# Marie Curie

**Care and support through terminal illness**

# Advance care planning

## More story than statement

# M

- Advanced DLBL of non-GCC type of bowel stage 4A
- Attended with wife, son, daughter
- 'Main issues' pain and fatigue
- Family holiday planned
- Discussed cannabis oil and Grenada holiday

# Where are we in his story?

- Thrillers – the formula
  - Ex special forces – useful skill set
  - Dysfunctional relationship with family
  - Stumbles upon grave injustice
  - Gets into lost of fights
  - Buddies up with someone
  - Is saved by buddy, saves his own family
  - Kills/imprisons /incapacitates baddies
  - Survives for the sequel

# Contextualising ACP
# - some components

- Will
- Life insurance
- LPA
- Advance direction
- DNACPR
- Advance statements – Thinking Ahead / PEACE / ReSPECT
- Organ donation
- Specific scenario – Living Will
- Multiple conversations over many years

# Definitions

..is a series of facilitated conversations in which the person, or those who know them well, actively participates to explore the management of their health and well-being within the context of their whole life and family situation

The process recognises the persons skills and strengths as well as their experiences and the things that matter to them most. It addresses the things that aren't working in the person's life and identifies outcomes and actions to resolve these.

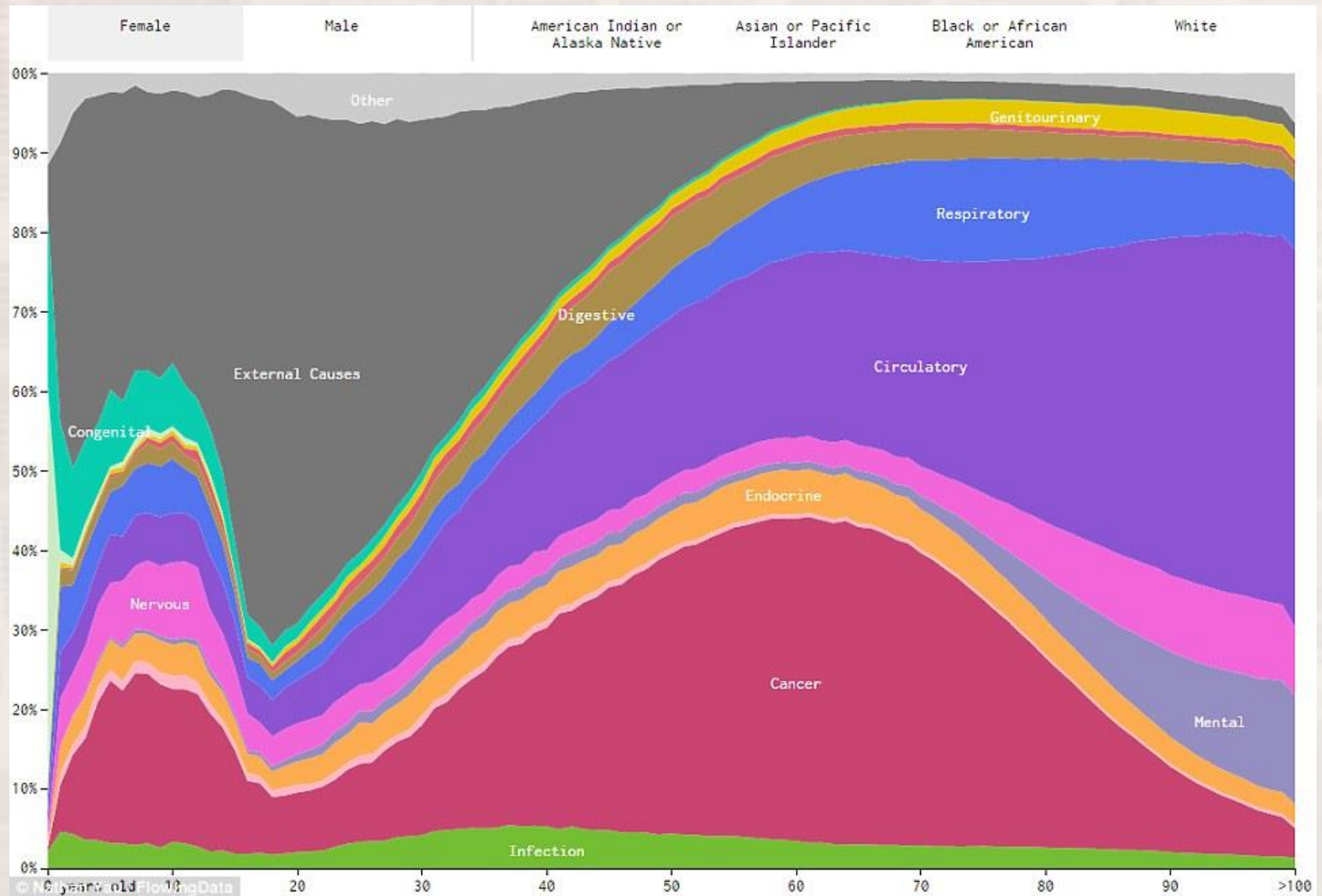….so they have one joined up plan that covers their health and wellbeing needs

# Definitions

...is the conversation between people their families and carers and those looking after them about their future wishes and priorities for care.

... is a key means of improving care or people nearing the end of life and of enabling better planning ad provision of care, to help them live well and die in the place and the manner of their choosing.  It enables people to discuss and record their future health and care wishes and also appoint someone as an advocate or surrogate, thus making the likelihood of these wishes being known and respected at the end of life.

# Priorities vs Time of life

# Growing up – early chapters
## The world is my playground

- Who cares?

- I'm immortal

- Off to Uni to try out new things....


'If I die on the table bury me in my chain mail'


Worried about – phone battery life

# Next chapters –
# Yuppie/Dinky/Hipster/Millennial
## The world is my oyster

- Travel insurance
- Adopt a vegan diet
- Philosophise about the meaning of life

- Will? – why bother – all I have are debts

- Worried about – plane falling out of sky

# Stories collide - Sitcom
## The world is an M&S sandwich

- Mortgage – company insists on life insurance
- Will – the protect the kids
- Concerned about sudden unexpected death
  - Will
  - Organ donor card


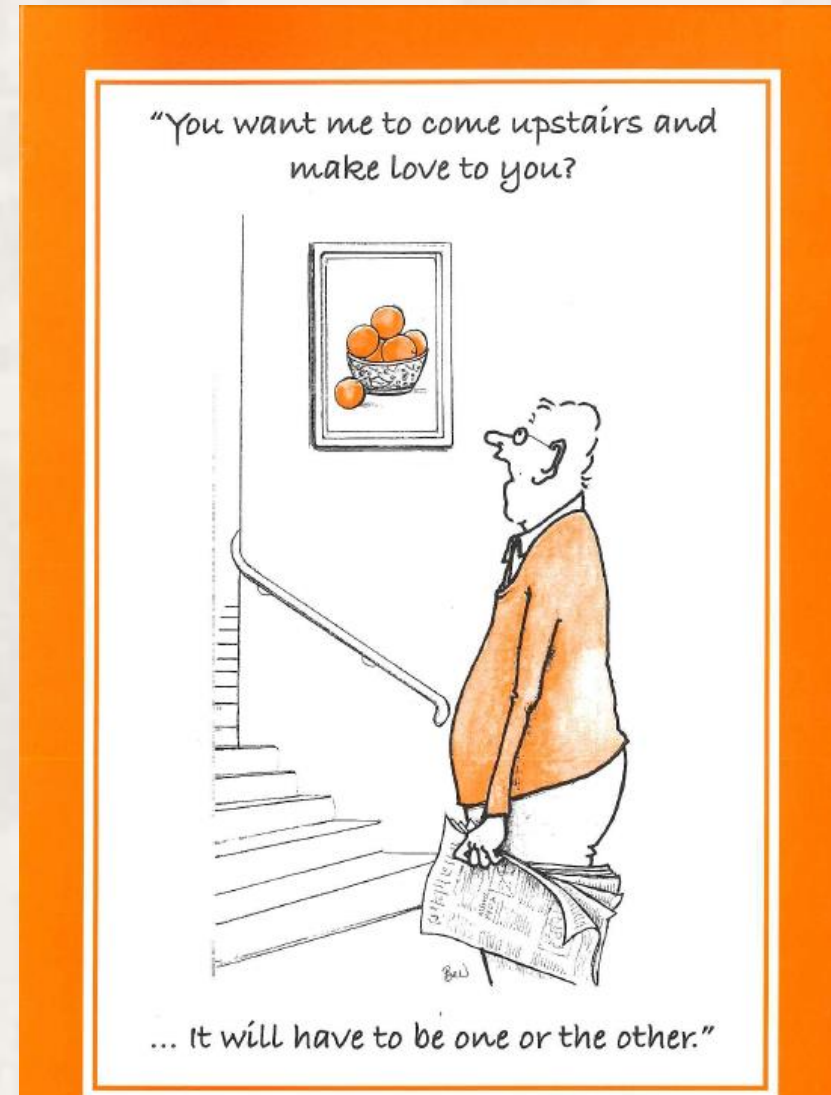- Worried about – family financial security

# Midlife chapters
## The world is my diet hummus

- Have peaked – starting to consider the future
- One or two friends/relatives have died
- Upped the life insurance – the gym insisted on life insurance
- Will has been re-written - kids no longer need guardians and don't want the ex-husband to inherit anything.

- Worried about – not getting to draw pension

# Declining chapters
## The world is my ready meal

- Things are looking more serious
- Considering funeral plans as advertised on daytime telly
- Established an LPA
- Completed a 'living will' ACP
- Started donating to Marie Curie

- Worried about – most things



"You want me to come upstairs and make love to you?

… It will have to be one or the other."

# Aged chapters
*The world is pureed*

- ACP

- DNAR

- On GSF register

- Finalise funeral arrangements


- Worried about – that no-bodies asking me anymore?

# Dead – the punctuation mark
## Not hungry

- End of life care plan

# Legacy -The epilogue chapters
## The world is my memories

- Bereavement and grief of those who miss me

- The things I am remembered for - legacy

- The memories I have created

# Peoples stories are never that simple

- Respect – these are their stories
  - Fighters, lovers, fantasists
- We are bit players
  - We don't appear on every page
  - However we can make an impact
  - We can ensure our stories overlap in a positive way
  - We have the privilege of having read widely

# Ideal advance care planning

- Always respects the persons wishes

- Is based on realistic expectations

- Takes into account impact on others

- Addresses changing capacity

- Addresses common decisions

- Is continually updated and kept current

- Is always accessible and accessed when required

- Directly influences all care

# Opportunities for failure

- Never a good opportunity to talk
- Caring professionals avoid the discussions
- Discussions occur but are never recorded
- Family impacted but not part of discussions
- Wishes are vague and therefore ignored
- When a crisis occurs the ACP can't be found
- When a crisis occurs the ACP is ignored by person/family/professional
- etc

# Process, process, process

- GSF – a simple five step process
- Nothing is 100% in health and social care
  - 50% is mean
  - Lets assume we do it right 85% on the time
  - After five steps…. 44%

# Culture, culture, culture

- Move from a culture of
  - Episodic
  - Task orientated
  - Safety anxious

- To a culture more
  - Relational
  - Goal orientated
  - Risk managing

# ACP

- An ongoing conversation which threads throughout the pages of our story
- Which adapts as our life changes
- Which reflects our personalities and our dreams
- Which is there when we need it the most

# Tips and challenges

➢ No difficult conversations – just conversations

➢ Normalise the conversation - few euphemisms

➢ As normal as asking about allergies

    ➢ Have you recorded your wishes…

    ➢ None of life's choices are truly binary

    ➢ It is OK to choose not to choose

➢ It is their story not ours – we don't need to appear on every page, but when we do, we should make our words count

➢ An ACP document is not a page in the story – it is the introduction of a theme which should be revisited throughout the final chapters of the book

➢ Anyone can facilitate if they are trained and supported

➢ M had a DVT

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# Thank you

Advance cake planning 2