

PALLIATIVE CARE: THE BENEFITS OF PLANNING YOUR FUTURE CARE

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THIS PRESENTATION WILL...

- Explain what palliative care is
- Introduce advance care planning
- Introduce the Mental Capacity Act 2005
- Explain how people can express and protect their choices and preferences about their future care

PALLIATIVE CARE

‘...the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.’ (NICE, 2004)

SOME KEY POINTS

- Holistic, with 4 main domains:
 - Relief of pain & physical symptoms
 - Psychological
 - Social
 - Spiritual
- Seeks to maximise quality of life, for carers as well as patients (patient and carer “pathways” in End of Life Care Strategy)
- Relevant throughout a disease journey, not just at the end
- Although a recognised specialism, should also be delivered by all health & social care professionals

END OF LIFE CARE

“End of life care is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.”

End of Life Care Strategy (July 2008)

Types of Services

Palliative Care Services might include:

- Self help and support
- User involvement (help shape the services you want)
- Information giving
- Psychological support
- Symptom control
- Social support
- Rehabilitation
- Complementary therapies (including massage, aromatherapy, art therapy etc)
- Spiritual support
- End of life and bereavement care

THE END OF LIFE CARE STRATEGY

“The most important objective is to ensure that people’s individual needs, their priorities, their preferences for end of life care are identified, they are documented, they are reviewed, they are respected and acted upon wherever possible. Now that message has to go out everywhere within the NHS and I think that’s the important starting point for everything else...”

Alan Johnson, Secretary of State for Health, speaking on Radio 4’s *Today* programme at the launch of the End of Life Care strategy, on 16 July 2008

ADVANCE CARE PLANNING IS...

- A continuing process of discussion between an individual and his/her care providers
- ACP discussions may include:
 - the individual's concerns
 - their important values or personal goals for care
 - their understanding about their illness and prognosis
 - their preferences for types of care or treatment that may be beneficial in the future and the availability of these
- It anticipates a time when the individual cannot make those decisions for him/her self

SOME POSSIBLE EXAMPLES

- *“If I am being washed, I prefer showers to baths*
- *I am allergic to lanolin; please don't put me in lambswool clothes or give me hand cream with lanolin in it*
- *I hate boiled eggs, and I love Marmite*
- *I want to stay at home as long as I can*
- *I don't like Coldplay. Please play Mozart.*
- *I am frightened of injections and needles*
- *Please could my daughter look after my cat?”*

SOME OBSERVATIONS

- Very widespread support, but currently a limited evidence base
- Voluntary – nobody should be forced to do it
- Equally, if people don't know what you want to happen, it's unlikely to happen
- Advance care planning, not Advanced
- Many people are still afraid of opening up these conversations, including professionals!

MENTAL CAPACITY ACT 2005

- Protects people with impaired capacity:
 - Duty to support them to make their own decisions
 - If they cannot, decisions must be in their best interests
- Protects those caring for them, provided the decisions made are justifiable as best interests
- People's wishes and values must be taken into account
- Covers health care, social care, finances...everything

MCA:
FIVE UNDERLYING PRINCIPLES

1. Presumption of capacity
2. Individuals should be supported where possible so that they can make their own decisions
3. People have the right to make decisions that may seem eccentric
4. Decisions should be in a person's best interests
5. Decisions should be as unrestrictive as possible

HOW CAN PEOPLE USE THE MCA TO EXPRESS/PROTECT THEIR CHOICES IF INCAPACITATED?

- **Appoint a proxy decision-maker** under a Lasting Power of Attorney
- **Refuse specific treatments** in advance
- In anticipation of other people assessing their best interests in the future:
 - **Nominate** somebody to be consulted (friend/relative)
 - **Identify** who should **not** be consulted
 - **Make written statements** about their values, priorities & preferences – these must be taken into account (Advance Care Planning)

INTERESTED FAMILY, FRIENDS & CARERS

- **Protected decision-making** for all professional and informal carers (if they reasonably believed a person lacked capacity & the act was in his/her best interests)
- They must **be consulted** about the person's best interests where practicable
- **Challenge decisions**, if felt not to be in best interests
- Be appointed as a **Lasting Power of Attorney**
- Apply to be **appointed as a Deputy** by the court

FURTHER RESOURCES

NCPC

Mental Capacity Act

- *The Mental Capacity Act in Practice: Guidance for End of Life Care*
- *Good Decision Making - the Mental Capacity Act & End of Life Care* (patients, carers, care assistants)

Artificial Nutrition & Hydration

- *Guidance on Artificial Nutrition & Hydration - Guidance in End of Life Care for Adults*
- *Artificial Nutrition and Hydration - Summary Guidance*

NCPC & the National End of Life Care programme

Advance decisions refusing treatment

- *Advance Decisions To Refuse Treatment: A Guide for Health and Social Care Professionals* (contains a check list to assess whether an apparent advance decision is binding, and the Code of Practice text)
- *Advance Decisions To Refuse Treatment: A Guide* (for patients & carers)

Advance care planning

- *Planning for Your Future Care* (for patients & carers)
- *Advance Care Planning: A Guide for Health & Social Care Staff*