



# Advance Care Planning

Australasian Chapter of Palliative Medicine  
May 2008



# Introduction

- Topical in Australia
  - *NSWHEALTH* 2005
  - “Respecting Patient Choices” **Austin Health**
  - *AMA* 2006
- Topical internationally
  - UK, USA, Canada
- NOT just a Palliative Care issue



## Sir Raymond Hoffenberg, RCP 2006

*“Dying was once a relatively straightforward affair. If you had a terminal illness, there was little your doctor could do apart from relieve your suffering and comfort your relatives”.*

- Then came the arrival of life-supporting and life-extending measures...
  - When should they be used?
  - When could they reasonably be withdrawn?



## And a second change...

Expansion of human rights to embrace a demand for more patient autonomy

- Mentally competent patients have the right to accept or refuse any treatment offered to them
- This applies even to end-of-life decisions in which patients know that such choices may lead to their death
- This right also covers mentally incompetent patients who have previously expressed their wishes in the form of an advance directive

# Workshop format

- Presentation
  - Illness trajectories
  - ACP Terminology
  - Legal perspective
  - Obstacles
  - Opportunities
- Cases in small groups
- Discussion



# Cases

- Ethics
  - Autonomy
  - Consent
- Clinical concepts
  - Best interests
  - Futility
  - Morality
- Cultural dimension





# Illness Trajectories

- Described initially in progressive chronic illness by Lynn and Adamson in 2003
- Role of Palliative Care being re-evaluated
  - Not simply terminal care
  - Not restricted to cancer or to Hospices
  - Not a “line in the sand”
- “Illness trajectories and Palliative Care”
  - Murray et al, BMJ 2005



## US figures for patients >65

- 20% will die young due to an illness with a relatively short final decline (weeks to months) – typical of cancer
- 25% will die of an illness characterised by a slow decline, punctuated by dramatic exacerbations with a high chance of sudden death – typical of CHF and emphysema (cognition generally intact)
- 40% have very poor long term functional status with slow decline (dementia, frailty.... younger patients with MND and strokes)

# Short period of evident decline

Function

High

Mostly cancer

← Specialist palliative care input available

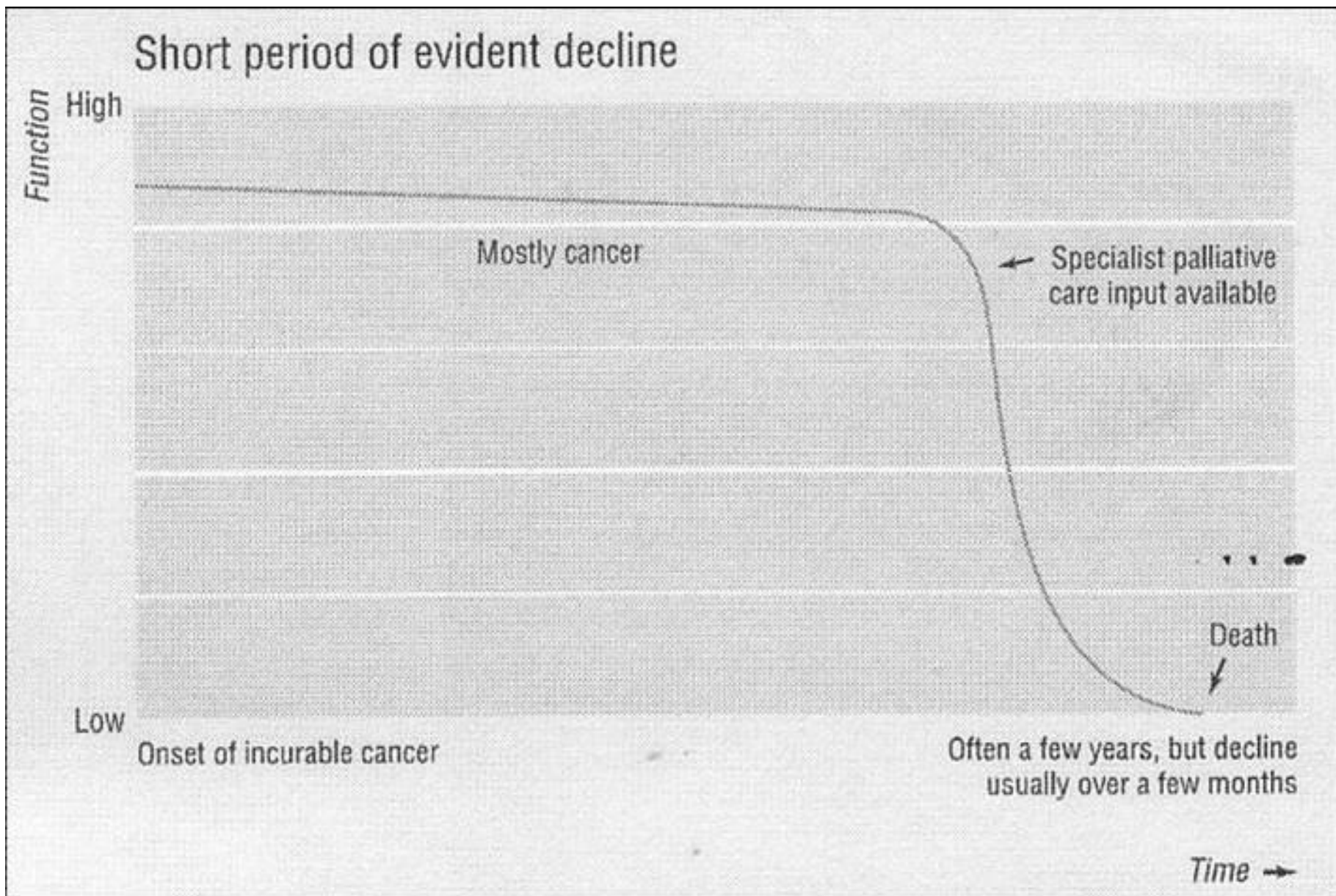
Low

Onset of incurable cancer

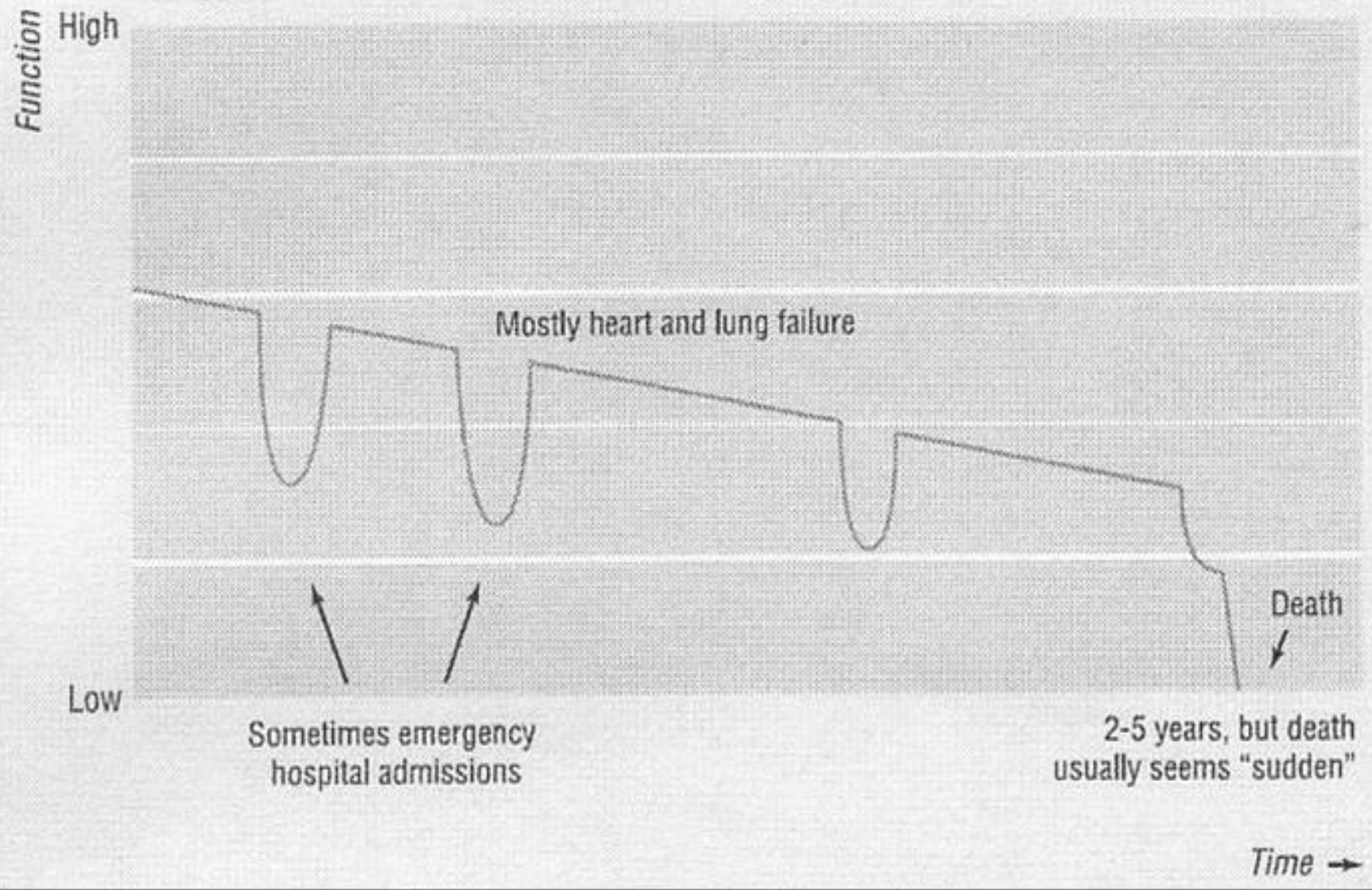
Often a few years, but decline usually over a few months

Death ↙

Time →



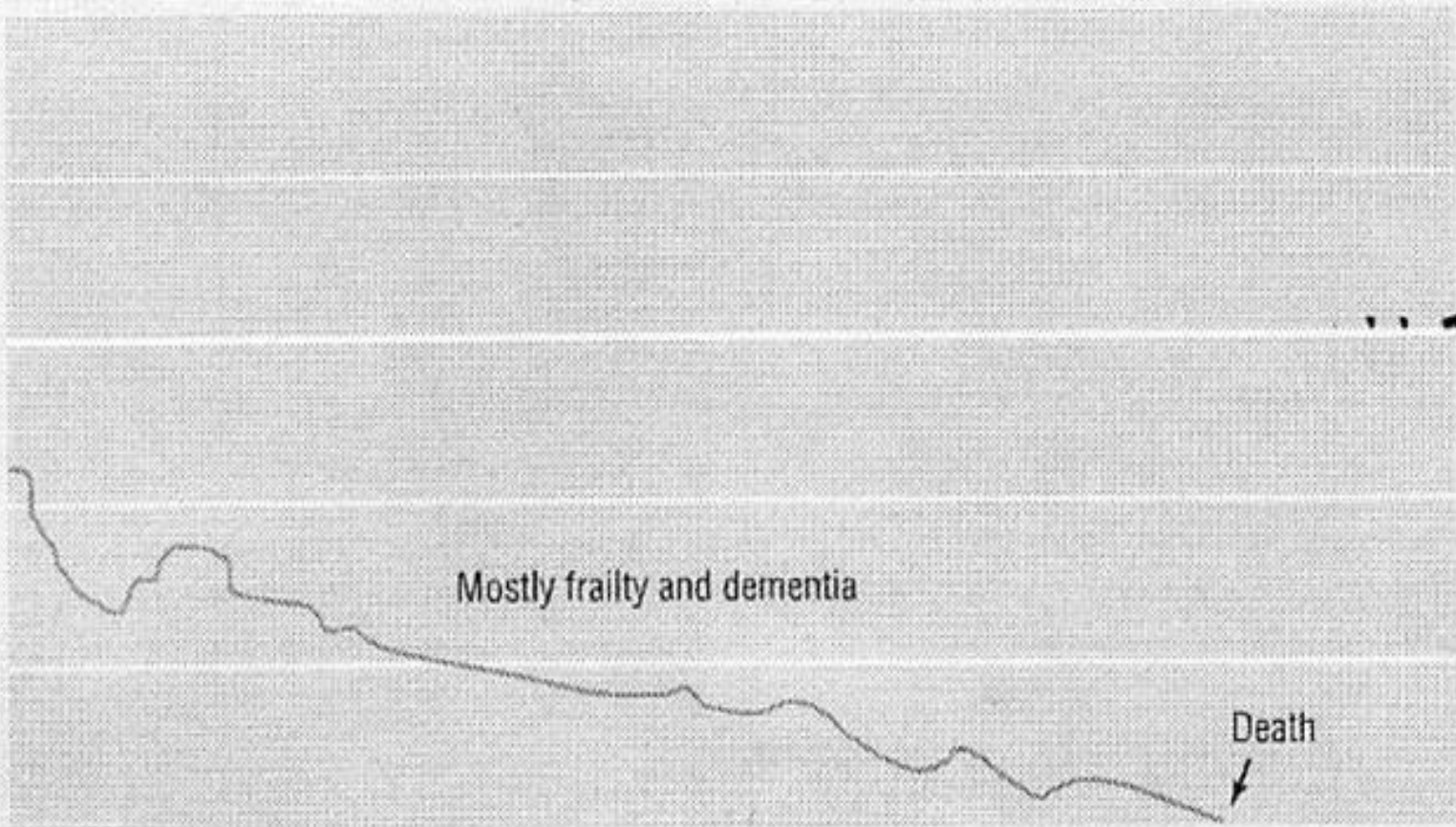
# Long term limitations with intermittent serious episodes



# Prolonged dwindling

Function  
High

Low



Mostly frailty and dementia

Death

Onset could be deficits in functional capacity, speech, cognition

Quite variable – up to 6-8 years

Time →



# Prolonged Dwindling

- These patients are likely to lose the ability to care for themselves long before death
  - Intensive personal care during period of dependency, imposing substantial burdens on paid and unpaid (family) caregivers
  - Occasional episodes of acute illness OR gradual loss of ground and eventual death
- “The numbers of people living with serious chronic conditions in old age will double in the next two decades in the US”

[www.agingstats.gov/](http://www.agingstats.gov/) (US Federal Statistics 2006)



## *Is this common knowledge?*

- For our patients? - probably not....
  - *“It won’t happen to me”*
  - *“I’ll worry when the time comes”*
- In the health care arena?
  - Would we make the same choices for ourselves (or our family members) than we make or advise for our patients?
- Can/should this information help shape services into the future?



## US and UK Directive regarding care for patients at the end of life

- Preferences for care are likely to vary more than for those with acute illness
- The authority to refuse interventions is an important protection for dignity and autonomy
- Care systems should encompass all people who are “*sick enough to die soon*”, even though some may live in fragile health for some years
  - NOT disease specific
  - NOT location specific



# ACP in Evidence

- Joanne Lynn (Am Coll Phys 2003)
- Gold Standards Framework (UK)
  - *Would you be surprised if this patient died within the next year?*
- “Preferred Place of Care” (UK)
  - Palliative Care/Aged Care Seminar, Sydney, 2007
- Respecting Patient Choices
  - <http://www.respectingpatientchoices.org.au>
- Five Wishes (40 States in the USA)



# Principles of ACP

Guidelines for end-of-life care and decision-making, NSW Dept of Health 2005

- Respect for life and care in dying (*dignity*)
- The right for patients to know and choose
- Appropriate withholding and withdrawal of life-sustaining treatment
- A collaborative approach to care
- Transparency and accountability
- Non-discriminatory care



## Principles (2)

- Healthcare professionals have rights and obligations
- Strive for continuous improvement

*Premise:*

*Timely and appropriate decision-making about end-of-life care is more likely to occur where those close to the patient understand the patient's wishes in advance.*



# Case 1

- 35 year old married mother of 2
  - Advanced breast cancer with brain and bone metastases - no longer responding to chemotherapy
  - Drowsy and withdrawn, but not confused
  - Recently treated hypercalcaemia, did not completely normalise
  - On IV fluids but clearly deteriorating
  - She has never spoken to medical staff or family about Hospice or end-of life issues.



## Case 1 (2)

- The ward Registrar meets her husband and best friend on the ward round. They both insist that she must not be told how sick she is, and indicate that she would want to have more chemotherapy even though it may not be working
- They ask about the hypercalcaemia and whether it can be re-treated



## Case 1 (3)

- What are your thoughts?
  - Decision making
  - Fluids
  - Calcium
  - Resuscitation status
  - Discharge planning

etc.....



# Let's re-cap...

ACP is.....

- Not only about the legal argument
  - Different jurisdictions
  - “Defensive medicine”
- Not only about loss of competence
  - Dementia, PVS
  - Intensive Care Units



# Motor Neurone Disease

- Personal interest
  - Close involvement with Dept Neurology
  - See patients early in course of disease
- Illustrates the issue very well
  - Fearful of losing capacity to communicate
  - Aware of the high likelihood of dependency
  - Aware of the decisions that lie ahead
  - Often “bursting to offload”



## Checklist for ACP in MND (Oliver)

- Medical therapy decisions
- Locus of care
- “Net” of care and support
- Psychological coping
- Personal organisation
- Advance directives
- Appointing a proxy



## ACP in MND

- Initial discussion to be initiated by physician
  - Part of a *durable* tri-partite relationship
  - Well in advance of terminal stages
- As detailed and specific as possible
- Appoint proxy in accordance with local laws/regulations
- Copies disseminated
- Regular plan of review (eg 6 monthly)



# Planning in advance – the options

- Patients can:
  - Develop an advance care plan in conjunction with their healthcare professional while being treated in a care setting
  - Discuss their preferences for life-sustaining treatment with their family before they are acutely ill (or after a health “scare”)
  - Formally appoint and inform a health care proxy
  - Write an Advance Directive (AD)



# Advance Care Planning

- Understood as a *process of communication* that may take place over a long or short period of time and may be initiated while a patient is healthy or when they are facing serious illness
  - Involves patient, family and physician (+/- others)
  - Not necessarily aimed at the creation of a legal document
  - Not just about future loss of competence



## Basically 3 options

1. Completing an Advance Directive to direct care
  - ACP/ Living Will/ Medical Directive
2. Appointing of a substitute decision-maker (also know as a Health Care Proxy)
  - Generally taken to be NOK/ spouse
  - Can be troublesome – esp in family conflict situations (resolution in court is very costly)
3. Personal letters/ wishes for care
  - Often oral



# Legal Issues

- Legal precedents
  - Persistent Vegetative States/ Jehovah's Witnesses
- Mental Capacity Act 2005 (UK)
  - “Advance Decisions to Refuse Treatment” came into force Oct 2007 (1<sup>st</sup> of 2 phases)
  - To be viewed as part of ACP, “*underpinned by Good Clinical Practice*” and incorporating the right for individuals to create a “lasting power of attorney”
  - Requires as assessment of mental capacity
  - An ADRT must Exist, be Valid and Apply to the circumstances outlined...



## In New Zealand

- In NZ, ADs are recognised in common law
- The appointment of an Enduring Power of Attorney (EPA) is the legal recommendation
  - Relates to property OR personal care (health)/welfare
  - It is easy to do
  - The patient and their SDM must be encouraged to develop their understanding
  - The hard thing is ensuring that the SDM is informed, supported and acknowledged



## NZ Code of Rights – Right 7

### *Right to Make an Informed Choice and Give Informed Consent*

- 1) Service provision is dependent on the consumer making an informed choice....
- 2) Assumes competence unless it can be demonstrated otherwise....
- 3) Diminished competence does not mean incompetence....



## Cont..

- 4) Where a consumer is not competent ... and no person entitled to consent on behalf of the consumer is available, the provider may provide services where it is in the best interests of the consumer and where reasonable steps have been taken to ascertain the views of the consumer



## Cont..

- 5) Every consumer may use an advance directive in accordance with common law
- 6) *Regards the issue of written consent...*
- 7) Every consumer has the right to refuse services and to withdraw consent to services
- 8) *Regards expressing preferences for carers...*
- 9 and 10) *Regards use and disposal of body parts and substances...*



## This can raise more questions...

- Would the provision of that service be consistent with the informed choice the consumer would make if he or she were competent?
- Have the views of other suitable persons who are interested in the welfare of the consumer .... been taken into account?



# In Australia

- In Australia autonomy is protected by:
  1. Common law - A doctor who knowingly conducts an invasive investigation or procedure against a patient's wishes can be charged with assault
  2. Statutory law – A doctor who knowingly conducts an invasive investigation or procedure against a legally binding AD (e.g. Refusal of Treatment Certificate in Victoria, an Advance Health Directive in Queensland, and the Natural Death Certificate in the NT) can be charged with medical trespass
- Legal protection if genuinely unaware



# In Australia

- 5 legally binding options:
  - Enduring Power of Attorney (financial/legal)
  - Enduring Power of Guardianship (lifestyle/medical)
  - Medical Power of Attorney (Health only)
  - Anticipatory Direction (Medical)
  - (Living Will)
- A competent person has the absolute right to refuse treatment and a valid and relevant Advance Directive is binding
  - An AD requesting the provision of life-sustaining treatment is not binding



# AMA position statements

- 2 complementary documents
  - The Role of the Medical Practitioner in End of Life Care – 2007
  - The Role of the Medical Practitioner in Advance Care Planning – 2006
  - ACP plays an important role in patient self-determination to articulate their current health care goals and values which may include the designation of a surrogate decision-maker to assist in health care decision-making



## AMA continued

- AMA acknowledges that ACPs are to become more prevalent in patient health care planning
- Recommends ALL States and Territories enact legislation that establishes advance directives as legally enforceable and consistent guidelines
- The same legislation provides statutory protection for doctors who comply with an AD (or who do not comply if they believe it is inconsistent with good medical practice)



## Case 2

- 72 year old married man
  - Supportive wife and adult children
  - Parkinson's Disease for more than 10 years
  - Independent until 12 to 18 months ago when began to experience physical as well as cognitive decline
- Gradually function has deteriorated & now;
  - Largely bed bound, incontinent
  - Confused intermittently and unable to participate in complex discussions
  - Increasing difficulty swallowing foods / meds



## Case 2 (2)

- There is NO advance care plan in place.
- You are asked to review him and his wife reports he is unable to swallow anything.
  - What are the options for his treatment?
  - How can you ascertain the patients wishes?
  - Who should be involved in the discussions?
  - How might you approach these conversations?



## Case 2 (3)

- On examination he is febrile, tachycardic, hypotensive and drowsy with bronchial breath sounds at his right base - you suspect aspiration pneumonia.
  - How does this alter the options, discussions and decisions?
  - When is the best time to have these conversations and who should be involved?
  - Are the patient's wishes in relation to resuscitation known?



## Why encourage ACP?

- Patients have a right to participate in the planning of their health care and Physicians have a “legal and professional responsibility” to assure this, even if the patient loses decision-making capacity
- The process of determining those preferences builds trust and a sense of teamwork between patient, proxy and physician
- The invitation to discuss future plan permits the patient to explore and understand his or her own values, goals, priorities and preferences...



and...

- The sense of control and peace of mind that this process can foster in the patient and the reduction in anxiety of the proxy decision makers are important benefits
- Advance Care Planning is “Preventive medicine”!
  - Reduces confusion and conflict

Education for Physicians and the End-of-life Project, AMA, 1999



# Incorporating ACP into Practice

## Challenges

- Scepticism
- Role barriers
- Communication skills
- Fear

But it should (and it can) be done....



## The sceptics...

- Limited evidence that ADs substantially alter the course of end-of-life care
- Religious groups equate with euthanasia
- Risk of family coercion
- *“ACP is too idealistic and too time-consuming”*
- *“Completing when person is well is meaningless - people change their minds”*
- *“Proxies are not a good judge of preferences (this probably reflects lack of discussion between patient and proxy)”*



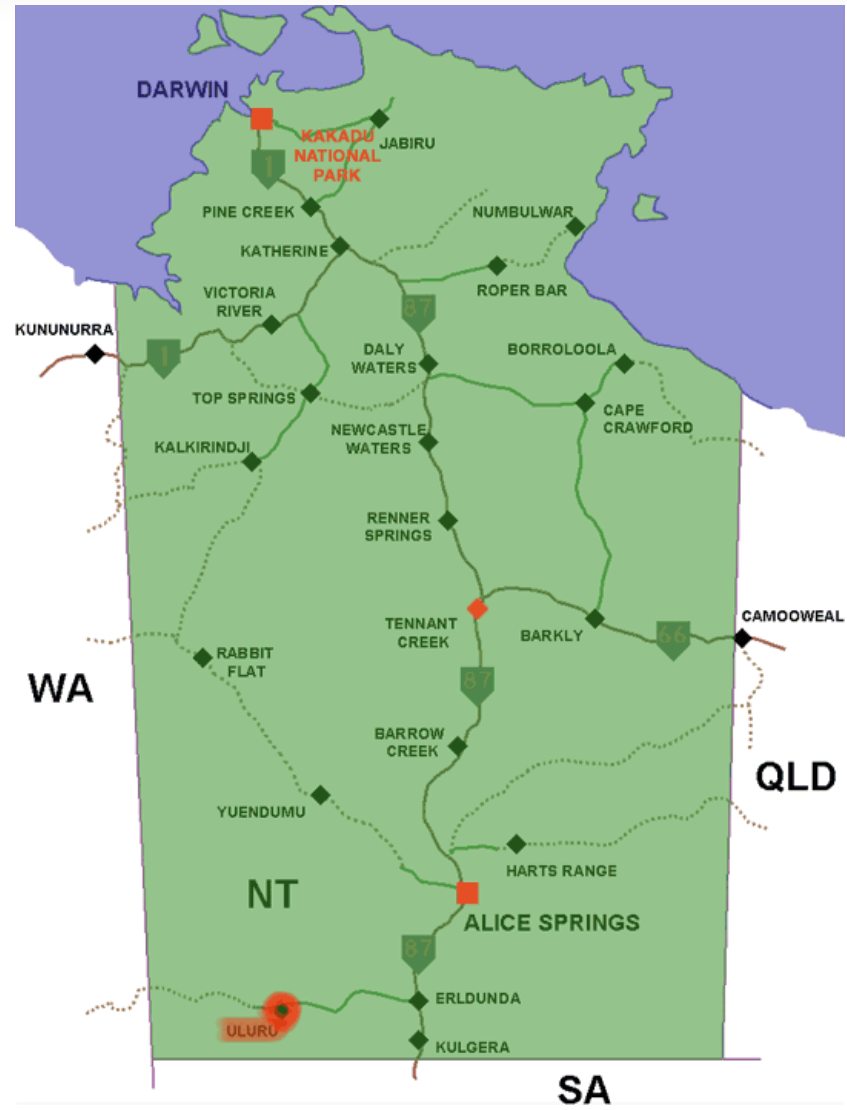
# ACP

- Not just about trying to ensure a patient's wishes are upheld when they can no longer advocate for themselves BUT...
- Also to facilitate/ encourage/ validate discussions about patient preferences at a time when they can calmly and in conjunction with loved ones, talk about what is important to them and what they hope for in the future
- Our obligation then is to refer to these wishes and requests - if and when such a situation arises



## Case 3

- Mrs CK, 48 year old indigenous woman
  - Married, 5 children, 8 grandchildren, carer for husbands parents, local school worker & important community member in Kalkirinji
  - Unwell for a few months but declined health worker advice to be seen at clinic in case kidneys were the problems : “ *people who go to town with kidney problems never come home, except for their funeral*”
  - In mid 2005 awoke in ICU - 500km away with “*a tube going into my neck and blood coming out into a machine*”





## Case 3 (3)

- Now required ongoing 3X week haemodialysis with consequent forced relocation from home to Katherine & town camp
- Early 2007 -Patient has not been home for 17 months and increasingly frets and requests cessation of dialysis to return home
- Late 2007 - Deterioration of physical function- moved from town camp to hostel but now local hospital dialysis unit cannot support care around dialysis provision – patient needs to move a further 300km to continue dialysis
- Decision - ACP meeting called



## Case 3 (4)

- The meeting
  - Patient
  - 5 pall care and hospital staff @ Katherine Hospital
  - 12 local family
  - Video link with 8 family on Qld/NT border town
  - 22 family and community members @ Kalkarinji



## Case 3 (5)

- What options are available for ongoing care planning around management of Mrs CKs renal problems?
- If the decision making doesn't sit with the patient how do we come to a decision and understand who is making decisions?
- Could advance care planning /decision making discussions have occurred at earlier points in the illness trajectory?



## Case 3 (progress)

- Initially there is concordance - patient and family decision makers (in the community) want dialysis to continue
  - Other family wants her transferred back to community and allowed to die
  - Transferred to Darwin renal unit awaiting accommodation
- 4 weeks later
  - Frail and depressed, now expressing the wish to be in her community irrespective of ongoing dialysis
  - Medical team recognises time for “finishing off” but decision makers not convinced



## Case 3 (conclusion)

- Family reconvened but this time on community with option of returning after 2 days for next dialysis via charter plane.....



# Points

- EOL decisions represent complex ethical and moral dilemmas that are likely to increase with advances in medical technology
- ACP does not always amount to cessation of treatment but may change as circumstances change
  - At some point it may no longer be seen as good medical practice to continue active treatment
- Autonomy for some cultures lies with others in a community/family structure
  - This may be formal or informal – ASK!!



## More points...

- The needs of ACP changes with time and understanding of the patients situation and how it relates to decisions may mean asking “*what is most important for that person and or his/her decision makers?*”
- Ask the patient/decision makers “ *Would it surprise you if you were to pass away/die from your condition in the next 12 months?*”
  - This is often a good way of initiating self reflection and framing a ACP discussion esp. for chronic illnesses



## To close....

- “Best interests”
- Communication skills
- Primary Care Context
- Gold Standards Framework
  - Five Point Plan
- Preferred Place of Care



## *“Best interests”*

- In an incompetent person the continuation or withdrawal of life-sustaining treatment is based on “best interests” or “good medical practice”
  - BUT not from a purely medicalised perspective
- Challenging concept
  - Clinical judgement and discretion
  - Huge variation in opinion
- As individuals...
  - What would we chose for ourselves/our family?
  - How can we truly know what is right for that specific individual?



# Taking our opportunities

- *“How long have I got?”*
  - Not merely a question of time but may also include questions about likely patterns of decline..
  - *“What will happen?”*, *“What can I expect?”*
- *“Planning for the worst but hoping for the best”*
  - Involves successful integration of active and palliative management
  - The aim is to help improve patients and families sense of control



# ACP in Primary Care BMJ Oct 2006

- Discussion on planning for the end of life is what many elderly patients want
  - Allows patients and carers to reflect on and reorient their aspirations
  - In reality it rarely happens even when continuity of care exists with a trusted GP
  - Probably a result of fear of destroying hope
  - But evidence suggest that such discussions engender hope rather than dispel it



# Gold Standards Framework

- GP practices in UK
  - Considerable evidence to support the integration of ACP into routine practice as part of good care for all patients with progressive life-threatening illness
- Five point plan
  1. Identify patients (Palliative care register)
  2. Assess current health and social needs



# Five point plan

## 3. Sensitive raise following points

- What elements of care are important to you and what would you like to happen?
- Is there anything you would wish not to happen?
- Do you have an EPA?
- If you deteriorate where would you like to be cared for?
- Have you any special preferences/requests/comments?
- Do you have a view on resuscitation?



## Five point plan (cont)

- These preferences should be communicated to other HPs (and family)
4. Provide proactive personalised care
    - Review regularly with patient and carer(s)
  5. If patients do not want a specific treatment should incapacity arise, seek specialist help to initiate a legal “advance directive”



# Preferred Place of Care (NHS)

- Nurse initiated
  - Deemed to be in advanced or terminal stages
  - Having input from SPC
- Patient held record
  - Taken into Hospital
  - Updated as needed
- Establish patient's understanding
- Some questions are very empowering
- *Not good enough if Health Professional doesn't feel like doing it....!!*

## Focus of ACP

- “...shifting from eliciting *refusal* of treatment from a minority of patients to identifying the *preferences* for care of most patients.
- Planning for death with our patients may be an uncomfortable concept but it is likely to engender hope rather than dispel it.” BMJ 2006





A very sick child once said to me.

*“The trouble with the health service is that it means people spend a longer time dying.”*

Perhaps she was right. There is a time to live and a time to die.

Personal View BMJ 2004

