Advance Care Planning

‘Process not panacea’

Dr Clare Farrington
Palliative Medicine Consultant
Aims of talk

- Advance Care Plan with whom? How well do we recognise the need?

- Advance Care Planning:
  - Purpose
  - Process
  - Challenges
How many people in hospital today will die within a year?
How many People within Hospital today will die within 1 year?

- Almost 1 in 3 patients will die within a year
- Rising to nearly 1 in 2 of those >85

Study all patients in Scottish hospitals 31st March 2010

10'743 pts
3098 pts (28%) died in a year
1 in 10 patients died during their current admission
Acute hospitals dealing with large numbers of people entering last year of life

- Do health care professionals HCP recognise this?
  - when patient in community/in hospital

- How do HCP communicate this with patients?
  - whose role is it primary care/secondary care?

- If a patient was aware they were in potentially the last year of life would that change their aims?
  - impact of ACP in hospital/community on a patient journey
How do we recognise someone is approaching the end of life?
Gold Standards Framework GSF
Supporting earlier recognition of EOLC, proactive care in alignment with preferences

‘predicting needs rather than exact prognostication’

Three triggers that suggest that patients are nearing the end of life are:

1. The Surprise Question: ‘Would you be surprised if this patient were to die in the next few months, weeks, days’?

2. General indicators of decline - deterioration, increasing need or choice for no further active care.

3. Specific clinical indicators related to certain conditions.
Prognostic indicators

- General
  Functional performance status
  Albumin<25g/l

- Cancer
  single most important predictive factor in cancer is performance status and 'functional ability' - if patients are spending more than 50% of their time in bed/lying down, prognosis is estimated to be about 3 months or less

- COPD
  confined to house, LTOT, recurrent admissions
Rainy day thinking.

“Hope for the best but prepare for the worst.”
Why Advance Care Planning ACP?

- To align goals of care and care received with patients’ needs, aims and preferred care. ¹

- GMC states duty of all doctors ‘work in partnership with patients’
  - Listen to patients and respond to concerns and preferences
  - Give patients the information they want or need in a way they can understand
  - Respect patients’ rights to reach decisions with doctors about treatment and care. ²
What is Advance Care Planning?

- Process where patients supported to express preferences for future, initially implemented mostly in nursing homes where concern regarding losing capacity.

- Majority of people will experience delirium at the end of life.

- Now in broader context of life limiting/advanced disease to support understanding of current situation, enable expression of preferences and effective planning of care and treatment.
Advance Care Planning Discussions may lead to...

- An Advance Statement (a statement of wishes/preferences)
- An Advance decision to Refuse Treatment (ADRT—a specific refusal of treatment(s) in predefined future situation).
- The appointment of a Lasting Power of Attorney (LPA).
ACP overall purpose

Main aim is to promote patient centred care, facilitate patient understanding of current situation and help inform care providers in planning and delivering future care through knowing what the patients wishes were.

Remember the presence of any ACP document does not override the decision of a competent adult.

But previous ACP discussions can help facilitate discussions between the patient, their family and HCP.
However

- **Patient choice** to engage in thinking/planning for future example
  
  Preferred Priorities of Care PPC document
  
  ‘In relation to your health what has been happening to you?’
  ‘What are your preferences and priorities for your future care?’

- **dynamic**, ongoing interaction as per patient wishes regarding current situation, understanding and care received and care preferred now and future.
Hugh Challenge for HCP

ACP not like a procedure, or box to be ticked

BUT service evaluations, KPI’s trying to measure amount ACP activity as an goal/outcome can subconsciously change our mindset and forget the purpose and true nature of ACP.
ACP can run the risk of being seen as a panacea for complex medical issues.

Need to remember primary focus

Alignment of medical care and treatment with patient wishes and preferences
Limitations of ACP

*Patient deteriorates in unexpected way*
Offering ACP

- Opportunity for discussion
- Patient and family understanding of condition and prognosis
- May say want CPR-point of discussion rather than contention. Why? What is their understanding/fears? What are their expectations?
Asking permission

- Pt choice to think about future or not
- How often do you ask permission to talk about future/their understanding-yet is it not more invasive than a blood test?

- Framing of ACP primary focus not on death and dying but about living and care. How can we best support/care for you now and in the future when you are less well/dying?
Societal Understanding and acceptance of EOLC

- Societal reaction to illness is seeking medical help
  - frequently hospital admission
- Patients may not be fully informed or ready/able to accept news of advanced nature of illness.
- Patient choice to ‘Live one day at a time’ however for people to make an ‘informed choice’ do they need to know risk/benefit of this approach and what ACP entails?

Good to know re evidence for ACP

- Majority of people happy to discuss ACP
  - primary and outpatient care setting when health stable
  - diagnosis of a life-threatening illness
  - initial entry into care home setting may cause additional upset at time of transition

- Increase patient satisfaction in patients with long term conditions and EOL care
Effects of ACP on End-of-Life Care

- DNACPR: reduce CPR measures, reduce hospitalisations and increase hospice care

- ACP interventions increased frequency of out-of-hospital and out-of-ICU care, increased compliance with patient wishes and satisfaction with care.

- Absence of adverse effects of ACP on psychosocial outcomes is noteworthy, Pts and families who participate in ACP did not report more stress, anxiety or depression compared to those who did not.

Tools offering opportunity to match care delivered with care wanted
Tools which support ACP

Last days of life Care Plan e.g. Barnsley My Care Plan
Who am I?
What is important to me?
What are the goals of care?
Tools which support ACP

AMBER care bundle recognition patient is at risk of dying during admission promotes

- discussing uncertainty, patient preferences
- Utilising/communicating discussions in MCP or discharge letter
How do we communicate patient wishes?
How do we communicate patient wishes

- Hospital discharge summaries
- Informal ACP documents PPC
- ADRT
- Individual care plans
- GP records/templates
- EPACCs

Remember ACP is not a one off test result but an ongoing dynamic process. Is this still what you want? e.g. changing preference for PPD common
Questions regarding ACP documentation

- Not a tick box exercise however tools/documents can support communication.

- who owns informal ACP records?
- communicating wishes between different settings, HCP providers
- how are they kept updated?
- how do we ensure process is dynamic but not repeatedly unnecessarily
ACP limitations

- How sure are we of what we would want before we experience it?

- Is ACP about preparing people for future transitions, enabling them to be more prepared and better informed and at these points checking out again care given=care wanted
Summary

ACP is an opportunity we can offer patients
- increase understanding of their circumstances
- opportunity to prepare and plan for future in an individual way
- use ACP tools to document and communicate discussions as pt wishes.
- If we know people well we are then well placed to act in best interests even if not engaged with formal ACP.

‘Hope for the best but plan for the worst’