

Talking about  
sex won't make  
you pregnant,  
and talking  
about death  
won't make you  
dead.

# **Need to acknowledge the team at ACP**

**In particular  
Peter Groom,  
Carla Arkless and the Level One and Two  
National ACP Training**



*Our job is improving  
the quality of life,  
not just delaying death.*

- Patch Adams

our voice | Advance  
tō tātou reo | Care  
Planning

**Why is ACP  
important ?  
We all  
die....and we  
only get to  
do it once !!!**



"My PARENTS DIED. THEIR PARENTS DIED. THEIR PARENTS DIED...  
IT RUNS IN THE FAMILY."

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Planning

# Why is ACP important ?

- **60% of people say that making sure their family is not burdened by tough decisions is “extremely important” to them**

Source: Survey of Californians by the California HealthCare Foundation (2012)



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# What our people say

- *"If I was stuck on life support, I'd want my family to turn me off and get on with their lives."*
- *"I'm less scared about my future healthcare now that we've talked about it"*
- *"I feel more relaxed knowing that I won't be leaving my family guessing."*
- *"It was good to talk about it with my wife as I didn't realise she had different ideas to me."*
- *"I feel more in control now that I get to decide what happens to me in the future."*
- *"Funny how it lightens the load"*

# And

- *“I am so relieved I know what Dad wants .... It felt like such a huge responsibility and I would have got it wrong ... I had no idea !”*
- *"I'd already done my will on what I want after I die, so it made sense to specify what I want while I'm still alive."*
- *“It feels less scary knowing they will do what I want even though at the beginning ... they did not want to”*
- *“I simply did not realise what mattered to me ... Taking the space to reflect has made it so much easier”*



# Why is ACP important? Research

- Advance care Planning encourages conversations about what is important for a person (Hudson & O'Connor, 2007)
- Helps a person achieve a sense of control as their illness progresses and death approaches (Lyon, 2007).
- Can positively enhance a patient's hope in the face of progressive disease (Davison, 2006).
- Reduces fear and anxiety (Ditto et al., 2001).
- Increases understanding and comfort (Ditto et al., 2001).



# Why is ACP important? Research

- Facilitates end of life wishes to be known and followed (Detering, Hancock, Reade, & Silvester, 2010).
- Reduces stress, anxiety and depression for family members when a patient dies (Detering et al., 2010)
- Improves patient and family satisfaction with overall care (Detering et al., 2010).
- Reduces time spent in hospital in the last year of life (Abel, Pring, Rich, Malik, & Verne, 2013)

## What we know from overseas

**56% have not  
communicated their  
end-of-life wishes**

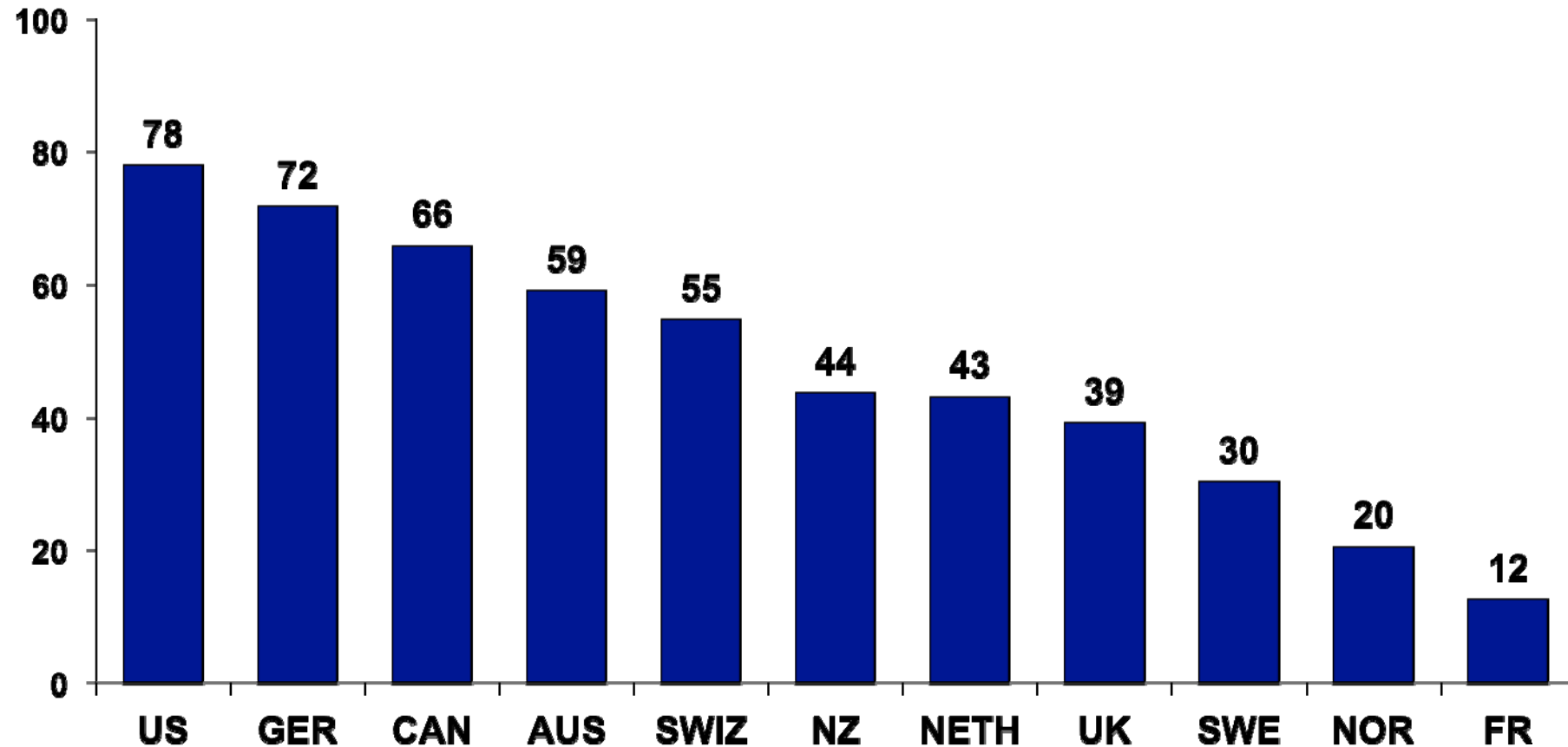
Source: Survey of Californians by the California HealthCare Foundation (2012)



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## Had a Discussion About Care Preferences If They Become Unable to Make Decisions for Themselves, Among Adults Age 65 or Older

Percent\*

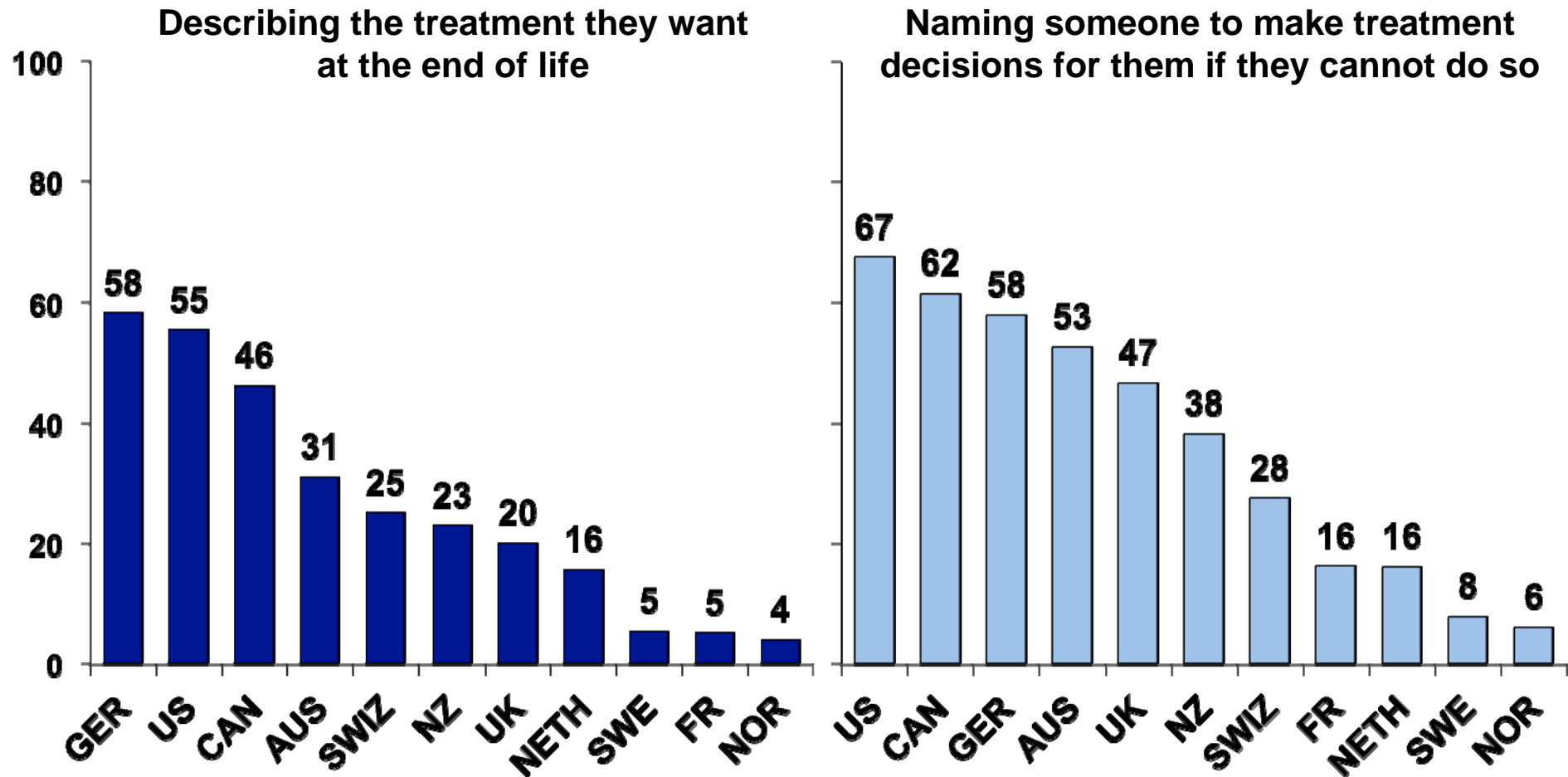


\* Had a discussion with someone, including with family, a close friend, or a health care professional, about the health care treatment they want if they become very ill and cannot make decisions for themselves.

Source: 2014 Commonwealth Fund International Health Policy Survey of Older Adults in Eleven Countries.

## Has a Written Plan About End-of-Life Care Preferences or Naming a Proxy Decision-Maker, Among Adults Age 65 or Older

Percent who have a written plan:

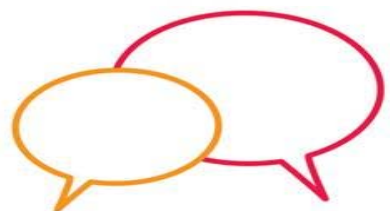


Source: 2014 Commonwealth Fund International Health Policy Survey of Older Adults in Eleven Countries.



SIPRESS

*"Don't freak out—it's just a save-the-date."*



**CONVERSATIONS  
THAT COUNT DAY**

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START A CONVERSATION  
OVER COFFEE



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tō tātou reo | Care  
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But .....what gets in the way of these crucial conversations ?



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# For us ?

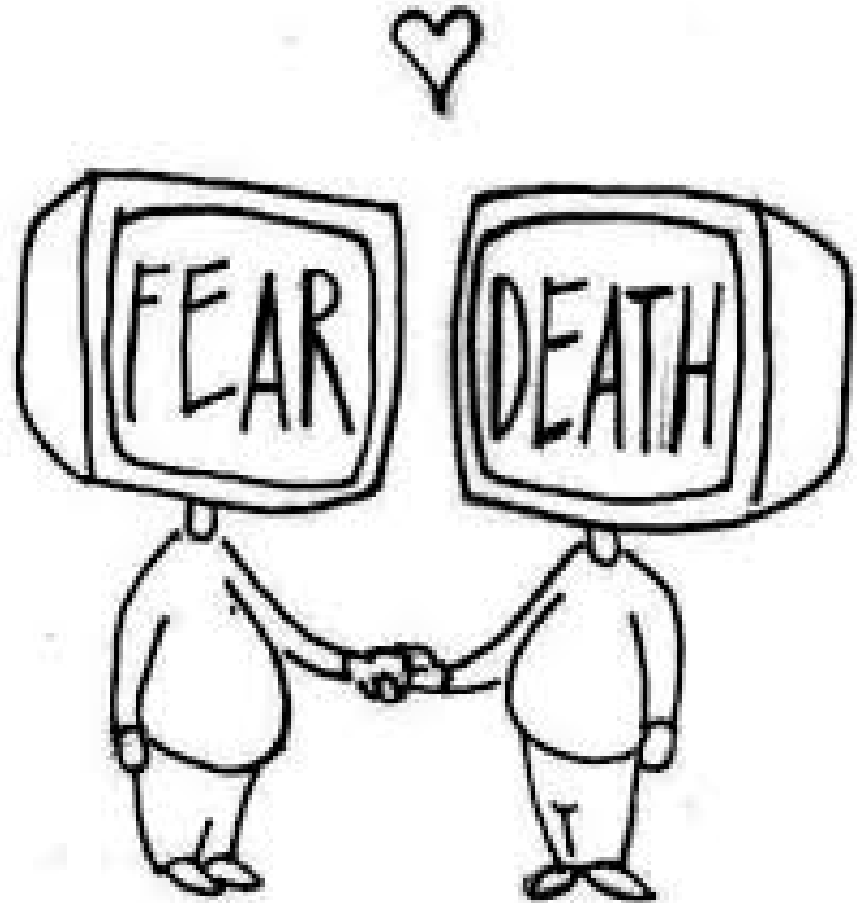
- Fear and anxiety
- Values, beliefs and culture
- Capabilities and confidence
- Context



"At this time I'd like to ask you to remain calm, fasten your seat belt and flap your arms just as fast as you can."

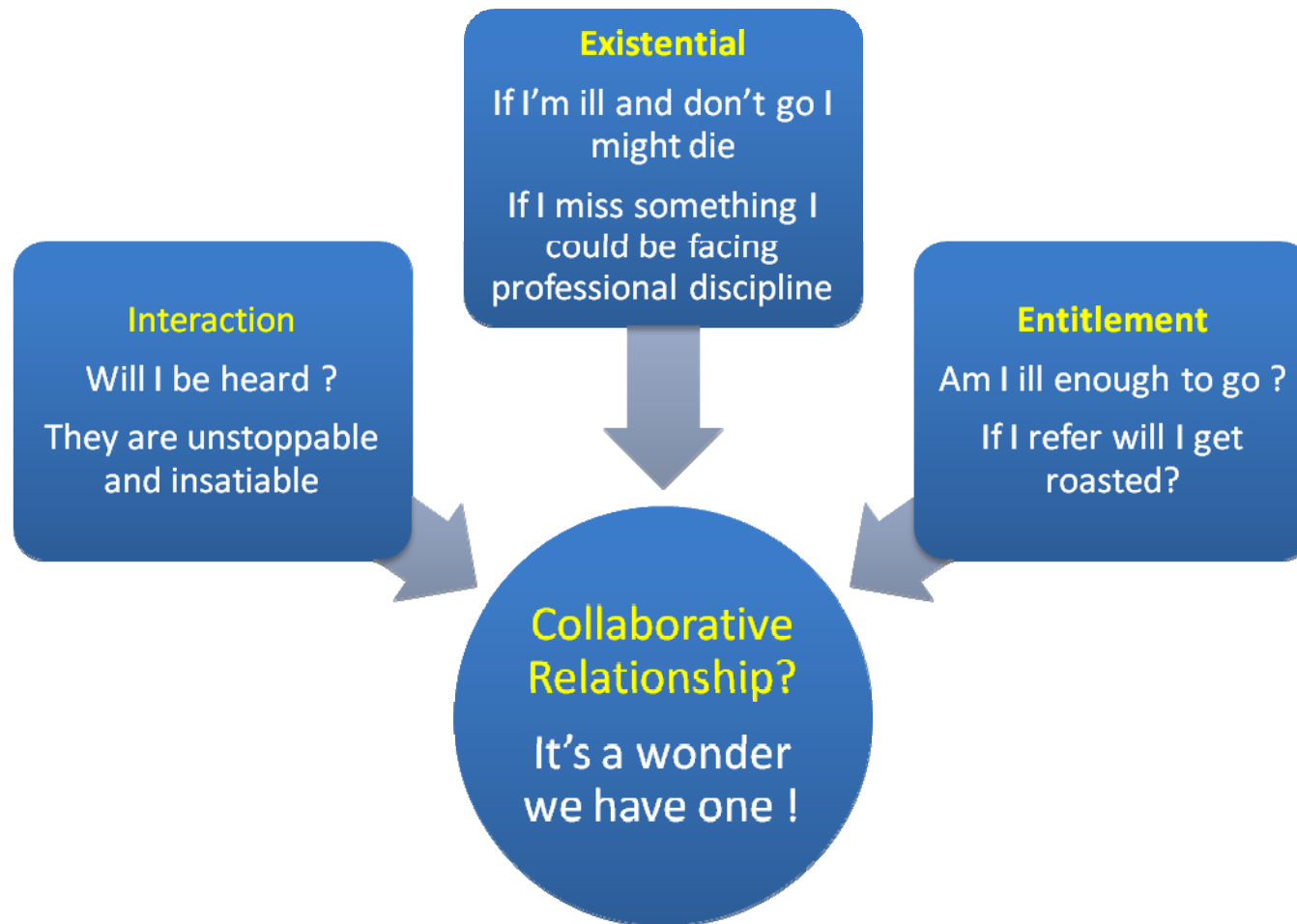
# Guess what ...For clients

- Fears
- Values, beliefs and culture
- Capabilities and confidence
- Context



# Anxiety

Health Foundation , 2012



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# Fears

## Health Professionals

- They might cry and get upset
- I won't be able to handle their response
- I may provoke a crisis
- Will I be able to handle their disappointment if I can't fix this
- They are unstoppable

## Patients

- I might cry and not be able to stop
- They won't hear me
- They will judge and label me
- They are so young they might not handle it

# Attitudes and beliefs

## Health Professionals

- Own spiritual and cultural beliefs
- This will take too long
- Not my job
- I'm here to "fix" things
- I can't do this ?
- Raising it means I have to fix it . They expect me to fix it
- I know what they need
- All the "isms"

## Patients

- Own spiritual and cultural beliefs
- I might annoy my whanau if I talk to them
- They don't really care about me
- They think I bought this on myself... and I do too
- I should be able to cope with this
- They don't have the time for me
- All the "isms"

# Capabilities

## Health Professionals

- Educated to cure not care
- Not educated to share power
- Difficulty with silence
- Difficulty handling intense emotions
- Level of communication skills, emotional intelligence and empathy
- Not having a structured approach
- Not knowing how to start
- Knowledge of trajectories

## Patients

- Health Literacy
- Health literacy
- Health literacy
- “Cultural” norms/ roles
- Issues of capacity
- Issues of self- efficacy

# Context

## Health Professionals

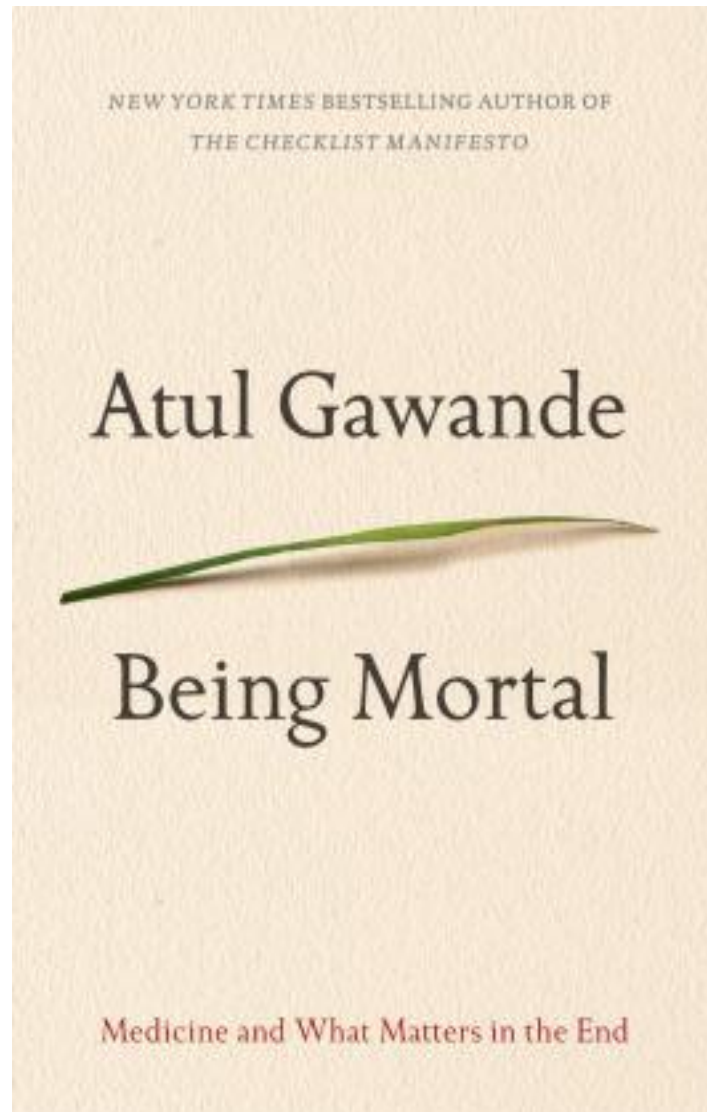
- Time ( 6 min consult )
- System
- Policies
- Funding / purchasing

## Patients

- Time
- Rurality
- Economy
- Employment



# Compassion and being mortal



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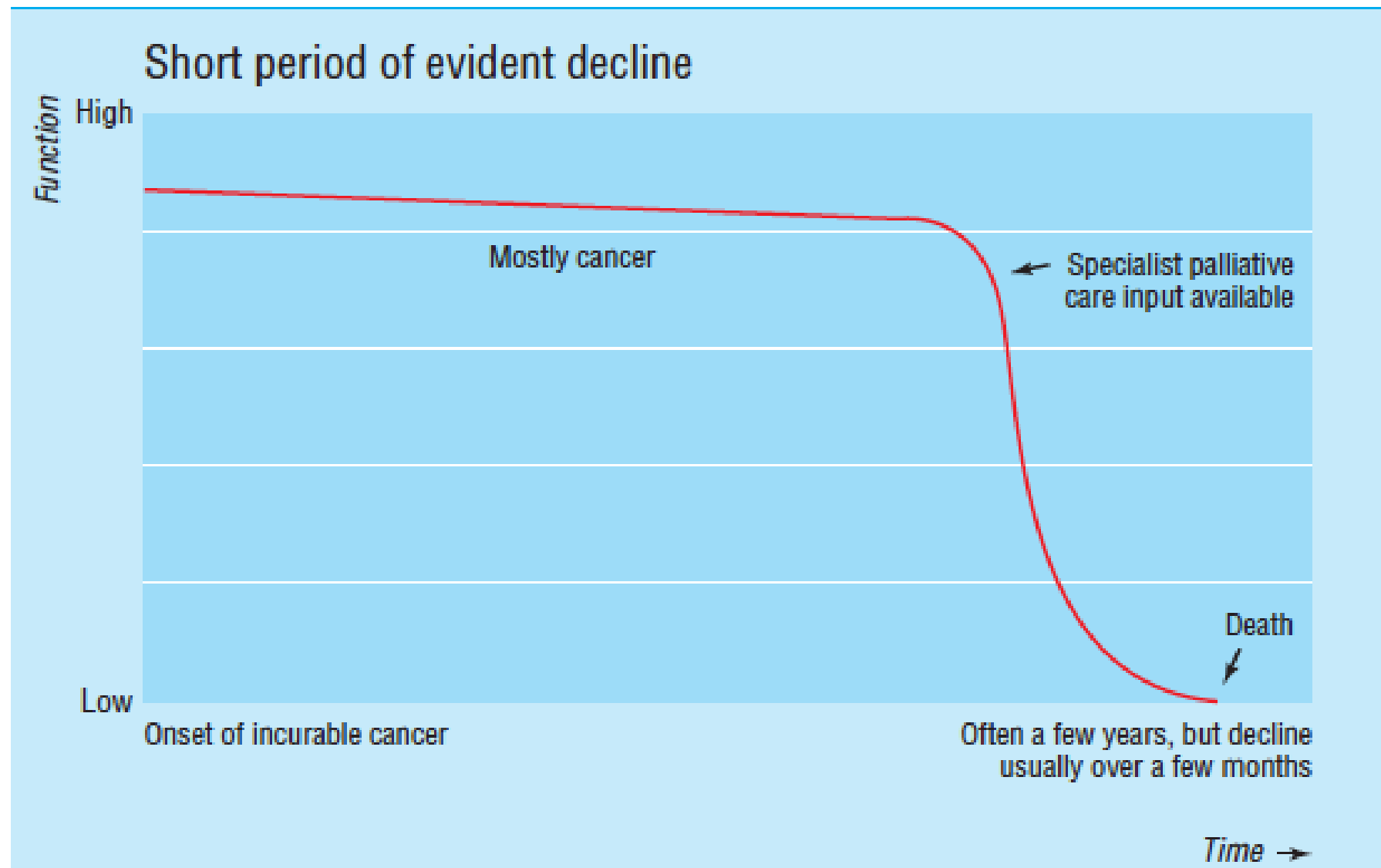


# START A CONVERSATION

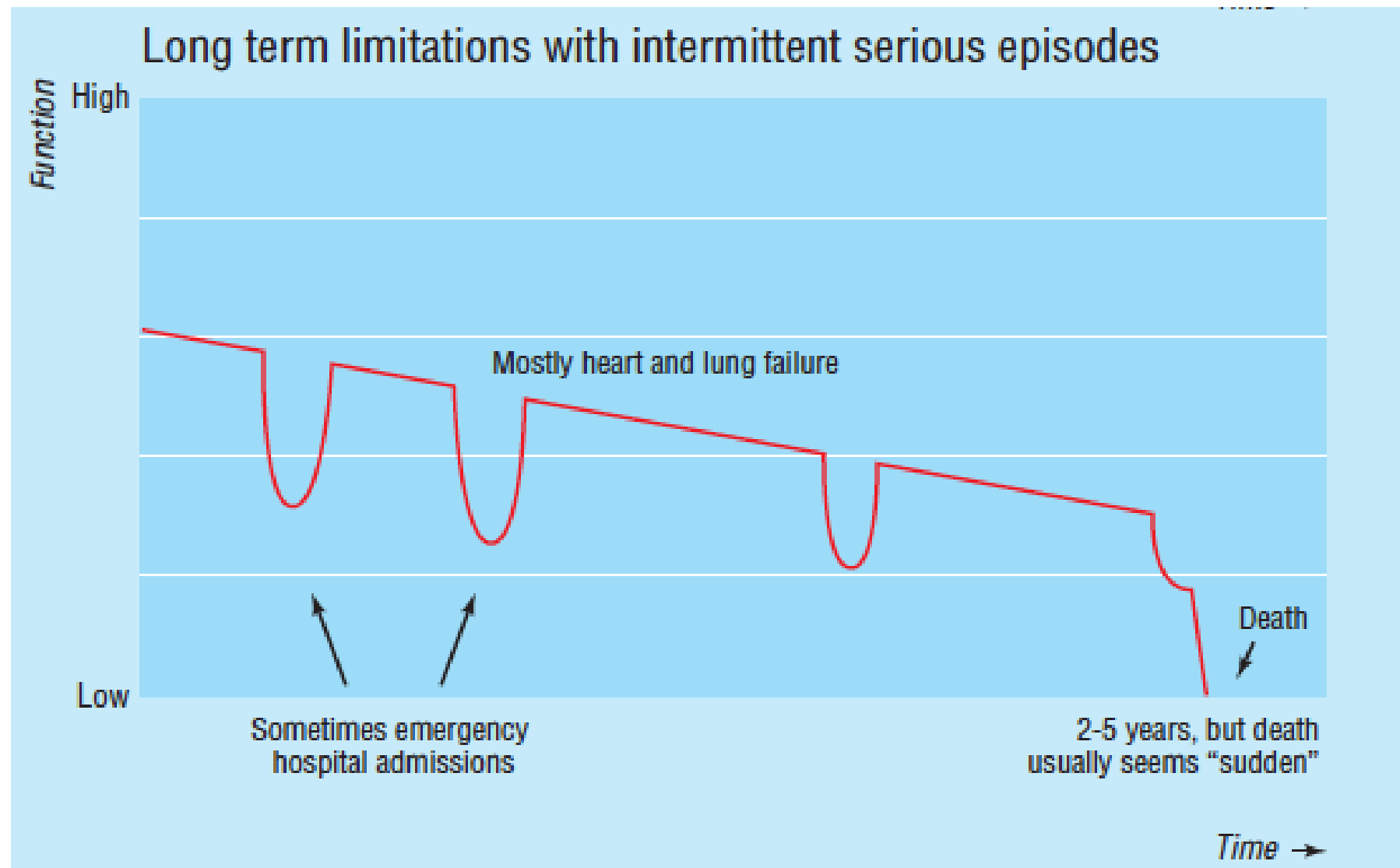
WITH AN IMPORTANT PERSON IN YOUR LIFE



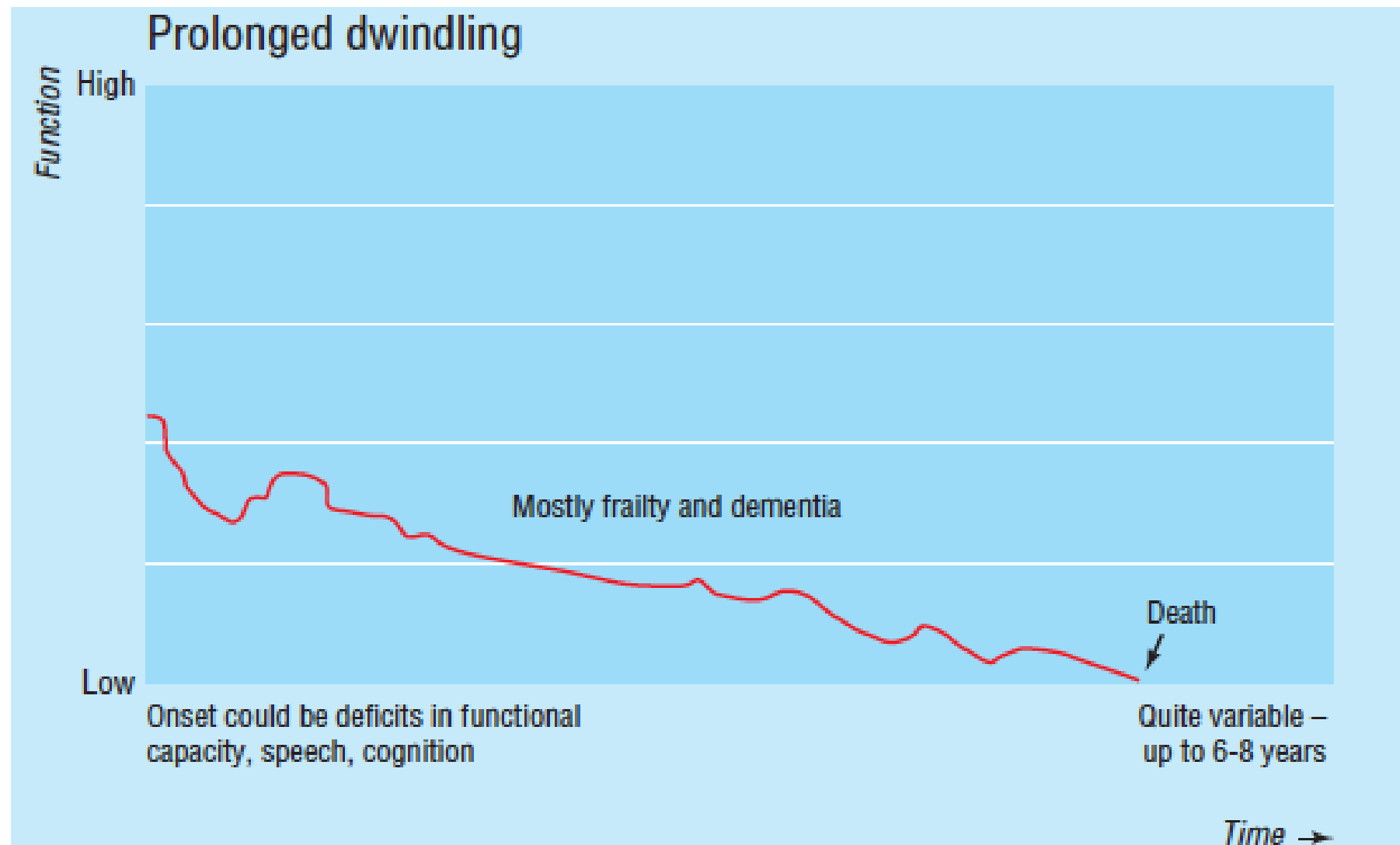
**Fig 1** Typical illness trajectories for people with progressive chronic illness. Adapted from Lynn and Adamson, 2003.<sup>7</sup> With permission from RAND Corporation, Santa Monica, California, USA.



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**Fig 1** Typical illness trajectories for people with progressive chronic illness. Adapted from Lynn and Adamson, 2003.<sup>7</sup> With permission from RAND Corporation, Santa Monica, California, USA.





# START A CONVERSATION

AT THE KITCHEN TABLE



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# START A CONVERSATION

ON THE COURSE







# START A CONVERSATION

WITH THE WHANAU





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# START A CONVERSATION

BEFORE IT'S TOO LATE



# It might just take a wee bit of courage



Courage is what it takes to stand up and speak.  
Courage is also what it takes to sit down and listen.  
- Winston Churchill



**COURAGE**

One man with courage is a majority.

Andrew Jackson

advertising.com

Michael Jackson

chancecounts.org

CO LACU TCO Planning

# What is Advance Care Planning

---

ACP is a process of discussion & shared planning for future health care. It **involves an individual, whanau & health care professionals.**

ACP gives people the opportunity to develop & express **their** preferences for future care based on:

- their values, beliefs, concerns, hopes & goals
- a better understanding of their current & likely future health
- the treatment & care options available.

(ACP Cooperative 2013).

# Our jobs are to enable well being

The questions are :

- What do you understand is happening and likely to happen ?
- What are your fears and hopes?
- What are the tradeoffs you are willing to make and not willing to make ?
- How might we achieve that together ?
- What matters most to you ... not what's the matter ?



“You’ve got six months, but with aggressive treatment we can help make that seem much longer.”

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**Conversations (context)**

ACP  
plan

AD

## MY LIVING WILL

Last night my kids and I were sitting in the living room and I said to them, "I never want to live in a vegetative state, dependent on some machine and fluids from a bottle.

If that ever happens, just pull the plug."

They got up, unplugged the television and threw out my wine.



\*Go wish cards

## Your role as translator

**What is important to the person?**



How does that translate into treatment & care preferences?  
What do we need to plan for, what arrangements do we need to make?

# Advance Directive:

**An Advance directive is consent or refusal to specific treatment(s) offered in the future when the person does not have capacity.**



# Advance Directives

## Criteria for validity:

- Person must have been **competent** when the AD was written
- They must have been adequately **informed**
- They must have been **free of undue influence**
- The Advance Directive must have been **intended to apply in the circumstances that have arisen**

## Advanced Directive

- An Advance Directive does not need to be in writing
- An Advance Directive only applies when a person lacks capacity
- An Advanced Directive cannot require the provision of specific treatment

## Advance Directive

**In the absence of reasonable grounds to doubt validity, it should ordinarily be honoured**

# What happens when person is no longer competent?

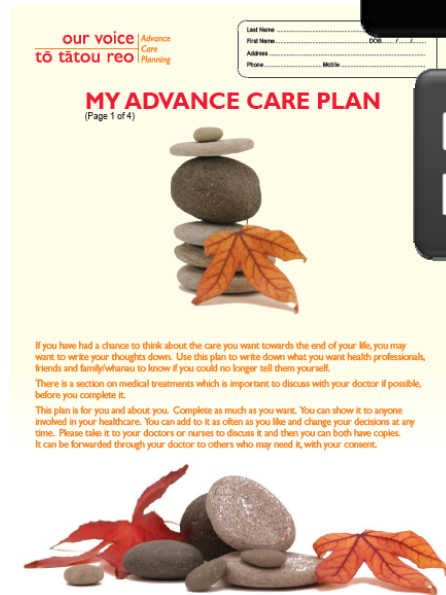
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Valid advance directive

EPA – cannot withhold standard life-sustaining treatment

Ascertainable preferences – apply patient preference

Best interests - other suitable people





<http://www.advancecareplanning.org.nz/>

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## Thinking about your Future Health Care

**Think through** these questions about your future health care on the following pages.

**Take notes** of your thoughts so that you can discuss what's important to you, with others.

NB. You can either **type** in your notes and save this document to your computer, or print it so you can **write** in your notes.



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# Five steps

# Thinking about

- What do you need to think about?
- What is important to you and gives your life meaning?
- Are there any treatments or types of care that you would or wouldn't want?
- Who would you want to make decisions on your behalf if you weren't able to?
- If there was a choice, how and where would you like to spend your last days?

# Talking about

- Who do you need to talk to about it?
- Once you have thought through some of the issues, it's a good idea to talk about them. Then others will know what is important to you and what you would like to happen, especially if you're not able to speak for yourself.

Who would it be good to share your thoughts with?

- Family/whanau?
- Friends and loved ones?
- Doctors, specialists and healthcare team?
- Enduring Power of Attorney?

# Planning for

- **What do you need to write down?**
- **When you know what's important to you, and what you want others to be clear about, it's a good idea to write it down. Then they can refer to it when you can't speak for yourself.**

**Having it in writing can save families/whanau (and healthcare teams) a lot of worry and concern if and when they have to make a decision on your behalf.**

# Sharing

- Who will you give it to?
- Once you have written down what is important to you and what you want to happen, make sure you give a copy to:
  - Key family members/whanau
  - Your GP
  - All members of your healthcare team
  - Your Enduring Power of Attorney (if you have one)

# Reviewing

- When will you review it?
- It's great to have your plan written down and to have shared that with key people.

**It's also a good idea to review it regularly to make sure nothing has changed for you.**

**People find it useful to decide on a day to review it every year, like their birthday, Labour Day or at the time they do their tax return. When would be a good time for you to review it each year?**

**ACP gives you the opportunity to:**

**understand what the future might hold...**

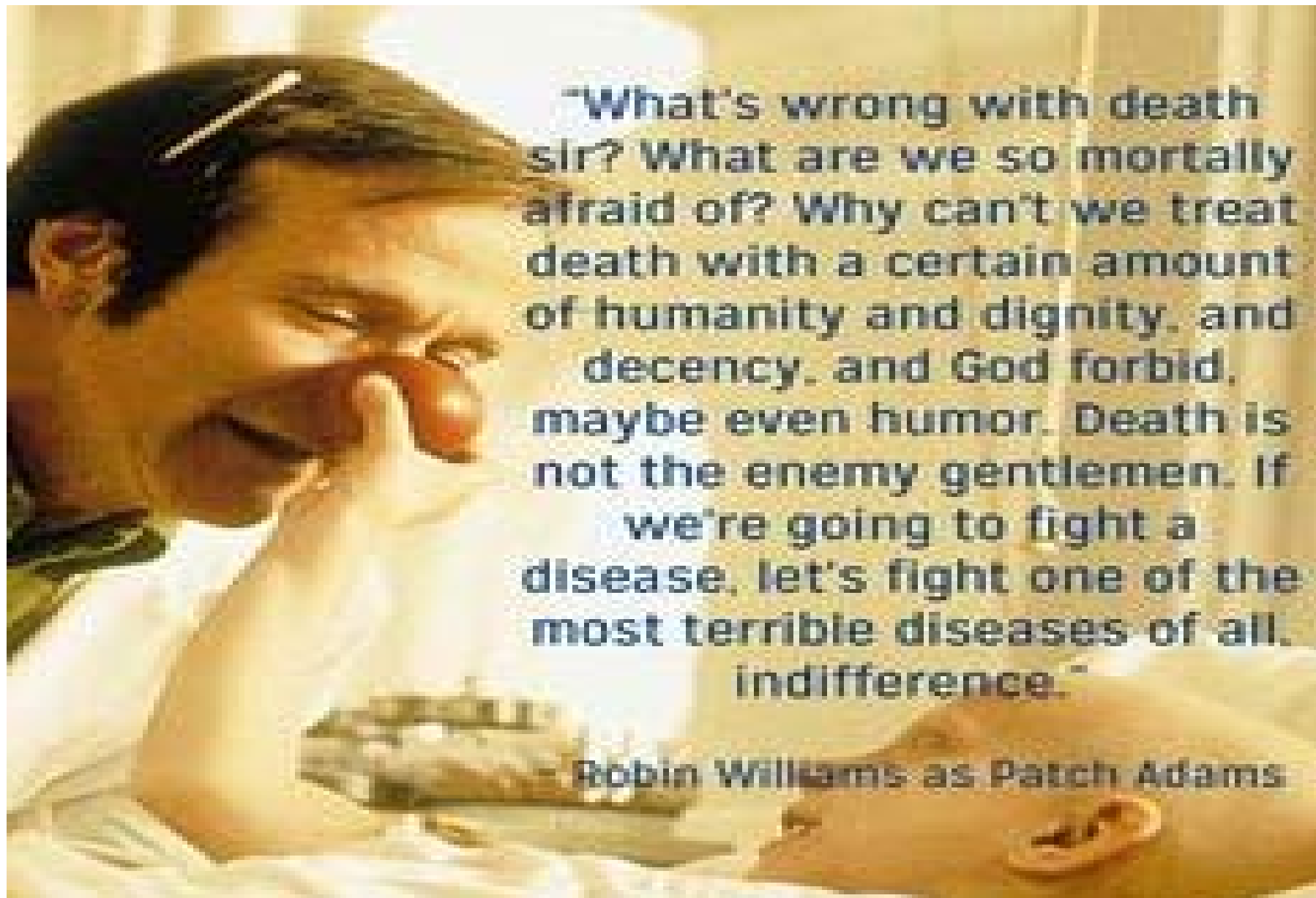
**so you can be better prepared...**

**and we can be better informed to make  
decisions in your best interests**



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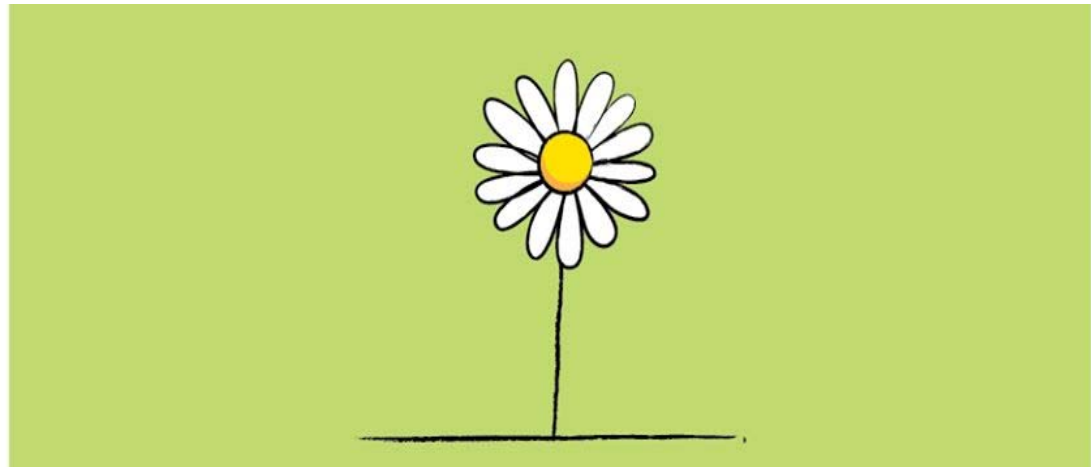
"What's wrong with death sir? What are we so mortally afraid of? Why can't we treat death with a certain amount of humanity and dignity, and decency, and God forbid, maybe even humor. Death is not the enemy gentlemen. If we're going to fight a disease, let's fight one of the most terrible diseases of all. Indifference."

- Robin Williams as Patch Adams

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# Things to remember....

- These conversations may reveal that you and your loved ones disagree. That's okay. It's important to simply know this, and to continue talking about it now—not during a medical crisis.



## Things to remember....

- Be patient. Some people may need a little more time to think.
- You don't have to steer the conversation; just let it happen.
- Don't judge. A “good” death means different things to different people.



[www.conversationscount.org.nz](http://www.conversationscount.org.nz)



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# http://www.advancecareplanning.org.nz/

The screenshot shows the homepage of the Advance Care Planning website. The browser address bar displays 'www.advancecareplanning.org.nz'. The page features a large banner with a background image of two people walking through a sunlit forest. The banner text reads: 'Advance Care Planning (or ACP) is the process of thinking about, talking about and planning for future health care and end of life care.' Below the banner is a navigation menu with links: Home, How To, Resources, Stories, and FAQ. The main content area is titled 'Advance Care Planning asks "What matters to you?"'. It includes a paragraph explaining ACP, a quote in an orange speech bubble: 'I'm less scared about my future healthcare now that we've talked about it', and a sign-up form for the newsletter. On the right, there is a section for '16th April 2015 CONVERSATIONS THAT COUNT DAY' with a play button icon and a video thumbnail showing a person at a market stall.

our voice to tatou reo | Advance Care Planning

HOME HEALTHCARE WORKERS ABOUT ACP COOPERATIVE

Advance Care Planning (or ACP) is the process of thinking about, talking about and planning for future health care and end of life care.

Home How To Resources Stories FAQ

## Advance Care Planning asks "What matters to you?"

Advance care planning gives everyone a chance to say what's important to them. It helps people understand what the future might hold and to say what treatment they would and would not want. It helps people, their families and their healthcare teams plan for future and end of life care.

This makes it much easier for families and healthcare providers to know what the person would want - particularly if they can no longer speak for themselves.

Looking to get started? [Find out how.](#)

*"I'm less scared about my future healthcare now that we've talked about it"*

Sign up for our Advance Care Planning newsletter if you'd like to stay updated

Enter email address

Quick links for Healthcare Workers

General Information

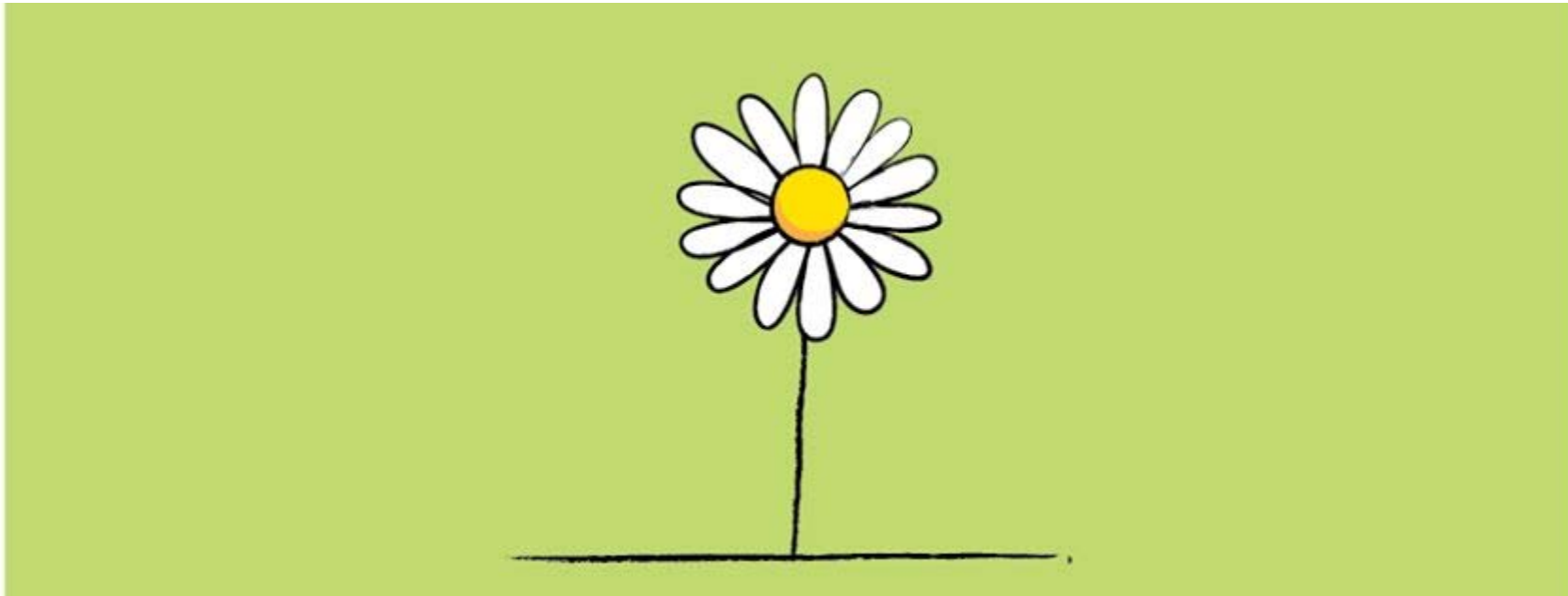
16th April 2015  
CONVERSATIONS THAT COUNT DAY

Break the ice, send an ePostcard and start a conversation with someone that matters to you

A short introduction to Advance Care Planning

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# Questions?



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