VTS Warwick
10th Feb 2011
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Death and Dying
Making plans in advance

Learning Objectives

- Curriculum Statement:
  Care of People with cancer and Palliative Care
- Key Messages (applicable to this session)

– role of GP extends from primary prevention to diagnosis and treatment to terminal care
– Many terminally ill prefer option of death at home
– Helping patients die with dignity and minimal distress is a fundamental aspect of medicine

Learning Outcomes for this session

"the GP will require Knowledge, Skills and Attitudes in the following areas".....

- Primary care management
- Person-centred care
- Attitudinal aspects
- Contextual aspects
- Community orientation
- Holistic approach

Acknowledging own mortality

- We are all going to die
- The prospect can be frightening
- Cultures vary in attitude
- Most personal experience of death is sad
- Many people do not prepare

Personal Reflection

"I don't mind dying…
I just don't want to be around when it happens!"

Stand up ☺

Advance care planning

Enabling your patients to express their preferences for care in the last stages of life

Advance care planning

- Advance Care Planning (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.

Advance care planning: A guide for Health and Social Care Staff. NHS End of Life Care Programme 2007

Why do advance care planning?

"How we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of society as a whole and it is a litmus test for health and social care services."

End of Life Care Strategy (2008)

Why is it important?

- Encourages deeper conversations at an important time
- Empowers and enables patients and family
- Facilitates shared decision making
- Encourages better provision of services related to patients needs and pre-planning of care
- Ensures clinical care is in keeping with the patients preferences

"I think it is very helpful. It gives us a clear indication of what people want. It gives us confidence to speak on behalf of our residents to doctors. I think it helps to establish a firm understanding and subsequently support for and from the family"

One care home manager's view of ACP

" using the advance care plan document provided a focus….it acted as a catalyst to prompt discussion…. To put into place the breathing space kit, plan for tissue donation and funeral arrangements. It did not make her death easier to bear, but provided reassurance that their wishes would and could be followed to the best of everyone's ability"

One specialist nurse's view of ACP

Impact of ACP on end of life care in elderly patients. Detering K. BMJ 2010; 340:c1345

- 154 patient of 309 randomised to ACP
- Wishes more likely to be known and followed
- Family members identified less stress, and anxiety and depression
- Perceived patient and family satisfaction higher

Where do people die?

- Around half a million people die in England each year
- Most deaths follow a period of chronic illness such as heart disease, cancer, stroke, chronic respiratory disease, neurological disease or dementia.
- 58% occur in NHS hospitals
- 18% at home,
- 17% in care homes, 4% in hospices and 3% elsewhere.

End of Life Care Strategy 2008

TOP TEN

Over to you

What do patients want?

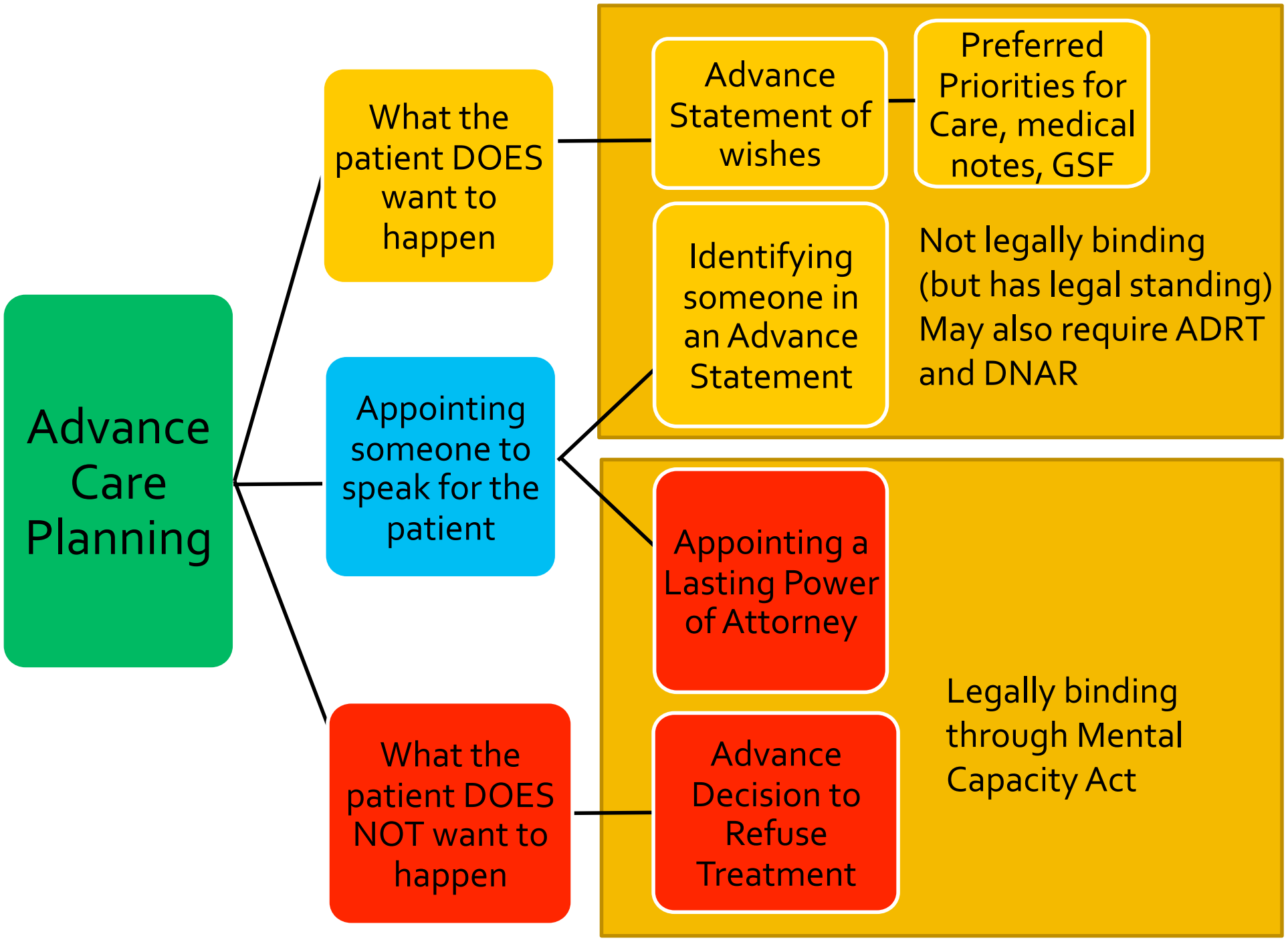
- Be treated as an individual, with dignity and respect
- Be without pain and other symptoms
- Be in familiar surroundings
- Be in the company of close family and/or friends.

What do Patients Feel?

- **Fear** diagnosis, mode of death, drug side effects
- **Guilt** becoming a burden, past life experiences
- **Anger** loss of dignity, missed opportunities, loss of independence
- **Uncertainty** spiritual questions, prognosis, future of the family
- **Depression** often as a consequence of the above
- **Acceptance** may feel ready, welcome death

Rule of Surprises……

"Would I be surprised if this patient were to die in the next week/month/six months?"


Advance Care Planning
What the patient DOES want to happen
Appointing someone to speak for the patient
What the patient DOES NOT want to happen
Advance Statement of wishes
Preferred Priorities for Care, medical notes, GSF
Identifying someone in an Advance Statement
Not legally binding (but has legal standing) May also require ADRT and DNAR
Appointing a Lasting Power of Attorney
Advance Decision to Refuse Treatment
Legally binding through Mental Capacity Act

Key terms

- Advance statements/ statement of preferences
- Advance decisions to refuse treatment
- Lasting power of attorney
- DNAR

Living will and advance directive are old fashioned and no longer used

Advance statement

- Statement of wishes and preferences
- NOT legally binding
- Taken into account if person lacks capacity, helping to inform 'best interests'

Advance decision to refuse treatment (ADRT)

- Legally binding if valid and applicable
- If relates to refusal of life-sustaining treatment needs to be in writing, signed and witnessed
- **Must state** clearly that it still applies ***even if life at risk***
- Person must have capacity at time of writing
- Must relate to exact circumstances being considered

Lasting power of attorney (LPA)

- The giving of authority by one person to another person to make decisions on their behalf in certain well defined circumstances
- Must be registered with the Office of Public Guardian

When to consider it

- Life changing event e.g. death of a spouse
- Following a new diagnosis of life-limiting condition
- Assessment of a person's need
- In conjunction with prognostic indicators
- Multiple hospital admissions
- On admission to a care home

So why aren't we doing it?

Difficulties

- Prognostication
- Difficult discussions/ need for advanced communication skills
- Lack of time/knowledge of process
- Practical challenges with documentation

TIME FOR A BREAK