

# What is advance care planning?

... ‘a process, whereby a patient, in consultation with health care providers, family members and important others, makes decisions about his or her future health care, should he/she become incapable of participating in medical treatment decisions’.

*Peter Singer et al 1996*

Ethical principles      - autonomy      - informed consent  
   - dignity              - prevent suffering

# Autonomy

“Every human being of adult years and sound mind has the right to determine what shall be done with his own body”

*Justice Benjamin Cardozo 1914*

## Autonomy

- informed consent
- dignity
- prevent suffering

## Why is advance care planning important?

Most people (~ 85%) will die after chronic illness, not a sudden event

Up to half of us are not in a position to make our own decisions when we are near death

Our family have a significant chance of not knowing our views without discussion

A doctor who is uncertain about what to do, and who has to make a decision, will often treat aggressively

Many of us will be kept alive under circumstances that are not dignified, frequently suffering and in a way that we would not have wanted

## A Successful Advance Care Planning Program

- *Respecting Choices*®
- Community wide program La Crosse, Wisconsin
- First applied to select patient groups in hospital then extended in the hospital and the community
- Recognised as “best practice” by The [US] National Coalition on Health Care and The Institute for Health Care Improvement

## What do they do that's different?

- trains targeted non medical staff to talk to patients and NOK about advance care planning
- supports patients to complete ACPs
- ensures that the ACPs are readily available
- educates medical and other key staff

## Respecting Choices: the result

- Community results 2 years post implementation
- 85% of patients who died had completed ACPs (increased from 15% pre-program)
- 96% of ACPs were available in “the green sleeve” in patient medical records (increased from 4% pre-program)
- In 98% of deaths the patient’s wishes, as stated in the ACPs, were followed
  - 100% no CPR
  - 18% no feeding tube
  - 32% no hospitalisation
  - 17% no ventilation

## Reasons for success?

- Treats advance care planning as an ongoing process, not as an event designed to produce a product
- The discussion is about living well and the person's goals, values and preferences, not about death and resuscitation
- Does not require doctors to initiate discussion
- Guides the discussion: “How can you guide your loved ones to make the best decisions for you?”
- Works with hospitals and GPs to ensure that completed advance directives are available

*Prendergast T.J. Advance care planning: pitfalls, progress, promise. Crit Care Med. 2001; 29 suppl:N34-N39*

## Pilot study at the Austin Hospital

- Funded by National Institute of Clinical Studies
- Aug-Dec 2002: Trained 120 nurses, social workers, pastoral care workers, interpreters, some doctors
- Piloted
  - aged care, oncology, cardiology,
  - nephrology, vascular & thoracic surgery
- > 1000 RPC discussions with patients/NOK

## The “Five Aims of RPC”

- *Initiate conversations with adults regarding views about future medical care*
- *Assist individuals with advance care planning*
- *Make sure plans are clear*
- *Ensure plans are available*
- *Appropriately follow plans*

# Pilot study evaluation

Evaluation 1<sup>st</sup> – 30 April 2003

306 patients

- Average age - 70 years
- 56% males
- 8.5% non English speaking background
- 14% patients in hospital < 48 hours
  - range < 24 hours to 94 days

## Pilot study impact

- Patients' wishes are being respected and followed through:
  - "if I deteriorate I do not want resuscitation or to go to intensive care, I want to be kept comfortable and dry"
  - "I want to die at home and not return to hospital"
  - "Please make sure that I die outside, under the stars"

# Patient anxiety & ACP

ACP does not create anxiety when introduced sensitively:

- ✓ Is routine of care... "We ask all our patients."
- ✓ Invites patient to clarify values, to have control, while addressing fears... "We are here to take care of you in all circumstances"
- ✓ Focuses first on discussion and be open to decisions... "It is helpful to discuss these issues so you and your family understand."
- ✓ No patient is force or required to participate.

## Where is the ACP going to be kept

- When a resident is introduced to the Respecting Patient Choices program a “green sleeve” containing a Discussion Card is placed at the front of their current medical file.
- If an Advance Care Plan is completed it is folded and placed behind the discussion card in the “green sleeve”