

Magnolia Cardona, PhD, MPH, MBBS
Health Services Researcher and patient advocate

# Australians offered chance to cheat death by freezing bodies



You only live twice: Cheating death with cryonics



# Bendigo woman Kerry Robertson becomes first Victorian to use Voluntary Assisted Dying Act

Updated 5 Aug 2019, 3:51pm



"Before this happened I was afraid of death, but Mum was incredibly brave and the way that she died gave me a whole new perspective on death itself," she said.



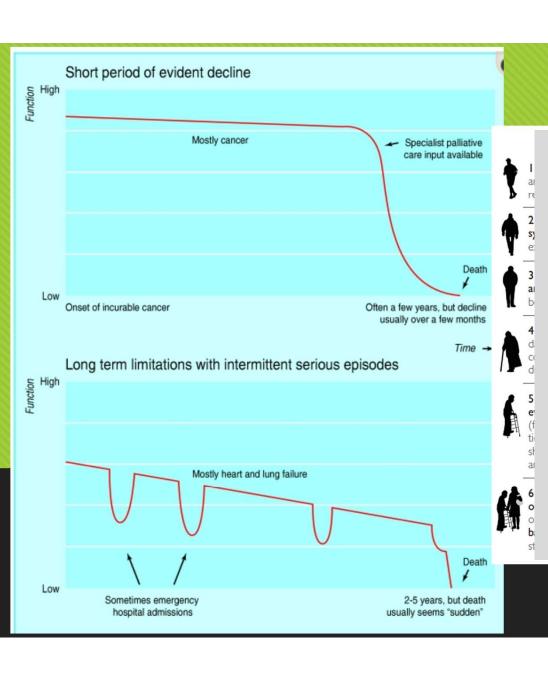
DR MAGNOLIA
CARDONA, PhD, MPH,
MBBS, Associate
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Systems Research and
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University Hospital, Bond
University, and NHMRC
Partnership Centre
for Health Systems
Sustainability



DR SALLY GREENAWAY, BMED, FRACP, FACHPM, Director, Supportive and Palliative Medicine, Westmead Hospital, Blacktown Hospital, Mt Druitt Palliative Care Unit and The University of Sydney

# The medicalisation of dying from natural causes

Unacceptable to patients, low-value for the health system.



# Dying is a journey. Not a point in time

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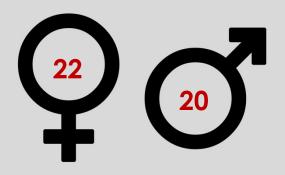
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HOUSIE

# 2017: Aus 3.7million aged 65+ years; QLD 720,000





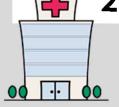
2018:

1 in 5 emergency presentations

**2050: Double** 



1 in 7 could have been managed by a GP AUS 85+y.o.
Resuscitation:
2,650





admitted to hospital

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# The role of hospitals from ancient Greece & Middle Ages





Sanitation Living conditions **Better nutrition Vaccination** 

**Education campaigns** 

Disease screening – early detection



1946 Chemotherapy

1981

Heart lung transplant

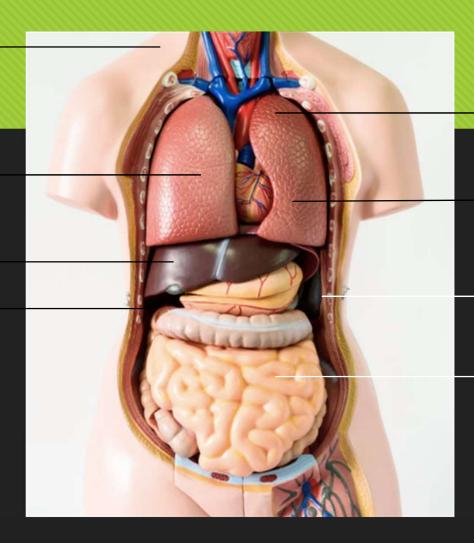
1967

Liver transplant

1950

ICU & Kidney transplant

1980s MRI 1985 Robotic surgery 1990s Gene therapy 2005 Keyhole heart surgery



1895

X rays

1967

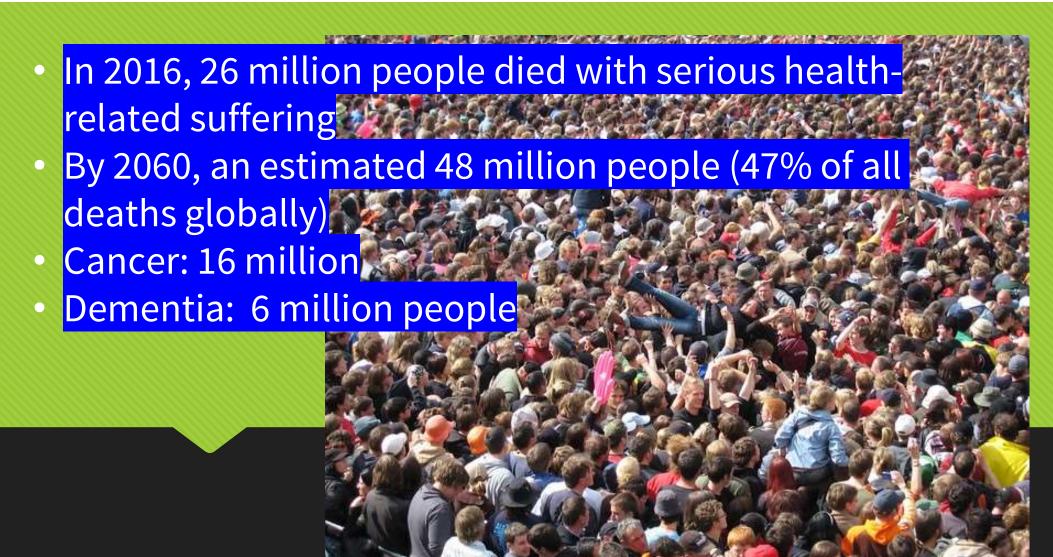
Heart transplant

1943

Kidney Dialysis

1940 Antibiotics





The Joint Commission Journal on Quality and Patient Safety 2018; 44:505-513

# Who Benefits from Aggressive Rapid Response System Treatments Near the End of Life? A Retrospective Cohort Study

Magnolia Cardona, PhD, MPH; Robin M. Turner, PhD, MSc; Amanda Chapman, BN, GradDip (Acute Care); Hatem Alkhouri, PhD, MSc; Ebony T. Lewis, MIPH, BN; Stephen Jan, PhD, ME; Margaret Nicholson, MN, DipAppSc; Michael Parr, MBBS, FCICM; Margaret Williamson, MPH, BPharm; Ken Hillman, MD, FCICM

**Background:** Many patients near the end of life are subject to rapid response system (RRS) calls. A study was conducted in a large Sydney teaching hospital to identify a cutoff point that defines nonbeneficial treatment for older hospital patients receiving an RRS call, describe interventions administered, and measure the cost of hospitalization.

**Methods:** This was a retrospective cohort of 733 adult inpatients with data for the period three months before and after their last placed RRS call. Subgroup analysis of patients aged  $\geq 80$  years was conducted. Log-rank, chi-square, and *t*-tests were used to compare survival, and logistic regression was used to examine predictors of death.

**Results:** Overall, 65 (8.9%) patients had a preexisting not-for-resuscitation (NFR) or not-for-RRS order; none of those patients survived to three months. By contrast, patients without an NFR or not-for-RRS order had three-month survival probability of 71% (log-rank  $\chi^2$  145.63; p < 0.001). Compared with survivors, RRS recipients who died were more likely to be older, to be admitted to a medical ward, and to have a larger mean number of admissions before the RRS. The average cost of hospitalization for the very old transferred to the ICU was higher than for those not requiring treatment in the ICU (US\$33,990 vs. US\$14,774; p = 0.045).

**Conclusion:** Identifiable risk factors clearly associated with poor clinical outcomes and death can be used as a guide to administer less aggressive treatments, including reconsideration of ICU transfers, adherence to NFR orders, and transition to end-of-life management instead of calls to the RRS team.

≥ 80 years, 40% died during the hospitalization, 10% in the ED

≥80 years had repeat admissions and repeat MET calls. Half of deaths within 2 days of MET call

1 in 10 had a NFR order – all with a NFR order had MET calls and all died within 3 months

Many with flags for imminent death: CPR, intubation, mechanical ventilation, IV fluids, transplant

Were they dying of natural causes?

# Medicine has evolved. Real-life quotes

"No-one is allowed to die anymore... it has almost become a dirty word" NSW doctor "Who wanted to talk mortality when he was feeing so alive? (at age 91)" NSW informal caregiver



"If you want to pass away don't come to the hospital. Most doctors will not let patients simply pass away even if is the patient's wish" NSW nurse

"You know I'm dying.
I don't want any more
treatments. I only agreed to
do this for my sons. I know it is
time". USA Older patient,
Overtreatment at end of life.
Teaster & O'Brien 2014

# Why is over-treatment happening?









**Treatments** 



# What do older people want?









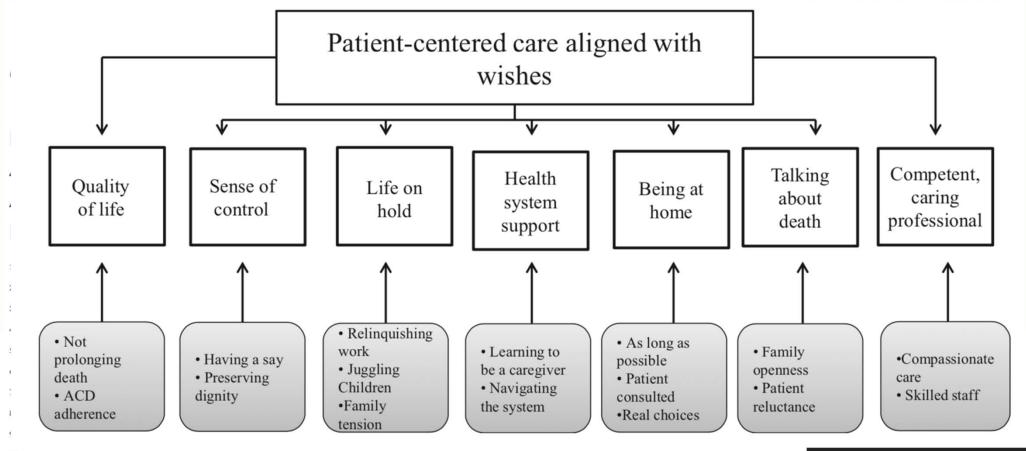


Accepted: 4 December 2018

DOI: 10.1111/hex.12860

### ORIGINAL RESEARCH PAPER

WILEY



<sup>10</sup>Centre for Research in Evidence-Based Practice, Faculty of Health Sciences and Medicine, Bond University, Gold Coast, Queensland, Australia

 $^{11}$ Gold Coast Hospital and Health Service, Gold Coast, Queensland, Australia

# What scientists do to contain overtreatment

Intensive Care Med (2015) 41:1700-1702 DOI 10.1007/s00134-015-3712-6

WHAT'S NEW IN INTENSIVE CARE



Ken M. Hillman Magnolia Cardona-Morrell The ten barriers to appropriate management of patients at the end of their life

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during their remaining few months of life. How did this happen, and what can be considered the top ten potential barriers to managing patients at their end-of-life (EoL) transition in a more appropriate way?

# Potential barriers to EoL management faced by intensivists

The top ten potential barriers encountered by intensivists in managing the EoL transition are presented in Table 1.

Unreal expectations People are constantly fed stories of medical miracles. Our society wants to believe that there are cures for most medical conditions, and members of the medical profession do little to put the miracles into per-

**Prognostic uncertainty** 

Family pressure Societal expectation

Not knowing patient wishes

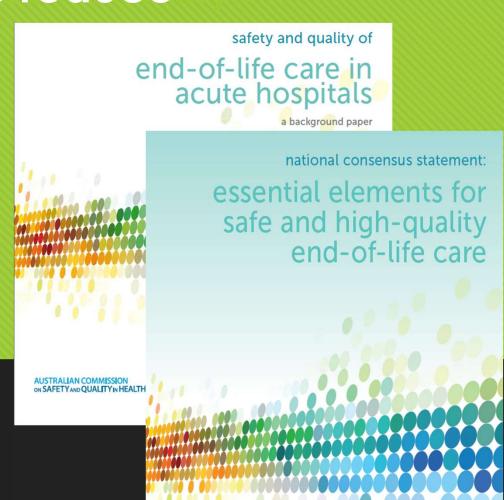
Lack of training

Ethical ambivalence

# How can clinicians help reduce

medicalisation?

- Recognise dying earlier
- Education to clinicians
- Inform goals of care
  - Curative if of benefit
  - Medical –LST no CPR
  - Comfort/palliative
- Models of care out of hospital
- Shared decision-making



Received: 28 February 2018

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Accepted: 24 January 2019

DOI: 10.1111/ajag.12630

### RESEARCH



Australasian Journal on Ageing

# Dissonance on perceptions of end-of-life needs between health-care providers and members of the public: Quantitative cross-sectional surveys

Magnolia Cardona<sup>1,2</sup> | Ebony Lewis<sup>3</sup> | Shantiban Shanmugam<sup>4</sup> |

Margaret Nicholson<sup>5</sup> | Margaret Williamson<sup>6</sup> | Laura Hanly<sup>6</sup> | Ken Hillman<sup>5,6</sup>

<sup>1</sup>Centre for Research in Evidence Based Practice, Faculty of Health Sciences and Medicine, Bond University, Gold Coast, Queensland, Australia

<sup>2</sup>Gold Coast University Hospital, Gold Coast, Queensland, Australia

<sup>3</sup>School of Public Health and Community Medicine, The University of New South Wales, Sydney, New South Wales, Australia **Objective:** To investigate views, determinants and barriers to end-of-life discussions for doctors, nurses and members of the public (MoP) and their acceptability of risk prediction tools.

Methods: Concurrent surveys of 360 doctors and nurses and 497 MoP.

**Results:** Sixty per cent of clinicians reported high confidence in initiating end-of-life discussions, and 55.8% regularly engaged in them. Barriers to end-of-life communication reported by clinicians were uncertainty on the likely time to death (44.7%) and

# How far do scientist go advocating?

Received: 15 March 2018

Accepted: 10 June 2018

DOI: 10.1111/ijcp.13222

## PERSPECTIVE



# Truth disclosure on prognosis: Is it ethical not to communicate personalised risk of death?

### Summary

Predicting risk of death based on personalised and objective clinical indicators is an improvement over intuition and clinical judgement. Risk assessment can benefit clinicians by improving prognostic certainty, and truth disclosure helps patients and families by preventing futile management. Some argue that consent should be obtained before a patient is given an estimate of their prognosis as disclosure of had news can overhurden natients. In this article, we army

ages, and in particular the very old, 5 provides information on likely outcomes, including death, and is but one essential component of truthful communication.

Delivering a prognosis, especially a bad one, is complex, takes time and requires sensitive communication filled with good judgement, skill, empathy and compassion. Some patients may hold beliefs that can distort their understanding or expectations of

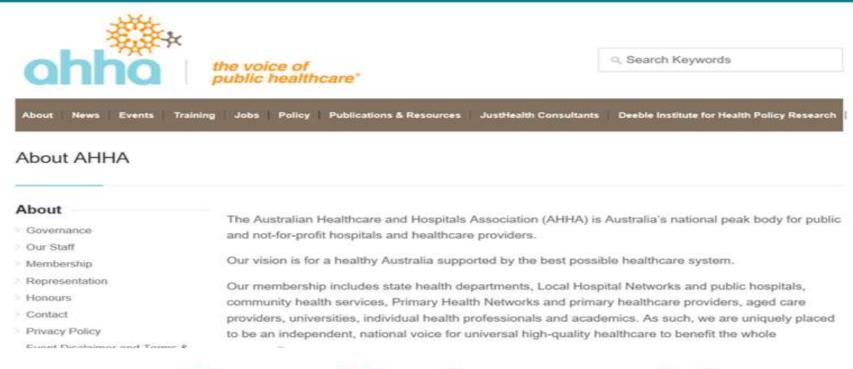
International Journal for Quality in Health Care, 2016, 28(4), 456-469 doi: 10.1093/intahc/mzw060



# ments in hospital at the end review on extent of the

I KIM<sup>2</sup>, RM TURNER<sup>3</sup>, M ANSTEY<sup>4</sup>,  $N^{1,6}$ 

search, SWS Clinical School and the Ingham Institute for Applied South Wales, PO Box 6087 UNSW, Sydney NSW 1466, Australia, n Sydney University, Narellan Road & Gilchrist Drive, Campbelltown and Community Medicine, Level 2, Samuels Building, Samuels Ave, nton NSW 2033, Australia, <sup>4</sup>Sir Charles Gairdner Hospital, Hospital tensive Care Unit, Building 12, Level 3, Canberra Hospital, Yamba and fintensive Care Unit, Level 2, Liverpool Hospital, Elizabeth St &



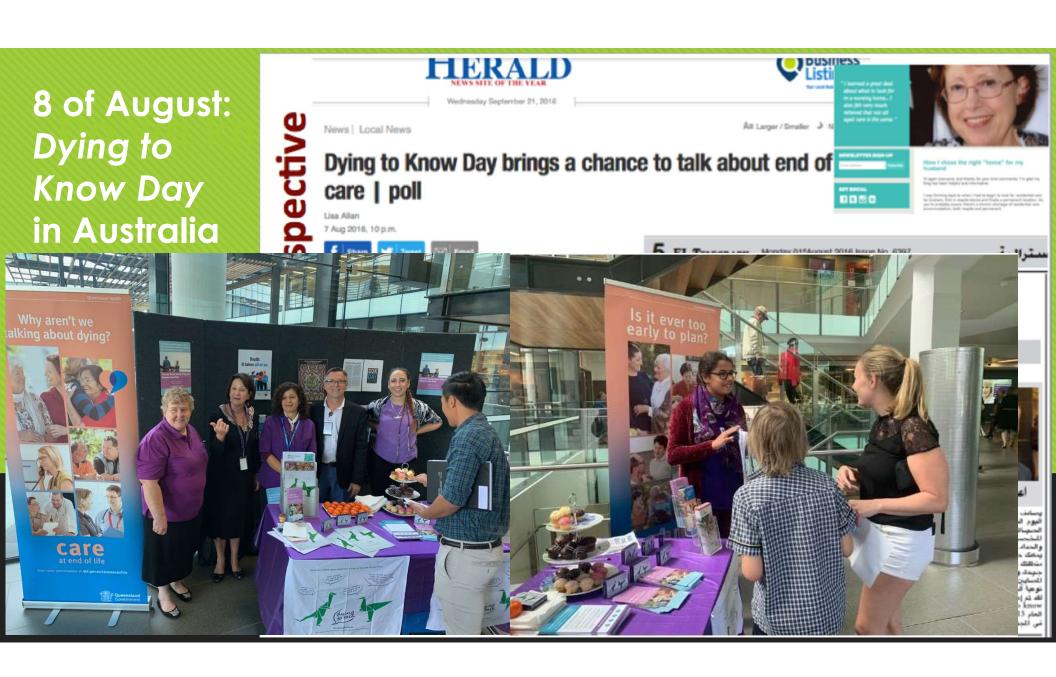
Become a Member

# The Health Advocate article

The medicalisation of dying from natural causes: Unacceptable to patients, low-value for the health system

# Helpful strategies

- 1. Prognostication
- 2. Shared decision making
- 3. Public Education
- 4. PBS Remuneration
- 5. Community based options
- 6. Compassionate Communities



# What you can do to help improve the situation



Senior Australian news and research

http://seniorau.com.au/8571 older-australians-want-thetruth-about-their-medicalprognosis

Reports and papers From the WEB Senior Associations Government Resources



### Older Australians want the truth about their medical prognosis

Two new surveys show older people want a straight answer to one of life's weightiest questions but clinicians are often reluctant to give one - "Doctor, how much longer do I have left to live?"

The research, led by Associate Professor Magnolia Cardona of Bond University and Gold Coast University Hospital, reveals older Australians want the truth about their prognosis, even if it is bad news.

Doctors and nurses, meanwhile, prefer to be cautious because of uncertainty around life expectancy and pressure from families asking them to withhold information from terminal patients. There is also a perception that patients and families lack the knowledge to make informed decisions.

"While this may have been the case 15 years ago, our recent findings strongly suggest that the public today may be more willing than clinicians realise to talk openly about what is in store and how or where they want to die," said Dr Cardona, of the Centre for Research in Evidence Based Practice (CREBP) at Bond University.

Researchers conducted concurrent surveys of 360 Australian nurses and doctors dealing regularly with patients near the end of life - such as those in aged care, palliative care and emergency departments - and 497 members of the public, mostly aged 60 and over.

More than 92 per cent of older people wanted information about life expectancy while almost 90 per cent wanted involvement in treatment decisions if the likelihood of death was high.

Almost 60 per cent of clinicians said they were highly confident of initiating end-of-life conversations and more than 55 per cent regularly engaged in them. But almost 44 per cent said uncertainty about life expectancy was a barrier to the fateful



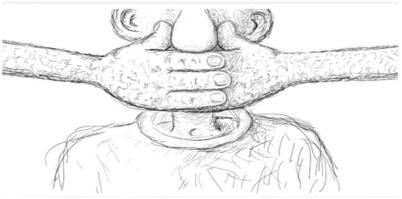
**NEWS** INDUSTRY+POLICY

PRACTICAL LIVING

CLINICAL

TECH RADIO+TV

# Home | News | Don't beat around the bush: older people on prognoses



### Don't beat around the bush: older people on prognoses

Give it to them straight, Doc.

When it comes to important questions about health and death, older adults want to know the truth,

New research has shown that while older Australians want the full picture of their prognosis, even if it is bad news, clinicians are sometimes hesitant to spell it out.

Study lead Associate Professor Magnolia Cardona, from Bond University and Gold Coast University Hospital, said the public may be more willing than clinicians realise to talk openly about what's in store and how or where they want to die.

The research team surveyed 360 Australian nurses and doctors dealing regularly with patients near the end of life and 497 members of the public, mostly aged 60 or older.

Just under 90 per cent of older adults wanted involvement in treatment decisions if the likelihood of death was high.

And 92 per cent wanted information about life expectancy, but almost 44 per cent of clinicians said uncertainty about life expectancy was a barrier to the conversation.

# **Conversation starters**

About me

About me

Being able to is the most important thing to me.

About me

..... is important for me to live well.

About me

For me, a life worth living is where I

About life

About life

What do you value most in life?

About life

What's in your bucket list?

About lif

What does a good day look like to you?

About choices

About choices

I was thinking about what happened to ...... and it made me realise that .....

About choices

If ...... happened to me, I would want About choices

I would want ...... to make medical decisions on my behalf if I was unable to.





# Statement

# **ADVANCE CARE PLAN**

**Advance Care Plan** 

About us

This Statement of Choices can have wishes, values and beliefs to guito make health care decisions or are unable to make those decisions.

My name
---------

### **B. Personal Values**

Describe what you value or enjoy most in your life: Think about what interests you or gives your life meaning.

Consider what you would like known about you when health care decisions are being made: *Think about your past experiences, wishes and beliefs or what is important to you.* 

Describe the health outcomes that you would find unacceptable:

Think about what you would **not** want, including situations you consider may involve severe disability.

Describe what would be important or comforting to you when you are nearing death: Think about your personal preferences, special traditions or spiritual support.

Indicate the place where you would prefer to die: (e.g. home, hospital, nursing home)

Consider how you would want to be cared for after you die:

Think about your spiritual, religious and cultural practices; organ and tissue donation; and any other wishes that you want noted.

# Queensland Advance Care Directive (form 4)

Available from <a href="https://publications.qld.gov.au/dataset/power-of-attorney-and-advance-health-directive/resource/6a3af073-cdba-4b82-8de7-eabe65950c24">https://publications.qld.gov.au/dataset/power-of-attorney-and-advance-health-directive/resource/6a3af073-cdba-4b82-8de7-eabe65950c24</a>

Form 4 Queen sland Powers of Attorney Act 1998 (Section 44(2))

### ADVANCE HEALTH DIRECTIVE

### This form deals with your future health care.

The time may come when you cannot speak for yourself. By completing this form, you can give directions about your medical treatment at such a time.

This document can be used by non-English-speakers if a qualified interpreter/translator reads it to the person in the person's own language and a signed Statement of Interpreter/Translator is attached. Blank statements are available from GoPrint offices, WC Penfold Stationers and most newsagents throughout Queensland.



_			The directions were also in this continuously selected to the entries of
8			The directions you give in this section apply only if, in the opinion of your treating medical practitioner:
	I do not want cardiopulmonary resuscitation.	Initial here:	you have a terminal, incurable, or irreversible illness or condition,
	I do want cardiopulmonary resuscitation.	Initial here:	or you are in a persistent vegetative state,
	I do not want assisted ventilation.	Initial here:	or you are permanently unconscious,
	I do want assisted ventilation.	Initial here:	<ul> <li>or you are so seriously ill or injured that you are unlikely to recover to the extent</li> </ul>
	I do not want artificial hydration.	Initial here:	that you can survive without the continued use of life-sustaining measures.
	I do want artificial hydration.	Initial here:	Complete this service has
		multi-	Complete this section by:
	I do not want artificial nutrition.	Initial here:	first considering the points carefully,
	I do want artificial nutrition.	Initial here:	<ul> <li>then ticking the boxes next to the points that you want to apply to you,</li> </ul>
			then writing your initials on the lines that follow those points,
	I do not want antibiotics.	Initial here:	<ul> <li>and finally, drawing a line across any part that you do not want to apply to</li> </ul>
	I do want antibiotics.	Initial here:	you.
	Other treatment (specify):		
	I do not want	Initial here:	7. I request that:
	I do want	Initial here:	7. Trequest that.
			everyone responsible for my care initiate only those measures that are considered
			necessary to maintain my comfort and dignity, with particular emphasis on the
			relief of pain.
9	. If I am permanently unconscious (in a coma):		
	I do not want cardiopulmonary resuscitation.	Initial here:	(Parkin) have
	I do want cardiopulmonary resuscitation.	Initial here:	[Initial here]
	I do not want assisted ventilation.	Initial here:	
	I do want assisted ventilation.	Initial here:	any treatment that might obstruct my natural dying either not be initiated or be
		13:11	stopped.
	I do not want artificial hydration.	Initial here:	
	I do want artificial hydration.	Initial here:	
	I do not want artificial nutrition.	Initial here:	[Initial here]
	I do want artificial nutrition.	Initial here:	
	Two want armicus numbers	multi-	
	I do not want antibiotics.	Initial here:	unless required for my dignity and comfort as part of my palliative care, no
	I do want antibiotics.	Initial here:	surgical operation is to be performed on me.
	Landson of control as a control	surestantianon esperatorato <del>di</del>	
	Other treatment (specify):		
	I do not want	Initial here:	[Initial here]
	I do want	Initial here:	

Form 4 QLD

More information at <a href="https://www.qld.gov.au/law/legal-mediation-and-justice-of-the-peace/power-of-attorney-and-making-decisions-for-others/advance-health-directive">https://www.qld.gov.au/law/legal-mediation-and-justice-of-the-peace/power-of-attorney-and-making-decisions-for-others/advance-health-directive</a>

# What ELSE can you do to help improve the situation?

2-Nominate an enduring power of attorney in case you are unable to make your own decisions due to incapacity

Who is an appropriate surrogate decision-maker?

# Me & my preferences

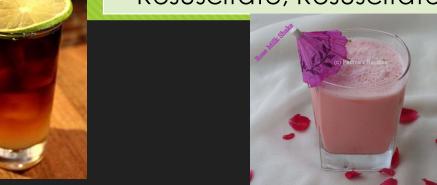
If in permanent vegetative state

- No Pain or prolonged suffering
- NO ICU admission
- No surgeries / IV drugs
- No tube feeding
- No resuscitation attempts
- Die in palliative care

# My surrogate's preferences

If in permanent vegetative state

- Do everything available
- Do not disconnect me in ICU
- IV medications / dialysis
- Stem cell research
- Head transplant
- Resuscitate, Resuscitate



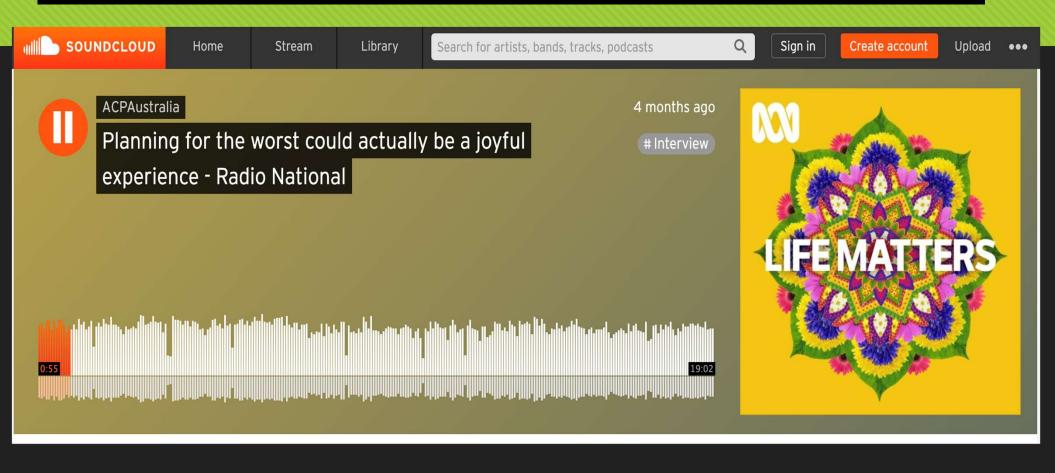
# What ELSE can you do to help improve the situation?

# 3-Have the conversation with your doctor Ask 5 questions

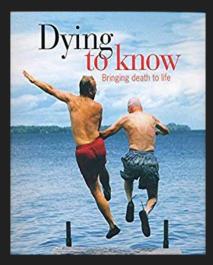
- Is this treatment really necessary?
- What are the benefits and risks?
- Are there simpler/safer options?
- What happens if I don't do anything?
- What are the costs to me/my family?

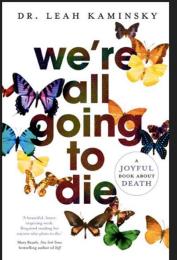


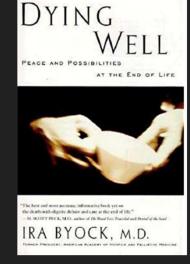
# https://soundcloud.com/acpaustralia/planning-for-the-worst-could-actually-be-a-joyful-experience-radio-national



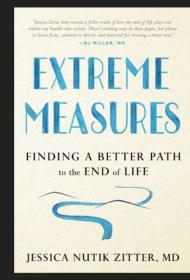
# **Normalising** The end-of-life discussion

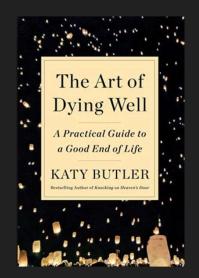


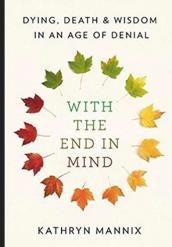




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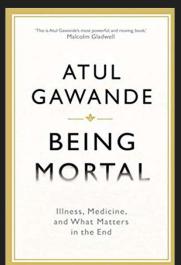






ON DEATH & DYING What the Dying Have to Teach Doctors, Nurses, Clergy & Their Own Families foregard by LRA BYOCK, M.D.

ELISABETH KÜBLER-ROSS, M.D.



# Science breakthroughs have gone too far

- Use fourth industrial revolution to support, not burden older people
- Older people-friendly hospitals
- Better access to Community-based services
- Allow them to die at a place of their choice
- Listen to their personal values & preferences
- Need to realign the health system to meet the needs of the ageing population



Look after our elders

Want to sign up as consumer? advisor to

help in future?

\*60+ year-olds

\*Personal/family experience

\*Open to discuss

\*Respect for different views

**Email me: Magnolia** 

mcardona@bond.edu.au

