End of Life Decisions

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I acknowledge the assistance of Leigh Manson, Advance Care Planning lead ADHB

Outline of seminar

- Identify unmet need
- Discuss evidence for Early decision making
- Review Advance Care Plans
- Consider our own wishes

Background

- Sudden unexpected death is rare
- 85% of us will die of Chronic diseases
- At least half will not be able to express their wishes prior to death
- Families frequently do not know what is wanted

- Doctors and Nurses want to intervene

- “You can be criticised for doing too little, but no one can be critical of a doctor for doing too much.”

  - BMJ 2011;343:d7074

- “My wife had a great fear of the mode of dying enforced on her. During the 50 years we shared…she often made me promise to do all I could to protect her from it. ... But at the moment of truth all I could do was pass on her wishes to the ….doctors knowing there was no legal way they could implement them”

Michael O’Donnell, BMJ 2010

Important distinctions

- Advance Directive
  - Legally binding
  - Specific foreseeable situation
  - Specific directives
- Advance Care plan
  - Record of wants/values/beliefs
  - Used as a guide to treatment decisions
  - When patient not able to express views
  - May include an Advance Directive

Why is it important ?

There is concern that modern medical technology has overrun some patients' needs.

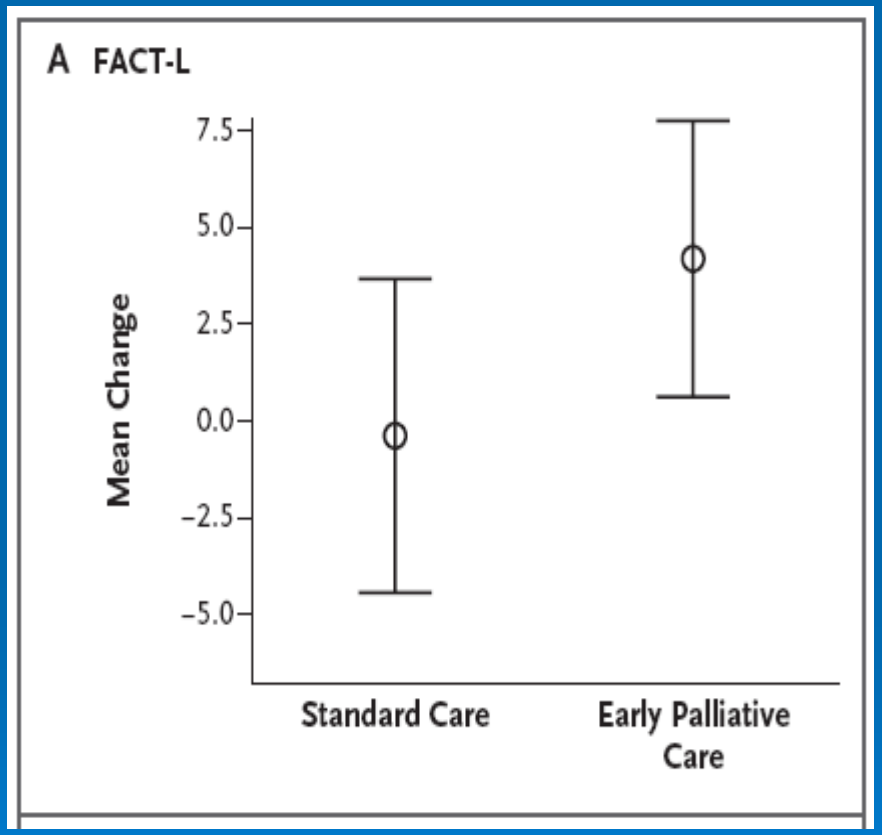
… and a strong call from medical and non-medical groups to improve our communication with patients and let them have a clearly recorded voice when their end of life care is planned.

Early Palliative care

- RCT
- Metastatic Non-small cell cancer lung
- N=151
- Intervention included “establishing goals” and “assisting in decision making” vs standard care
- FU 12 weeks

Ternel JS et al. NEJM; 2010

Quality of Life



More is better

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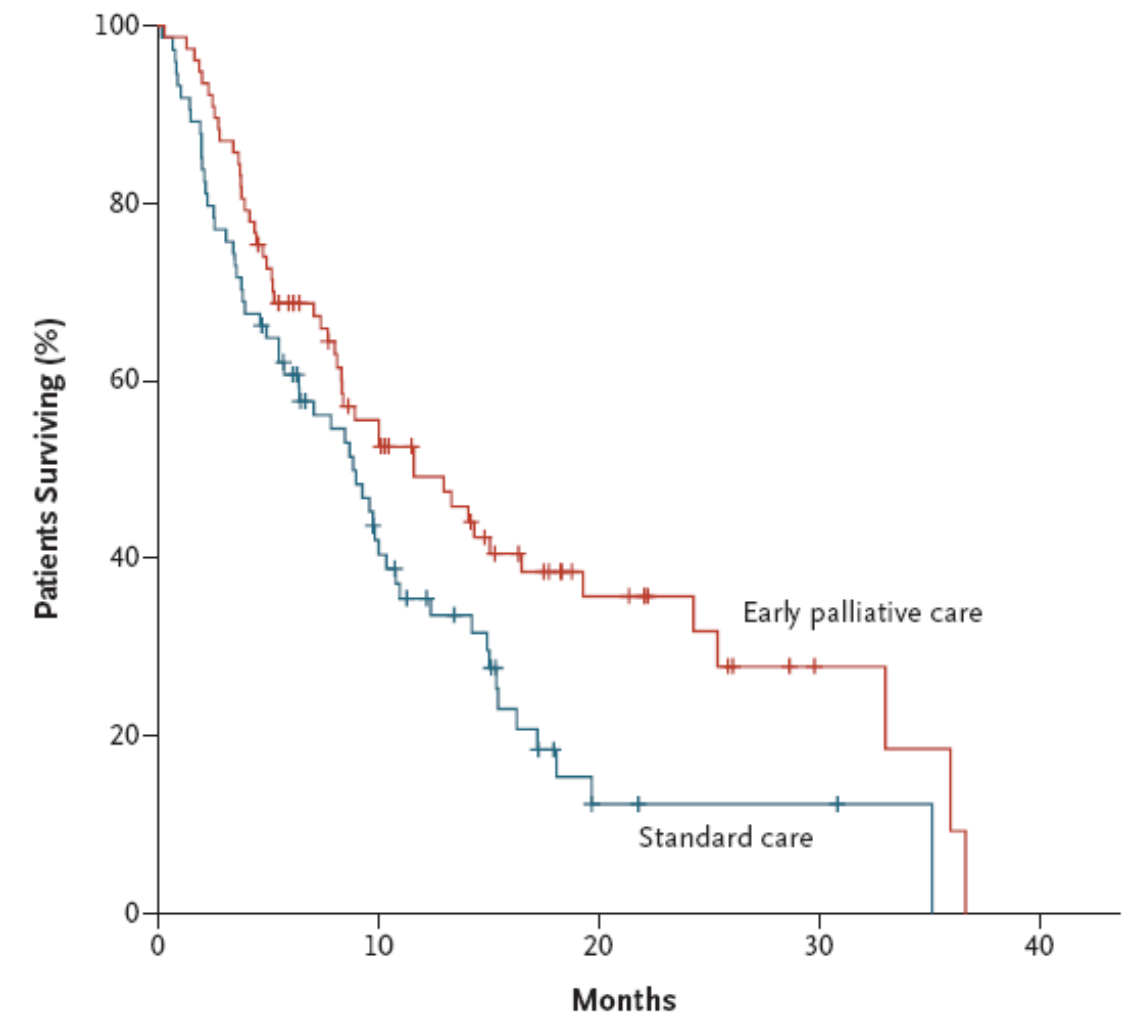
Survival



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Advance Care Plans - do they work?

- RCT, Melbourne
- 309 patients >80year old
- Admitted under GenMed, Resp or Cardio
- Randomised to usual care or “facilitated advance care planning”
- FU 6 months
- 56 died

Detering KM, BMJ 2010;340:c1345

Results

- Wishes known 86% vs 30% $p<0.001$
- Family reduced stress ($p<0.001$), Anxiety (p0.02), depression (p0.002)

Table 3 | Outcomes in 56 patients who died. Values are numbers (percentages) unless stated otherwise

Outcomes	Intervention group	Control group	P value
Patients	29 (19)	27 (17)	0.75
Median (interquartile range) age (years)	85 (84-89)	84 (81-87)	0.06
Men	17 (59)	13 (48)	0.43
Completed advance care planning	25 (86)*	0 (0)	<0.001
Wishes known and followed	25 (86)	8 (30)	<0.001
Wishes unknown	3 (10)	17 (63)	<0.001
Wishes known but not followed	1 (3)	2 (7)	0.51
Location of death:			0.09 (overall)
Acute hospital but not intensive care unit	16 (55)	12 (44)	0.42
Intensive care unit	0 (0)	4 (15)	0.03
Home or non-acute hospital	6 (21)	8 (30)	0.19
Palliative care	7 (24)	3 (11)	0.20
End of life decision making:			
None—died suddenly	6 (21)	6 (23)	0.02
Involved in decision making	17 (58)	10 (37)	
Not involved in decision making	6 (21)	11 (30)	
Impact of events scale:			
Median (interquartile range) score	5 (2-5.5)	15 (5-21)	<0.001
Score >30†	0 (0)	4 (15)	0.03
Hospital anxiety and depression scale:			
Median (interquartile range) depression	0 (0-1.5)	5 (0-9)	<0.001
Score >8‡	0 (0)	8 (30)	0.002
Median (interquartile range) anxiety	0 (0-3.5)	3 (0-6)	0.03
Score >8‡	0 (0)	5 (19)	0.02
Satisfaction with quality of death			
Family member§¶:			
Very satisfied	24 (83)	13 (48)	0.02
Satisfied	2 (7)	8 (30)	
Not satisfied	3 (10)	6 (22)	
Family member's perception of patient's satisfaction**:			
Very satisfied	25 (86)	10 (37)	<0.001
Satisfied	1 (4)	10 (37)	
Not satisfied	3 (10)	7 (26)	

Summary

- Many die without making our wishes known
- There is considerable concern in society and medicine about over-treatment
- Early Palliative care dose NOT result in earlier death
- Being given an opportunity to consider dying matters improves outcomes

People only die once;
they have no experience to draw upon.

They need doctors and nurses who are willing to have the hard discussions and say what they have seen, who will help people prepare for what is to come.

Gawande, A. (2010): Letting go,
Annals of Medicine, The New Yorker

Components of discussion

- Patient understanding of
  - Disease
  - Choices
  - Values and beliefs
  - Wishes
  - Substitute decision maker

Detering KM, BMJ 2010;340:c1345

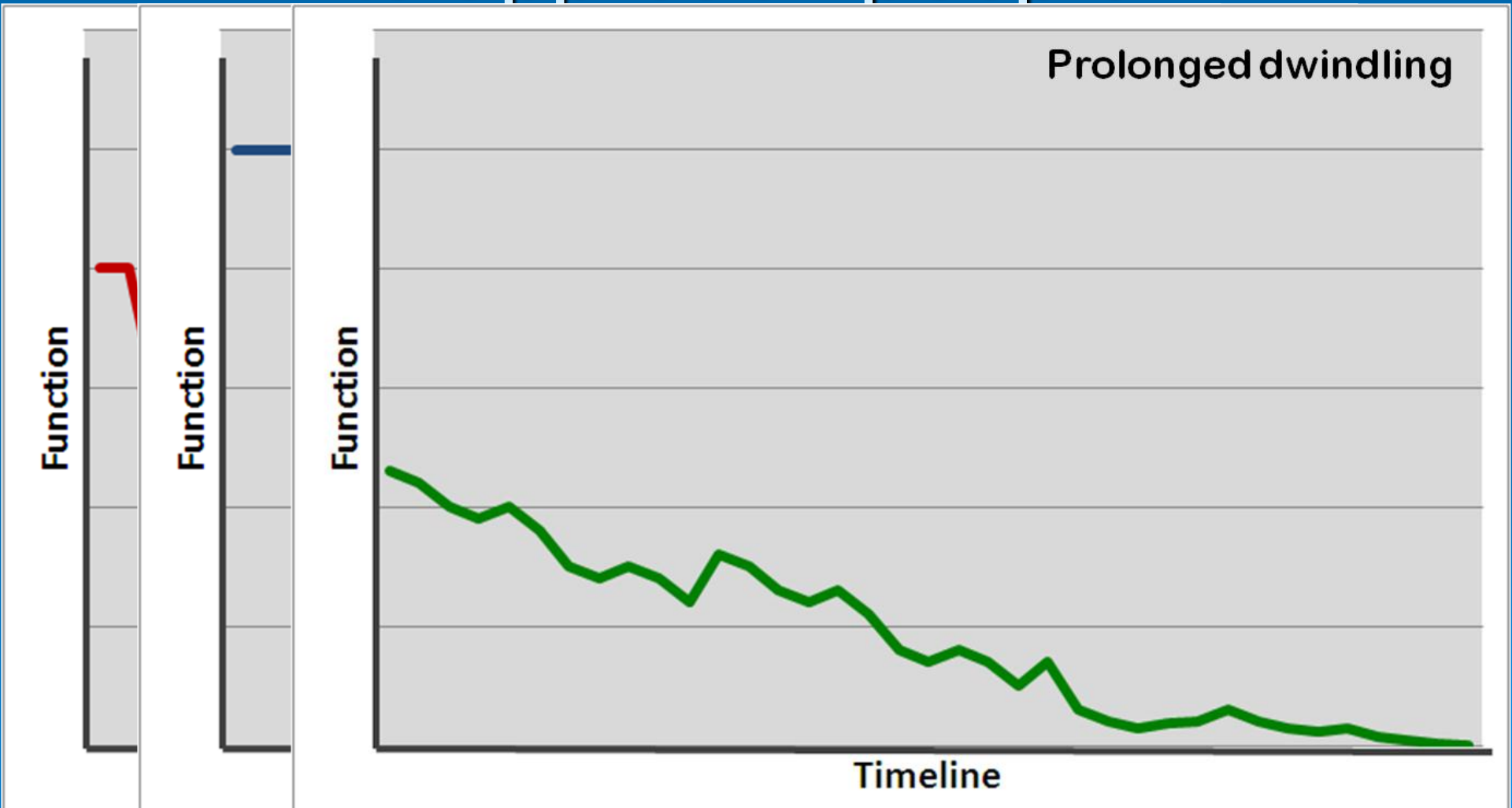
Barriers to having advance care planning conversations?

- **Cure culture**
  - **Health professionals**
  - **Consumer beliefs**
- **Medical specialisation and role specialism**
- **Pater-/Mater- nalism**
- **Cultural sensitivity**
- **Complexity of prognostication**

Common concerns

- Am I the right person to be taking this on?
- Is the patient too well/sick?
- Should the family be here?
- How to start the conversation?
- What happens if it goes wrong?
- How long with it take?

Barriers to having advance care planning conversations … WHEN to approach people



Missed cues

- Veteran Affairs, Heart failure out-patients
- 13/71 consultations cues were given
- 11/13 were missed by doctors
  - Fail to acknowledge
  - Termination
  - Hedging
  - Denial

Sangeeta CA, J Gen Int Med; 2011

Table 3. Patient Statements Representing Opportunities for Advance Care Planning

Categories of Patient-Initiated Statements	N (%)	Quoted Example
Expressions of emotion regarding the possibility of future decline or death	21 (40)	"I made 72 on Sunday, now I just have to make it to 73. I hope I make it."
		"Getting ready to die pretty soon…everybody got to die."
Requests for information regarding prognosis or trajectory	19 (36)	"About my weak heart, when will it get stronger?"
		"I'm just wondering how fatal do you think—? I mean, any time?"
Articulation of preferences regarding heart failure-related treatments	12 (24)	"I didn't want to take Coumadin, y'all fought me to get the Coumadin. But I don't want it."
		"I don't know. I don't want to do [surgery]…I was about ready to say no. Nothing. Leave me alone."

Suitable patients

- “I would not be surprised if this patient died within one year”
- Seriously ill
- Likely to kill them
- Predictable decline.

Will it take more time?

Consultations which were cue based were shorter that those in which cues were missed

- GP consultations 12.5%
- Surgical consultation were 10.7% shorter

Levinson et al 2000

In oncology consultations, addressing cues, reduced consultation times by 10-12%.

Butow et al 2002

Essential steps

- Be prepared
- Stop and listen – Silence can help Eide et al 2004
- Allow the patient to control the pace
- Document discussion
- Ensure all team members are aware

Advance care planning is a process not a form

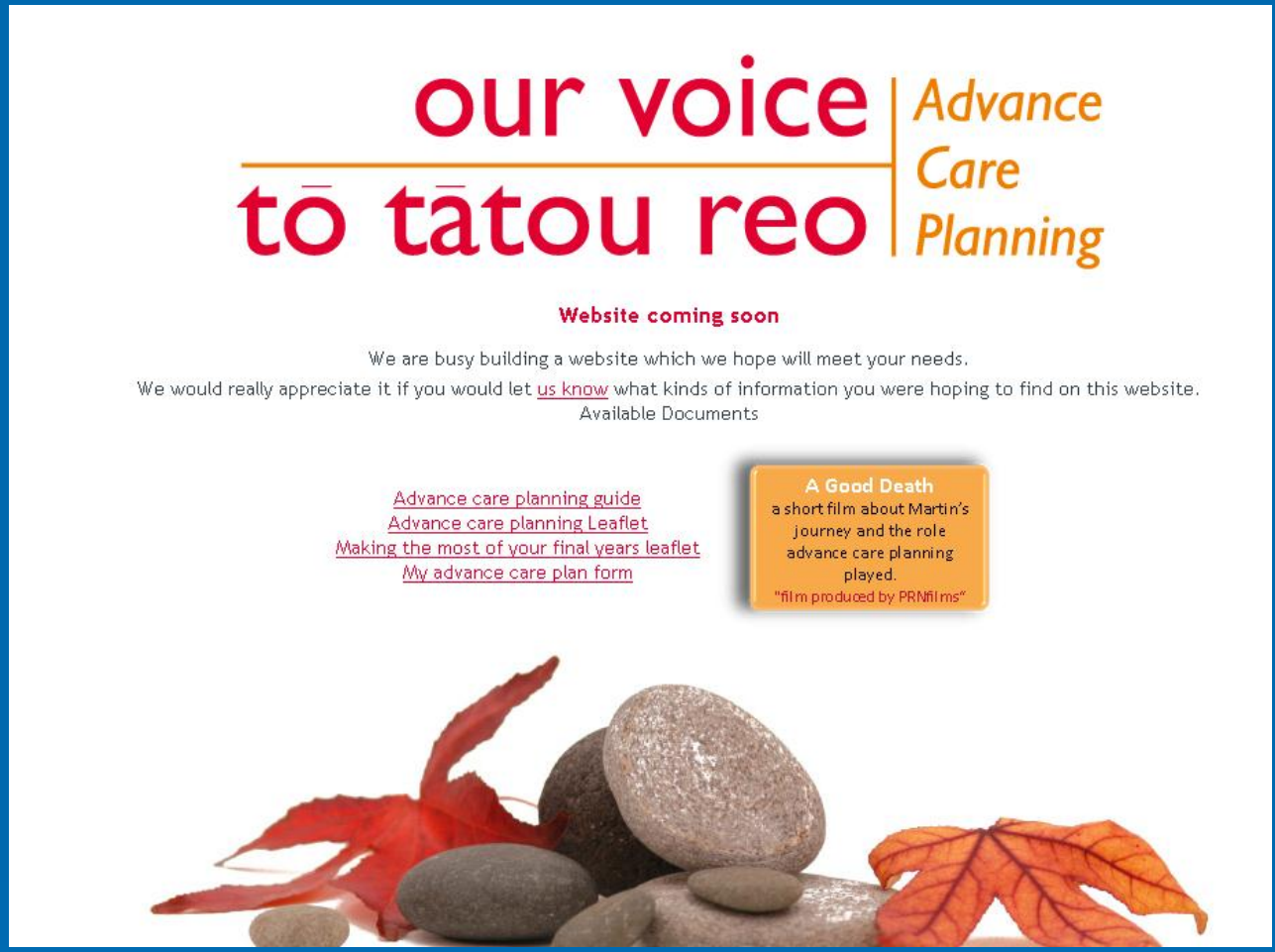
c/f consent for surgery

Please consider your own Advance Care Plan.

GPCME Dunedin 2012

Discussion

- What is good?
- What is bad?
- What is hard?
- Where are the blocks?



advancecareplanning.org.nz