

Advance Care Planning

for adults affected by life limiting conditions and the MCA

Implementing the MCA in End of Life care Oct 08

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Plan

1. ACP- why is it important ?
2. What can we learn from international developments and research?
3. ACP in the UK
4. Update on use of ACP in GSF- our experience in care homes and primary care
5. How can we begin? Where next?



Summary

1. ACP is a key part of the solution to improving end of life care. Relates to MCA- comes from a need to align activities and care with patient's wishes
2. ACP is well used and has been found to be of value in several countries, (with some hesitations)
3. ACP is now part of the NHS End of Life Care Strategy. Good experience of using it eg GSF, PPC. Needs to be offered routinely
4. The process of ACP is important- various tools.
5. Sensitive area- counterintuitive but also constructive



Advance Care Planning and the MCA Sect 4.6

- **4 Best interests**
The person making the determination must consider all the relevant circumstances and, in particular, take the following steps.
- 4.6. He must consider, so far as is reasonably ascertainable—
- **(a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),**
- (b) the beliefs and values that would be likely to influence his decision if he had capacity, and
- (c) the other factors that he would be likely to consider if he were able to do so.



We need some guidance on the way ahead - can this be ACP?



1.ACP- why is it important -1?

- Not yet getting it right with care towards the end of life.
- Pre-planning of care a means to improve this
- Close relation to implementation of Mental Capacity Act
- Research evidence that it is of benefit to patients, (with some caveats)



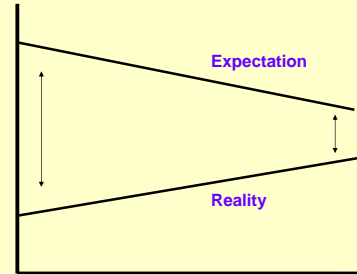
ACP- Why is it important 2

- Used extensively across the world
- Encourages pre-planning of care
- Enables better provision of service, related to pt needs
- Empowers and enables pt and family
- Some find increases 'realistic hope' and resilience
- Encourages deeper conversations at an important time



The Calman Gap Reality and Expectation

(Journal Medical Ethics, 84, 10, 124-127)



2. International Use +research - Advance care planning: original goals

- Ensuring that clinical care is in keeping with patient' preferences when the patient has become incapable of decision making;
- Improving the health care decision making process by facilitating shared decision making;
- Improving patients' well being by reducing the frequency of either under or over treatment

Teno, JM, Nelson, HL, Lynn, J. Advance care planning: priorities for ethical and empirical research. *Hastings Center Report* [special supplement] 1994; 24:532-36



Contemporary use in other countries

- Canada and Australia have followed the US example.
- Europe: varied but increasing.
- Often promoted in relation to choices about place of care, DNAR , documentation etc .
- In England, promoted as part of an 'End of Life Strategy'.



USA examples

- American ones web links
- Joan teno's work
- National Hospice and Palliative Care Organisation. *Advance care planning*. www.caringinfo.org/i4a/pages/index.cfm?pageid=3278 (accessed 13 Oct 2006).
- Fraser Health. *Advance care planning. Let's talk*. www.fraserhealth.ca/HealthInfo/AdvanceCarePlanning/Default.htm (accessed 13 Oct 2006).



Traditional vs Developing model of Advance Care planning as used in USA

Traditional Model

Purpose
Prepare for incapacity

Focus
Written Advance Directive

Context
Doctor/patient relationship

Developing Model

Prepare for death
Achieved control in health system

Relieve burden
Strengthen relationships

Written advance directive only aspect

Patient/family



Canadian examples

- ACP doc from Canada- Lets talk advancecareplanning@fraserhealth.ca
- Advance care planning guide - Ontario
- Victoria health



Hope and ACP

Davison Simpson BMJ

- ACP can enhance hope not diminish it
- Hope helps determine future goals and provide insight
- Information leads to less fear and more control
- Helps maintain relationships, preserve normality, reduce feeling of being a burden, encouraging sense of being in control,
- Empowering and enabling
- Current practice is ethically and psychologically inadequate

But...barriers

- Left to HCP to initiate discussion
- Busying over routine clinical issues



Australian examples

- **PREPARED - Thinking Ahead and Being Prepared Guidance for Advance Care Planning Discussions** From 'Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers'. Josephine M Clayton, Karen M Hancock, Phyllis N Butow, Martin HN Tattersall and David C Currow, *MJA* • Volume 186 Number 12 • 18 June 2007
- Hospital project - respecting patient choices - <http://www.respectingpatientchoices.org.au/background/about-us.html>
- Living and dying in style
- Hunter New England NSW Health. *Advance care planning*. www.hnehealth.nsw.gov.au/advanced_care_planning (accessed 13 Oct2006).



Communication Skills - being PREPARED

- P- prepare for the discussion
- R- relate to the person
- E- elicit pt and carer preferences
- P- provide information
- A- acknowledge emotions and concerns
- R- realistic hope
- E- encourage questions
- D- document



Research evidence 1

- Associated with death in place of choice and with use of palliative care¹⁻³
- May increase a sense of control⁴
- May increase congruence between preferences and treatment^{5,6}
- Narrow interventions focusing on AD completion not as successful as complex, multiple interventions.

1. Ratner E, et al *J of the American Geriatrics Society* 2001;49:778-78.
2. Degenholtz HB et al *Annals Of Internal Medicine* 2004;141: 113-117.
3. Caplan GA et al. *Age and Ageing* 2006; 35: 581-585.
4. Morrison RS et al *J of the American Geriatrics Society* 2005;53(2):290-294.
5. Hammes B, Rooney B. *Archives of Internal Medicine* 1998;158:383-390.
6. Molloy DW et al et al. *JAMA* 2000; 283(102):1437-1444.



One complex intervention: 'Respecting your Choices'

- To help people understand what options and decisions might be faced; to reflect on those and make decisions and communicate these.
- To enable systems to track and make use of documents and preferences
- To make sure retrieval from the medical record was possible
- To influence care so that advance directives would be carefully considered in decision making.

Hammes B, Rooney B. *Archives of Internal Medicine* 1998;158:383-390. See also:

<http://www2.edc.org/lastacts/archives/archivesJan99/featureim.asp>



Research evidence 2

ACP may improve patients' quality of life by contributing to:

- Mutual understanding
- Enhancing openness
- Enabling discussion of concerns
- Enhancing hope
- Relieving fears about the 'burden' of decision making
- Strengthening family ties



But...Cultural and Psychological Challenges

- Sensitive to cultural interpretations
- Changing views over time
- Clash of viewpoints
- The impact of a 'bad news' interview
- A desire to 'live for the moment' or 'take one day at a time'



Controlling Death- the false promise of Advance Directives

Harold S Perkins *Annals Int Med* 07 147:51-57

" Advance Directives promise patients a say in their future care but actually have little effect. ... the AD concept may be fundamentally flawed.

ADs simply presuppose more control over future care than is realistic. ...unexpected problems often arise to defeat ADs.

Advance care planning should emphasise not the completion of directives but the emotional preparation of patients and families for future crises. ...

Then when the crisis hits, physicians should provide guidance, should help make decisions despite the inevitable uncertainty, should share responsibility for those decisions, and above all should courageously see patients through the fearsome experience of dying.



Open questioning

- Could you tell me what the most important things are to you at the moment?
- Can you tell me about your current illness and how you are feeling?
- Who is the most significant person in your life?
- What fears or worries, if any do you have about the future?
- In thinking about the future, have you thought about where you would prefer to be cared for as your illness gets worse?
- What would give you the most comfort when your life draws to a close?

Horne, G., Seymour J.E. and Shepherd, K. (2006) *International Journal of Palliative Nursing* 12(4): 172-178.



Timing: possible trigger points

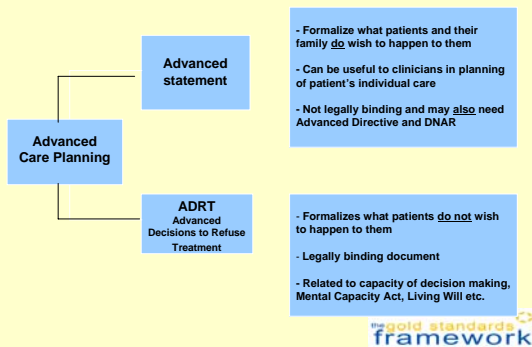
- life changing event e.g. death of spouse
- following a new diagnosis of life limiting condition
- assessment of a person's need
- in conjunction with prognostic indicators
- multiple hospital admissions
- admission to a care home



3. What is ACP in the UK ? Confusion about language



Advance Care planning



Advance care planning

- ACP is a process of discussion between an individual and their care provider, and this may or may not also include family and friends.



the gold standards framework

Advance Statement

- A requesting statement reflecting an individual's preferences and aspirations.
- This can help health professions identify how the person would like to be treated
- Not legally binding
- Past and present and future wishes



the gold standards framework

Advance Decision

- An advance decision must relate to a specific treatment and specific circumstances
- It will only come into effect when the individual has lost capacity to give or refuse consent.
- Used to be called Advance Directive/ Living will



the gold standards framework

Proxy/Lasting Power of Attorney

- a person (an "attorney") to take decisions on their behalf if they subsequently lose capacity
- can extend to personal welfare matters as well as property and affairs
- may be appointed to make specific health and welfare decisions on their behalf, should they lose capacity, as if he/they were the person receiving care



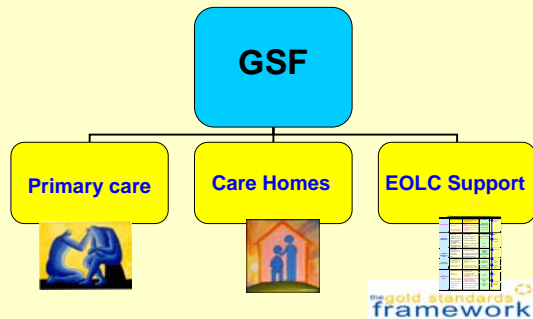
the gold standards framework

. Difficulties

- Prognostication
- Difficult discussions
- 'Death Anxiety' of staff
- Making time
- Sensitivities and sadness
- May require extra communication skills

the gold standards framework

4. Use of ACP in GSF Three Work Streams of GSF



GSFCH Care Homes Programme

- Over 600 nursing homes so far
- Structured programme over 1-2 years
 - 3 stages-Preparation, training, consolidation
 - 4 years, 4 workshops + homework
 - Facilitator training and support
- Fully resourced+ Locally facilitated
- Quality assurance- Accreditation process
- Evaluation-Improved quality of care, Decreased hospital admissions by 12% , Decreased hospital deaths by 8%
- See Briefing Paper and DVD



When? Triggers

- All residents on admission to care home
- Also.....
- Life changing event e.g. death of spouse or close friend or relative
 - Making or changing a will
 - Retirement
 - Following a new diagnosis of life limiting condition
 - Assessment of patient need
 - In conjunction with prognostic indicators
 - Multiple hospital admissions



GSF - Advance Care Planning

GSF template includes:

- Thinking ahead - open questions
 - what matters to you
 - what you wish to happen and what not to happen
- Proxy - who else involved (LPOA) +Who to call in a crisis
- Preferred place of care & death, options
- Other requests eg special instructions



Advance Care Planning review sheet

- May refuse discussion first time offered
- Ongoing discussions
- May need regular reviews
- May involve other family members



GSF Prognostic Indicator Guidance- identifying pts with advanced disease in need of palliative/ supportive care/for register

Three triggers

- Surprise question-** would you be surprised if the pt was to die within 1 year
- Patient preference** for comfort care/need
- Clinical indicators** for each disease area eg Ca metastases, NY Stage FEV1, Karnowski, etc



Needs Support Matrix



	Pt needs	Support from hospital/SPC	Support from GP
Years			
Months			
Weeks			
Days			

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framework

ACPs in care Homes

- Improved communication with residents and families early on
- Improved planning of care
- Reduced crises
- Helped formalise discussion using a tool
- Some gave to families, some senior nurses
- DNAR difficult- prefer 'Allow Natural death'.
- Some found they were difficult discussions
- All liked having them - useful and clear

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5. How?

- Sensitive discussion
- 'Relationship' questions
- Take time
- May need special communication skills/ training
- May need leaflets/ guidance materials
- Staff's own Death anxiety

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Tools

- Advance statements/ACPs
- PPC document
- GSF ACP
- ADs from specific groups eg MND
- Canadian Let's Talk campaign
- USA 'Its about how you live'
- LPOA/ Proxy
- Other

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The Future.....?

- 'Initiation of such a discussion for the many is increasingly seen as being more valuable than specific refusal of treatment for the few.'
- ACP routine part of care
- AD for some specific pts
- Negotiate more patient- centred end of life care

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Summary

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3. Need to align activities and care with patients wishes.
4. ACP is now part of the NHS End of Life Care Strategy. Good experience of using it eg GSF, PPC. Needs to be offered routinely
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Death teaches us about life
Dying teaches about living

"The end of life

points us

to the end of life"



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