

# Palliative care along the pathway and end of life care

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# What do you understand by the terms 'palliative care' and 'end of life care'?

There are a number of terms used when describing the care people may need as they approach the end of life.

There is a lot of overlap and often different terms are used to mean the same thing, so it can be confusing.



## Palliative care is....

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

WHO

# Key Principles of Palliative Care

- Focus on quality of life
- Whole person approach
- Care for both the person with life threatening disease and those that matter to that person
- Respect for patient autonomy and choice
- Open and sensitive communication

# End of Life Care is...

- **End of life care** is about the total care of a person with an advanced incurable illness and does not just equate with dying. The **end of life care** phase may last for weeks, months or years.
- **End of Life Care** is defined as care that helps those with advanced, progressive, incurable illness to live as well as possible until they die.

What's important to me : A review of choice in end of life care .2015

I want to be cared for and die in a place of my choice

I want involvement in, and choice over, decisions made about my care

I want the people who are important to me to be supported and involved in my care



What choices are important to me at the end of my life and after my death?

I want access to high quality care given by well trained staff

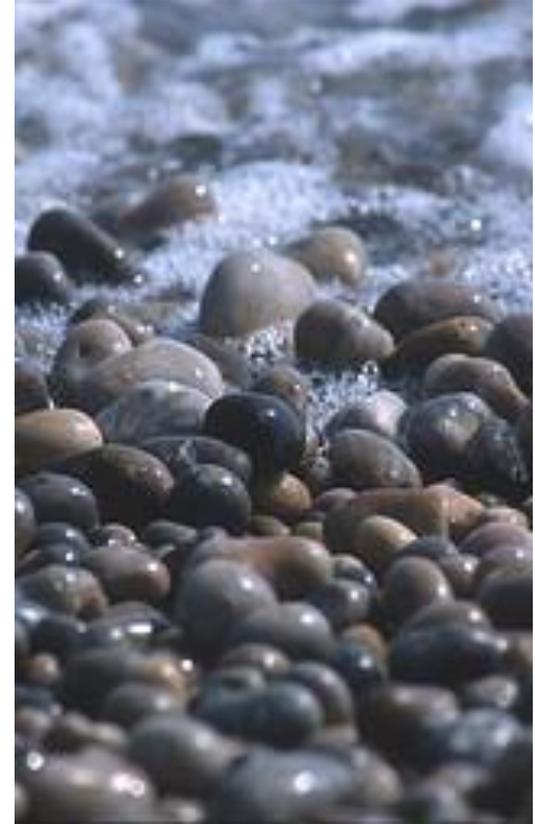
I want the right people to know my wishes at the right time

I want support for my physical, emotional, social and spiritual needs

I want access to the right services when I need them

# Key points:

- Advanced disease or illness – no cure
- Holistic approach to care
  - physical, emotional, psychological, social and spiritual
- Open and sensitive communication
- A multi-disciplinary approach to care
- A support system for the individual and those close to them



Palliative care along the pathway...



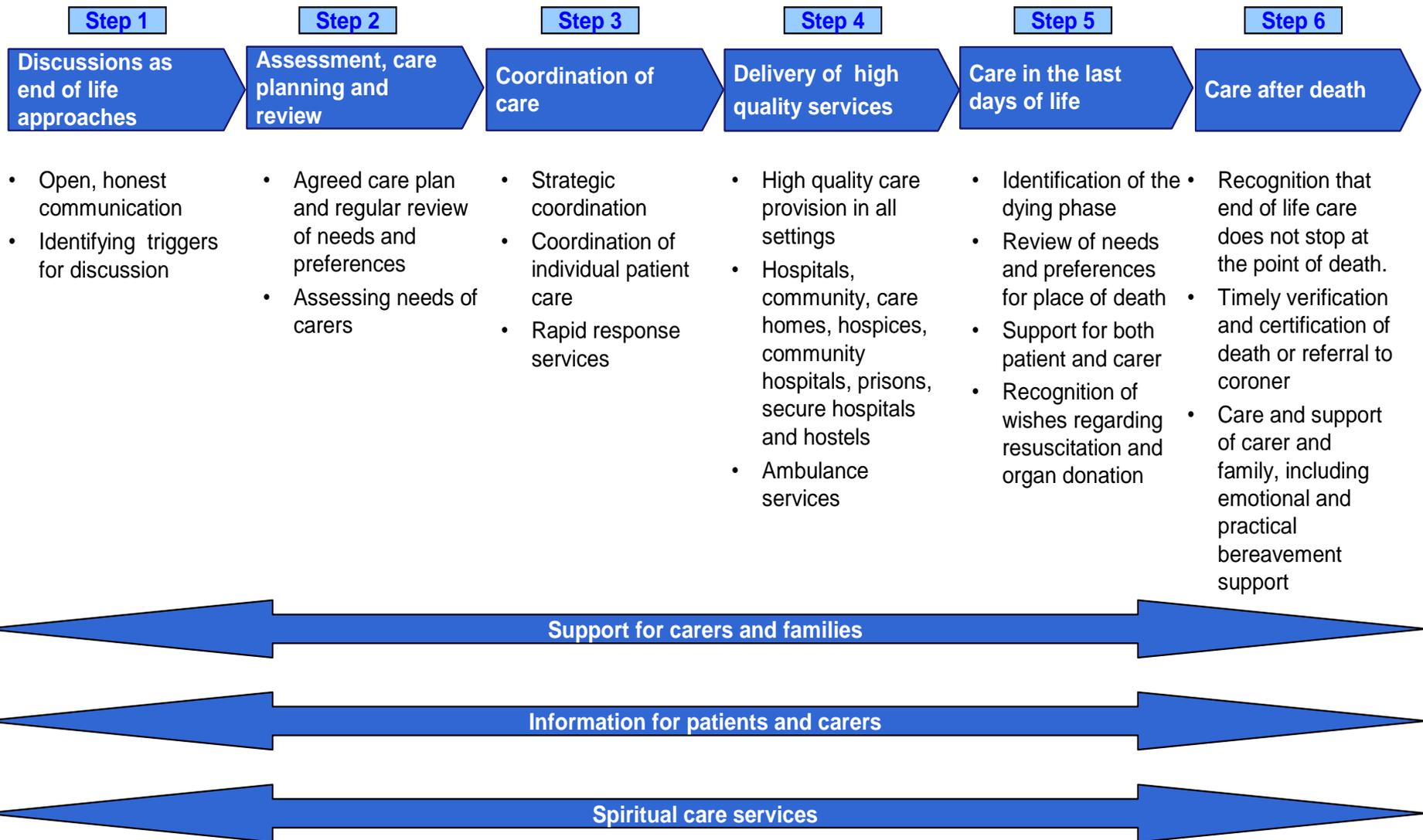


# Independent review of Liverpool Care Pathway (2013)

- Plenty of evidence showed that when they LCP was used well it facilitated good care of dying people
- However there were also many instances where its use was associated with poor experiences of care
- 44 recommendations including phasing out of LCP by July 2014
- Replacing the LCP with an individual end of life care plan



# The End of Life Care Pathway



# Five Priorities for Care of the Dying Person

- Recognise dying
- Communicate
- Involve
- Support
- Plan and do

Leadership Alliance for the Care of Dying People (2014)



# General Medical Council definition of 'end of life' (2010)

People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and coexisting conditions that mean they are expected to die within 12 months
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events.

# How do you recognise end of life?

There are 3 triggers:

1. The 'surprise question'

“Would you be surprised if this person died in the next 12 months?”

2. General indicators of decline

3. Specific clinical indicators related to certain conditions

The focus is upon anticipating likely needs rather than working out exact time remaining

# General indicators

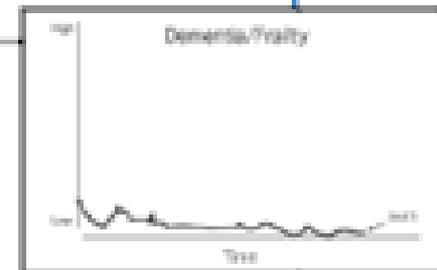
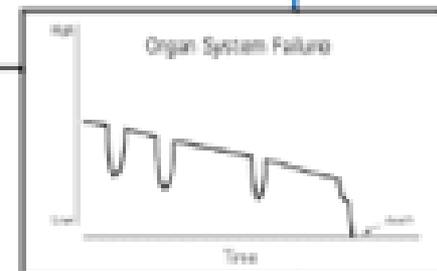
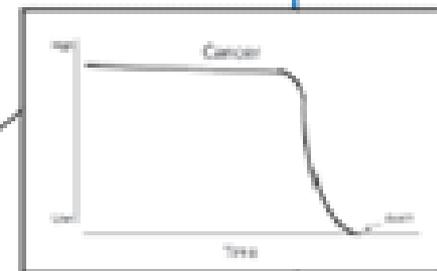
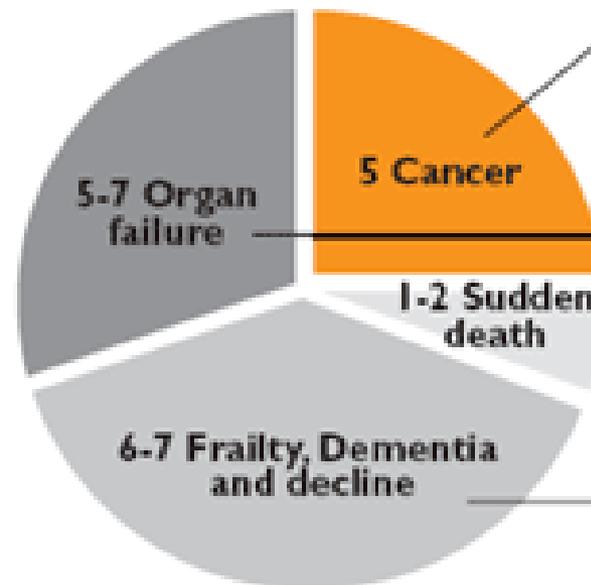
- Decreasing activity (functional performance status decline), limited self care, increasing dependence in most activities of daily living
- Co-morbidity
- General physical decline
- Advanced disease, unstable, deteriorating complex symptom burden
- Decreasing response to treatments, decreasing reversibility
- Progressive weight loss (>10% in past 6 months)
- Repeated unplanned/crisis admissions
- Sentinel events e.g. serious fall, bereavement,
- Serum albumin <25g/l

# Specific clinical indicators

- Advanced cancer
  - Rapid or predictable decline
- Organ Failure
  - Erratic decline
- Frailty /dementia
  - Gradual decline

Fig 2.

## Three trajectories of illness GP's Workload - About 20 Deaths/GP/yr



After Lynn, J et al

# Advanced Cancer

- Metastatic cancer
- More exact predictors for cancer patients are available e.g PiPs (UK validated prognosis in palliative care study) PPI, PPS etc; ‘prognosis tools can help but should not be applied blindly’
- ‘the single most predictive factor in cancer is performance status and functional ability’ if patients are spending more than 50% of time in bed/lying down, prognosis is estimated to be about 3 months or less

Gold Standards Framework prognostic indicator guidance (2011)

# Why it is important to identify individuals who are at end of life?

- The person themselves may want to know.
- To ensure preferences and wishes end of life issues and care are discussed and documented.
- Research shows us that people close to someone who is dying also want to know, so they can emotionally prepare and prioritise what is important.
- To involve appropriate services from health and social care professionals (GP, community nurses, specialist palliative care teams (hospital/hospice))
- To enable support to be re-evaluated and changed taking into account a holistic perspective of what an individual needs.

# Your role

- Trust your intuition and ask the question “would I be surprised if this person was to die in the next 12 months?”
- To recognise when signs/symptoms increase or condition deteriorates
- Identify those who need supportive end of life care / specialist palliative care services
- Carefully consider if the individual wishes to openly discuss prognosis and future care options
- Recognise and create opportunities to have a conversation with the patient about their wishes for end of life care

Thank you for listening...

**Any Questions...  
Just Ask!**

