

# Teaching End of Life Care to Respiratory Specialists

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# Pushing boundaries in palliative and end of life care

## Work with the unfamiliar

- Research
- Policy
- Clinical collaboration
- Education

# The Need for Palliative Care in

Anna Spathis and Sarah Booth. End of Life Care in COPD: in search of a good death. International Journal of COPD 2008 3 (1): 11-29

- Skillbeck 1998, Gore 2000
- Steinhauser et al 2000
- Edmonds et al 2001
- Solano et al 2006
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Extensive end of life care needs

Death follows prolonged functional decline

Heavy symptom load

Emotional distress

Social isolation

Fear of dying in distress

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Death follows prolonged functional decline

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Existing provision unable to meet the needs

Reactive crisis interventions rather than continual supportive care

## RESEARCH

Curtis (2005) describes what patients with COPD considered to be high quality end of life care:

- Emotional support
- Accessibility to health care professionals
- Continuity of care

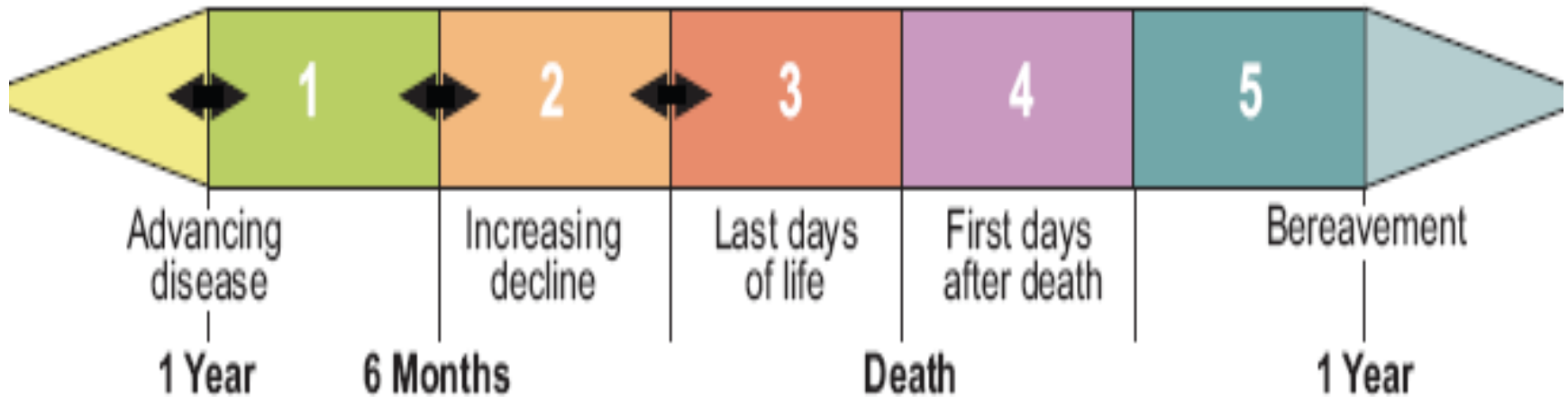
In addition patients wanted to understand and talk about 5 core areas

- Diagnosis and disease process
- Treatment
- Prognosis
- What dying might be like
- Advance care planning

**Communication with professionals and with their loved ones was considered an essential component of good care**

# Adapting our language

Figure 28 The North West End of Life Care Model



# End of Life Care Strategy 2008

## Workforce Development

### Problems

- The specialist palliative care workforce is relatively small (~5,500). The total number of health and social care professionals who deliver end of life care is huge (several hundreds of thousands)
- Many staff at all levels have received little or no training or continuing professional development in end of life care

# End of Life Care Strategy 2008

## Workforce Development

- Need for education, training and CPD related to
  - Communications skills (e.g. starting the conversation)
  - Assessment and care planning
  - Symptom control
  - Provision of psychological, social and spiritual care
  - Care in the last days of life
- Action will be required by
  - Regulators (e.g. GMC, NMC etc.)
  - Medical schools and higher education institutions
  - Strategic Health Authorities
  - Local commissioners / providers
  - Individual practitioners

# Working with clinical nurse specialists in respiratory care

Association of Respiratory Nurse Specialists (ARNS)

- They don't know what they don't know
- But they know they need communication skills training
- They worry about
  - discussing death and dying with their patients
  - labelling their patients as 'palliative'
  - uncertainty of prognosis
  - Unnecessary suffering at the end of life

# Devising a course

- Teaching team

RESPIRATORY CARE SPECIALISTS  
PALL CARE SPECIALISTS  
NURSES AND DOCTORS

BTS/ARNS

- Delegates

RESPIRATORY CARE  
SPECIALISTS  
NURSES, PHYSIOTHERAPISTS  
AND DOCTORS

# Balanced healthcare

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- Treatment agenda
  - Investigation
  - Diagnosis
  - Management with medication
  - Rehabilitation
  - Oxygen therapy
  - Invasive and non-invasive ventilation

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- Treatment agenda

- Investigation
- Diagnosis
- Management with medication
- Rehabilitation
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- Support agenda

- Symptom control
- Coordination of care
- Information and patient involvement
- Face-to face communication
- Psychological assessment and support
- Rehabilitation
- Social and practical support
- Spiritual support
- Care for the dying

# Day 1

- COPD and Interstitial Lung Disease
- The Gold Standards Framework
- Listening and responding to concerns SAGE & THYME
  - Rehearsals
- The Liverpool Care Pathway

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Setting - privacy

Ask - about concerns

Gather - all concerns

Empathy

Talk - who have you got?

Help - have they helped?

You - what do you think would help?

Me - do you want me to help in some way?

End -can we leave it there?

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# Day 2

- Lung cancer and motor neurone disease
- Sharing difficult information SPIKES
  - Rehearsals
- Symptom management in advanced respiratory disease
- Working within multidisciplinary teams SBAR
  - Rehearsals
- Advance planning (Mental Capacity Act)

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Setting

Perception

Invitation

Knowledge

Emotions/empathy

Strategy

# Day 2

Baile et al 2000

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Situation

Background

Assessment

Request

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Opiates and benzodiazepines for breathlessness

Management of anxiety and depression

Jennings 2002

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Henry and Seymour 2007 Advance planning: a guide for health and social care professionals

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# Demystifying end of life care

- Discuss real cases
- Develop confidence in communication skills
- Maximise discussion
- Explain end of life tools
- Basic symptom management

# To teach end of life care to disease specific specialists

- Comfort with inadequacy
- Comfort with difficult prognostication
- Preparedness to step into their world
- Ability to:
  - Distil our messages
  - Apply our messages to their reality
  - Demystify our experience

# Specialist diagnostic silos

## Better treatment outcomes

- Cancer
- Stroke
- Heart disease
- Respiratory disease
- Care of older people
- Specialist Palliative care

Taking the insights  
from our experience  
in end of life care

Applying to their  
experience

# contacts

- SAGE & THYME
- <http://dx.doi.org/10.1016/j.pec.2009.06.004>
- [julie.orford@uhsm.nhs.uk](mailto:julie.orford@uhsm.nhs.uk) (enquiries)
- [annette.duck@uhsm.nhs.uk](mailto:annette.duck@uhsm.nhs.uk) (respiratory care course)