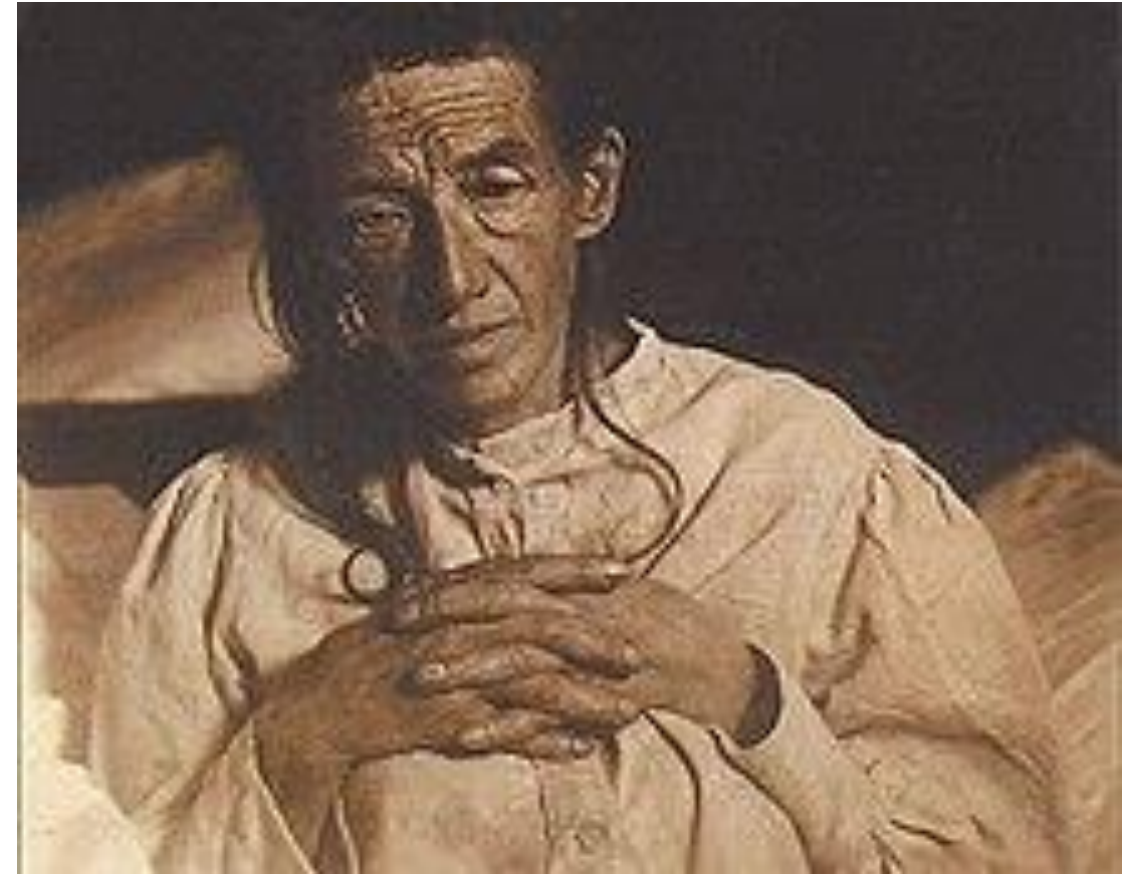
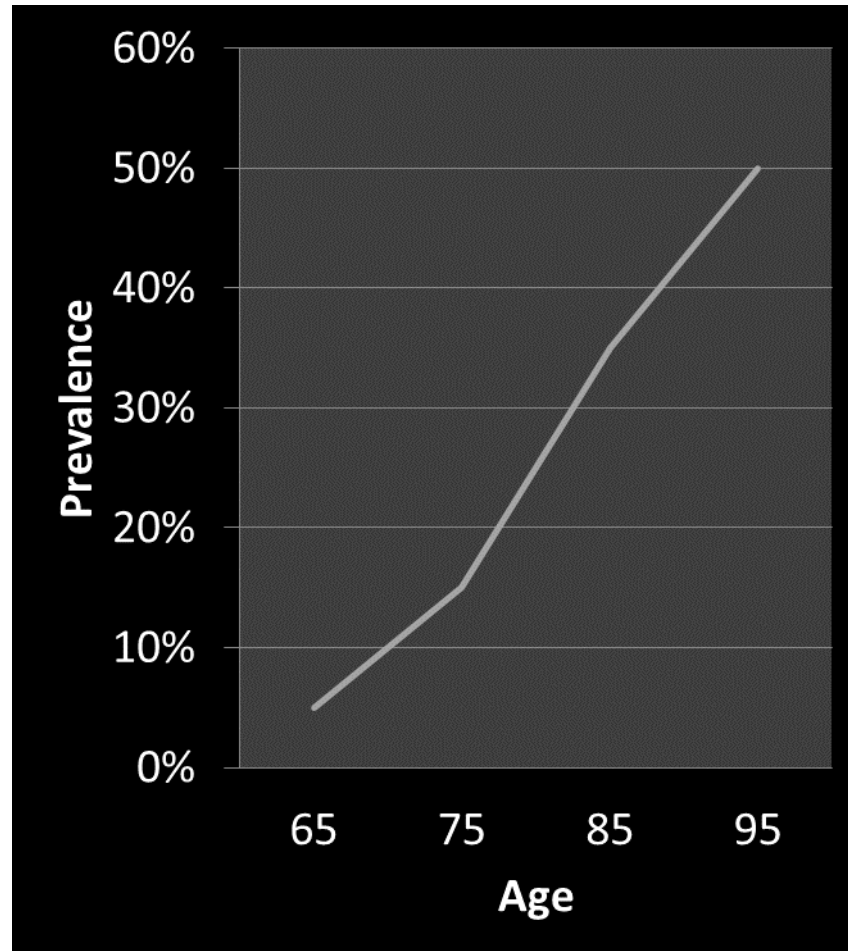
What pathway do you wish for yourself

www.menti.com

Code:762062



Alzheimer's Disease



Dementia

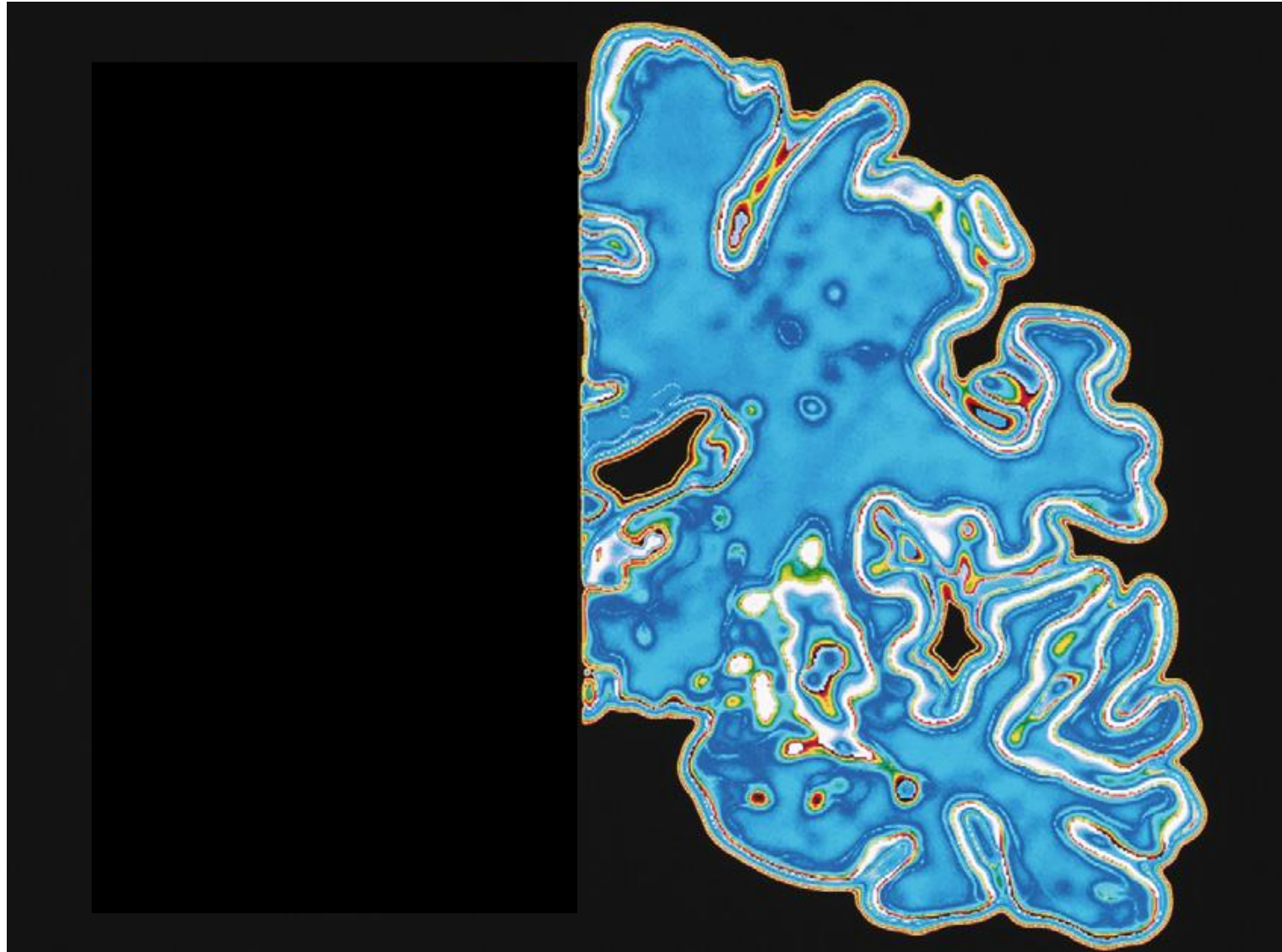


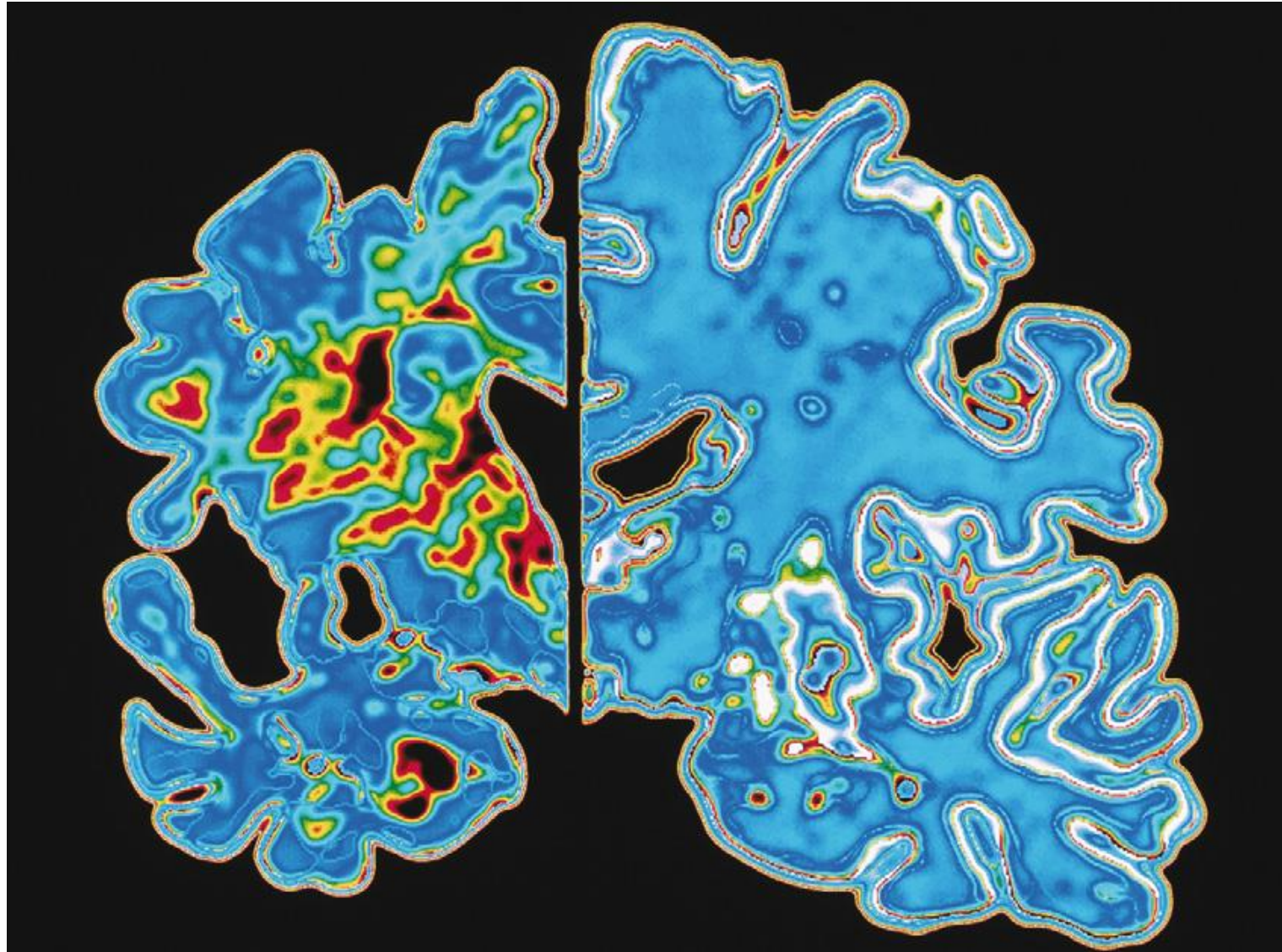
- ◎ Syndrome of acquired persistent decline in several domains of intellectual ability
- ◎ Combinations of impairment occur in
 - Memory
 - Disturbed language
 - Visuospatial abnormality
 - Loss of cognitive ability
 - Calculation, abstraction, problem solving
 - Recognition (agnosia)
 - Motor planning & sequencing (executive functioning)

Causes of dementia

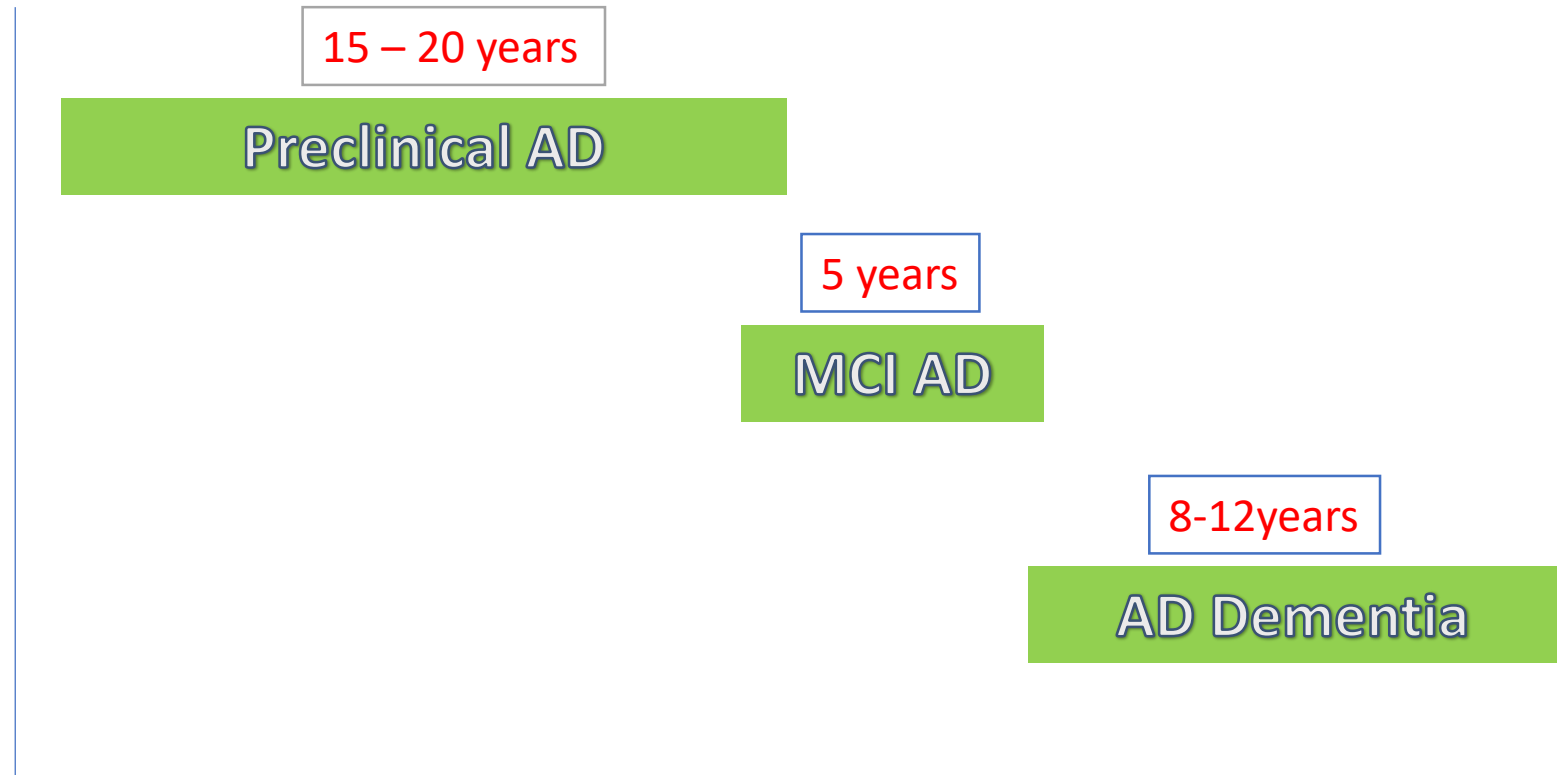


- Alzheimer's Disease
 - most common – 60 - 80%
- Vascular dementia – vascular risk factors
- Diffuse Lewy Body Disease
- HIV
- Age related – 20 - 40% over 85years old
- Numerous Others





Continuum of Alzheimer's Disease



Dementia Causes Significant Functional Impairment



IADL

- Ability to work
- Drive
- Finances
- Shopping
- Transport
- Housework
- Medications

BADL

- Bathing
- Dressing
- Toileting
- Grooming
- Walking
- Transferring
- Feeding

Dementia Eventually Causes People to Lose the Ability to Make Decisions About Their Lives

Testamentary Capacity & Competency

South African Law

- South Africa does not recognise an enduring power of attorney
 - Power of attorney becomes null and void in setting of dementia
- Mental Health Care Act 17 of 2002
 - Chapter VIII
 - “Care and administration of property of Mentally Ill Person or Person with Severe or Profound Intellectual Disability”
 - Appointment of an Administrator
- Rule 57 of Supreme Court Rule
 - Sets out the procedure to be followed
 - The court is requested to address three aspects in its enquiry
 - declare the patient of unsound mind and incapable of managing his/her affairs;
 - to appoint a curator ad litem;
 - to appoint a curator bonis or curator personae or both;

On a daily basis people have to make decisions...

- Managing their affairs
 - Financial decisions
 - Property
 - Estate
- Their daily lives
 - How to live their lives
 - Where to live their lives
- Health
 - Whether to seek healthcare
 - When to seek healthcare
 - Whether to accept the advice of healthcare professional

Ability to make daily decisions is predicated upon...



- Autonomy
- Beneficence
- Informed Consent
- Confidentiality

Incapacity

- Function based
 - Is the person able to make the decision at a particular time?
- People have fluctuant and temporary incapacity
- Cognitive ability – requires clinical assessment
- Not an inability to communicate
- Illiteracy does not equate to incapacity
- Need to safeguard against the interference in lives of eccentric
- Cultural environment
- Past & present wishes of person if known need to be considered

Advanced Care Planning

Process of communication between

individuals,

families

and

healthcare professionals

Advanced Care Planning

Purpose

to understand, discuss and plan

future healthcare decisions

in the event that an individual loses capacity

Advanced Care Planning

Written Advance Care Directive (ACD)

Reflects individual's preferences for future healthcare

Advanced Care Planning - Why

- Improves the quality of end of life care
- Improves patient and relative satisfaction
- Respects patient autonomy
- Less in-hospital death and increased use of hospice
- It can occur as part of routine patient care
- Can be delivered in a wide variety of settings.

What is covered in an ACP

- Proxy decision maker
- What type of treatments one wants at end of life
 - Resuscitation
 - Ventilation
 - Tube feeding
 - Intravenous therapies
 - Oral antibiotics

Autonomy and the Demented Self

RONALD DWORKIN

Oxford and New York Universities

CONSIDER THE RIGHTS, NOT OF SOMEONE WHO WAS born and always has been demented, but of someone who was competent in the past. We may think of that person, as the putative holder of rights, in two different ways: as a demented person, in which case we emphasize his present situation and capacities, or as a person who has become demented, in which case we emphasize that his dementia has occurred in the course of a larger life whose whole length must be considered in any decision about what rights he has. We shall have to face a series of problems that seem to contrast, in different ways, the interests of the person conceived in one of these two ways with his interests conceived in the other.

Does a competent person's right to autonomy include, for example, the power to dictate that life-prolonging treatment be denied him later, even if he, when demented, pleads for it? Should what is done for a demented person be in his contemporary best interests, that is, such as to make the rest of his life as pleasant or comfortable as possible? Or in the best interests of the person who has become demented, that is, such as to make his life judged as a whole a better life? (Suppose a demented patient wants care and treatment that would make him a serious burden to other members of his family, and we think that people lead better lives when they are not a serious burden to others. Is it in his best interests, overall, to allow him to become

Dworkin – Precedent Autonomy

- Respect autonomy in terminal care for persons with dementia
- Precedent autonomy
 - To be considered the genuine expression of the person's autonomous self
 - This meant that the person with dementia no longer had a right of respect for their present autonomy.

Dworkin & Autonomy

Evidentiary View of Autonomy

- ‘...as a general matter each person **knows what is in his best interests** better than anyone else’

Dworkin & Autonomy

Evidentiary View of Autonomy

- ‘...as a general matter each person knows what is in his best interests better than anyone else’

Integrity View of Autonomy

- ‘the value of autonomy lies in the scheme of responsibility it creates: **autonomy makes each of us responsible for shaping his own life according to some coherent and distinctive sense of character, conviction, and interest**’.

1) Dworkin R. Autonomy and the demented self. Milbank Q. 1986;64(Suppl. 2):4–16

2) Gillett G. Advance decisions in dementia: when the past conflicts with the present. J Med Ethics. 2018 Jul 9;

Dworkin & Autonomy

- capacity for autonomy should depend on a patient's ability 'to evaluate decisions in the structured context of an overall life organised around a coherent conception of character'
- patients with advanced dementia often lack the cognitive capabilities necessary to evaluate decisions in such a way

THEREFORE

- Patients with advanced dementia lack a contemporary right to autonomy

Case 1 - Maud

- 67 yrs old, lifelong vegan, animal rights activist, single, lives alone
- Diagnosed with Alzheimer's disease
- Admitted to Nursing home with early dementia 1 year later
- Insists on vegan diet and signs a declaration that all her meals must be vegan.
- 3 years after admission, now has advanced dementia
- She starts demanding the same food as other residents including meat
- Do you allow her to eat meat?
- www.menti.com Code: 96790

Right to Die

- Talking about death is taboo in many societies
- Most people wish to die at home
- But for reasons beyond their control they don't
 - Advanced dementia
 - Acute illness
 - Lack of support from family
 - Fear of being a burden to family
 - Fear of loss of dignity in front of family
 - Fear of being remembered

Countries allowing Voluntary Euthanasia / Physician Assisted Dying

- Belgium
- Netherlands
- Luxembourg
- Switzerland
- Colombia
- Canada
- Some states of the USA
 - Oregon, Washington, California, Colorado, Washington DC, Vermont

Physician Assisted Dying...

Physician Assisted Suicide

- Suicide by a patient
- Facilitated by means of
 - a prescription or
 - advice provided as to a lethal dose of medication
 - by a physician aware of the patient's intent

Voluntary euthanasia

- Choice of patient
- Deliberate intervention undertaken with the express intention of ending a life, to relieve intractable suffering

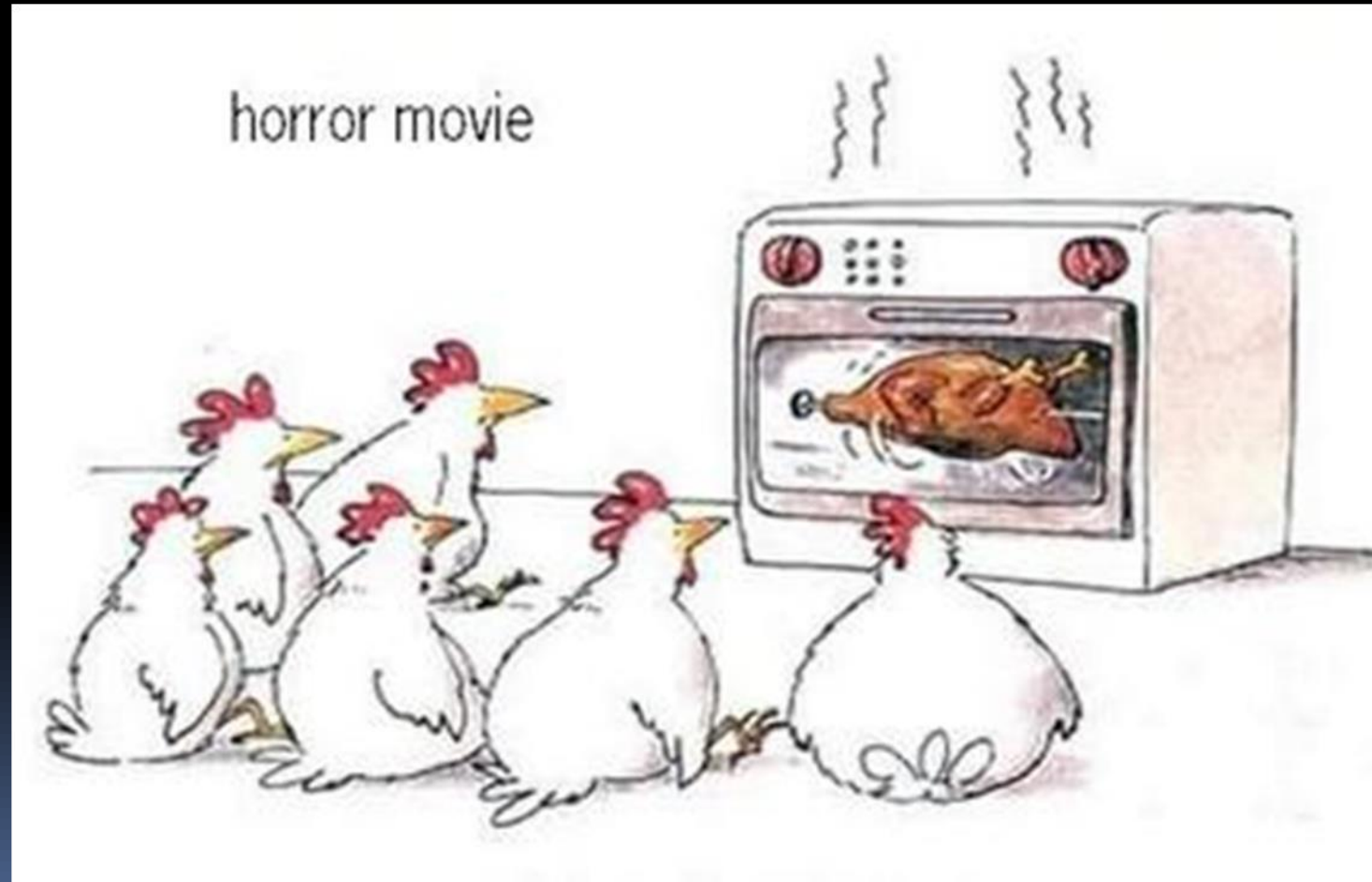
Case 2 - Fred

- 72 yrs old, married, 3 grown up children
- Retired Accountant
- Fit, healthy
- Independent in all activities of daily
- Recent onset Alzheimer's disease
 - Difficulty with word finding
 - Unable to manage his own finances
 - Unable to drive
- “Life is going to become unbearable & I am going to drain my families resources”
 - “Can you help me die?”
- www.menti.com Code: 860088

Conclusion

- Do we just pay lip service to Autonomy, Beneficence & Non Maleficence?
- Do we advocate for change to the law?
- Do we break the law?
- When we face people living with intractable suffering, do we have feelings of our own and think – “I hope this isn’t how I end my life”
- If so, what do we do to relieve

Successful Alzheimer's Disease Treatment Today



Do not go gentle into that good night,
Old age should burn and rave at close of day;
Rage, rage against the dying of the light.



Though wise men at their end know dark is right,
Because their words had forked no lightning they
Do not go gentle into that good night.

Good men, the last wave by, crying how bright
Their frail deeds might have danced in a green bay,
Rage, rage against the dying of the light.

Wild men who caught and sang the sun in flight,
And learn, too late, they grieved it on its way,
Do not go gentle into that good night.

Grave men, near death, who see with blinding sight
Blind eyes could blaze like meteors and be gay,
Rage, rage against the dying of the light.

And you, my father, there on the sad height,
Curse, bless, me now with your fierce tears, I pray.
Do not go gentle into that good night.
Rage, rage against the dying of the light.