Advance Care Planning –
a necessary response to the successes of modern medicine

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We are all going to die!

How can we help to prepare for and deal with that reality

Presentation

- The evolving context of healthcare
- How our culture around death is changing
- Communication
- ACP process and documents

Context – how dying has changed

Human History

- For the first 10-20,000 generations (~200-400,000 yrs.) of human existence, median human life-expectancy was about forty years
- Before about 200 years ago
  - You got sick and you got better, or you died
- Not much that medical intervention could do about it

Over the 19th and 20th centuries

- Public health measures, and then health technology dramatically reduced early death progressively and,
- Infant/childhood mortality decreased from 30% to 1%
- Over the last 6 generations of my family median life-expectancy has doubled to 80 years

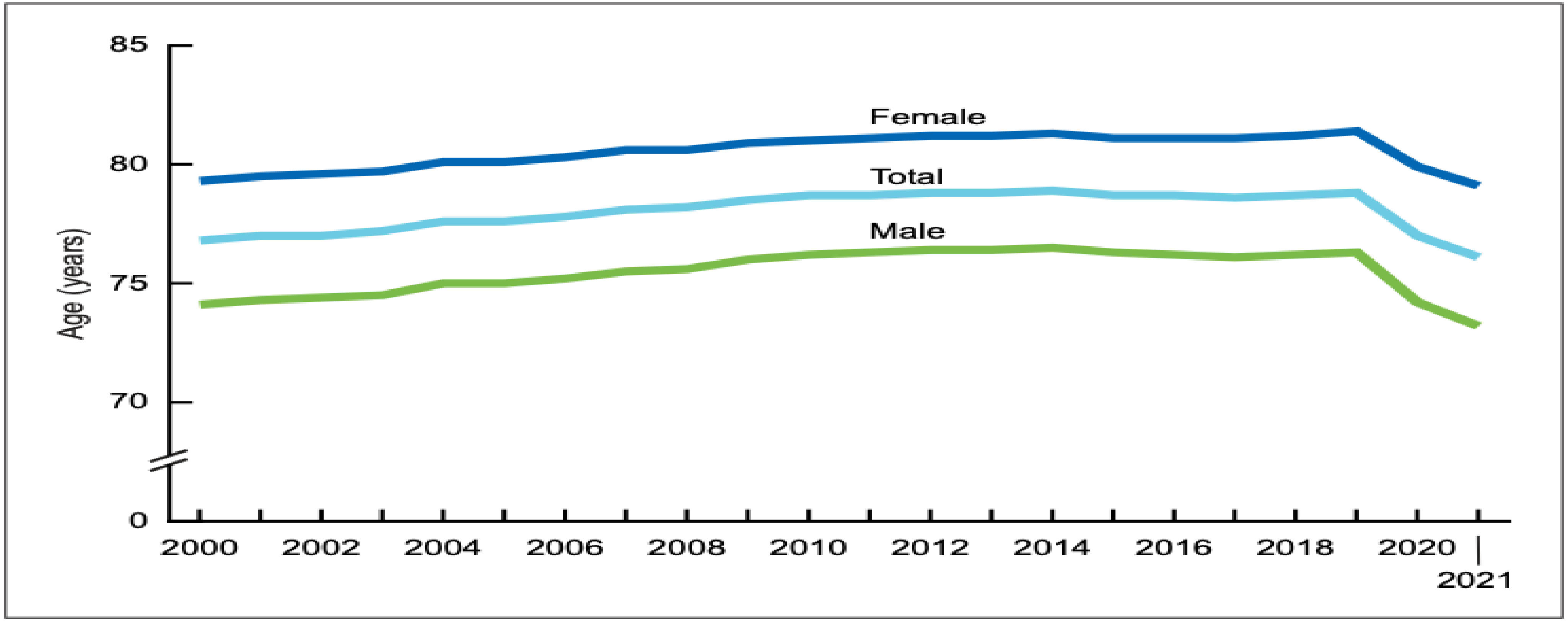
Can this continue?

We are not very good at stopping people from dying in old age

Our biology seems to limit our maximum life expectancy, at least for now

US Life expectancy at birth
CDC – https://www.cdc.gov/nchs/data/vsrr/vsrr023.pdf

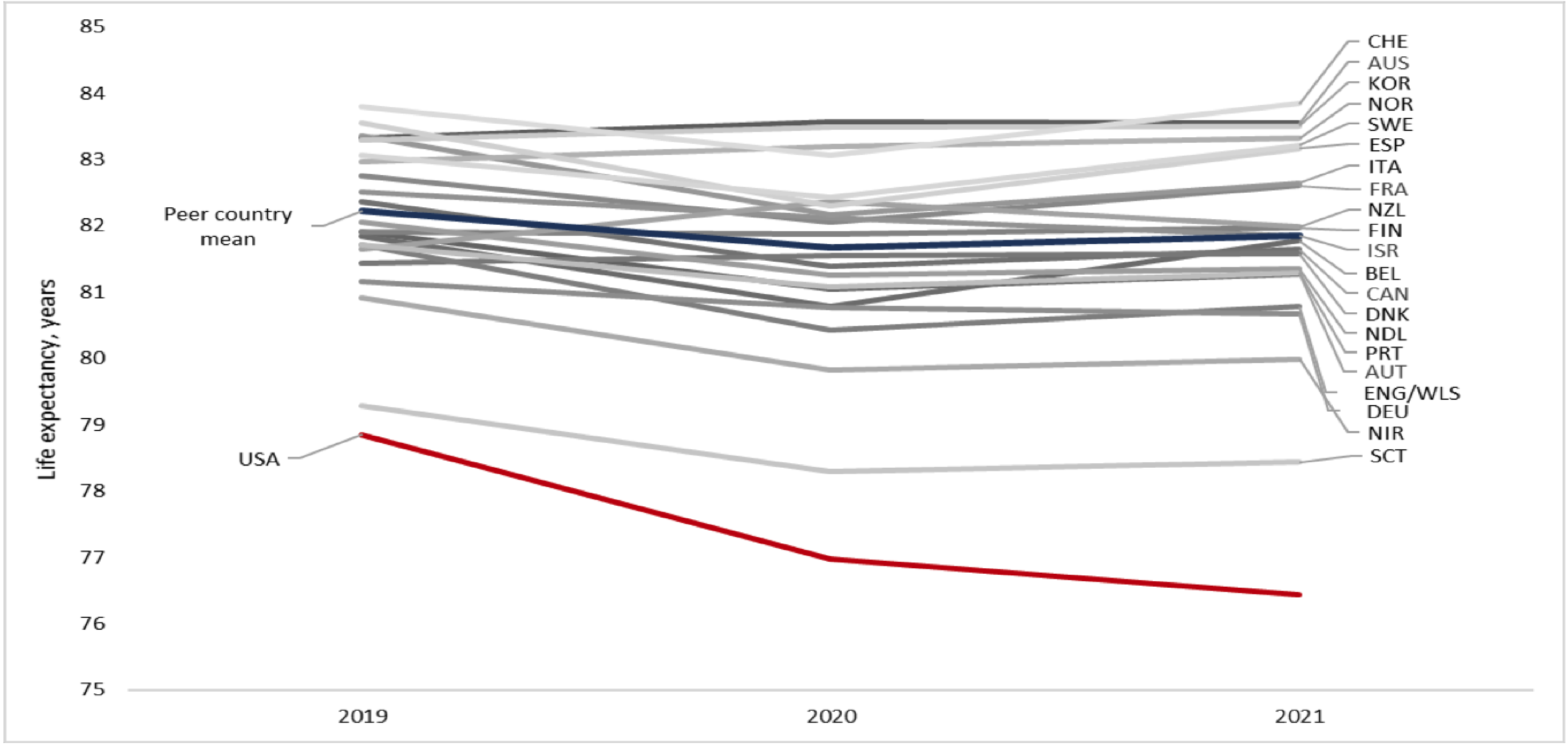
Figure 1. Life expectancy at birth, by sex: United States, 2000–2021



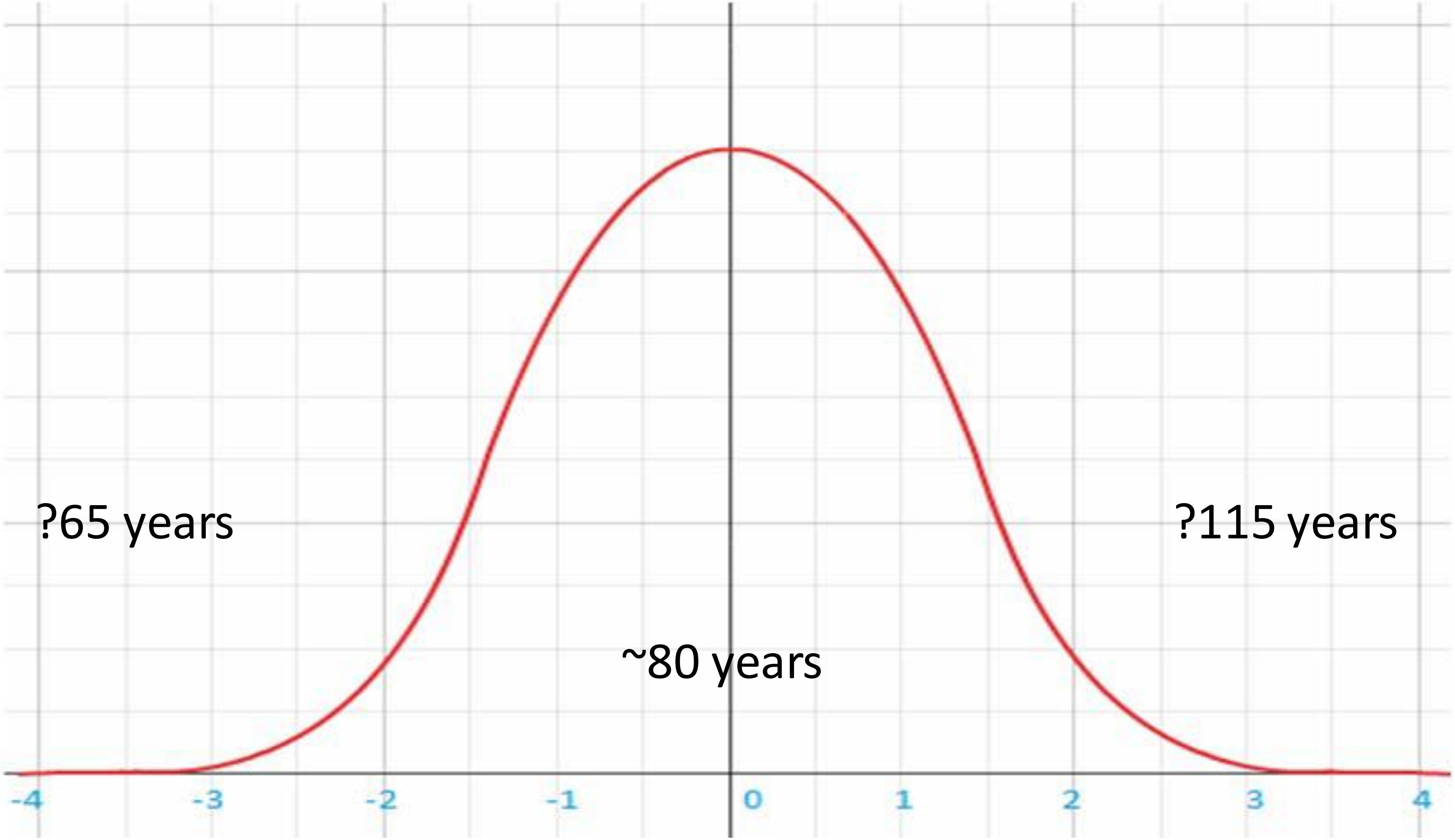
NOTES: Estimates are based on provisional data for 2021. Provisional data are subject to change as additional data are received.
Estimates for 2000–2020 are based on final data.
SOURCE: National Center for Health Statistics, National Vital Statistics System, Mortality.

Life expectancy in more industrialised countries

https://www.medrxiv.org/content/10.1101/2022.04.05.22273393v4.full.pdf



Distribution of maximum life expectancy – some people are old at 65, others not until their 90's



Expectations for the 21^{st} century

- ~90% of deaths >65 years of age
- The interventions that dramatically reduced death in childhood do not work for the elderly
- From now on
  - Persist with those measures that prolong life with quality
  - Death is becoming explicitly re-recognised as a normal part of life, mostly in old age
  - Living towards our individual maximum life expectancy (with quality)
- The challenge is to identify that point

People at the end of their life now are very different from even just 50 years ago

- Multiple illnesses
- General frailty
- Greater risk of poor outcomes from treatment
- Death while being treated (particularly in the US)

However:

- Shifting of goals from quantity to quality of life
- “Oldhood” – “Don’t treat 90 year-olds like 70 year-olds”

Culture

Evolution of medical culture and practice

1. We could wish that those we love did not die, but could do little about it
    - When people died, we grieved and (usually) moved on
2. When I trained in the 1970s no-one was prepared for death, neither patients nor doctors – we tried to resuscitate almost everyone
3. Now
    - We can delay death, but are now realising that we cannot escape either death or the distress of grief.
    - Recognition of increasing complexity of disease management, diminishing QoL, and extended burden of disease and of care provision

Changing sense of **locus of control**

Locus of control is the degree to which people believe that they, as opposed to external forces (beyond their influence), have control over the outcome of events in their lives.

- Right to exercise autonomy: to control/manage/chose our own destiny
    - Right to make choices about ones own life, including treatment or refusal of treatment for disease
    - More recently, right to VAD.

Evidence of cultural change

- In the community
  - The spoken words of an AI medical diagnostician computer in the movie Passengers
    - *"Various treatments are possible, none will meaningfully extend the patient's life."*

- Healthcare system
  - Creation and promotion of ACP and ACP documents

- In medical profession
  - "Why do you want to be a doctor?" ans. "To save lives."
  - What is the role of doctors in the 2020's?
  - Code of Conduct – ***Good Medical Practice***

Good Medical Practice: a code of conduct for doctors in Australia (AMC publication, 3rd ed. 2020)

Good Medical Practice

4.2 Doctor–patient partnership

… involves:

…. supporting patients to be well informed about their health and to use this information wisely when they are making decisions.

4.3.4 Discussing with patients their condition and the available management options, including their potential benefit and harm and material risks.

4.13 End-of-life care

… In caring for patients towards the end of their life, good medical practice involves:

4.13.3 Understanding the limits of medicine in prolonging life and recognising when efforts to prolong life may not benefit the patient.

4.13.4 Understanding that you do not have a duty to try to prolong life at all cost. However, you have a duty to know when not to initiate and when to cease attempts at prolonging life, while ensuring that your patients receive appropriate relief from distress.

4.13.5 Accepting that patients have the right to refuse medical treatment or to request the withdrawal of treatment already started.

“Our junior doctors working overnight are too busy treating our very sick patients to be able to do ACP on them.” – hospital consultant

How can you treat patients unless they (or their substitute decision maker) know what their options are and what they mean (likely benefits and burdens), and you know what they would prefer you to do?

The consultant should have done it in the daytime!

Communication

Practical challenges

- Many patients (and their families and their doctors) have focused on the treatment of their disease, and not on what is most important to them
- Many have difficulty understanding the balance of risk, uncertainty, burden and benefit, and the implications for the way that they will be able to live their lives in the future
    - Think brain tumours or extreme prematurity
- It is hard for any of us not to bring our values and emotions to the table

Building connection with patients

- Founded on trust best built over time – e.g. GP's long-term relationship with a patient and their family
- Make acknowledgement of death part of the conversation
    - Every little bit counts, like regular savings and compound interest
- A skill and an art
- Whole person care – illness has a context

Who is this person in front of us? / Where were they born and where did they grow up? / Family? / Work / Leisure? / Revealing something of self – being human?

The benefits of open communication

- The information we gather about our patients does not belong to us, it belongs to them. Our job is to help them understand the information, and its implications
- At some level patients generally already know what is going on – patients are much more aware than we think
- Patients and families are often relieved that at last someone is talking openly with them
- Imagination generates more fear than information
- Knowledge is power, and helps the patient to regain some control

ACP process and documents

- ACP is the means to patient control of decision-making
- ACP across the lifespan
- Whenever possible, ACP should be done early (when well, or with diagnosis), before it is needed – ***"Thinking, Fast and Slow"*** by Daniel Kahneman
- Speed-dating and ACP in an emergency
- Be familiar with the use of all relevant documents in your state or territory

Engaging in ACP

- Starting the conversation
- ACP is a dialogue between hope and reality – agreeing on the possible
- addressing the uncertainties
- accommodating the unexpected

Process of ACP

- Promotion
- Information and contemplation
- Discussion
- Documentation
- Dissemination
- Implementation

Promotion

- Part of protocols
  - opportunistic
  - routine checks (e.g. license validation, health checks, Will creation)
  - with referral for a new or recurrent disease
  - admission to treatment programs
  - admission to hospital or RACF
  - paramedics on arrival in the home

Information and contemplation

- Our patient needs to understand their issues – stage in life, health and knowns and unknowns
- Communicating information that is relevant and in a form that can be understood by the patient – language and jargon
- Consideration of values, goals and preferences
- Homework as contemplation and discussion with family
- Resources – ACP Australia

Discussion – urgent and non-urgent

- Urgent requires direct approach
- Don’t suggest options that you think are not available or appropriate
- Patient can only choose from the options that are available
    - e.g. ?CPR if not a candidate for ICU, which is for people who can get better – if there was something to fix we would do it now
- If non-urgent and not progressing then offer further contemplation
- 2nd opinion when appropriate
- Fine art of being effective and efficient while not seeming to be rushed
- Avoid definitive predictions (e.g. life expectancy) or guarantees of outcomes (e.g. we will fix your pain) – guarantees are of care

Documentation

- ACP should be documented, usually in writing, as guidance for others – documents vary by state and territory
- Documentation depends on the circumstances
  - Capacity – if not the patient, then who?
  - Personal statement can guide decision maker
  - (Will), Appointment of Enduring Guardian, substitute decision maker
  - Advance Care Directive – legally binding, even if substitute decision makers disagree with the instruction
  - Resuscitation order – medical instruction about the course that has been decided – for use by clinicians

Online Resources

- NSW Health

https://www.health.nsw.gov.au/patients/acp/pages/default.aspx

- Advance Care Planning Australia

https://www.advancecareplanning.org.au/create-your-plan

- QUT End of Life Law in Australia

https://end-of-life.qut.edu.au/treatment-decisions/adults/state-and-territory-laws/new-south-wales

Dissemination – patient/family role

- Who needs to know?
- Where should documents go? – where they might be needed.
    - Family
    - GP
    - Hospital
    - My Health Record
    - RACF
    - In the home
    - On holiday – mostly respected in other Australian jurisdictions

Implementation – clinician, patient and family roles

- Request status of ACP on engagement with health care services
    - conversations – do you understand what is going on?
    - decision makers – who?
    - documents– where?
- Promote and communicate

Summary

- We cannot be blind to the reality that every life has a beginning, a middle and an end

- The success of modern medical technology in prolonging life has brought with it the risk that in our enthusiasm for our work, we simply prolong dying.

- Our role is to help patients to make wise, realistic choices from the options that are open to them.

“Two weeks in ICU can save you an hour of conversation”

Vex not his ghost: O, let him pass!
He hates him much that would upon the rack of
this tough world stretch him out longer.

Kent (discouraging Edgar from trying to raise King Lear who had just died)

– William Shakespeare
King Lear, Act 5 Scene 3
written 1605 or 1606