



Respecting Patient Choices

**Advance Care Planning for all
Australians**

Dr Karen Detering
Austin Health

Case study of Patient AG

Patient Background

81yo married man

- Diagnosed with interstitial lung disease
- Poor response to treatment.

Respecting Patient Choices

RPC was introduced.

- initial contact he declined.
- 6/12 latter approached again
- Over 3 visits documented his wishes:
 - Not for intubation or ICU
 - Not for other aggressive management



AG Continued

- Discussed his wishes with his GP
 - These were documented
- 3/12 latter
 - became acutely breathless at home
 - wife rang GP, not ambulance (as he would have previously done).
 - GP attended him and provided comfort care at home and he died.



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’.

Singer, Peter A., Robertson, Gerald & Roy, David J. (1996). Advance care planning. Bioethics for clinicians series 6. *CMAJ*. Volume 155(12).



Advance Care Planning Is Based On...

Ethical principles

- Autonomy
- Informed consent
- Beneficence vs. non maleficence
- Dignity
- Patient suffering
- Patients' rights



Why is ACP important?

- Most people die after chronic illness, not sudden event
 - 80% of deaths occur under medical care
 - Up to half of us not able to make our own decisions when we are near death
 - Family & friends have a significant chance of not knowing our views without discussion
 - A doctor who is uncertain about what to do, will, with good intention, treat aggressively
- ⇒ Many of us - kept alive under circumstances that are not dignified, and in way we would not have wanted



Is Advance Care Planning needed?

- Discrepancy between wishes of dying patients and their actual end-of-life care
- Conflicts may arise in medical decision-making at the end-of-life
 - Within families
 - Between families and health team
 - e.g. Terri Schiavo, Maria Korp
- Difficult for family members, health workers to make decisions where wishes of patient are unknown



Some Previous ACP Initiatives

- Medical Treatment Act Victoria 1988
- USA – Self Determination Act
- SUPPORT Study - US \$28M (1995)



Reasons for Failure....

- Communication between doctors and patient's sub-optimal
- Cultural resistance to discussing EOL care
- Individual's values and preferences not known
- Written plans:
 - do not reflect an individual's preferences
 - not accessible
 - not clear or are irrelevant



Some Previous ACP Initiatives

- Medical Treatment Act Victoria 1988
- USA – Self Determination Act
- SUPPORT Study - US \$28M (1995)
- Respecting Choices® - La Crosse, Wisconsin



What is Respecting Patient Choices?

- An advance care planning program
- Medical and **trained non medical staff** facilitate advance care planning (RPC consultants)
- Uses current state legislation
- Promotes discussion
- Encourages patients
 - Document wishes (medical & non-medical)
 - Appoint a surrogate decision maker



Key Elements of the RPC Program

- On-going process
- Focuses on discussions and not documents
- Discussions about beliefs, values, goals and preferences
- Staff undertake a two-day training program
- Most RPC consultants are non medical
- Documentation incorporates current available legislation



Program Aims

1. Initiate conversations with adults regarding views about future medical care
2. Skilfully facilitate planning with each individual
3. Make sure all advance care plans are clear to all involved and specific to each person
4. Make sure that plans are available when needed
5. Appropriately follow plans in a thoughtful and respectful way



Evaluation of RPC program

- Registered aged care facility (RACF) implementation
- Acute hospital implementation
- What does the community think?



Evaluation of RACF implementation

- 1108 residents in 17 RACFs over 2 years
 - Median age 86 years (76% female)
 - 37% competent, 38% incompetent
- 51% introduced to RPC
 - 52% residents / families completed Advance Care Plans – cf 3% not introduced ($p < 0.0001$)
 - 42% completed by resident



What was requested?

- 90% - **no life-prolonging** measures
- 87% - **symptom and pain** management
- 34% - to be **cared for at the facility** at end-of-life
- 17% requested brief admission to hospital
- 6% requested admission to hospital for aggressive treatment

- Many other personal requests



What were the outcomes in RACF's?

- 16% of residents died during the 2 year evaluation
 - 58% of the deceased - introduced to RPC
 - 89% ACP (42% no RPC)
 - 96-100% of their wishes were respected
- 85% with ACPs EOL care at facility (33% no ACP)
- Likelihood of dying in hospital
 - greater without RPC introduction
 - Longer LOS
(46% with LOS 15.3 days vs 18% with LOS 6.9 days)



Austin Hospital - implementation

- Pilot phase
 - > 1000 RPC discussions with patients /NOK
 - 63% of patients had RPC discussion
 - 68% of discussions resulted in documented request (ACP, NFR, other)

(Pre-program - no ACPs / 10% with NFRs)

- By August 2003 - 49 (16%) patients had died
 - 74% had documented wishes in medical record
 - 95% of main wishes have been respected



Austin Hospital – outcomes cont.

- Since 2003 – RPC has continued in pilot areas, and been expanded in these areas
- Also introduced to respiratory and general medicine, some outpatient areas



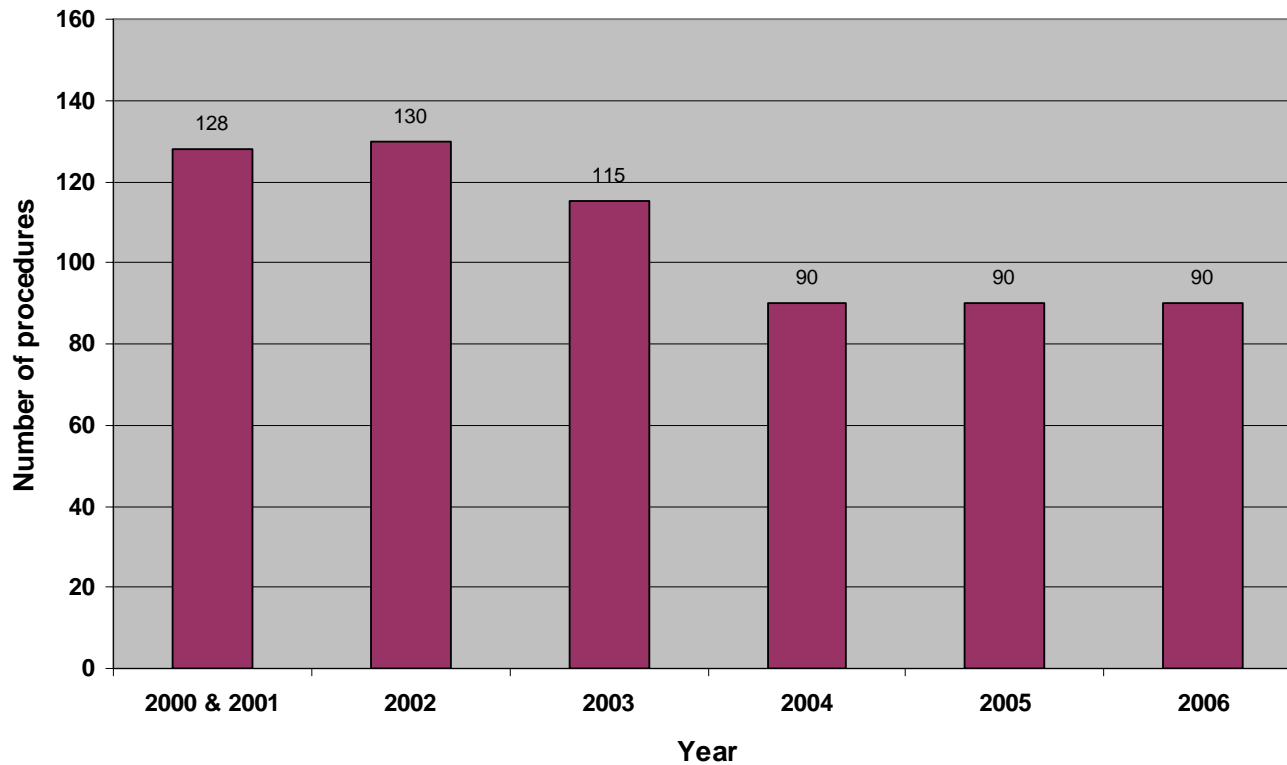
Austin Health Respiratory RPC

- Pre program – Off patients who died
 - 70% had NFR (only 15% discussed with patient)
 - 5% MEPOA
 - No clear documentation of patient wishes
- Post implementation
 - 100% wishes documented
 - Most - discussion with patient/ family
 - Most did not want life-sustaining treatment
 - Some change in location of death



Austin Health: Tracheostomies

Number of Tracheostomies inserted at Austin Health



Austin Health : Impact - Patients

- Patient's wishes - being discussed & documented, and are available for staff and loved ones to see:
 - “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“
 - “I want to donate my organs, but not for research”
 - “I want the Essendon 1993 Grand Final playing



Austin Health: Impact - Staff

- Marked change in culture in staff in RPC areas
- ‘Now most staff are much more comfortable with addressing end-of-life issues with patients’
- Doctor’s now address treatment options & CPR status with patients earlier
- Less conflict btw staff regarding patient management
- Increased and effective communication between staff and patients as Advance Care Plan is available



Patient anxiety and ACP

ACP does not create anxiety

- “We ask all our patients.”
- Patients can clarify values, maintain control, & address fears - “we will take care of you in all circumstances”
- Discussion is encouraged
- No patient is forced to participate.
- Patients expect us to raise the topic, and most are interested in ACP



What Does the Australian Community Think?

- Advance care planning is a new concept
- Needs to be introduced by health professionals in a non-threatening and sensitive way
- People want reassurance that completing an ACP does not mean they will be 'abandoned'
- Advance care planning needs to be differentiated from euthanasia
- Most people are willing to discuss issues about end-of-life
- Individuals want assistance to talk with family about end-of-life care



Where is RPC

- Victoria
 - 5 acute health services
 - 17 Nursing Homes and Hostels
 - Palliative Care – 2 sites
 - 2 divisions of general practice for implementation in RACF's
- Interstate – one lead hospital in each state



Case study of Patient GK

Patient Background

65 yo man, separated with 5 children

- Severe COPD
- Ischaemic cardiomyopathy

Respecting Patient Choices

Participated in RPC

- son appointed as MEPOA
- wished “trial” of life-sustaining treatment



GK continued...

- Presented with exacerbation of COPD
 - Managed on ward & deteriorated
 - Intubated, ICU for 3/7
 - No reversible factors & patient extubated
 - 1/7 latter,died with sons & wife present
- 1/12 later – family extremely happy with care received



Impact of RPC in pt GK

- Family very happy with care received
- Staff felt comfortable
 - Clear plan of management
 - No conflict
 - Reduced staff time required to manage patient and family
 - Staff happy with outcome as they knew patient wishes followed

