A Modest Advance Care Plan!

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What's new in this document?

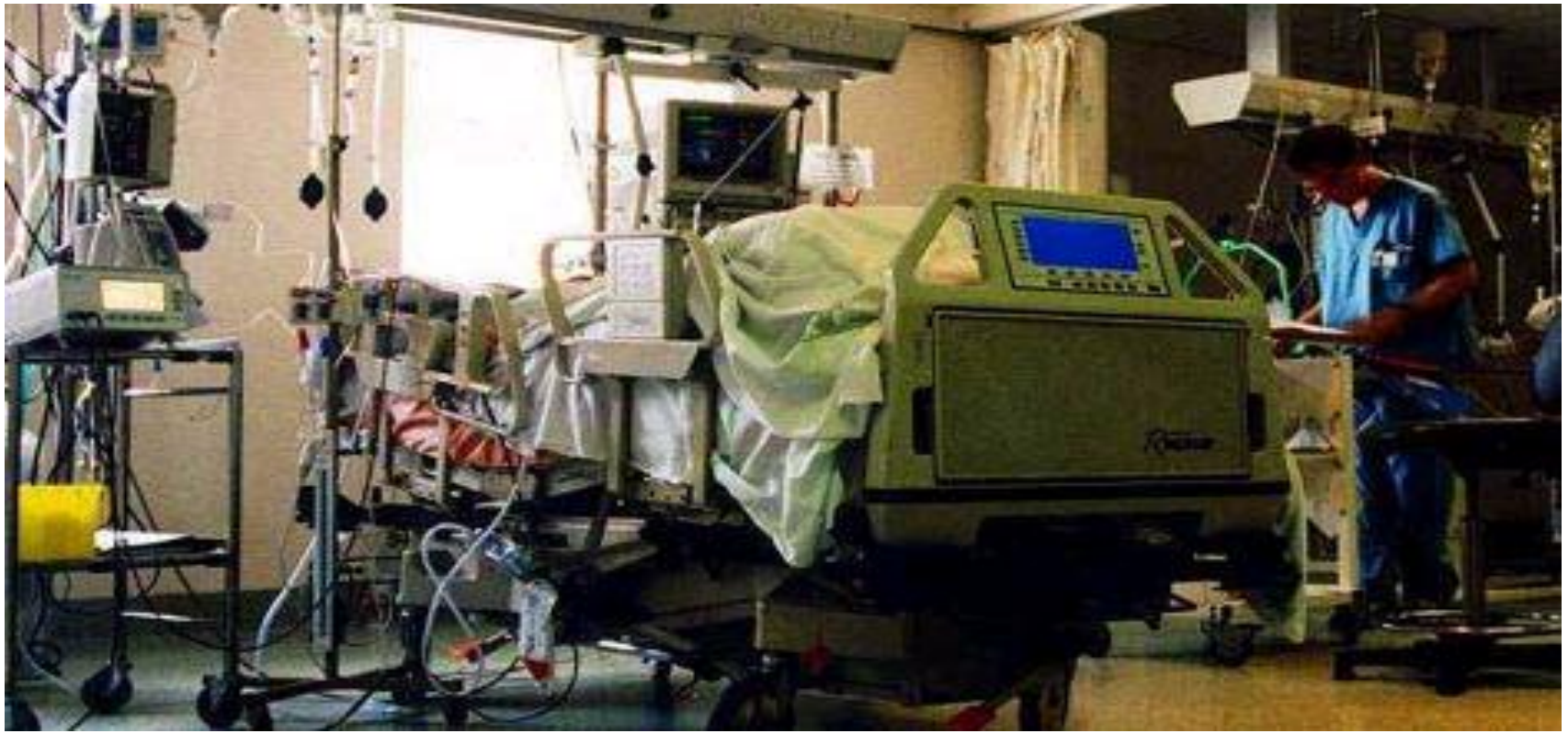
- It's shorter and more succinct; the print is bigger!
- With an emphasis on the positive – ***what would be important to me at this time?***
- It clarifies the legal situation – **there's always someone who will represent me**
  - *Do I know who it is? Do I want to determine who it is? How will my doctors know who it is?*
- But **making decisions for someone else can be difficult**
  - ***So how can I help that person?***

A Modest Document!

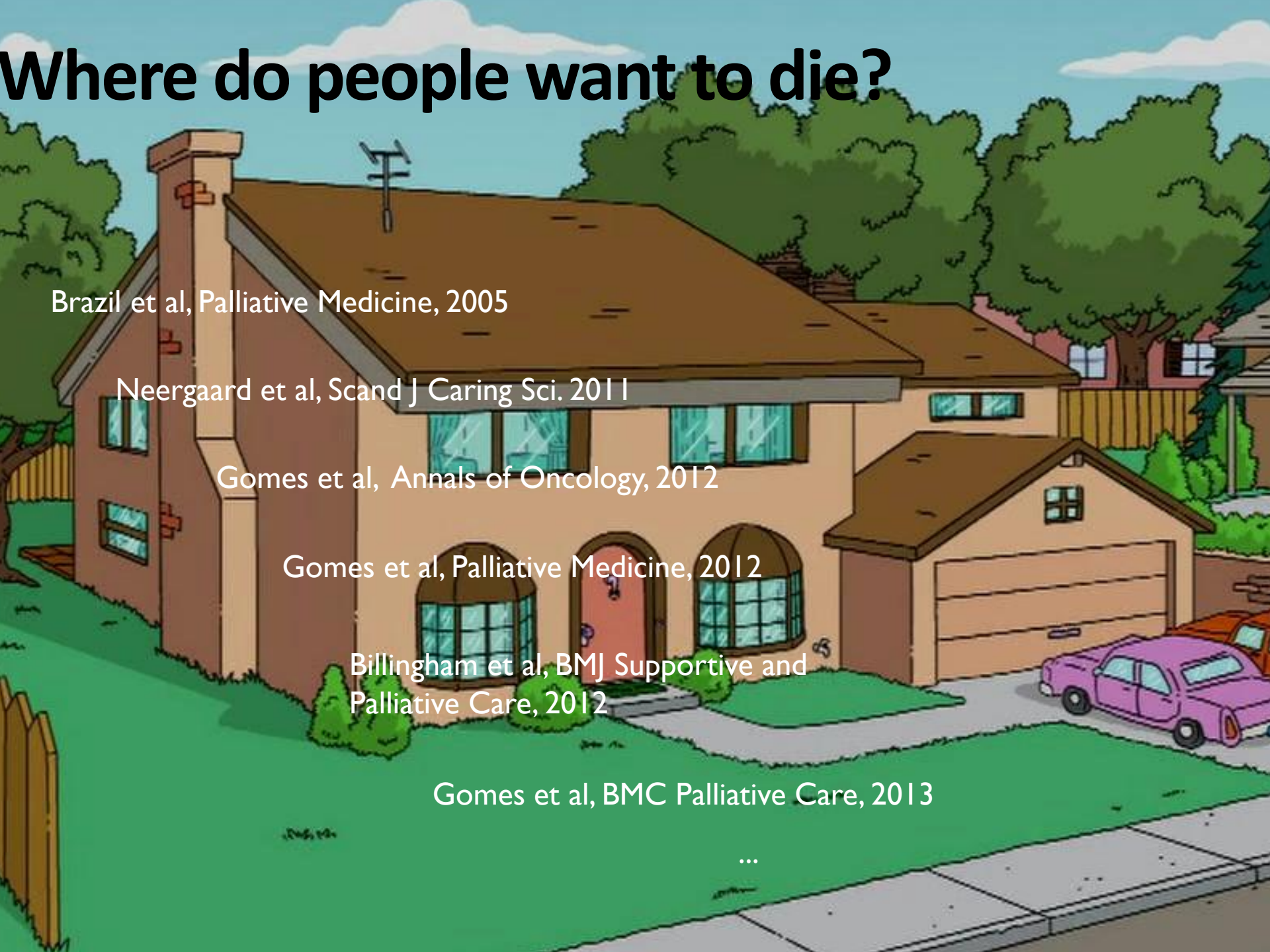
- Not the same as a "Medical Care Plan" that <u>should</u> be developed by & with one's health care professionals
- *e.g. End of Life Integrated Care Pathways & Supportive Care Plans, involving medical consultants, palliative care, GP, nursing and home care etc.*

- The primary challenge for EoL planning is for health professionals. One study found:
  - **Patients informed they were dying: Haem/Onc/XRT 33/192; Non-cancer 58/290**
  - **Relatives aware of patient dying: Haem/Onc/XRT 171/192; non-cancer 224/290**

67% of Australians die in an acute hospital



Where do people want to die?



Brazil et al, Palliative Medicine, 2005

Neergaard et al, Scand J Caring Sci. 2011

Gomes et al, Annals of Oncology, 2012

Gomes et al, Palliative Medicine, 2012

Billingham et al, BMJ Supportive and Palliative Care, 2012

Gomes et al, BMC Palliative Care, 2013

...

Dying in Hospital: Medical Failure or Natural Outcome?

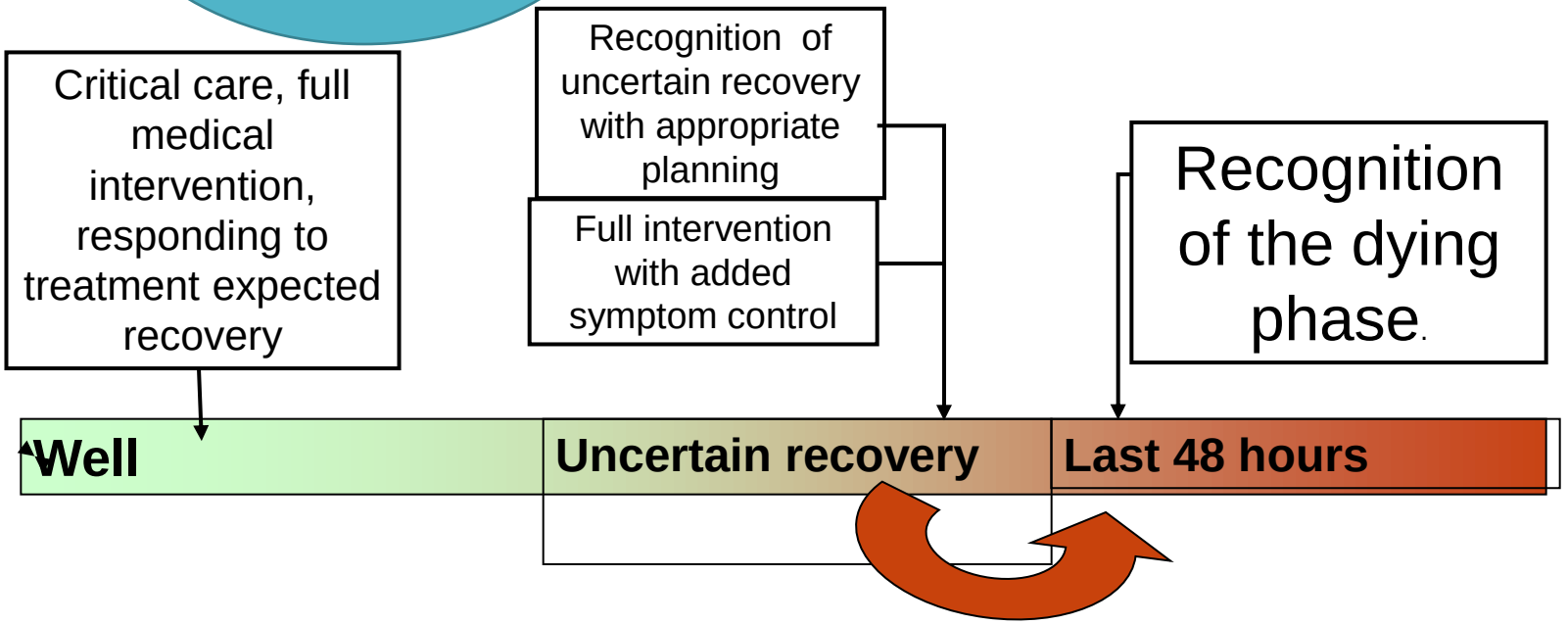
Middlewood et al, JPSM, 2001

The results of one study found:

- Late implementation of care plans and lack of clarity within plans
- Many patients subjected to invasive interventions up to the time of death
- Unrealistic imperatives to prolong life.

A Critical Approach to Clinical Thinking

What is needed?



Early planning	**Gold Standards Framework Approach**	EoL Integrated Care Pathway

Some signs that detailed Supportive & Palliative Care planning is needed

- Cross-sectional ward census, "would you be surprised…still alive 1 month?"
  - *Rapidly deteriorating, clinically unstable, limited reversibility?*
  - *3 or more hospital admissions past 6 months?*
  - *Possibility of rapid deterioration?*
- Decreasing functional status?
- Organ failure with limited recovery or continuing deterioration?
- End-stage organ disease/Prognostic indicators?
- Length of stay in ICU/HDU?
- Conflicts in care, including psychosocial?
- Complex or uncontrolled/refractory symptoms?

Advance Care Plans are not "set and forget"!

- These plans are **one** important contribution towards the more detailed integrated planning needed towards the end of life
- My Advance Care Plan should help **begin** an integrated planning process
  - E.g. If John really wishes to die at home, then plans need to be made about if & how he can be cared for at home, what will happen in case of emergencies, when admission to hospital might be appropriate, what limitations on treatment would be appropriate etc.
- This is why it is best not to give specific medical instructions far in advance, but rather to focus on what would be important to me when EoL planning is needed

When EoL planning is needed, how can my **Advance Care Plan** help my representative?

- **By being based on sound ethical principles – *do what is right!***
- **Key question: when is it right to stop (or not start) a treatment?**
- **<u>Key Principle</u>**
- **Life is a gift from God, a gift to be cared for by all reasonable means**
- ***But not by means that prolong distress or impose serious burdens on ourselves or others, including financial burdens!***
- **Why not? [*Why not just suffer the burdens!*]**
- **Because length of life is not an end in itself; just staying alive is not an absolute value.**
- **"when life is ending we trust in the providence of God" (CHA Code, p. 2)**

Care towards the end of life

- **Always provide basic nursing care**, which ordinarily includes food and water
- **[RESPECT FOR THE GIFT OF LIFE, RESPECT FOR THE PERSON]**
- **Judge other treatments** by whether they will be **effective**, and/or by whether they will impose **serious burdens** on the patient or on others (including the community)
- **[PHYSICAL LIFE IS NOT AN ABSOLUTE, PERSONS ARE MORE THAN BIOLOGICAL]**

Care towards the end of life

- Often a judgment is needed about whether the burdens of a treatment option are proportionate to its benefits for a particular patient
- **For John, the side-effects of radiation therapy may not be worth any short extension of life that *might* be achieved.**
- **Mary might prefer to put up with some pain, in order to stay lucid for some time each day**
- **For Peter, the unpleasant side-effects of treatment might be accepted if he can stay alive till his daughter's wedding**
- **Kate would prefer to forgo a treatment that might just prolong her life because it would mean going to hospital, and probably dying there!**

So we need to know *what is important* to those we speak for!

- Time with family and friends
- Respect for my culture
- Effective pain relief
- Interventions that would not be distressing
- Not putting financial burdens on my family
- Time for family reconciliation
- Time for spiritual counsel and prayer
- Music and art
- “Hospital in the home” and “Home in the hospital”

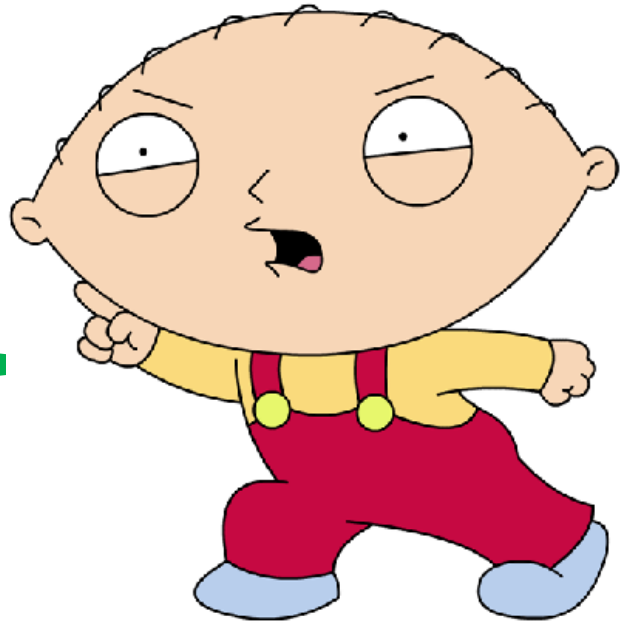
Bad Words

If her heart stops do you want us to restart it?

Do you want us to do everything?

There's nothing more we can do

We're going to stop treating her



http://emcrit.org/podcasts/critical-care-palliation/

A (Modest) Advance Care Plan

- Records what would matter most to me when I near the end of life
- Does not require my life to be prolonged at any cost
- Recognises the limits of medicine, and limits of my obligation to prolong my life, and the non-medical factors also relevant
- Does not try to anticipate in detail all the possible medical scenarios that might eventuate
- Helps my family and health professionals in their EoL planning to ensure that my wishes will be respected and acted upon as well as reasonably possible