NHS
Health Education England

End of Life Issues: Organisation of Palliative Care in the UK

Dr John Potter and Dr Ben Zylicz, MD, PhD
Dove House Hospice, Hull

Developing people
for health and
healthcare

www.hee.nhs.uk

History

- 1905 St Joseph's Hospice, London
- 1967 St. Christopher's Hospice, London, Dame Cicely Saunders
- 1987 Palliative Medicine as a specialty
- + 200 hospices in the UK
- Each hospital should have the input of a palliative care specialist

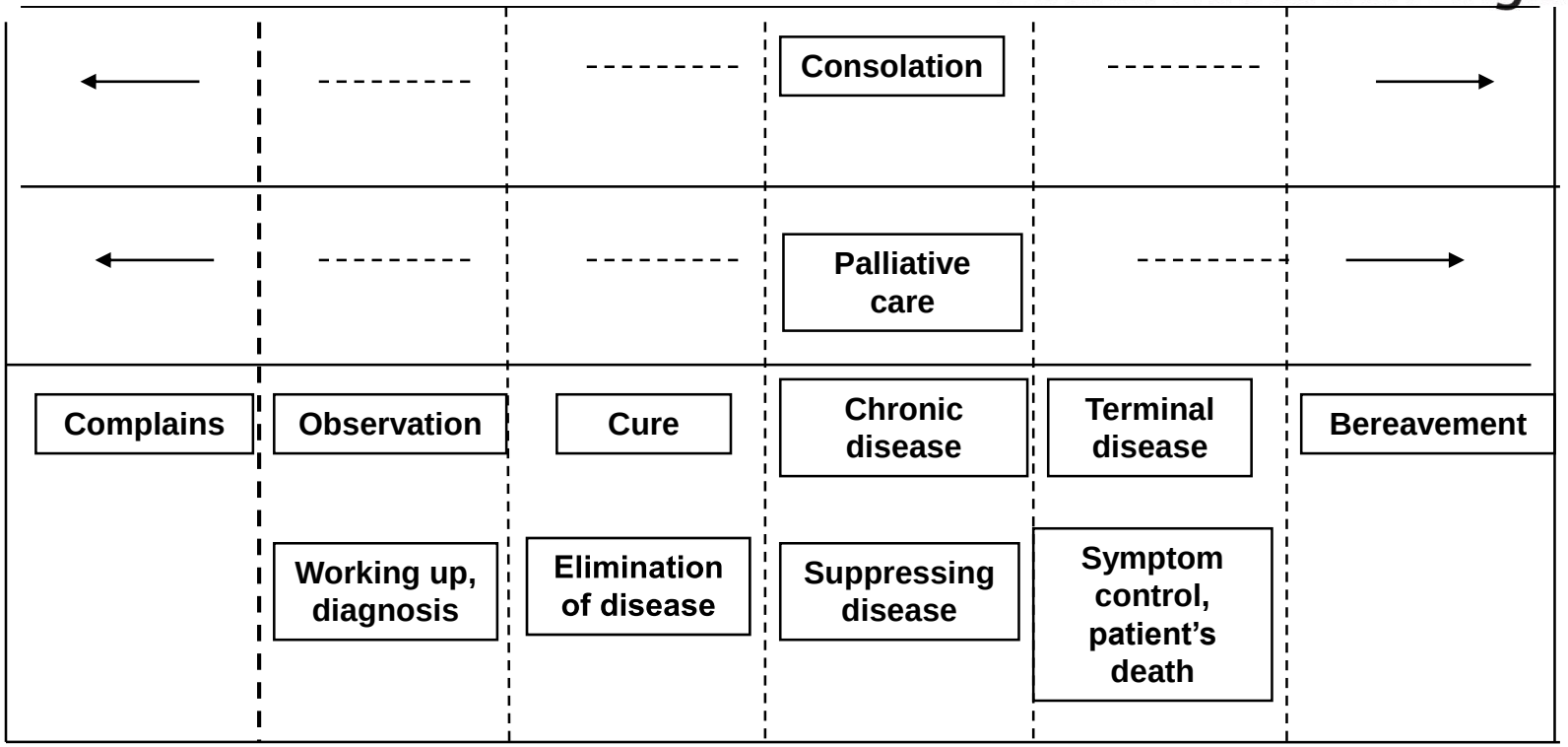
Main areas of Palliative Care

Health Education England

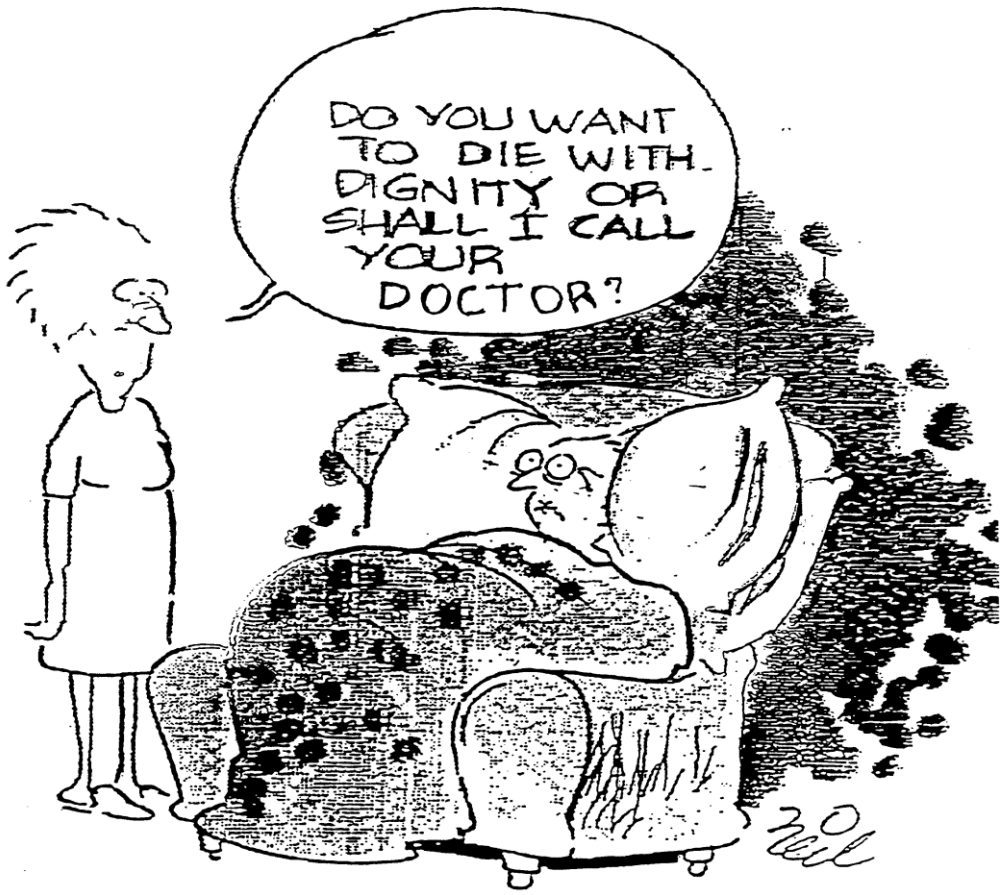
- Hospices (free standing, day care, clinics)
- Hospitals (consultations by nurses and doctors, clinics)
- Community (consultations by Macmillan Nurses)

Palliative Care is the integration of:

- Physical
- Psychological
- Social
- Spiritual



The place of palliative care in the history of (malignant) disease


DO YOU WANT TO DIE WITH DIGNITY OR SHALL I CALL YOUR DOCTOR?

Types of treatment

- Curative
- Revalidative (rehabilitation)
- Palliative
- Symptomatic

Components needed for the feeling of dignity

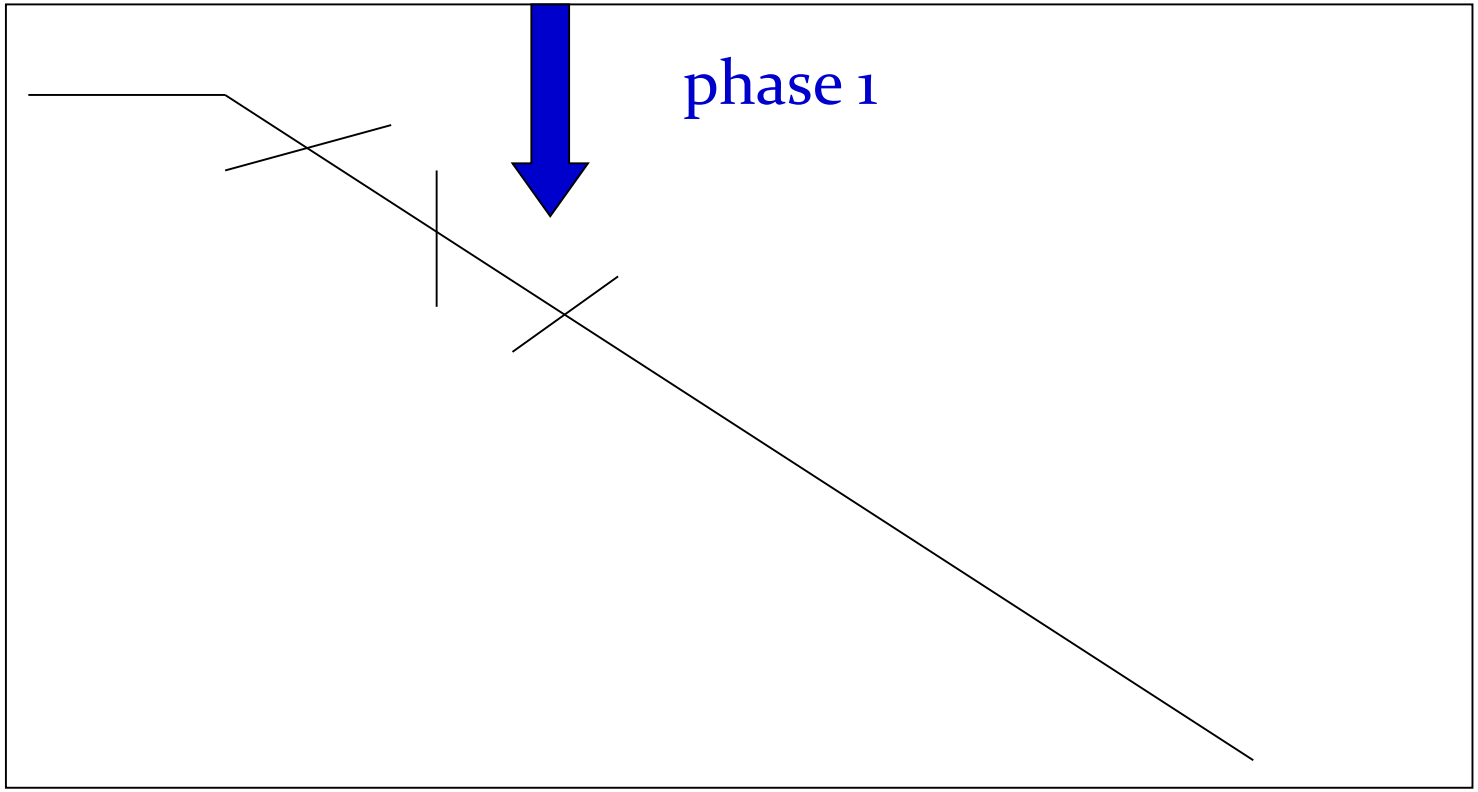
Health Education England

- Distress caused by symptoms
- Lucidity
- Quality of relationships
- Spiritual “space” for the adaptation process
- Acceptance
- Safety
- Peace and quiet
- Caring surroundings/able to receive care
- Good communication between the family and carers

Patterns and predictors of place of cancer death

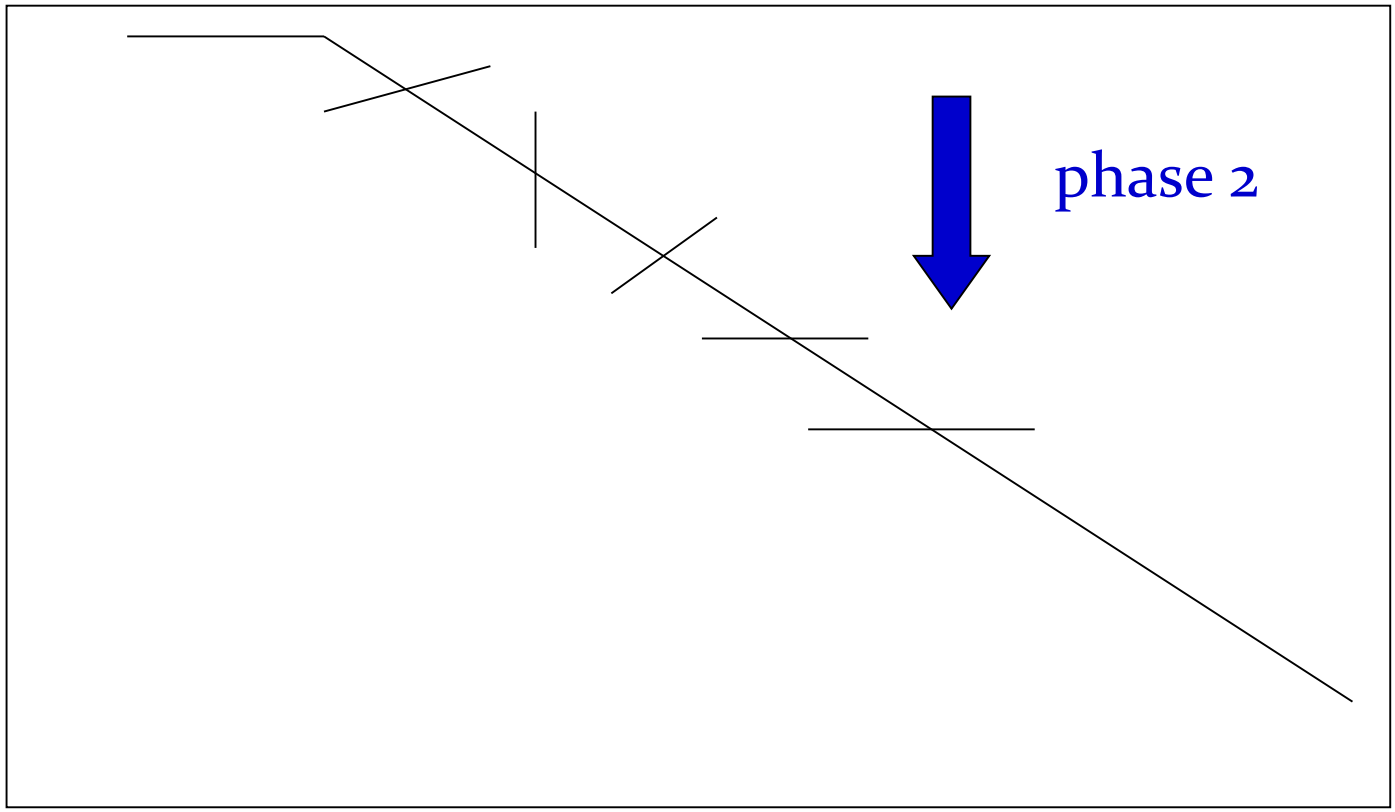
Health Education England

- Married men with cancer usually die at home
- Women with cancer tend to die in care homes & hospices
- Those dying of lymphatic & haematopoietic malignancies tend to die in hospital
- Young people (< 30) tend to die in hospital or at home


phase 1

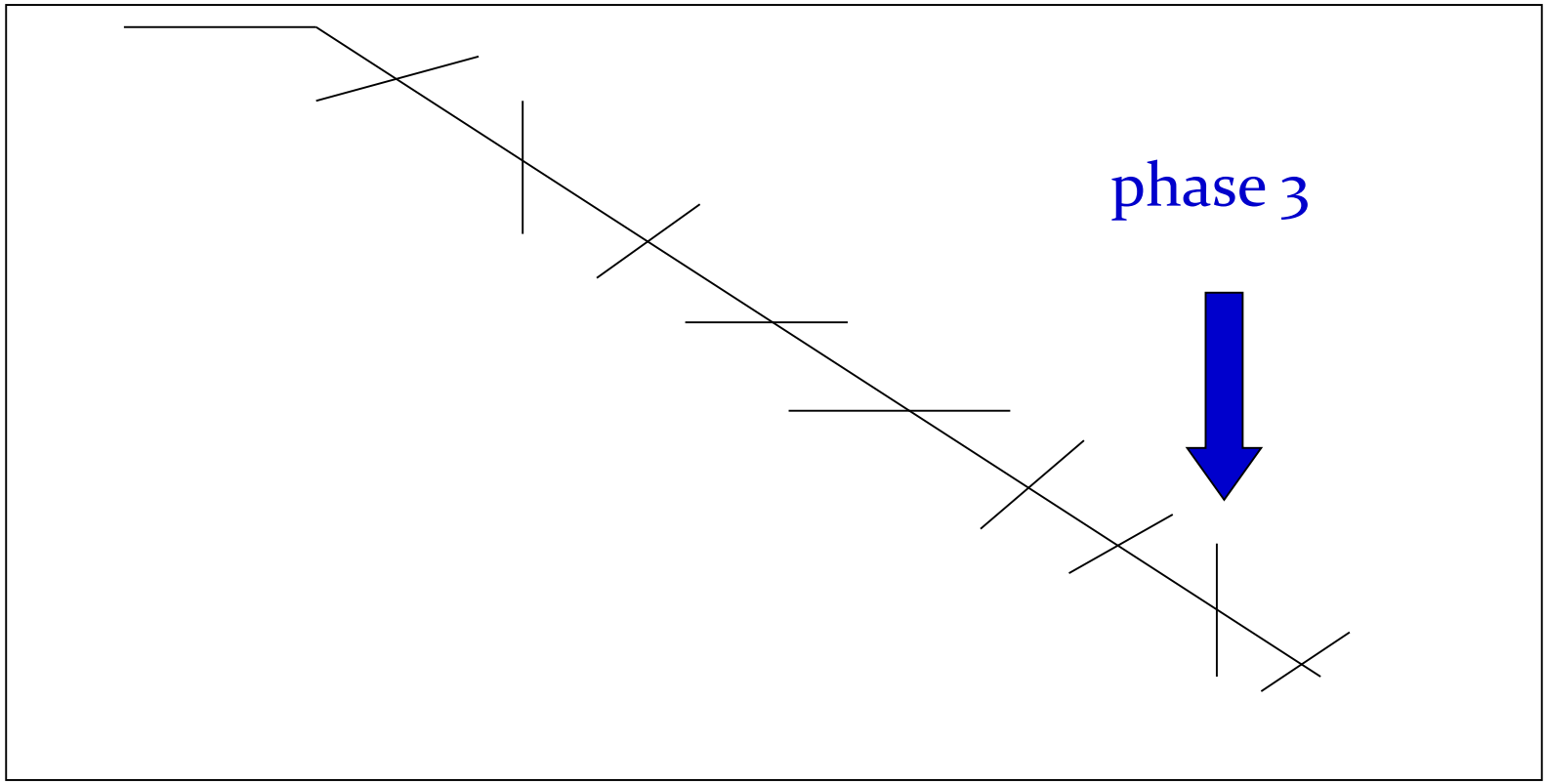
Phase 1

- Lack of balance between facts and emotions
- Disappointment, disbelief, lack of confidence
- Lack of acceptance
- The goals are unclear
- “trial and error” in symptom control
- **Important:** preserve the cognitive functions
- Many patients contemplate euthanasia


phase 2

Phase 2

- Balance is recovered
- Confidence is back
- (Physical) symptoms are not at the foreground
- The patient gets space for his adaptation process
- Intact cognitive functions of paramount importance
- Euthanasia requests practically fade away


phase 3

Phase 3

- Every day a new symptom/complication
- Increased intensity of symptoms (pain, breathlessness)
- Patient not able to swallow
- Further lack of balance
- Cognitive functions less important
- The patient may not be competent to take decisions any more
- Sedation, if symptoms are refractory, maybe a good solution.

The Liverpool Care Pathway

- To improve the care of the dying patient
- Imminent and inevitable death diagnosed by Team
- Based around achieving goals of care and recording and managing “variances”

LCP Key Elements

Health Education England

- An explicit statement of goals of care based on evidence and best practice
- To facilitate communication between teams/patient/families
- Co-ordinate care by co-ordinating and sequencing the activities of the MDT
- Documenting, monitoring and evaluating variances and outcomes
- Identification of appropriate resources

Terminal Sedation in Palliative Care

Health Education England

Refractory Symptom

"A symptom that cannot be adequately controlled despite aggressive efforts to identify a tolerable therapy that does not compromise consciousness"

Cherny and Portenoy, 1994

Arguments in Favour

- Dying patients are more comfortable with parenteral hydration
- No evidence fluids prolong life
- Dehydration can cause confusion, restlessness and neuromuscular irritability
- Parenteral hydration is a minimum standard of care

Arguments Against

- Comatose patients do not experience symptom distress
- Parenteral fluids may prolong dying
- Fewer urine results and less need to void or use catheters
- Less gastrointestinal fluid, nausea and vomiting

Health Education England

When you seek advice

- www.Palliativedrugs.com
- www.pallcare.info
- www.biomedcentral.com/bmcpalliatcare

Conclusions

Health Education England

- Palliative Care is a new and dynamically developing specialty dealing with end-of-life issues
- Integration of physical, psychological, social and spiritual aspects is paramount
- Death is not a defeat but it belongs to life
- End-of-life care takes place not only in hospices but also at home, in care homes, nursing homes and hospitals
- Know your consultant (nurse & doctor) in palliative care!