Advance/Anticipatory Care Planning (ACP) Motor Neurone Disease and Dementia

MND Scotland
Advanced Study Day
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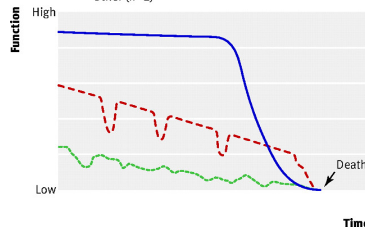
APC and Palliative Care

- Good palliative care is planned and is not "crisis intervention"
- ACP and Palliative Care are inextricably linked
- Challenge is how to extend this anticipatory philosophy to conditions with very different trajectories

Figure 1: The three main trajectories of decline at the end of life



Murray, S. A et al. BMJ 2008;336:958-959

BMJ

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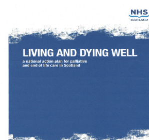
GSFS

- **Identify palliative care needs (prognostic indicator)**
- **Assess palliative care needs**
- **Plan palliative care**

- **Patient led** focused on meeting the needs of patients, families and carers
- **Care for all** those with any end stage condition, non-cancer and cancer

Living and Dying Well

- Palliative Care should be available to all those who need it
- To embrace ACP into daily care provision of patients diagnosed with long term or palliative condition is integral to good practice (SLWG 3)



Advance Care Planning (ACP)

Definition:-

- *ACP is a process of discussion between an individual and their care providers irrespective of discipline. If the individual wishes, their family and friends may be included. With the individual's agreement, this discussion should be documented, regularly reviewed, and communicated to key persons involved in their care.*

Taken from *'Advance Care Planning: A guide for Health and Social Care Staff'*, NHS End of Life Care Programme, February 2007

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Component of ACP

- Legal such as will, adults with incapacity act
- Personal such as preferred place of death, goal setting
- Medical such as refusal of antibiotics/blood transfusion

ACP key terms

- Advance Statements
- Advance Decisions
- 'Living Will'
- Power of Attorney

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ACP provides the patient opportunity to discuss ...

- Understanding about illness and prognosis
  - Including physical problems and changes
- Spiritual and religious issues
- Potential deterioration in health and decision-making about future treatment
  - Including advanced statement/power of attorney
  - Do not attempt Cardio-pulmonary Resuscitation (DNACPR)
  - Organ donation (as appropriate)

ACP provides the patient opportunity to discuss ...

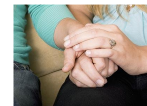
- The possibility of dying
- Preferences for types of care and values and personal goals for care
  - advanced statement

Who does it ?

- Doctors
- Nurses
- Social workers
- Social carers
- Nursing care assistants

ACP discussion requires

- Communication skills
- Shared decision making skills
- Skills in building relationship and trust
- Therapeutic use of self



Key Principles

- The ACP planning process needs to be tailored to patients' needs and wishes (including respecting wishes to not discuss these issues)
- The timing and content of the discussion needs to be flexible and the process should be as fluid and dynamic as possible, allowing it to be patient-led

Informing and Preparing

- A sensitive approach is needed, so that people are not alarmed.
- Reassurance that thinking about, discussing and recording wishes for the future is a voluntary process.
- There is no compulsion to take part, but is an 'opportunity' only.
- ACP can be seen as a natural progression from thinking about care **now**, to thinking about possible care in the **future**

When should ACP discussion take place

Triggers

- Prognostic indicator/Surprise question
- Person's choice/need
- Clinical indicator
- Multiple hospital admissions
- Admission to a care home
- After exacerbation
- Reduced functioning/ADL

Examples of Opening Questions

- 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.

Practical Considerations for ACP

- Where should wishes for the future be recorded?
- Where should the document be stored?
- Who should have a copy?
- Who should be aware of a resident's ACP?
- How often should an ACP be reviewed?

Where should wishes for the future be recorded?

- In the care plan (service user plan)?
- In a separate document?
- On the computer?

Issues to consider:-

- Accessibility
- Confidentiality

How often should an ACP be reviewed?

- On the request of the person – at any time
- When the care plan is reviewed each month
- A formal review at least annually

Challenges of ACP discussion- health care professionals

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

Challenges of ACP discussion- patients and families ……

- Cultural interpretations of death and dying issues
- 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'

Benefits of APC in QOL

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

ACP discussion 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

Davison S Simpson C (2006) BMJ 333,886